a person with Ubuntu is open and available to others, knowing that he or she belongs in a greater whole and is diminished when others are humiliated or diminished, when others are tortured or oppressed

Disabled people in rural Kenya: can the United Nations Convention on the Rights of Persons with Disabilities make a difference?

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Abstract

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is the fruition of a protracted struggle by disability activists to wake the international community from its comatose on the issue of disability, presenting a real opportunity to address the needs of the world’s largest minority. Whilst the recognition of disability rights completes the paradigmatic conceptual shift from medical to social disability model, the realisation of these rights is reliant upon multitudinous factors.

This dissertation focusses on some of the underlying causes and barriers pertaining to disability and how those factors impact upon the ability of disabled people, particularly in the global South, to claim their rights, and governments to provide them. The paper builds upon previous literature and research to examine the conditions surrounding Kenya’s promulgation of the CRPD and the ability of rights holders, the majority of who live rurally, to realise the rights bestowed upon them by government ratification of the CRPD.

The study is predicated on empirical research in a rural community and a comparison of collected primary data with a 2007 study by the African Union of the Blind. The lived experience of rural disabled communities is also observed through the lens of photo elicitation interviews.

The findings show that disability is a social experience influenced by intersectional disadvantages where impairment has some underlying reality. Simple awareness raising measures and improved data collection with nuanced analysis can benefit the implementation of the CRPD and improve the lived experience of rural disabled communities.


Cover page quote: Desmond Tutu, (1999)
Acknowledgements

To enter a community as a stranger and be welcomed into its heart is perhaps one of life’s greatest pleasures, so my deepest gratitude and appreciation to the people around Tawa for welcoming me so warmly into their lives and homes.

My thanks of course to my supervisor Richard Carver, whose knowledge and passion of human rights made me realise that I should give the subject some attention beyond ‘half listening to that human rights woman on the news’. His thoughtful contemplativeness was reassuring throughout the research and as always his feedback was ‘most effective’. My thanks also go to all the staff at CENDEP.

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The times I felt like giving up two thoughts kept me going. One was of Marielle, who has suffered me from the inception of the project. Thank you for always believing in me, and of course for the many, many hours of translating. The other was the Musunguu Peasant Farmers Self Help Group and all the interviewees who gave their time so generously and shared their experiences with me; at times I admit I struggled to maintain my objectivity, but they always kept theirs – I hope the Kenyan government will help you realise your great potential.
Statement of originality and ethics declaration

This thesis is the result of my own independent work/investigation, except where otherwise stated. Other sources are acknowledged by explicit references.

Signed........................................ (candidate) Date ...27th September 2013................................

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

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Statement of Ethics Review Approval

This dissertation involved human participants. A Form E1BE for each group of participants, showing ethics review approval, has been attached to this dissertation as an appendix.
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Acronyms

AFUB: African Union of the Blind
DPOs: Disabled People’s Organisations
NCPWD: National Council for Persons with Disabilities
KNCHR: Kenyan National Commission on Human Rights
NGO: Non-Governmental Organisation
UN: The United Nations
WHO: World Health Organisation
Glossary of terms

**Disabled people:** whilst terminology varies across cultures and languages, ‘people with disabilities’ (PWDs), has not been used in this report. This decision was made after careful consideration of the concepts and literature surrounding disability. The term ‘people with disabilities’, assumes that the individual has the disability; similar to how a person may have brown hair for example. Disability does not represent a personal characteristic in this way - the person does not own the disability, so disabled people is used in recognition of social oppression. Using the term disabled people also avoids referring to disabled people by an acronym, as in PWDs.

**The global North:** refers to the 57 countries categorised by the United Nations to have a high human development index rating. These countries are largely in the Northern Hemisphere.

**The global South:** refers to the countries of the rest of the world - the marginalised majority that have low human development rankings and are predominantly located in the Southern Hemisphere.

**Models of disability:**

**Medical Model:** it is the impairment itself that causes limitations and therefore people should be medically ‘cured’ of their impairments to become ‘normalised’ within society. The problem is individualised without recognition of socially constructed barriers.

**Charity/Welfare Model:** a policy response to the medical model that aims to assist people through welfare approaches.

**Social Model:** disability is determined not by individual impairments but by social systems which segregate and exclude disabled people from society.

**Ontoformative concept:** a means to capture social dynamics in bodies – a form of global social embodiment. It is seen as an avenue to bridge the politics of disability with the politics of impairment.
**Biopsychosocial concept**: disability is seen as a multidimensional concept that constitutes the outcome of interactions between intrinsic features of the person and the person’s physical, built, attitudinal and social and political environment (Bickenbach, 2011). In other words it is an integration of the medical and social models. It was developed by the WHO as a basis for its international Classification of Functioning, Disability and Health (ICF) model.¹

**Structure of the Study**

This study is comprised of six chapters:

**Chapter One** provides the conceptual background and study rationale. The aims and objectives are stated before introducing the Kenyan context and an overview of the research area.

**Chapter Two** explores the subject literature, from the roots of disability oppression through to the current disability discourse and the debate surrounding the introduction and implementation of the CRPD.

**Chapter Three** discusses the research methodology and the approach taken to collect data, as well as considering the ethical implications and challenges to the fieldwork.

**Chapter Four** presents the findings of the research and a thematic comparative analysis of the data.

**Chapter Five** displays the photographs from the photo elicitation interviews and discusses the findings of the exercise.

**Chapter Six** makes recommendations for future research into disability and the implementation of the CRPD. A concluding discussion summarises the main findings before considering the future of disability rights in Kenya.

¹ ICF is the conceptual basis for the definition, measurement and policy formulations for health and disability. It is a universal classification of disability and health for use in health and health related sectors (World Health Organisation, 2002).
Chapter One: Introduction

Background

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is the first human rights treaty of the 21st century. The convention only came into force in 2008; therefore implementation is still in its infancy in many states – as are research and studies relating to the CRPD. The raison d'être of the CRPD is first and foremost an exposition of disability rights, but this belies its multi-faceted role as an international development monitor and implementer. After being heralded as finally empowering the world’s largest minority, there is little research or evidence as to whether any rights have actually been realised, or if it can help citizens claim their rights vis-à-vis their nation state’s adoption of the Convention. Can the CRPD make a difference in the face of other deep rooted social and economic factors?

Study rationale

Approximately 10 per cent of the world’s population have a disability (United Nations, 2013), yet unlike other factors pertaining to vulnerability, such as gender or ethnicity, it receives relatively little attention and is rarely mainstreamed in development policy. Furthermore, at some point in life, and increasingly in old age, almost everyone will experience some difficulties in functioning – disability is therefore ‘part of the human condition’ (World Health Organisation, 2011, p. 3). Development policies may target special interest groups such as disabled people without fully recognising competing identities and forms of disadvantage, such as gender and class. A disabled person’s primary identification of self is not necessarily concomitant with impairment; different or multiple identities may be socially hierarchical. The ‘intersectionality’ of disadvantage is partly reflected in Articles 6 and 7 of the CPRD, which apply to the rights of disabled women and children.

Rights are an important issue for disabled people and although they are entitled to the same rights as everyone else, in reality they are often not realised due to a range of obstacles which prevent them from:
• receiving an education
• obtaining a job
• accessing information
• obtaining proper health care
• getting around
• being accepted by society

The CRPD confirms these universal rights and binds countries to protect them, viewing disabled people as ‘subjects’ with rights who are capable of claiming them as active members of society (United Nations, 2013). The barriers disabled people face in realising their rights are magnified by social and economic disadvantages in the global South – which contains 80% of the world’s disabled people (NCAPD, 2008). There is an imminent need for further research into the root causes and compounding factors that impinge upon the realisation of rights in the global South. The focus for this dissertation emerged as a response to those needs and to develop a more nuanced understanding of the link between rights and development in the global South.

The research was driven by positivist and participatory methodology. This approach gives voice to some of the most marginalised whilst ensuring their evidence is more than anecdotal. To examine the CRPD in a global South context Kenya was selected on the rationale that it has recently ratified the Convention and I have personal contacts and access to research subjects in Mbooni East District; therefore fieldwork will focus on this area. The country also promulgated a new constitution in 2010 that promotes equality and non-discrimination. This adds an interesting and recent dimension to the topic in so far as it examines a new UN convention which under Kenya’s 2010 Constitution ‘shall form part of the law of Kenya’ (The Government of the Republic of Kenya, 2011). The topic was further defined to focus on ‘rural Kenya’ as 80% of the population live rurally (African Union of the Blind, 2007).
Aims and objectives

The project aims to find out how the concepts of the CRPD are realized in those communities in terms of respect for dignity; non-discrimination; participation and inclusion; respect for difference; equality of opportunity; accessibility; equality between men and women; and respect for children.

This will be achieved by first establishing the barriers disabled people face in the community. Secondly, how the exercise of those rights is affected by intersecting forms of disadvantage; and thirdly - how are those rights realised and monitored? The dissertation therefore poses three guiding questions:

- What barriers do disabled people face with respect to the exercise of the rights in the UN Convention?

- How is the exercise of rights by disabled people affected by intersecting forms of disadvantage and social identity?

- How is the CRPD monitored and implemented?
The Kenyan Context

Kenya is an East African country with a population of approximately 38 million (Kenya National Bureau of Statistics, 2009). The National Survey on Disability estimates a disability rate of 4.6%, or about 1.6 million people (NCAPD, 2008). The figure may be even higher due to the inherent difficulties of classifying disability, and the purpose of classification - the World Health Survey 2002-2004 estimated a disability prevalence of 15.2%, which would equate to over 5 million people. Accurate data for developing countries is ‘mostly lacking’ according to the WHO (2011), resulting in systemic problems for planning, policy making and implementation. The majority of the population live rurally, with 75% of the workforce engaged in agriculture, predominantly as subsistence farmers (African Union of the Blind, 2007). Physical impairment is the most common disability, with a prevalence rate of 34% (NCAPD, 2008).

In Kenya half the population live below the poverty line (CIA, 2012). Analysing multidimensional poverty in developing countries, Mitra et al (2012) found that in Kenya whilst 52% of individuals without disability were poor, 67% of individuals with disability were poor – representing a 15 per cent difference, the largest across the 15 countries studied. The Kenyan government launched a Poverty Reduction Strategy Paper in 2000-2001, which amongst other classifications, includes people with physical disabilities. However, other categories of disabled people are not included (Nilsson & Nilsson, 2011). Further research in Kenya is needed on why the incidence of disability amongst the poor is so high, and how multidimensional poverty can be reduced.

One important factor is an absence of economic opportunity, particularly in rural areas. The 2003 Persons with Disabilities Act (hereafter referred to as PDA) contains affirmative measures to address this issue, notably the 5 per cent employment reservation for disabled people (Government of Kenya, 2004). The new Constitution, adopted in 2010, compliments...
this step with the ‘principle that at least five per cent of the members of the public in elective and appointive bodies are persons with disabilities’, Article 54 (2). It should be noted that the requirement is for the progressive implementation of the principle; the PDA has already been criticised for its slow and phased implementation (African Union of the Blind, 2007).

Whilst these steps are of course positive, the fact remains that only a small proportion of the disabled population are formally employed or even work for pay, making these measures largely redundant in their effectiveness (Cobley, 2012). The National Council for Persons with Disabilities (NCPWD) was established under the PDA to realise and enforce much of the Act. In addition to the creation of a database of formal employment and contacting organisations to demand the 5 per cent quota, the NCPWD also raises awareness of disability employment issues in the informal sector (S Tipape, 2013, pers. comm, 21st June). A National Development Fund for Persons with Disabilities was also created to provide monetary assistance to disabled people and organisations (Kamundia, 2012).²

Whilst only minor parts of the PDA have been implemented, it was perhaps an important forerunner for establishing disability rights and principles of non-discrimination. The Act and the promotion of human rights by The Kenyan National Commission on Human Rights³ (KNCHR) were significant steps towards ratification of the CRPD and the theoretical underpinnings for the inclusion of disability measures in the drafting of the new Constitution.

In addition to the affirmative measures of Article 54 discussed earlier, the new Constitution prohibits discrimination by health and disability status (Article 27) and requires the fulfilment of citizen’s social and economic rights by the state (Article 43). Crucially, under Article 2 (6) of the Constitution, the CRPD shall form part of the law of Kenya (The Government of the Republic of Kenya, 2011). Kenya is therefore required to monitor and report on the implementation of the CRPD to the Committee. Previously Kenya has ratified

² In 2010 the government allocated KES 200 million to the fund (Nilsson & Nilsson, 2011). The government proposes to fully implement the fund with appropriate budgetary allocations in line with Vision 2030, Kenya’s long term development blueprint. Additionally, the Ministry of Gender, Children and Social Development started a cash transfer system for severely disabled people in 2011 (Kamundia, 2012).

³ It should be noted that KNCHR was formerly involved, and made important provisions to, the drafting of the CRPD (Mute, 2011).
or acceded to six of the major international human rights instruments, but many of the country’s reports to the treaty monitoring bodies are long overdue (African Union of the Blind, 2007). Although late, Kenya’s state report has been submitted to the Committee, though they have yet to consider it (OHCHR, 2013). The fact that Kenya has submitted a report should be regarded as a sign of political commitment. However, the report has been criticised for being too general with a lack of evidence or data to support assertions on several important issues (Kamundia, 2012). Whilst strengthening of the political profile of disability in Kenya is welcomed, without reliable statistical data it is difficult to see how the government can plan and implement long term disability policy and services.

The research context

“The bodaboda (motorcycle taxi) weaves and bumps its way down twisting dirt tracks, past withered brown crispy shrub, strolling-basket-weaving women and skinny cows. Once at the banks of the dried-up river, the bodaboda spins away, leaving you standing in the expansive shade of the most beautiful mwembe (mango tree) you have ever seen. My friend, you have arrived in the land of Ukumbani.”

Source: Personal photograph

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4 No data is provided on the number of programs or health and education facilities established, or the number of subsidised assistive devices provided (Kamundia, 2012).
5 Extract from my research diary.
The fieldwork was undertaken in Mbooni East District in South Eastern Kenya, a constituency of Makueni County. This land is called Ukumbani and is home to the Kamba (Akamba in the plural), a Bantu ethnic group who live in the semi-arid Eastern Province of Kenya. The rains here only fall twice a year (150mm to 650mm per annum), which is frantically irrigated by local farmers. Figure 2 shows the geographical area of the Kamba.

Figure 2 Kenya ethnic groups. Source: <http://www.exploringkenya.com/images/kenya_ethnic_1974.jpg> accessed on 15/09/12

The main economic activities are subsistence agriculture, beekeeping, small-scale trade, dairy farming and limited coffee growing, commercial businesses (Kenya Decides, 2013). Agricultural products are fruits – mangoes, pawpaws, water melons; maize, cow peas, beans, pigeon peas and lentils, livestock keeping, and dairy farming (ibid). The Kamba are most famous for their basket-weaving, which are traditionally weaved from sisal. Sixty per cent of the rural population live below the poverty line (ibid).
Geographically the research area is situated approximately one hour from Machakos, around the commercial centre of Tawa, a small market town. The Musunguu Peasant Farmers Self Help Group, whose chairman helped organise the interviews, meet in the town and its members live in the surrounding villages. The interviews either took place in Tawa where the group meets or in the villages for home visits. The interviewees were from the following villages:

Musunguu, Imale, Kyalá, Kee, Kakuswi, Katuma, Kithuia, Wambali, Kivani, Kasyelia, Syumbe, Sinai and Kwa Kulomba.

Three deaf children who were interviewed attend the Kakuswi Special School for the Deaf. The key informant interviews were undertaken in Tawa and Nairobi.
Chapter 2: Literature review

Roots of disability oppression

In the seminal book ‘Nothing about us without us’ (the clarion call of the disability movement) Charlton wrote that the ‘poverty, isolation, indignity, and dependence’ of half a billion\(^6\) disabled people ‘is evidence of a major human rights catastrophe and a fundamental critique of the existing world system’ (Charlton, 1998, p. 1). Within this statement there are three underlying concepts – that the systemic oppression of disabled people and the denial of fundamental human rights are rooted in the global capitalist system; a system that, exacerbated by Northern state policies such as structural adjustment programs, resulted in the marginalisation of disabled people in the South to the ‘global periphery’ (Connell, 2011), despite being the global majority\(^7\).

Therefore human rights violations ‘are not accidents….but symptoms of deeper pathologies of power’ (Farmer, 2005, p. 7). The domination and subordination of social groups, dogmas of ‘superiority and inferiority’ are embedded in the values of the dominant culture (Charlton, 1998, p. 8). Culture is shaped by history and by social processes, the dominant culture a fruition of the processes and forces of globalisation. This is a socio-cultural and political-economic system reliant upon the value of the body and its labour output. Connell (2011) refers to this process as social embodiment, a reality-forming ontoformative\(^8\) process capturing social dynamics in the body. Importantly, those bodies that do not generate profit are disvalued and categorised as defective. Russell (cited in Charlton 1998, p.22) asserts that we live in a ‘physicalist’ society, predicated on able-bodied norms and terms; those that are dis-abled are systematically excluded and marginalised (Meekosha & Soldatic, 2011).

These are concepts that have shaped the disability discourse and the emerging models of disability. Historically, disabled people have been categorised by their impairments and diagnosed with treatment so they can become as ‘normal as possible’ (Lang, 2009, p. 268). Only through assimilation to the ‘social norm’ could a person become productive and of

\(^6\) Figures vary from 500 million to 1 billion depending on the definition of disability and indicators used. The U.N approximate that 10 % of the world’s population have a disability, the WHO and World Bank denote 15%.

\(^7\) 80 % of disabled people live in the global South.

\(^8\) An explanation of the ontoformative concept can be found in the glossary of terms.
value to society - those that were unproductive were exiled or institutionalised and reliant upon welfare or charity (Kayess & French, 2008). In response to the limitations of this categorisation the emerging disability movement in the 1980’s conceptualised and promoted the currently fashionable social model view of disability. The crux of this concept is the assertion that a person’s functionality is not limited by impairments but by the physical and social environment.

**Intersecting forms of disadvantage**

Disabled people face discrimination not just as a result of the interaction of their impairment with the environment but from intersecting forms of disadvantage and social identity – ‘attitudes displayed by the people around them can be a bigger problem for people with disabilities than the medical condition they must cope with’ (NCAPD, 2008). Kayess and French (2008) point out that disability is a concept that only describes one form of oppression, whereas a woman with an impairment could be subject to both disability and gender oppression – this can be seen as the myriad of identity-based interests that make up each individual’s life experience (Walker, et al., 2013). These multiple forms of discrimination are represented in Figure 1 below:

![Multiple Identities - Groups: Recognition and representation – Intersectionality – Social Complexity](#)

**Figure 3 Identities & social complexity, Source: Development Planning Unit UCL (2010)**
A study by Mitra et al (2013, p. 9) across fifteen ‘developing’ countries found that women had ‘higher multidimensional poverty adjusted headcounts than men’, and persons aged 40 and above are more likely to be poor if they have a disability. Therefore, for example, on average disabled women over the age of 40 in the global South will experience higher levels of discrimination and disadvantage than young men, or even young disabled men. The study also found that higher rates of disability prevailed among women than men. Whilst the determinants for this occurrence are not established, there is some evidence suggesting that women are more likely to become disabled due to rights abuses (Lwange Ntale et al., 2002, cited in Yeo and Moore, 2003).9

Disability seen as a socially constructed concept is one that is not only constructed by non-disabled people as Yeo and Moore (2003) suggest, but also one that is perhaps perpetuated by modernisation. Yeo and Moore describe a video by Jupp entitled ‘Dreams are the worst’, depicting a physical environment constructed by wheelchair users, where buildings have low ceilings and the able-bodied have to stoop and develop back problems (Jupp, 1984, cited in Yeo & Moore, 2003). Proponents of the social model infer that ‘impairment has no underlying reality’ (Kayess & French, 2008, p. 7), but is this true of all environments, particularly pre-modernised ones where people’s lives are dominated by a sometimes unforgiving natural environment? In the global South, these are the places where disabled people most often reside.10 The emergence of the social model led to an increased international politicisation of disability and a paradigm shift towards a rights-based agenda, culminating in the adoption of the CRPD in 2006.

The CRPD

If human rights are universal and apply to everyone, then why is there a need for a convention to protect the rights of a particular group, in this case disabled people? The CRPD largely reaffirms, recognises or guarantees existing rights that are already recognised in instruments such as the Universal Declaration of Human Rights, The International Covenant on Civil and Political Rights and the International Covenant on Economic, Social

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9 An estimated 100 million girls and women in Africa are disabled due to female genital mutilation (Lwange Ntale et al., citen in Yeo & Moore, 2003).

10 The study of Mitra, et al. (2013) found that in 11 out of 15 ‘developing’ countries studied the prevalence of disability was higher in rural areas than in urban centers. 80 % of the Kenyan population live rurally (African Union of the Blind , 2007).
and Cultural Rights (Megret, 2008). However, these rights instruments have largely failed disabled people (Kayess & French, 2008).

Stating the seemingly obvious, the CRPD applies human rights that are specific to disabled people, and encompasses fundamental principles of respect for dignity, non-discrimination, participation and inclusion in society, respect for difference, equality of opportunity, and accessibility. Megret (2008) refers to rights targeted at certain groups as the ‘pluralisation of human rights’, which may seem at odds with the concept of universality and equal rights for all; an ideal which Megret suggests is ‘both helpful and insufficient’. Kayess and French (2008) expand on this rationale in their discussion of substantive and formal equality. The latter describes how the ‘disregard of difference’ and equal treatment of disabled people will inevitably require ‘different treatment’. On the other hand substantive equality requires ‘alteration of the norm to better reflect human diversity’. In the case of disability, the norm may require alteration due to the ‘irreducible experience’ of disabled people (Megret, 2008, p. 498). The sometimes inhumane treatment of this group infers a necessity to establish that, by the virtue of being human, they have the ‘right to have rights’ (Megret, 2008, p. 516).

Whilst acknowledging the potential of a universalist approach (that is recognising and expecting the diversity of humanity) and its influence on the CRPD, Kayess and French (2008) also consider how its ‘Utopian aspirations’ may be difficult to realise. In fact, because the ideological premise underpinning the notion of universalism is predominately an egalitarian concept originating and led by countries of the global North, it further reinforces the cultural hegemony of a rights based approach – an approach that is not always the normative reality across states. For instance, Lang (2009) found that Nigerian social and economic policies were not based on rights but on notions of charity. Even in the disability sector (including disabled people’s organisations), the medical model of disability predominated.

The CRPD is clearly premised on the social model. Paragraph (e) of the preamble recognises that ‘disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (United Nations, 2013). Disabled people are therefore
not viewed as objects of charity but rather ‘as subjects of rights able to claim those rights as active members of society’ (statement by Louise Arbour, cited in Kamga, 2013, p. 227).

However, due to factors such as historical discrimination, not everyone is starting from the same position when claiming rights, and hence instead of merely proclaiming rights the CRPD guides states to how rights should be implemented (Megret, 2008). This is achieved through measures such as awareness raising, reform and adoption of domestic legislation (substantive equality measures), training, employment quotas and provision of services. These measures emphasise the duty of states to the individual, which in some societies rarely exists or is even pejorative. Kamga (2013) argues that the CRPD ignores the communal approach to human rights in Africa and the notion of ubuntu, which Desmond Tutu described as meaning ‘a person is a person through other persons’ (Tutu, 1999, p. 31). The individualism of rights eminating from industrialised societies does not always reflect community structures based on traditional practices such as agriculture (Meekosha & Soldatic, 2011).

On the other hand, Megret (2008) suggests that the CRPD’s general principle of ‘full and effective participation and inclusion in society’ and Article 16’s right to ‘freedom from exploitation, violence and abuse’ imply a social dimension that also, perhaps contensiously, makes a broader demand ‘not only to the state but also to society’. From an African perspective, Kamga (2013) further contends that it is the duty of all communities to supplement the role of the state. Whilst the anti-discrimination initiatives contained in the CRPD are essential in curtailing state discrimination against disabled people, the expectation of governments to create an enabling environment by enforcing individuals to discourage discriminatory practices are, according to Lang ‘virtually impossible’ (2009, p. 281). While Kamga supports community supplementation of the role of the state, Lang advises caution against the ‘privileging of local knowledge that ignores broader structural oppression that exists in many local communities’. This is not to say that participatory methods to development do not work, but that they can be influenced by local power relations and hierarchies.

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11 On the notion of ubuntu Desmond Tutu (1999) wrote ‘A person is a person through other persons; you can’t be human in isolation; you are human only in relationships’. 13
A universal approach undoubtedly faces certain contextual problems, particularly in implementation, but wallowing in a stagnant pool of cultural relativism will not help disabled people realise their rights either. Charlton (1998) considers that cultures are not static separate entities, but shift under the weight of politics, power and modernisation. In the same way, the concept of disability has been shaped by these forces, which is why the CRPD recognises it as an ‘evolving concept’ ensuring ‘the full and equal enjoyment of all human rights and fundamental freedoms by all (emphasis added) persons with disabilities’; long term impairments (Article 1) being the only limits placed on the application of the convention (United Nations, 2013). Defining disability posed a risk of ‘time-locking’ the convention and imposing a predominantly Northern view of disability on Southern cultures. (Kayess & French, 2008). Meekosha and Soldatic (2011) suggest that people in the global South, facing overwhelming issues such as poverty or inadequate housing, do not recognise they have a disability and even contest disability as a concept. Disabled people may not necessarily define themselves primarily though their impairments, and for those that experience multiple deprivations – which rights come first (Watson, 2002, Lang, et al., 2011)?

In South Africa a study by Aliber (2001, cited in Yeo and Moore, 2003) found that ‘the incidence of joblessness and poverty are so extremely high, being disabled is in a sense superfluous’.

Poverty and Disability

Lang (2009, p. 279) suggests that research of the disability-poverty nexus is ‘complex, ill-defined and under-researched’, whereas Coble (2012, p. 372) asserts there is a ‘strong correlation...that is virtually undisputed’. Somewhere in between there is ‘strong ancedotal evidence to suggest that disability and poverty are highly correlated’ (Groce, et al., 2011, p. 1495). What the latter do point to is a critical review of literature on the subject which found that out of 293 peer reviewed articles, only 9.3 % were evidence-based. There is also a dearth of studies that combine quantitative and qualitative methodologies (Groce, et al., 2011). In a study of multi-dimensional poverty in 15 ‘developing countries’ Mitra, et al. (2013), found that the multidimensional poverty gap was higher in all countries for disabled people compared to those without disabilities, concluding that disabled people – ‘on
average, experience multiple deprivations at higher rates and in higher breadth, depth, and severity than persons without disabilities’ (p. 11). Furthermore, the low economic activity rates of disabled people negates from the potential economic outputs of national economies. An International Labour Organisation study found that the exclusion of disabled people from work resulted in 3 % (Malawi and Vietnam) to 7 % (South Africa) of losses in gross domestic product (Buckup, 2009, cited in Cobley, 2012). Further research into the exclusion of disabled people from the workforce would make a positive contribution to the dialogue about the costs to inclusion that states may incur.

The lived experience of disability oppression is a contextual one, not only between the global North and South but also within the global South; a ‘legacy of invasion, colonisation and globalisation’ – leaving in its wake impoverished conditions endured by the majority of disabled people living there (Meekosha & Soldatic, 2011, p. 1389). The poverty levels faced by disabled people ‘are far higher relative to the rest of society’ – they are among the ‘poorest in poor countries’ (Kenya National Commission on Human Rights, 2007, p. v, Coleridge, 1999, cited in Groce, et al., 2011, p. 1493). In Africa, 80 million\textsuperscript{12} people are disabled, and one of the biggest challenges facing this marginalised group is extreme poverty (Kamga, 2013). Due to a multitude of factors ‘poverty breeds disability and disability is a harbinger for more poverty’, resulting in a vicious circle of poverty and disability (Kenya National Commission on Human Rights, 2007, p. v)\textsuperscript{13}.

Poverty is increasingly understood as a multidimensional issue involving more than the measurement of individual income placing a person above or below a constructed poverty line (Mitra, et al., 2013). Issues such as lack of access to health care, food, education, employment, participation, and knowledge about civil rights combine with varying levels of functioning that accentuate deprivation and poverty (Ingstad & Grut, 2007). Sen further identifies poverty as a deprivation of capabilities, an approach that incorporates a persons lack of opportunities and entitlements in addition to income poverty (Sen, 1999). This can be opportunity to earn an income as well as more complex factors such as achieving self-respect and social inclusion. Disabled people have been found to have lower basic capabilities than non-disabled people with the same income – due to the ‘inequality of

\textsuperscript{12} Figures vary between 60-80 million; the higher figure is from the African Studies Centre, 2013.

\textsuperscript{13} Appendix A shows details of Yeo and Moore’s poverty and disability circle.
access to basic capabilities’ connected with the disability (Groce, et al., 2011). Additionally, disabled people require more resources to achieve the same level of functioning as non-disabled people and have greater difficulty in converting resources; Sen (2009) refers to this as the ‘conversion handicap’.

Disabled people are therefore more likely to be poor due to a range of institutional, attitudinal and environmental barriers, resulting in social exclusion and violations of human rights (Lang, 2009, Groce, et al., 2011). For disabled people to achieve a good quality of life existing barriers have to be removed and adequate opportunities offered (Lang, et al., 2011).

Barriers

Mitra et al. (2012) found evidence across several studies that disabled people are less likely to be employed which is compounded by ‘consistent evidence’ that disabled adults attain fewer educational qualifications. Most work in the informal sector, the majority are either self-employed or contribute at the household level providing unpaid labour – working on the family farm or shop (Groce, et al., 2011). In a Kenyan study only 16% of disabled respondents had worked for pay, amongst those residing rurally this fell to 9% compared with 25% in urban areas (Cobley, 2012). Cobley contends this is due to a combination of lack of opportunities, availability of assistive devices, difficult terrain and inadequate infrastructure in rural areas, which generally make school and work attendance more difficult. Imrie (1996, cited in Yeo and Moore, 2003) refers to this as ‘apartheid by design’.

These physical dimensions are excacerbated by the limited citizenship and social discrimination of disabled people. These are often systemic of prevailing negative attitudes amongst policy makers, government officials and members of their own communities or even families (Groce, et al., 2011). Micro-finance schemes are an increasingly popular way for poor and marginalized groups to access capital for small business enterprises, however many disabled people find that micro-finance institutions avoid them (United Nations, 2006).

The inclusion of a disabled person at the household level will inevitably require the reprioritisation of household resources, which if not achieved can lead to poor coping for
both the individual and household unit (Ingstad & Grut, 2007). The evidence to whether
disabled households are economically worse off is mixed (Mitra, et al., 2013). A Tanzanian
survey showed households with a disabled member to have ‘a mean consumption of less
than 60% of the average’ (Elwan, 1999). Links are increasingly being found to suggest that
households with disabled members are caught in the same mutually self-reinforcing
negative cycle of poverty and disability with cross-generational impact (Lang, 2009, Groce,
et al., 2011). If disabled people in the global South are not to be left behind in the rush for
development it is imperative to break this cycle and remove the barriers they face in their
everyday lives. Achieving this through the lens of a rights-based approach and the CRPD
requires a great deal of national responsibility and international cooperation.

Realising rights

Through ratification of the convention states are required to create national focal points to
implement and monitor the CRPD. Considering the substantial and substantive range of
rights, devising targets that are ‘feasible, yet progressive, achievable but not trivial…and
measurable’ is a considerable challenge to governments (Bickenbach, 2011, p. 5). Lang
(2009, p. 276) contends that in developing countries ‘there are no disability statistics
whatsoever’, which is contestable. Some disability activists argue that statistics cannot
capture the levels of discrimination and oppression encountered by disabled people (Lang,
2009). However, without any statistical data it is extremely difficult to hold governments to
account, internationally or locally. For example, Uganda passed the Persons with Disabilities
Act in 2006, yet as of 2011, had not passed any regulations for its implementation (Lang, et
al., 2011). There is a risk of allowing states to take the progressive realisation of rights
extremely progressively. However, with the blending of civil and political rights with
economic, social and cultural rights, the CRPD effectively abandons a traditional progressive
realisation of rights (Kayess & French, 2008).

Whilst there is no agreed universal definition of disability, the nature of national monitoring
allows institutions to be ‘tailored to the political, cultural and institutional traditions of each
state’ (Carver, 2011, p. 21). Whether states should designate ‘one or more focal points
within government’ (United Nations, 2013), can be seen as the result of competition for
finite resources amongst minority groups. The argument for separate institutions that can
empathise with particular group needs perhaps highlights the need for robust statistics and data rather than institutional empathy. If a state has more than one monitoring institution is it not at risk of pandering to the influences of leadership elites amongst social groups? The efficiency of various national monitoring apparatus will perhaps be tested over time through their successful (or unsuccessful) submission of reports to the Committee on the Rights of Persons with Disabilities (hereafter referred to as the Committee) every four years.

If governments are held accountable for the enforcement of rights this in turn should increase awareness and action from rights-holders to demand their rights. Whether this circle is mutually reinforcing depends on the capacity of states to enact legislation and deliver services and the knowledge of citizens that they have rights in the first place.
Chapter 3: Research design and methodology

The initial research strategy and subsequent design is a result of the symbiotic and reflexive process between the preliminary review of the literature (and research proposal), selection of realistic primary research objectives and the fieldwork.

During formulation of the research proposal a test-run of the proposed data collection methods was undertaken. The pilot study involved interviewing two disabled people in London and testing the potential of using photo-elicitation methods for interview. Once the initial topic and the avenues for fieldwork had been investigated, a preliminary literature review highlighted a survey carried out by the African Union of the Blind (AFUB) in 2007, which showed great potential for a comparative study of human rights issues pre and post Kenya’s ratification of the CRPD. The AFUB survey employed a monitoring tool that used human rights standards defined by the UN. The comparative nature of the research necessitated the collection of primary data from the research area to ascertain whether the CRPD can make a difference to people in rural Kenya.

Qualitative methodologies were chosen with the aim of communicating directly with disabled people so they could articulate the nuances of their circumstances. This was to discover what barriers, physically, environmentally and socially, people face in order to achieve the human rights laid out in the UN Convention; and to further identify the issues that influence the ability to pursue their goals. The initial target sample was 20 participants. Fortunately my local research partner, Marielle Griggs, lives and works in the area and was able to make initial arrangements for the fieldwork, and also acted as a translator.

The research also sought to examine how the exercise of rights by people with disabilities is affected by intersecting forms of disadvantage i.e. gender, ethnicity, geographic location, age, education level and income level. What issues are influenced solely by their disabilities or by factors relating to other aspects of social identity? This is an attempt to unpack issues relating to human rights, intersectional identity and well-being. Key informants were also identified and contacted for interview to establish how the CRPD is being implemented and monitored in Kenya.

14 The full report can be viewed at http://www.yorku.ca/drpi/files/KenyaReport07.pdf
Data collection

As the research was targeting a specific population with particular characteristics i.e. disability, purposive\(^{15}\) and snowball\(^{16}\) sampling was used to select local disabled people to interview. These methods are particularly useful when the research subjects are hard to find, such as stigmatized groups. After contact with the chairman of a local disabled group was made, some initial interviews were arranged. Subsequently, as word spread amongst the local disabled community (with the help of the group chairman and local community health workers), the process ‘snowballed’ as more people either ‘turned up’ every week for interview or home visits were arranged. Home visits were encouraged over time to try to contact those who were house-bound or could not travel far; and to try to widen the research area geographically.

The research was based on in-depth structured interviews and a photo-elicitation exercise (PEI)\(^{17}\). Written surveys are inappropriate for those who are visually impaired or have been excluded from education, and are very hard to carry out in rural areas (Yeo & Moore, 2003). Structured interviews were necessary to enable the data to be codified, analysed and compared to the 2007 data.\(^{18}\)

The PEI exercise used disposable cameras that were given to people for a few days. These are designed to give people autonomous space to identify aspects of their lives that they like or dislike and the values and aspirations that they are, or are not, able to realise (Walker, et al., 2013). Photo elicitation is essentially the idea of introducing photographs into a research interview. They can add intimate dimensions of the social – photos of family, social groups, images of the body; all intimate connections of self to history, society and culture (Clark, 2004). PEI can potentially evoke more information, a different kind of information, and also ease rapport between the interviewer and interviewee (Harper, 2002). This last aspect is particularly important if the interviewer is crossing cultural boundaries. Even if there is nothing superficially interesting about the photographs, they

\(^{15}\) In purposive sampling subjects are selected because of a known characteristic relevant to the research questions posed (Bryman, 2012).

\(^{16}\) Snowball sampling occurs where the initial person or small group of people relevant to the study are sampled, and subsequently lead the researcher to other members of the same population (Bryman, 2012).

\(^{17}\) Copies of the interview questions can be found in Appendix D.

\(^{18}\) A copy of the coding scheme can be found in Appendix C.
can act as a medium of communication and disrupt the power dynamics of traditional interviews (Harper, 2002). Harper sums it up succinctly – ‘when two or more people discuss the meaning of photographs they try to figure out something together’.

To ascertain how the convention is monitored (CPRD Articles 32-50) interviews were conducted with governmental and non-governmental organisations, such as the National Council for Persons with Disabilities and the Kenyan National Commission on Human Rights. Interviews were also undertaken with staff from local organisations that work with the disabled community, and last but not least, the Senior Chief of the area.19

In addition to this collection of primary data, secondary data was used that further informs the research on the rights of disabled people in Kenya and the organisations that are responsible or assist them in realising and monitoring human rights. Two surveys were carried out by national and international organisations in 2007 and 2008,20 prior to Kenya’s ratification of the CRPD.

Ethical considerations

As the subjects are vulnerable members of society there are numerous ethical considerations. It would be slightly delusional to imagine that the research results will be of great benefit to the subjects, however sometimes people benefit from recognition of their needs and the opportunity of talking about their problems, which in fact was commented upon. Care also has to be taken that recognising needs does not lead to the expectation that through the research somehow those needs will be fulfilled. Before the interviews participants were given a research information sheet and an informed consent form to sign.21 The content of the forms and the purpose of the study were discussed prior to commencing the interviews, and anonymity was assured. It became apparent quite quickly that the information sheet was of little use due to low literacy levels, so considerable time and care was taken to explain why we were doing the research and the outcome discussed. Once the dissertation is completed I plan to meet with the group to discuss the outcome.

19 A list of key informant interviews can be found in Appendix B.
21 Copies of the information sheet and informed consent form can be found in Appendices E and F.
and give them a copy of the report. Ethics approval was granted by Oxford Brookes University prior to the fieldwork.22

The project will also improve my research skills and potentially indicate new research areas. Any adverse research impacts will be negated by the long term presence and community involvement of my local research partner, and my own potential future involvement. Since completion of the fieldwork my contact has undertaken ‘sack garden’ training with the group.23

Challenges to the fieldwork and limitations of the research

There were numerous challenges. Firstly, most interviewees spoke the local language, Kikamba, whilst some also spoke Kiswahili to varying degrees. My local research partner could translate those interviews that were able to be conducted in Kiswahili and translate to English for note taking purposes. However, for some of the interviews it was necessary to use a second translator (either the group chairman or a community health worker) to translate from Kiswahili to Kikamba, and vice versa, and then finally into English. This is not only time consuming but inevitably some rapport with the interviewee is lost. There are also local power structures to consider in this process, with the interviewee perhaps feeling wary of imparting certain information.

The second challenge was time. The marginalisation faced by disabled people can make it time-consuming for ‘non-poor, non-disabled outsiders’ to find and communicate with them (Yeo & Moore, 2003). This was negated by the long-term presence of my research partner in the area, but the interviewees were inevitably busy with livelihood activities and contributing to or running households. They also faced difficulties travelling or be willing or have the desire to travel, therefore arranging interviews took time. Additionally because of the translation process the interviews were very time consuming and tiring for both the interviewees and the translator(s), making only a maximum of three interviews per session possible. Home visits also took considerable time.

22 Signed copies of the ethics forms can be found in Appendix G.
23 A sack garden, also referred to as a vertical garden, is basically an empty sack filled with soil that can be used to grow plants. They are used primarily in inner city slums (due to lack of space) but can be beneficial for disabled people as they require less maintenance than a traditional garden. They also use water efficiently.
Over the duration of the fieldwork, as word spread amongst the disabled community, the group chairman and local community health workers were able to contact and mobilise increasing numbers of people, and towards the end of my time in the area the number of potential interviewees was greater than the time remaining for interviews. Therefore we took an emergent approach and decided to organise a group interview on the last week, which also gave me the opportunity to present the concept of the CRPD and talk about rights with the group. Whilst I was unable to codify the data from the group discussion information it certainly enriched the study.\(^{24}\)

This slightly negated one of my main concerns, the size and representativeness of the sample and data set. Given the small scale of the research it does not and cannot claim to be representative of all disabled people in rural Kenya. However, overall it does provide a platform for analysis of an under-researched issue. Another concern was representing a broad spectrum of impairment types in the survey. Whilst, with home visits, this was achieved to a degree, the intellectual and visually impaired are under-represented. Therefore findings cannot be generalised across types of impairment; although due to the evolving and undefined concept of disability, it would be difficult for any survey to make broad comparisons across impairment types.

\(^{24}\) The group discussion also worked as a catalyst for participation amongst the local disabled community. Upon commencement of the fieldwork membership of the Musunguu Peasant Farmers Self Group stood at 15 members, after the group meeting an additional 25 people signed up, swelling the membership of the group to 40 people.
Chapter 4: Research findings and discussion

A total of 16 people with various impairments were interviewed during May and June of 2013, with an even balance of gender and a broad representation of age groups. Two-thirds had mobility impairments; three were deaf, one visually impaired and one mother represented her daughter who is intellectually impaired. The 2007 AFUB survey did not incorporate analysis of occupation, marriage or prevalence of children. I decided to include these demographic characteristics as they can inform the objectives of the research, even though comparisons cannot be made to the earlier survey. The demographics of the surveyed population is summarised below in Figure 4.

Demographic characteristics of interviewees

<table>
<thead>
<tr>
<th>Subject</th>
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<td>ST</td>
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</tbody>
</table>

Figure 4 Demographic characteristics of interviewees
Key

N/A = Not applicable

Sex: M = Male F = Female

Relationship status: M = Married S = Single

Occupation: SE = Self-employed F = Farming SC = Selling charcoal ST = Student SW = Sewing

Type of disability: SI = Sight impaired MB = Mobility D = Deaf I = Intellectual impairment

It is interesting to note, even though the sample size is small, that the ratio amongst correspondents who are married or single is almost reversed according to gender – the majority of males are married, the majority of females single. These types of findings are consequential for policymakers, especially as the majority of the single females have children. All the interviewees involved in livelihood activities are self-employed which reflects the occupational reality for rural communities and particularly disabled people in Kenya (KNSPWD).\(^\text{25}\)

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\(^{25}\) One quarter of disabled people in Kenya residing in urban areas work for pay, compared with 9% rurally.
Coding frequency

The interview codes were numbered from 1 through to 57 to determine a thematic frequency and enable a comparative analysis. The results can be seen below in Figure 5.

<table>
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<th>Subject</th>
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</table>
**Data analysis**

The coding frequency was converted into percentiles and compared to the 2007 results, revealing a percentage point difference which allowed for a thematic analysis of the data. The results are presented in Figure 6 below.

<table>
<thead>
<tr>
<th>Interview themes</th>
<th>2007 AFUB report results</th>
<th>2013 research results</th>
<th>% point difference</th>
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<td><strong>Discriminatory attitudes...</strong></td>
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<td></td>
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<tr>
<td>in the family</td>
<td>45.3%</td>
<td>37.5%</td>
<td>-7.8</td>
</tr>
<tr>
<td>at work</td>
<td>29.5%</td>
<td>18.75%</td>
<td>-10.75</td>
</tr>
<tr>
<td>in society</td>
<td>74.7%</td>
<td>81.25%</td>
<td>+6.5</td>
</tr>
<tr>
<td>by public authorities</td>
<td>8.4%</td>
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<tr>
<td>in the family</td>
<td>35.8%</td>
<td>18.75%</td>
<td>-17.05</td>
</tr>
<tr>
<td>in the workplace</td>
<td>25.3%</td>
<td>12.5%</td>
<td>-12.8</td>
</tr>
<tr>
<td>Category</td>
<td>Value 1</td>
<td>Value 2</td>
<td>Difference</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>----------</td>
<td>----------</td>
<td>------------</td>
</tr>
<tr>
<td>in the community</td>
<td>56.8%</td>
<td>75%</td>
<td>+18.2</td>
</tr>
<tr>
<td>in relationships with public authorities</td>
<td>11.6%</td>
<td>6.25%</td>
<td>-5.35</td>
</tr>
<tr>
<td>Barriers &amp; obstacles...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>in accessing the physical environment</td>
<td>31.6%</td>
<td>87.5%</td>
<td>+55.9</td>
</tr>
<tr>
<td>in communicating with others</td>
<td>15.8%</td>
<td>25%</td>
<td>+9.2</td>
</tr>
<tr>
<td>in accessing education</td>
<td>33.7%</td>
<td>37.5%</td>
<td>+3.8</td>
</tr>
<tr>
<td>in accessing work</td>
<td>22.1%</td>
<td>62.5%</td>
<td>+40.4</td>
</tr>
<tr>
<td>in accessing public services &amp; authorities</td>
<td>6.3%</td>
<td>31.25%</td>
<td>+24.95</td>
</tr>
<tr>
<td>and negative experiences that are religion-related</td>
<td>6.3%</td>
<td>6.25%</td>
<td>-0.05</td>
</tr>
<tr>
<td>Poverty</td>
<td>40%</td>
<td>50%</td>
<td>+10</td>
</tr>
<tr>
<td>Positive life experiences...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>in the family context</td>
<td>41.1%</td>
<td>62.5%</td>
<td>+21.4</td>
</tr>
<tr>
<td>in the school context</td>
<td>5.3%</td>
<td>18.75%</td>
<td>+13.45</td>
</tr>
<tr>
<td>in the community</td>
<td>36.5%</td>
<td>56.25%</td>
<td>+19.75</td>
</tr>
<tr>
<td>religion-related</td>
<td>9.5%</td>
<td>18.75%</td>
<td>+9.25</td>
</tr>
<tr>
<td>Human rights implications-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dignity...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>feelings of being respected &amp; valued</td>
<td>25.3%</td>
<td>37.5%</td>
<td>+12.2</td>
</tr>
<tr>
<td>feelings of being disrespected &amp; devalued</td>
<td>94.7%</td>
<td>81.25%</td>
<td>-13.45</td>
</tr>
<tr>
<td>Autonomy...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>self-determination</td>
<td>36.8%</td>
<td>31.25%</td>
<td>-5.55</td>
</tr>
<tr>
<td>lack of autonomy</td>
<td>70%</td>
<td>75%</td>
<td>+5</td>
</tr>
<tr>
<td>Equality...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>can participate equally</td>
<td>11.6%</td>
<td>18.75%</td>
<td>+7.15</td>
</tr>
<tr>
<td>inequality</td>
<td>86.3%</td>
<td>81.25%</td>
<td>-5.05</td>
</tr>
<tr>
<td>Inclusion...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excluded</td>
<td>80%</td>
<td>75%</td>
<td>-5</td>
</tr>
<tr>
<td>Included</td>
<td>68.4%</td>
<td>37.5%</td>
<td>-30.9</td>
</tr>
<tr>
<td></td>
<td>2022 (%22)</td>
<td>2023 (%23)</td>
<td>Change (%23 - %22)</td>
</tr>
<tr>
<td>-------------------------</td>
<td>------------</td>
<td>------------</td>
<td>--------------------</td>
</tr>
<tr>
<td><strong>Respect for difference...</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>being respected</td>
<td>4.2%</td>
<td>31.25%</td>
<td>+27.05</td>
</tr>
<tr>
<td>being labelled</td>
<td>53.7%</td>
<td>68.75%</td>
<td>+15.05</td>
</tr>
<tr>
<td><strong>Responses to discrimination...</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>distancing</td>
<td>47.4%</td>
<td>87.5%</td>
<td>+40.1</td>
</tr>
<tr>
<td>resistance</td>
<td>31.6%</td>
<td>12.5%</td>
<td>-19.1</td>
</tr>
<tr>
<td>reporting</td>
<td>45.3%</td>
<td>12.5%</td>
<td>-32.8</td>
</tr>
<tr>
<td><strong>Reasons for not reporting...</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>nothing would have happened</td>
<td>26.3%</td>
<td>18.75%</td>
<td>-7.55</td>
</tr>
<tr>
<td>fear</td>
<td>14.7%</td>
<td>6.25%</td>
<td>-8.45</td>
</tr>
<tr>
<td>corruption</td>
<td>6.3%</td>
<td>6.25%</td>
<td>-0.05</td>
</tr>
<tr>
<td>god will see it</td>
<td>n/a</td>
<td>6.25%</td>
<td></td>
</tr>
<tr>
<td><strong>Roots of discrimination...</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>economic</td>
<td>33.7%</td>
<td>81.25%</td>
<td>+47.55</td>
</tr>
<tr>
<td>social</td>
<td>34.7%</td>
<td>50%</td>
<td>+15.3</td>
</tr>
<tr>
<td><strong>Recommendations...</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>raise awareness</td>
<td>48.4%</td>
<td>37.5%</td>
<td>-10.9</td>
</tr>
<tr>
<td>economic support</td>
<td>26.3%</td>
<td>25%</td>
<td>-1.3</td>
</tr>
<tr>
<td>social support</td>
<td>34.7%</td>
<td>68.75%</td>
<td>+34.05</td>
</tr>
<tr>
<td>monitoring</td>
<td>n/a</td>
<td>25%</td>
<td></td>
</tr>
<tr>
<td>legislation</td>
<td>29.5%</td>
<td>6.25%</td>
<td>-23.25</td>
</tr>
<tr>
<td>education</td>
<td>n/a</td>
<td>25%</td>
<td></td>
</tr>
<tr>
<td>training</td>
<td>n/a</td>
<td>12.5%</td>
<td></td>
</tr>
<tr>
<td>peer support</td>
<td>12.6%</td>
<td>6.25%</td>
<td>-6.35</td>
</tr>
<tr>
<td><strong>Gender, ethnicity, class &amp; disability...</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>gender</td>
<td>n/a</td>
<td>37.5%</td>
<td></td>
</tr>
<tr>
<td>ethnicity</td>
<td>n/a</td>
<td>25%</td>
<td></td>
</tr>
<tr>
<td>class</td>
<td>n/a</td>
<td>68.75%</td>
<td></td>
</tr>
</tbody>
</table>

*Figure 6 Thematic data analysis*
Data comparison

In this section the research findings are compared, analysed and discussed according to the survey themes - barriers, human rights implications, roots of discrimination, interviewee recommendations and social complexity, intersectionality and disability.

Barriers

*Discriminatory attitudes*

Results indicate that discrimination on the basis of disability, resulting from attitudinal behaviour in the family and from society at large follow a similar pattern to the 2007 survey. Over 80% of interviewees reported they experienced discrimination in their everyday lives from within their communities, and 37% in the family context.

Experiences ranged from being ignored - ‘people don’t see me as a person’ and subsequent feelings of isolation and loneliness - ‘some are kind but most don’t want you around’. In over two thirds of cases these feelings were compounded at home - ‘I am ignored at home; my parents tell me that my work is just sitting or eating’. Children interviewed at the local deaf school felt completely disrespected by hearing children and the community at large. They felt some respect at home but also communication difficulties and isolation.

In comparison to the 2007 results my research indicates a 10% decrease in reports of discrimination at work. Whilst access to work was a major problem, it is likely the decrease in discrimination at work is due to the occupations of the interviewees in my research. All the participants were self-employed and many worked at home, either farming their own land or incorporating additional activities such as sewing or producing charcoal. Therefore the lines between types of discrimination are blurred for those who experience it at home and at work. A quarter of the women interviewed faced discrimination at home (compared to 12.5% of the men) yet none reported discrimination at work, as work and home often overlap and the discriminatory themes are cross-cutting.

Lack of formal employment was not simply a lifestyle choice or an ethnic or cultural tradition. Some respondents explained how they had sought work in Nairobi, usually earlier on in their working lives, but faced many obstacles and discrimination. They were not picked
for factory jobs due to their disability, and whilst the non-disabled who were picked could pay daily bribes to get work, the disabled workers were left behind in a hopeless cycle of ‘no money no work, no work no money’; so eventually gave up and returned to their villages.

As in 2007, only a relatively small percentage of people experienced discrimination by public authorities. Particularly in rural areas, contact with public services is limited to health and education for most disabled people – few have utilities and public transport is privately owned, which as discussed later, further compounds barriers and inequality.

Increased awareness of disability amongst public authorities cannot be ruled out either. The NCPWD works with district and village chiefs on disability awareness and rights (S Tipape, 2013, pers. comm, 21st June) and indeed Senior Chief Felix Syano Missyoki (Mbooni East District) stated that the NCPWD have previously consulted with him on disability rights (2013, pers. comm, 28th June).

**Abuse and violence**

Incidences of abuse and violence naturally followed a similar pattern to discriminatory attitudes, with the majority (75 %) occurring in the community. Commonly this is in the form of name calling – ‘people don’t see me as a whole person and they call me names’. All abuses in the family context were reported by women, although there is a 17 % decrease in comparison to the 2007 results. This could simply be representative of the sample differences – the AFUB report had a slight female bias and my research included three students who boarded at school.

Abuse in the community and in the family are inextricably linked. One participant reported that her husband’s family want him to leave her because she ‘wasn’t a good wife’. Now the situation has spread to the community, the majority of abuse coming from men. Whilst her husband is her only support, her main motivation to persevere and stay ‘is to help the children’.

Instances of abuse occurred in strikingly similar situations in both reports. A common theme was abuse from public service vehicle operators. Often busses do not stop due to the perceived extra time it will take for a disabled person to board in comparison to the value of
the fare, and when they do stop the person is often not given sufficient time to board. There is also an extra level of discrimination inherent in the system due to the charge that is levied for the transportation of luggage, such as mobility aids. Additionally disabled people face the prospect of standing if no-one offers them a seat. One interviewee reported receiving abuse from other passengers and ‘had to stand for the whole journey, crying, but no-one helped’.

In a parallel to the AFUB research one interviewee, who due to a lack of other work options hawks goods in the city, also reported instances of abuse from city council officials when trying to sell goods in Nairobi – ‘they come in a car and raid my stall every 2 or 3 months, they target me especially as they know I cannot run after them’.

Access

Accessing the physical environment (including transport) was a major barrier to respondents, with 87% experiencing problems, a 55% increase on the findings of the AFUB report. There could be several reasons why such a large increase was found. Firstly, over two-thirds of my interviewees had a mobility disability, (compared with 22% in 2007) thus problems of mobility are compounded by intersecting forms of disadvantage - a physically demanding rural environment and uncompromising transport infrastructure. Secondly, all the participants lived in rural areas whereas in 2007 a third of the respondents resided in Nairobi. Undoubtedly Nairobi presents some different challenges to mobility, but overall the transport infrastructure is far superior (for instance most roads are tarmacked) and many services are more accessible compared to those in rural areas.

Across the two surveys a similar percentile of people reported problems accessing education. Often this is simply because they cannot afford the school fees. Many respondents commented on a lack of schools for disabled children, particularly parents of intellectually impaired children. Kakuswi Special School for the Deaf is only able to operate through donations received from the local community – since it was registered as a deaf school it ‘has not received one shilling from the Kenyan government’ (E Jackson, 2013, pers. com, 25th June).
Almost two thirds of participants had problems accessing work, an increase of 40% on the AFUB report. As all interviewees lived rurally and formal employment is virtually non-existent, access to work is a major problem for most people and the situation is often exacerbated by a lack of education amongst disabled people. If not working in the family business (often subsistence farming) correspondents mostly turned to small home based enterprises or hawked goods. Starting a small business is a common desire that is unattainable due to lack of capital, or the means to accumulate it. Half of those interviewed defined poverty as a major obstacle in their lives and it is systemic in limiting access to the disabled community.

Positive life experiences

Of course people’s lives are not a constant flow of negative experiences and participants reported, perhaps unsurprisingly, most positive experiences in the family context. This is maybe more prevalent in rural areas where families often live and work together. Over half of the interviewees also reported positive community experiences, particularly common amongst those who were active in community groups and the church.

Human rights implications

The AFUB 2007 report examines four key human rights principles – dignity, autonomy, equality and inclusion. These are all included in the General Principles of the CRPD (Article 3) and provide a basis for comparison between the two surveys, pre - and post - promulgation of the CRPD.

Dignity

An increase in positive community experiences is perhaps reflected in a 12% increase in feelings of being respected and valued, compared with the 2007 survey. However, 80% of interviewees still felt disrespected, an issue that was highly prevalent amongst single mothers living at home – ‘I feel less worthy, it hurts my heart when I’m ignored’. Sometimes visitors are sent away, increasing feelings of isolation and unworthiness. One participant described how she was sent to the back at events such as weddings – ‘so I am not seen, so I just leave’.
Whilst the majority of both women and men felt devalued, double the amount of men, in comparison to women, reported some instances where they felt valued. From the interviews there was a sense that, although abuse and violence levels are high for both men and women, the fact that women experience it at home erodes a fundamental sense of self-worth in the one place where it is needed the most. If a person does not feel valued at home, they are less likely to feel valued outside of it.

**Autonomy**

The ability of disabled people to make decisions pertaining to their own lives showed similar results across the two surveys. Three quarters felt their lives lacked autonomy, particularly evident in choices regarding work. Even though many correspondents showed tremendous entrepreneurial vision and determination, many were forced into situations as a result of their disability and transecting forms of disadvantage, such as class and gender.

Many mothers of intellectually impaired children spoke of a lack of autonomy, not only for their child’s ability to make decisions, but for their own capacity to make choices for themselves and their families. This can be especially difficult when a family is not united due to a child’s disability. When one mother finally got a referral from the hospital for her daughter to attend a boarding school specializing in education for the intellectually impaired, she was not given any information about the school or possible alternatives, even though it was far away. One of the deaf students interviewed also commented that he ‘didn’t get to make his own choices at home’.

**Equality**

Similar to the AFUB survey, the majority of interviewees felt they were not able to participate on equal terms in family, work or community contexts. One mother described how her parents had taken her child to cook and do chores for them. Whilst making her life harder the child also suffered and had no time to do homework or any other activities.
**Inclusion**

Three quarters of participants felt excluded and often isolated within their communities and sometimes their own families. In the AFUB survey 68% also reported feelings of inclusion, particularly in public meetings or community groups. My research results indicate a 30% decrease in this figure, although 37% still reported instances where they felt valued and included. Some found that participation in community groups allowed them to contribute on more equal terms and their views were respected.

However interviewees also felt left out. Often this is due to access problems and the physical demands of travelling to different locations; but participants also said some groups do not want to include them, installing feelings of unworthiness and isolation. Five times as many men than women felt included, reflecting community gender roles. Students at the deaf school also felt excluded outside of school. A few members of the local community have been taught basic sign language by Peace Corps Volunteers but the students felt ignored and excluded most of the time.

**Respect for difference**

Whilst 68% of respondents felt they were labelled as a result of their disability, 31% also felt respected, compared with only 4% in the 2007 survey. This maybe reflects some of the positive community experiences discussed earlier and the involvement of the local disabled group in the research. However, labelling such as designated nicknames for types of disability, were all too common.

**Responses to abuse and discrimination**

Responses in this category are in contrast to the findings of the AFUB survey. As per the 2007 results the majority of respondents chose to distance themselves from abuse and discrimination, although the percentile change from my research shows a 40% increase in those that distance themselves from situations. Correspondingly the number of participants resisting or reporting abuse showed twenty and thirty per cent reductions respectively.
One respondent who regularly has his goods taken by city council officials makes a complaint several times a year to the NCPWD but so far has not heard anything and the situation continues. He has joined the disabled persons register at the National Council and has received an ID card which – ‘sometimes helps’. The chairman of the local self-help group is currently in the process of applying for more ID cards and is a pragmatic advocate for disability rights.

For those interviewed that had justification to report abuses, the most common reason for not reporting was that nothing would happen. This reflects not only mistrust in public authorities but also feelings of inferiority. One participant said she did not complain about mistreatment from bus operators because she ‘is afraid of the matatu (bus) people’. Others suggested that they did not report as they forgave the perpetrators, or that ‘god will see it’.

None of the interviewees mentioned ‘lack of access’ as a factor for not reporting, which was a predominant reason in the 2007 survey. This is perhaps a reflection of the lack of knowledge, expectation and availability of public services in the area.

**Systemic roots of discrimination (social, political and economic factors)**

Whilst lack of legislation was cited as a major cause of discrimination by respondents in the AFUB report, it was not recognised as a discriminatory factor by participants in my research. This again reflects the almost non-existent expectations (and knowledge) that the interviewees have of the government and legislative process.

Instead over 80 % of correspondents indicated that underlying economic issues excluded them from fully participating or advancing in society. In addition 50 % of those interviewed reported that exclusion and discrimination is entrenched in society, their communities and homes; which are exacerbated by stereotypes of disability and prevailing social constructs. As discussed earlier, poor families sometimes consider disabled members a burden whose only use is ‘to sit’. Barriers or access to employment, or any livelihood, are linked to existing means of economic production, which in rural communities rarely extends beyond the family farm or informal small enterprise. Without access to capital or formal employment, which is generally only obtainable through bribes or social relationships, disabled people often become ‘trapped in a spiral of increasing poverty and exclusion’ (African Union of the
Blind, 2007). The effectiveness of disability rights and legislation is therefore dependent upon the existing social and economic system - for example formal employment is a precondition to effective employment law.

**Recommendations of interviewees**

Expectations of the government and public authorities, as seen, are low which was further evident when people were asked for recommendations that could improve the lives of disabled people. Only one participant mentioned legislation, whilst 68% suggested social supports in the form of capital for business, financial support and assistance with transportation and employment.

Over two thirds of those interviewed advocated raising the awareness of communities about disability issues, whilst one quarter recommended improved access and assistance to education. Targeted training of disabled people was not suggested in the 2007 survey but was recommended in this research by several people. Many people living rurally are more familiar with NGO’s than governmental organisations and therefore NGO run training programs were mentioned on more than one occasion. An unanticipated new recommendation was monitoring of disabled people by public authorities or NGO’s. Whilst of course this is vital and necessary, particularly in relation to the CRPD, considering the low expectations of public authorities it was somewhat unexpected.

**Social complexity, intersectionality and disability**

The research also attempted to examine how the exercise of rights by disabled people is affected by intersecting forms of disadvantage. Interviewees were asked how they viewed disability in relation to multiple forms of discrimination – class, ethnicity and gender.

**Class**

Interviewees frequently identified with the concept that a poor person would be treated in the same way as a disabled person, and that disabled people who are also poor are ‘totally ignored and disrespected’, and denied basic human rights. This view was common not only in my research but also in 2007, with only a 1% difference between the results in this
category. As discussed above, poverty was considered a major contributor to systemic social inequality.

**Ethnicity**

Only one quarter of participants commented on the precept that a person of a different ethnicity may face oppression in the community, or that ethnicity could compound disability discrimination. This is unsurprising considering the interview sites are in the same region and are largely comprised of the same ethnic group. However, even though the 2007 research was across several regions, including Nairobi, the perceived interrelatedness of ethnicity and disability was also low.

**Gender**

The significance of the intersection of gender with disability largely depended on ‘who you talked to’. The majority of men did not consider gender had an impact, whereas many women, particularly single mothers, recognised how their gendered community and family roles led to social inequality – often exclusion or isolation. Interestingly, as seen in Figure 7 below, women were less likely than men to report discriminatory attitudes, but faced higher levels of abuse and violence.

**Barriers by gender**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discrimination</td>
<td>53.8%</td>
<td>42.3%</td>
</tr>
<tr>
<td>Abuse &amp; violence</td>
<td>44.4%</td>
<td>55.5%</td>
</tr>
<tr>
<td>Access</td>
<td>50.9%</td>
<td>49.1%</td>
</tr>
</tbody>
</table>

When barriers are examined by gender they largely follow the same patterns as the 2007 survey. In my research all incidences of abuse and violence in the family context were experienced by women, whereas at work only men reported incidences. This evidence supports the theory in the AFUB report that women experience oppression in Kenya as a result of their gendered roles in society, which can be exacerbated by disability.
Human rights implications by gender

<table>
<thead>
<tr>
<th>Human rights principles</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Autonomy...</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>self-determination</td>
<td>18.75%</td>
<td>6.25%</td>
</tr>
<tr>
<td>lack of autonomy</td>
<td>81.25%</td>
<td>93.75%</td>
</tr>
<tr>
<td><strong>Equality...</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>equality</td>
<td>18.75%</td>
<td>6.25%</td>
</tr>
<tr>
<td>inequality</td>
<td>81.25%</td>
<td>93.75%</td>
</tr>
<tr>
<td><strong>Inclusion...</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>included</td>
<td>31.25%</td>
<td>6.25%</td>
</tr>
<tr>
<td>excluded</td>
<td>81.25%</td>
<td>93.75%</td>
</tr>
<tr>
<td><strong>Respect for difference...</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>respected</td>
<td>18.75%</td>
<td>12.5%</td>
</tr>
<tr>
<td>labelled</td>
<td>81.25%</td>
<td>87.5%</td>
</tr>
<tr>
<td><strong>Dignity...</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>valued</td>
<td>25%</td>
<td>12.5%</td>
</tr>
<tr>
<td>devalued</td>
<td>87.5%</td>
<td>93.75%</td>
</tr>
</tbody>
</table>

When human rights implications are gendered it is evident that women lack the self-determination of many of the men, and perceive they are less equal and less included than men. In turn they felt more disrespected and less valued. Again, this reflects the gender patterns of Kenyan society and women’s subordination and oppression (African Union of the Blind, 2007).

**Barriers by age**

<table>
<thead>
<tr>
<th>Theme</th>
<th>0-18</th>
<th>26-40</th>
<th>41-55</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discrimination</td>
<td>26.9%</td>
<td>20.8%</td>
<td>35.7%</td>
</tr>
<tr>
<td>Abuse &amp; violence</td>
<td>15.3%</td>
<td>20.8%</td>
<td>25%</td>
</tr>
<tr>
<td>Access</td>
<td>57.6%</td>
<td>58.3%</td>
<td>39.2%</td>
</tr>
</tbody>
</table>

The intersection of age with disability (Figure 9) was considered for further discussion but upon examination of the barriers and human rights implications no clear conclusions could be drawn across age ranks. Suffice to say that whatever their age, disabled people in rural Kenya face discrimination, abuse, exclusion and inequality on a daily basis.
Chapter 5: Photo elicitation interviews

Disposable cameras were given to four members of the disabled group in Tawa and five cameras were given to students at the nearby deaf school. Members of the disabled group had not used cameras before so detailed guidance was given on how to use them, as well as the concept of the exercise — i.e. to take pictures of barriers in their everyday lives, things they like or do not like, family, community and so on. Ethan Jackson, the deaf education teacher at the school, explained the concept and issued the cameras to his students. After approximately one week I collected the cameras and developed the photos. One set of pictures from the Tawa group and one set from the deaf school did not develop, additionally one student from the school who had a camera was absent. In total six sets of pictures were available for interviews.

Results of the PEI

With the disabled group the photos were discussed either prior to the main interview, to ease rapport, or if that was not possible, on separate occasions. Some of the emergent issues are shown below.

Barriers

 Interviewees reported difficulties collecting water. Many relied on the help of family or friends.

26 Interviewees gave their consent for the photographs to be used.
'I walk long distances, it’s difficult, I’m very slow.'  'The market, I don’t feel included in the community'

Livelihoods

'Sometimes I’m able to do some work in the shamba.'  'I rent out a motorcycle taxi, I wish I could ride it'

'I sell charcoal here if I have some money.'

Rearing chickens is another common livelihood activity.
Home life

'Mama and Baba, they don’t respect me.'

'We only have one room for the whole family.'

'Disabled neighbours, there are many of us in the community, we should come together more'

Kakuswi Special School for the Deaf

The photo elicitation exercise was undertaken before the main interview with the three students. The photographs were laid out over tables whilst the teacher, Ethan Jackson, led the discussion. The students all took their photos on the school grounds, a selection is shown below.
Main findings of the PEI

Asking interviewees to take their own pictures is a more inductive approach to photo elicitation and can be used as an interview stimulus (Clark, 2004). Overall, I would contend that this was the most positive aspect of the exercise. The PEI also substantiated the main findings, reaffirming themes such as physical and social barriers – reliance on other people for collecting water, difficult terrain, discrimination at home or in the community, and access to substantial livelihood activities. The PEI was a worthwhile exercise with great potential for transforming power dynamics in interviews. It is important that the researcher
does not judge the photo on how interesting it appears, and that the significance of the photograph is discovered together with the interviewee.

At the deaf school what the pictures do not show is perhaps just as important as what they do show. It was clear from the interviews that the students loved their school and not one picture was taken outside the grounds, not even in the non-disabled school in an adjacent building. This emphasises the problems deaf people face in communicating outside of the deaf community, and why they are one of the most abused groups in Kenya (E Jackson, 2013, pers. comm, 25th June). Additionally this poses questions for the adoption of affirmative or transformative development strategies. Affirmative strategies can address the needs and nuances of a particular group but can also solidify identities and ignore intersecting forms of disadvantage, leading to ‘intersectional invisibility’ (Purdie-Vaughns & Eibach, 2008). Segregation is nowadays seen as an outdated concept and swept into the same pile as charity, incompatible with the fashionable social model of disability and the universality of rights based approaches and the CRPD. There is a danger that whilst promoting universal rights and advocating for inclusion, the raison d’être of why vulnerable groups are vulnerable is overlooked and no services are delivered at all.

**Group discussion**

During the last week of the fieldwork a group discussion was arranged through the disabled group. The meeting was attended by 40 disabled people from the local area representing a broad spectrum of age, gender and impairments; although again those with physical

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27 Affirmative strategies generally divide identity-based groups through special treatment of the target group, whereas transformative strategies adopt a more universally inclusive approach to entitlement (Walker, et al., 2013).
impairments represented the largest group. However, several parents of intellectually impaired children attended. After discussing rights and the CRPD, we decided to split into two groups, over 40 and under 40 years of age, to examine what people thought about their rights and ideas for how they could improve their lives. The results are presented below.

**Rights – over 40’s**

<table>
<thead>
<tr>
<th>Rights</th>
<th>Over 40’s Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life</td>
<td>- idleness, attack because of mobility problem</td>
</tr>
<tr>
<td></td>
<td>- a grown child with mental illness has no-one to care for them</td>
</tr>
<tr>
<td></td>
<td>- grandparents care for their children when parents leave</td>
</tr>
<tr>
<td>Work</td>
<td>- often one parent/family member is the carer</td>
</tr>
<tr>
<td></td>
<td>- physically unable to do manual labour</td>
</tr>
<tr>
<td>Good health</td>
<td>- stay home without treatment because no transport</td>
</tr>
<tr>
<td>Live in the community</td>
<td>- no support</td>
</tr>
<tr>
<td>Education</td>
<td>- no transport for children with disabilities</td>
</tr>
<tr>
<td></td>
<td>- transport, many disabled people stay home</td>
</tr>
</tbody>
</table>

*Figure 10 Group discussion results - over 40’s group*
Rights – under 40’s

Life – we have right to live, we have right to freedom

Work – no discrimination, we have right to work any work

Good health – we are able to be treated like any other person

Live in the community – 50% have challenges, 50% well liked

Say what you think – donors should interfere in problems, government and NGO

Education – we have right to be educated to improve our lives, especially young people

What we can do to improve our lives...

Find and talk to other disabled people using mobiles and compile a phone list to communicate

Talk to local organisations and the community

Improve schools for disabled children – inexpensive, local, and certified
Analysis

The difference between the responses of the two groups is interesting. Whilst the younger group put forward many rights based ideas, the older group concentrated on barriers and care based suggestions. It is difficult to draw any broad conclusions from one discussion, however on this occasion the younger group demonstrated greater awareness of the concept of human rights. Of course, I had just made a brief presentation about rights, so maybe some people simply listened more intently or understood more of the translations.

When asked what people could do to improve their lives, there was a strong community ethos. Perhaps this was due to the fact that we had just come together for the first time. There were some good suggestions, such as compiling a contact list and communicating with other disabled people by phone, especially those at home. Awareness raising initiatives were also proposed, such as improving schools for disabled children, making them inexpensive, local and meaningful, i.e. so certificates are available upon completion of schooling.

Overall, in addition to enriching the research, discussing and sharing ideas helped raise awareness of the issues involved and bought some people together for the first time.

Realising rights – key informant interviews

Interviews were conducted with key institutions in Nairobi to discover developments in monitoring the CRPD. An interview was also conducted with Women Challenged to Challenge (WCC), a national organisation concerned with matters relating to disabled women. This was to try and gain an insight into the multiple disadvantages and barriers faced by disabled women, such as reproductive health. Local key informants were also interviewed to determine how rights are perceived and monitored in the rural context.

It is too early to report on the effectiveness of state reporting as the Committee has yet to consider Kenya’s report. However Kenya does have a vibrant civil society that has produced effective shadow reports to government, along with the alternative reports of the Commission on Human Rights. Over the last two years KNHCR has been monitoring
implementation over the 47 counties in Kenya. Progress is slow, so far only 8 counties have
been monitored (A Wanyoike, 2013, pers. comm, 20th June). KNHCR have also been
interviewing government officers about rights awareness, but ‘so far they are not aware of
the CRPD’ (ibid.). The NCPWD have also been working with district and village chiefs on
disability rights (S Tipape, 2013, pers. comm, 21st June). Chief Felix Syano Missyoki (Senior
Chief Mbooni East District) told me the NCPWD have worked with him on disability rights,
and if you are in the area, he will gladly discuss the subject with you at great length.

As discussed earlier, one of the biggest barriers to disabled people in Kenya is employment.
Most initiatives are confined to the formal sector and have only limited impact. In addition
to raising awareness of disability issues in the informal sector, the NCPWD is also in the
process of compiling a disability register and issuing identity cards to disabled people. Jane
Kihungi of the WCC contended that those who live rurally are often not aware of the
scheme and are rarely registered. However, one interviewee in my research had one of the
identity cards, and the local group chairman, John Kawasya, is in the process of registering
more group members.

Realising rights is still a major problem in education. The performance of disabled students
is poor, and out of an estimated 1.5 million disabled children, only 1.7 % have access to
some form of education (Nilsson & Nilsson, 2011). Furthermore, the performance of those
that do attend school is generally not good, teachers are not trained and the quality is
‘alarming’ (A Wanyoike, 2013, pers. comm, 20th June). The reading level of most deaf
students is pre-school or class one (E Jackson, pers. com, 25th June). The curriculum is also
too rigid to adapt to disabled students. Whilst there are initiatives such as standardising
Kenyan Sign Language (KSL) and increasing the number of signers, Ethan Jackson contends
that there are only 60 to 70 trained KSL signers in Kenya and not enough Kenyan deaf
education teachers in classrooms. There are quality assurance officers, but they ‘never come
to villages’ (ibid.). Despite the rhetoric coming from the government and NCPWD about
school funding, there are few indicators that this is trickling down to rural areas. For
example, the Kakuswi deaf school ‘has not received one shilling from the government since
registration’, even though it should be state funded, and relies on contributions from the
local community (ibid.).
Kamundia (2012) contends that state funded assistance to disabled people is largely inadequate. Discussing the cash transfer project, Amos Wanyoike asserts that there are not enough funds and only 70 homes were targeted across 290 constituencies. KNHCR are monitoring the project and the 2013 budget should see the fund increased to 140 homes (ibid).

During the fieldwork transport was identified as a major problem by the disabled community. Regulation is difficult, matatus are individually owned and whilst the NCPWD is engaging with the transport sector there is little sign of any changes – in fact currently there is only one disability accessible bus in Kenya (A Wanyoike, 2013, pers. comm, 20th June).

In the reproductive health field rights are still violated. Doctors continue to sterilise disabled women without consent due to perceptions of disabled people as burdens (J Kijhungi, A Wanyoike, A Tipape, 2013, pers. comm). Many doctors are unaware of disability issues and communication is a major issue. Kenyatta hospital is now running basic KSL courses for nurses and last year 100 nurses were trained at Nairobi University (A Wanyoike, A Tipape, 2013, pers. comm).

As we have seen communication is a problem not just in hospitals, but in schools, public offices and in the general community. The CRPD remains largely inaccessible to the public, signers are not provided by government and accessible formats are generally not available (A Wanyoike, ibid.). When I asked the chairman of the disabled group about the UN Convention he said he had heard of it, it was something to do with sports. If disabled people are not aware of their rights, they cannot claim them.
Chapter 6: Recommendations and conclusion

Recommendations

In the light of some of the great knowledge and work I have witnessed emanating from individuals and organisations in Kenya, this section has the same feeling one would have telling Amartya Sen how to write a book, or Lionel Messi how to play football. But in order for obligations to be fulfilled, a brief synopsis is presented in this final chapter. My main recommendations are summarised below:

- If the clarion call of the disability movement is ‘nothing about us without us’, then the clarion call of the development field is ‘statistics, and more statistics’. Whilst this study is not simply a call for more data, for the CRPD to link rights to development there is surely a case for data involving a nuanced analysis that will not only improve implementation of the CRPD but also help break the cycle of poverty and disability.

- More research on the poverty/disability nexus is needed, as well as research into the particularities of rural and urban disabled communities.

- Parents of intellectually impaired children are often isolated and further research is needed into systems of support and education.

- Increasing recognition of intersecting forms of disadvantage are precipitating a growing body of literature, but not enough is understood of how disabled people perceive themselves amongst a hierarchy of multiple identities and disadvantage.

It is beyond the scope of this study to offer policy solutions on how to improve local economic opportunities for disabled people or prise open the door of an uncompromising rural environment. What is offered is a reflective view from the fieldwork and the participants involved. Awareness of disability issues amongst rural communities is imperative to address existing barriers. Busses will not stop for disabled people, employers will not offer them work and families will not include them unless perceptions change. In my
view, this can partly be achieved at the local level through inexpensive measures and in a relatively short time. The fieldwork was an example of this. In less than two months a small network of disabled people and community health workers mobilised five times their number, who came together to formulate and exchange ideas and, more importantly, became more visible. From fifteen members the group now stands at over forty. Small change sometimes just needs a catalyst.

Conclusion

Cat-a-lyst > n.*one that precipitates a process or event, especially without being involved in or changed by the consequences*

The CRPD has been described as a catalyst for change, which I would contend it already is, but it is in essence much more than this. In chemistry the catalytic substance remains unaffected – the CRPD on the other hand forms a reflexive and on-going relationship with the process it precipitates, whilst being rooted in a normative reality. This study has empirically examined another reality, which is the lived experience of disabled people in rural Kenya. Whilst this small scale research cannot and does not claim to be representative of all the experiences of rural Kenyan disabled communities, it does demonstrate some key points.

**Barriers and intersecting forms of disadvantage**

While following a similar pattern to that of the 2007 survey, there were some differences between the results with respect to the barriers experienced, and certain nuances that were not covered or revealed in the AFUB report. Instances of abuse and violence in the family context were solely reported by women. Furthermore, women lack the self-determination displayed by men and in turn feel less valued and respected. It would also appear that in the rural context access to the physical environment and work is a major problem. This is largely down to an unregulated and uncompromising transport infrastructure and lack of, or virtually non-existent, access to formal employment. These barriers are linked to existing means of economic production, poverty and societal discrimination.

Due to the non-existent expectations (and delivery) of rural public services and awareness of legislation discrimination is not reported, disabled people instead distancing themselves
from the issues. Alternatively people turn towards more immediate social supports, such as working capital. There were positive signs of a communitarian ethos, and whilst micro-finance loans are hard to access, some support came from harambee’s.28

Right now, if it is a question of money or your rights, people will take the money. The question is how to convince people that rights can bring change. By virtue of Kenya’s promulgation of the CRPD disabled people are rights holders, but few know how to claim their rights. Furthermore, five years after its promulgation, many government officers are still not aware of the CRPD. However, the group discussion showed that the concept of human rights is perhaps filtering down to the younger generation. Even though Nairobi is only 60 kilometres from the research area, it feels a long way from the government’s short reach.

**Monitoring and implementation of the CRPD**

It is easy to recognise rights, but not so easy turning them into reality. Without obligations maybe there are no rights at all, just a showreel of unbridled morality. Obligations are one of the CRPD’s strengths and also one of the biggest challenges. If the question is whether the convention can make a difference, the answer is it already has. The CRPD influenced Kenya’s new Constitution and there are signs, albeit small ones, that some changes are trickling down. However, in rural areas the infrequent rains and dried up river beds are a metaphorical representation of just how fast, or far, the flow of change has come.

Disabled schools are paid for by local people and there are not enough teachers, cash transfer projects do not have money, disabled people do not have jobs, and busses still do not stop. If a road is to be tarmacked it is called an investment, if a disabled school is to be built, it is a cost. Negative attitudes exist at all levels of society and continued advocacy is imperative to convince the government that the benefits of universal and inclusive public policy outweigh the costs in the face of a plethora of national developmental challenges. If disabled people constitute 5 % of the population and only 9 % have worked for pay in rural Kenya, this is a tragic waste of human potential, not just for the individuals themselves but

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28 Harambee denotes togetherness, a collective community system that provides for individuals in need of support – this could be in terms of food or money; ‘merry-go-rounds’ are a popular conception enabling a person to periodically receive a lump sum for purchases that are normally out of reach.
also for the community and the nation. Therein though lies one of the problems, are there 1.6 million disabled people or 5 million? Currently no-one really knows the answer, which makes it difficult for policy makers to make policy, and easy for government to find excuses.

Whether the CRPD will bring about a change in societal perceptions and attitudes to disability depends on the willingness of politicians in promoting a rights-based agenda, and the effectiveness of the state to monitor it. Kenya already has the monitoring apparatus and a vibrant and active civil society. It also has rural communities who are capable of change. Raewyn Connell said that village society had its own brutality, and its own triage, but it also offered protection and had a certain resilience. Perhaps some brutality still exists, for it exists everywhere, but not everywhere can boast of the sense of humanity, diversity and interdependence that ubuntu can bring.

It has been said that the CRPD is predicated on a northern view of rights and individualistic obligations to the state. However, the Kenyan government can invoke the ‘respect, protect, fulfil’ paradigm of international law advantageously. The state has a responsibility to protect, assuming a secondary obligation on society - a society that in Kenya is ready to oblige, is already open and available to others, knowing that its greater whole is diminished when others are humiliated or diminished, when others are tortured or oppressed.29

29 Partial quote from Desmond Tutu (1999).
Bibliography


Available at: http://kenyadecides.co.ke/county/makueni/ [Accessed 31 08 2013].


Watson, N., 2002. Well, I know this is going to sound very strange to you, but I don’t see myself as a disabled person: identity and disability. *Disability and Society*, Volume 17, pp. 509-527.


Appendices

List of appendices

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Appendix A - Yeo & Moore’s Circle of Poverty and Disability

Figure 1 illustrates the reasons why disabled people experience disproportionately high rates of poverty, and Figure 2 displays the ways in which being poor dramatically increases the likelihood of getting an impairment, and becoming disabled (Yeo & Moore, 2003).

Figure 13 Disability/poverty cycle

Figure 14 Poverty/disability cycle

Source Yeo and Moore (2003)
Appendix B - List of key informant interviews

Amos Wanyoike – Kenyan National Commission on Human Rights, Nairobi, (20th June 2013)


Jane Kihungi – Women Challenged to Challenge, Nairobi, (21st June 2013)

John Kawasya – Musunguu Peasant Farmers Self Help Group, Tawa, (20th June 2013)

Ethan Jackson – Deaf Education Volunteer, US Peace Corps, Tawa, (25th June 2013)

Chief Felix Syano Missyoki – Senior Chief Mbooni East District, Tawa, (28th June 2013)
Appendix C - Coding Scheme

• Types and incidence of ‘barriers’ and obstacles experienced in daily life by the interviewees (including negative perceptions of disability, discriminatory attitudes, abuse and violence, poverty, and limited opportunities to participate in social and economic life)

• Ways in which barriers and obstacles experienced by interviewees translate into violations of the key principles of human rights (‘human rights implications’)  

• Ways in which interviewees have dealt with or responded to situations of abuse and discrimination (‘responses to discrimination’)

• Reasons why interviewees have not reported situations of abuse and discrimination (‘reasons for not reporting’)

• Interviewees’ ideas about the social, economic and political factors in Kenyan society that create or reinforce the discrimination they experience or have experienced in the past on the grounds of their disabilities (‘systemic roots of discrimination’)

• ‘Recommendations’ for future social and political action to prevent discrimination and abuse of people with disabilities

In addition to these 6 areas, 3 themes were created to code interviewees comments that alluded to intersections of ‘gender and disability’, ‘ethnicity and disability’ and ‘class and disability’. Only the codes in **bold** are used in coding interviews.

BARRIERS - TYPES OF BARRIERS - barriers and obstacles experienced by interviewees throughout their lives

DISCRIMINATORY ATTITUDES - Perceptions, images of disability and attitudes that the interviewee has faced in her/his life that isolate, exclude or discriminate against her/him

1. **ATTFAM** - Perceptions, images of disability and attitudes that the interviewee has faced in her/his family that isolate, exclude or discriminate against her/him

2. **ATTSCHO** - Perceptions, images of disability and attitudes that the interviewee has faced in school that isolate, exclude or discriminate against her/him

3. **ATTWK** - Perceptions, images of disability and attitudes that the interviewee has faced in the workplace that isolate, exclude or discriminate against

4. **ATTSOC** - Perceptions, images of disability and attitudes that the interviewee has faced in the community or in society at large that isolate, exclude or discriminate against her/him

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30 Adapted from AFUB survey (African Union of the Blind, 2007)
5. ATTGVT - Perceptions, images of disability and attitudes by public authorities that discriminated against the interviewee

ABUSE & VIOLENCE - situations of abuse and violence that the interviewee has experienced

6. ABFAM - situations of abuse and violence that the interviewee has experienced in the family context

7. ABSCHO - situations of abuse and violence that the interviewee has experienced at school

8. ABWK - situations of abuse and violence that the interviewee has experienced in the workplace

9. ABSOC - situations of abuse and violence that the interviewee has experienced in the community and in society at large

10. ABGVT - situations of abuse and discrimination that the interviewee has experienced in her/his relationship with public authorities

LIMITED ACCESS - lack of opportunities and barriers encountered by the interviewee in access to diverse contexts and settings

11. ACCPHYS - barriers and obstacles faced in accessing the physical environment (including transportation)

12. ACCCOM - barriers and obstacles faced by the interviewee to communicate with others

13. ACCEDU - barriers and obstacles faced by the interviewee in accessing education

14. ACCWK - barriers and obstacles faced by the interviewee in accessing work

15. ACCGVT - barriers and obstacles faced by the interviewee in accessing public services and authorities

16. POVERTY - economic deprivation experienced by the interviewee

17. RELIGION - obstacles, difficulties and negative experiences religion-related

POSITIVE EXPERIENCES - positive life experiences reported by the interviewee

18. POSFAM - Positive life experiences in the family context

19. POSCH - Positive life experiences in the school context

20. POSWK - Positive life experiences in the context of work

21. POSOC - Positive life experiences in the community/society

22. POSGVT - Positive life experiences with public authorities/government

23. POSRELIG - Positive life experiences religion-related

HUMAN RIGHTS IMPLICATIONS - Life experiences reported by the interviewee as they relate to key human rights principles

DIGNITY - impact of particular life experiences on interviewees’ perceptions of self-worth
24. POSDIG - interviewee reports being respected and valued in her/his experiences and opinions and able to form opinions without fear of physical, psychological and/or emotional harm

25. NEGDIG - interviewee reports feeling disrespected and devalued in her/his experiences and opinions and not able to form opinions without fear of physical, psychological and/or emotional harm in consequence of the disability

AUTOMONY - ability to make choices and decisions on issues that affect one’s own life (including choosing forms of supported decision-making)

26. SELF-DETERMINATION - interviewee reports ability to make decisions on issues affecting her/his own life (including choosing forms of supported decision-making)

27. LACK OF AUTONOMY - interviewee reports inability to make decisions on issues affecting own life and/or being forced into situations on the grounds of disability

EQUALITY - having own differences respected and disadvantages addressed and being able to participate fully in equal terms

28. EQ - interviewee reports being respected in her/his differences, having her/his disadvantages addressed and being able to participate fully in equal terms

29. INEQ - interviewee reports a lack of respect for her/his differences, a lack of consideration for her/his disadvantages and not being able to participate on equal terms.

INCLUSION - reports of being recognized and valued as an equal participant and having own needs understood as integral to the social and economic order and not identified as special needs

30. INC - interviewee reports being recognized and valued as an equal participant and/or supported in own needs

31. EXC - interviewee reports being segregated, isolated and/or not supported in own needs on the grounds of disability

RESPECT DIFFERENCE - reports of how society deals with difference

32. BEING RESPECTED - interviewee reports being respected regardless her/his differences

33. BEING LABELLED - Interviewee reports being labelled in consequence of disability

RESPONSES TO ABUSE & DISCRIMINATION - ways in which the interviewee responds or has responded in the past to situations of abuse and discrimination

34. DISTANCING - when the interviewee chooses to avoid or distance her/himself from situations and contexts in which she/he has experienced abuse and discrimination
35. RESISTANCE - when the interviewee chooses to keep returning to and or tries to change situations and contexts in which she/he has experienced abuse and discrimination

36. REPORT/LEGAL ACTION - when the interviewee chooses to report or complain about the situation or context in which she or he has experienced discrimination

REASONS FOR NOT REPORTING - reasons that the interviewee gives for not having reported situations or contexts in which she/he has experienced discrimination

37. ‘NOTHING WOULD HAVE HAPPENED’ - the interviewee is convinced that report and legal action would not have had any significant consequences in terms of changing situations and contexts of discrimination, including because she/he does not trust authorities.

38. LACK OF ACCESS - when the interviewee was prevented from reporting due to lack of access to appropriate administrative and/or legal structures or lack of access to information about how to proceed to make a claim

39. FEAR - when the interviewee was prevented from reporting for fear of its consequences

40. LACK OF FINANCIAL MEANS - when the interviewee was prevented from reporting due to lack of financial resources

41. CORRUPTION - interviewee did not report because she/he knew or thought that she/he would have to bribe the authorities

42. SELF-BLAME - interviewee did not report because she/he has interiorized feelings of shame and inferiority

43. GOD – interviewee did not report because ‘god will see it’

SYSTEMIC ROOTS OF DISCRIMINATION - social, political and economic factors that create the discrimination interviewees experience or have experienced in the past on grounds of their disabilities

44. ECONOMIC - the acts of exclusion and discrimination against people with disabilities are related to the ways in which economic (production) activities are organized and delivered

45. SOCIAL - acts of exclusion and discrimination against PWDs are related to the ways in which social (reproduction) activities and social relationships operate and are organized

46. LEGISLATIVE - acts of exclusion and discrimination against people with disabilities are related to the lack of adequate laws or policies to protect their rights and/or to the way existing laws and policies operate

RECOMMENDATIONS – suggestions to improve the situation of people with disabilities in Kenya
47. RAISE AWARENESS - raise awareness and educate society about disability and how to deal with people with disabilities
48. ECON SUPP - government supports to improve access to work for people with disabilities
49. SOC SUPP – government/non-governmental organisations provide support to improve the living conditions and income of people with disabilities and their families
50. MONITORING – government/non-governmental organisations to monitor people with disabilities
51. LEGISLATION - develop and implement new laws and policies to protect the rights of people with disabilities
52. EDUCATION – government to improve access to education for people with disabilities
53. TRAINING – training for people with disabilities from government/non-governmental organisations
54. PEER SUPP - people with disabilities should get together and support each other

GENDER, ETHNICITY, CLASS & DISABILITY – ways in which disability intersects with gender, ethnicity and class

55. GENDER & DISAB - ways in which gender and disability intersect to compound or protect from discrimination
56. ETHNIC & DISAB - ways in which ethnicity and/or race interacts with disability to compound or protect from discrimination
57. CLASS & DISAB - ways in which class (being poor or rich) intersects with disability to compound or protect from discrimination
Appendix D – Interview Questionnaire\textsuperscript{31}

STEP 1 – Introductions, Background Information, Consent & Collection of Personal Data:

(a) Introduction of interviewer/translator

(b) Review of Information Sheet and Free & Informed Consent Form: [Proceed with questioning ONLY if consent is given.]

(c) Collection of personal information:
- Sex ___________________
- Age Range [check one]
  _18-25 _26-40 _41-55 _56-70 _71 and older
- Type of Disability [mark as many as apply]
  _ mobility
  _ sensory – if so, _ blind _ deaf
  _ intellectual
  _ psychiatric
  _ other _________________
  (specify)

Occupation:

Relationship status:

Children:

STEP 2 – Asking the Prompting Questions

1. What are the most difficult barriers or challenges that you face in your life?

2. Have you been left out or treated badly because of your disability?

\textsuperscript{31} Adapted from AFUB survey (African Union of the Blind, 2007)
3. Have you been prevented from participating in activities that you wanted to do?

[DEALING WITH ISSUE / SITUATION #1 RAISED BY THE INTERVIEWEE:]

STEP 3 - Getting Details About the Issue(s)/Situation(s) Raised

WHAT?
- What happened?
- How did it happen?

WHEN?
- When did it happen? (date?, time of day?)
- Is it still happening or has it stopped?
- Is this an ongoing situation?

WHERE?
- Where did it happen? (if the situation is specific to a location, get city/village, province/state)
- Did it happen in only one place? In more than one place? (record all of the places)

WHO?
- What type of person caused the situation? (for example: government official, doctor, bus driver, neighbour ...)

WHY?
- Why did it happen?

REPORTING?
- Did you report the situation to anyone?
  - yes  - no

[• If you did report the situation: ]
what kind of person/organization did you report it to?

• how did that person react?

• what action was taken?

[ • If you did not report the situation: ]

- why did you not report it?

STEP 4 – Relating the Issue(s)/ Situation(s) Raised to the General Human Rights Principles:

DIGNITY

1. Did you feel:
   _ disrespected ? [or]
   _ respected? [or]
   _ did respect not have anything to do with the way you felt ? What made you feel that way?

2. Did you feel that your feelings were ignored or that no one cared for you?

3. Did you feel that people were paying attention to you and your needs?
   [ - Why or why not ?]

4. Did this situation make you feel less worthy?
   _ yes
   _ no
   [ - If yes, what made you feel that way?] 

5. Did you feel isolated in this situation?
   _ yes
   _ no
   [ - If yes, what made you feel that way?] 

AUTOMONY

1. Did you feel that you had a choice [or that you made a decision on your own]? 
   _ yes 
   _ no 
2. Did you have real options in this situation? 
   [ If not, what stopped you from having options? ] 
3. Did you want to make a different decision or did you want to do something else? 
4. Did you have enough information to make that decision? 
5. Did you feel pressured to act the way you did?

NON-DISCRIMINATION AND EQUALITY

1. In what way do you think your disability had something to do with what happened? 
2. Do you think that people without disabilities would be treated the same way you were? [Why?] 
3. Do you know anyone else who was treated in the same way you were? [Why?] 
4. Do you feel that you were treated like you were less valuable than other people in the same situation?

INCLUSION

1. Did your community support you in this situation? [If so, how?] 
2. Were you separated from people without disabilities? [If so, how?] 
3. Did you need a service or some assistance so that you could participate? [If yes, what service(s) or assistance?] [Did you receive them?]
RESPECT FOR DIFFERENCE

1. Were you treated the way you were in this situation because people thought you were different? [If yes, why?]

2. Do you think that other people would have been treated in a similar way in this situation?

3. Would someone of a different ethnicity be treated that way? Would a woman be treated that way? Would a poor person be treated that way?

4. Do you feel that people label you and then treat you differently because of the label?

FOLLOW-UP INFORMATION

• Is there someone we could contact who saw this happen or who could provide us with more information?

  _ _ YES _ NO

  If yes:

  _ What is their name? [record name on Coding Sheet]

  _ Can we contact this person? _ YES _ NO

  - If yes, what is the best way for us to contact him or her?

  [record details on Coding Sheet]

POSSIBLE SOLUTIONS, WAYS TO AVOID FUTURE VIOLATIONS

In your opinion, what action[s] should be taken to improve [or prevent] the situation?

SUMMING UP ISSUE#1
Is there anything else that you would like to say about that issue/situation?

NOW, We are going to return to the issue you raised earlier about (insert brief reference to SITUATION / ISSUE #2)

THE SAME SET OF QUESTIONS WERE THEN RE-ASKED ABOUT SITUATION #2 AND SITUATION #3 (DEPENDING ON WHETHER THERE WAS SUFFICIENT TIME)

STEP 5 – Interview Conclusion

[Do you have anything else you would like to add?]

[Do you have any questions?]

Thank you very much for your time.
Appendix E – Information Sheet

Name, position & contact address of researcher:

Adam Tomlin, Student, School of Architecture, Oxford Brookes University, Headington Campus, Gipsy Lane, Oxford, OX3 0BP

Study title

Disabled people in rural Kenya: can the United Nations Convention on the Rights of Persons with Disabilities make a difference?

Invitation

You are being invited to take part in a research study. This information is provided so that you can make a decision about whether or not you want to participate in this study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. I am giving you a lot of information because I want you to be able to make the decision that is best for you. Please take time to read the following information carefully.

What is the purpose of the study?

I am collecting information about the lives and experiences of people with disabilities by talking directly to people with disabilities. I want to see if their human rights are being respected. The information collected will be studied and used in an essay. The names of participants will not be mentioned in the reports unless they have given clear permission to do so.

The research is looking into:
• Violations of the rights of people with disabilities
• Examine the steps that the government has taken or has failed to take in order to fulfil the promises it has made to people with disabilities when it signed agreements at the United Nations saying that it would protect, promote and fulfil the rights of people with disabilities

Why have I been invited to participate?

I am undertaking research for a project about the rights of people with disabilities. I am inviting you to participate in this research because as a person with a disability you may feel you have been treated unfairly in the past.

After the interview, I will keep all the notes in a secure place. The interview will be confidential and your name will not be on any of the information without your clear permission.

Do I have to take part?

You are free to choose to participate or not to participate in the study; your participation is completely voluntary. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

Can you stop participating if you don’t want to continue participating?

If, at any time during the study, you want to stop participating, for any reason, just let the interviewer know and they will stop asking you questions. If you want to answer some questions, but not others, you can do that, too. It is entirely your decision. If you decide not to participate in the study, or if you
decide to stop participating in the study, your information will not be used. Any notes made up to the point you decided to stop will be destroyed.

What will happen to me if I take part?

If you agree to participate, you will be asked a series of questions about your life and your experiences. I particularly want to know if you feel your human rights have been violated and how they have been violated. In other words, I would like to know if there are unfair things that have happened to you which have stopped you from participating in society in the way that people without disabilities participate in society.

If you agree to participate, you will be interviewed by the researcher and if applicable a translator. During the interview, I will take notes. Depending on the methods of communication that are used, the complete interview should take approximately 1 to 2 hours to complete.

**Are there possible negative things that might happen if you participate in the study?**

There are no negative things that will happen to you by participating in this study. However, you may feel uncomfortable when you start thinking about some of the questions that you are asked. For example, you may remember some things that have happened to you that are not pleasant to think about. If that happens, you can take a break from the interview or, if you want, you can stop the interview completely. If you want to continue to talk about these things, that’s fine, too.

**Are there good things that might happen if you participate in this study?**

You may or may not receive any direct benefit from participation. You might find that it makes you feel better to talk about some of your experiences. This research will further the interviewers understanding of the topic and improve future research.

**Will what I say in this study be kept confidential?**

The information you provide will be kept strictly confidential and unless you specifically provide your consent your name will not appear in the report. The information collected complies with the policy of The University Research Ethics Committee (UREC) which ensures confidentiality, privacy and anonymity in the collection, storage and publication of research material.

**What should I do if I want to take part?**

If you would like to continue with the interview please inform the interviewer you would like to do so and you will be asked to sign a consent form.

**What will happen to the results of the research study?**

The research will only be used in a project that partly fulfils the requirement of the Masters course in Development and Emergency Practice at Oxford Brookes University.

**Who is organising and funding the research?**

The researcher is conducting and funding the research as a student at Oxford Brookes University.

**Who has reviewed the study?**
The research has been approved by the University Research Ethics Committee, Oxford Brookes University.

**Contact for Further Information**

For further information you can contact Adam Tomlin at 12077040@brookes.ac.uk. If you have any concerns about the way in which the study has been conducted, you should contact the Chair of the University Research Ethics Committee on ethics@brookes.ac.uk.

Thank you for taking the time to read the information sheet.
Appendix F – Consent Form

**Full title of Project:** People with Disabilities in rural Kenya: Will the United Nations Convention on the Rights of Persons with Disabilities make a difference?

**Name, position and contact address of Researcher:** Adam Tomlin, Student, School of Architecture, Oxford Brookes University, Headington Campus, Gipsy Lane Oxford, OX3 0BP

Please initial box

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.

I agree to take part in the above study.

**Note for Principal Investigator / Supervisory team:**

I agree that my data gathered in this study may be stored (after it has been anonymised) in a specialist data centre and may be used for future research.

Please tick box

I agree to notes being taken in the interview

I agree to the use of anonymised quotes in the report

_____________________________  ______________________  ______________________
Name of Participant                  Date                        Signature

_____________________________  ______________________  ______________________
Name of Researcher                    Date                        Signature
Appendix G – Ethics Forms

RESEARCH ETHICS FORM E1BE FOR STUDENTS ON TAUGHT COURSES
Please read the Guidance Notes at www.brookes.ac.uk/res/ethics/forms

Section A - You & your project
What is your name?
First name: [Name]
Surname: [Surname]

What is your student number?
1234567890

What is your email address?
[Email Address]

What is your supervisor's name?
First name: [Name]
Surname: [Surname]

What is your supervisor's email address?
[Email Address]

In which Department are you studying?
[Department]

What course are you taking?
[Course]

What kind of data will you be collecting?
[Data Type]

Will it be possible to ensure the participants remain completely anonymous?
[Yes/No]

Will it be possible to ensure the participants do not suffer any negative consequences?
[Yes/No]

Section B - Your participants
What kind of participants will be involved in your research? (Please tick one – If more than one, then complete a separate form)
[Professional, Management, General Public, Vulnerable Individuals]

Briefly describe these participants
[Description]

How many participants will be involved?
[Number of Participants]

How will the participants be selected?
[Selection Method]

Section C - Your data collection
When is your data collection likely to start?
[Date]

What will be your method of data collection?
[Method]

What kind of data will you be collecting?
[Data Type]

Will it be possible to avoid asking for personal data from the participants?
[Yes/No]

Will it be possible to ensure the participants are not being deceived in any way?
[Yes/No]

Section D - Declaration
I declare that I will:
[Declaration]

Student signature: [Signature]
Date: [Date]

Supervisor signature: [Signature]
Date: [Date]

Module Leader signature: [Signature]
Date: [Date]

You may only start fieldwork when this form has been signed by your supervisor & your Module Leader.
### Section A - You & your project

**What is your name?**
- **First name**: Adam
- **Surname**: Tomlin

**What is your student number?**
12077040

**What is your email address?**
12077040@brookes.ac.uk

**What is your supervisor’s name?**
- **First name**: Richard
- **Surname**: Cerver

**What is your supervisor’s email address?**
PCG20009@brookes.ac.uk

**In which Department are you studying?**
- Architecture

**What course are you taking?**
- Development & Emergency Practice

**What is the topic area of your research?**
- Disabled persons human rights

**On what kinds of topics will you be collecting data from the participants in the research?**
- Monitoring of UN Convention on the rights of PWDs

### Section B - Your participants

**What kind of participants will be involved in your research?**
- Professionals/management group
- Members of the general public
- Vulnerable individuals

**Briefly describe these participants**
- Professionals working in the field of human rights

**How many participants will be involved?**
- Number of people

**How will the participants be selected?**
- Through email and contact suggestions of supervisor

### Section C - Your data collection

**When is your data collection likely to start?**
- January 14, 2013

**What will be your method of data collection?**
- In-depth interviews
- Face-to-face surveys
- Direct observation
- Other, please specify

**What kind of data will you be collecting?**
- Quantitative/statistical/numerical
- Qualitative/written/text
- Images/drawings/maps

**Will it be possible to avoid asking for personal data from the participants?**
- Yes [X], No [ ]

**Will it be possible to ensure the participants are not being deceived in any way?**
- Yes [X], No [ ]

**Will it be possible to ensure the participants remain completely anonymous?**
- Yes [X], No [ ]

**Will it be possible to ensure the participants do not suffer any negative consequences?**
- Yes [X], No [ ]

### Section D - Declaration

I declare that I will:
- give all participants an information sheet conforming to university guidelines
- not contact any participant until my supervisor has approved my information sheet, research questions and methodology
- be sufficiently well-trained in necessary methods of data collection and analysis

**Student signature**
- Name: Adam Tomlin
- Date: 22.05.13

**Supervisor signature**
- Name: [Signature]
- Date: 25.05.13

**Module Leader signature**
- Name: [Signature]
- Date: 13.06.13

You may only start fieldwork when this form has been signed by your supervisor & your Module Leader.
Faculty Of Technology, Design & Environment, Oxford Brookes University
ARCHITECTURE / PLANNING / REAL ESTATE & CONSTRUCTION

RESEARCH ETHICS FORM E1BE FOR STUDENTS ON TAUGHT COURSES
Please read the Guidance Notes at www.brookes.ac.uk/res/ethics/forms

Section A - You & your project
What is your name?
<table>
<thead>
<tr>
<th>First name</th>
<th>Surname</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABBAA</td>
<td>TOMLIN</td>
</tr>
</tbody>
</table>

What is your student number?
1234567890

What is your email address?
1234567890@brookes.ac.uk

What is your supervisor’s name?
<table>
<thead>
<tr>
<th>First name</th>
<th>Surname</th>
</tr>
</thead>
<tbody>
<tr>
<td>RICHARD</td>
<td>CRUZER</td>
</tr>
</tbody>
</table>

What is your supervisor’s email address?
1234567890@brookes.ac.uk

In which Department are you studying?
- Architecture
- Planning
- REC

What course are you taking?
- DEVELOPMENT & DEVELOPMENT PRACTICE

What is the topic area of your research?
- DISABLED PERSONS HUMAN HUMAN RIGHTS

On what kinds of topics will you be collecting data from the participants in the research?
- DISABILITIES & HUMAN RIGHTS & INTERSECTING FORMS & DISADVANTAGE

Section B - Your participants
What kind of participants will be involved in your research? (Please tick one - if more than one, then complete a separate form)
- Professionals/managers
- Members of the general public
- Vulnerable individuals

Briefly describe these participants
DISABLED MEN WOMEN DISABLED

How many participants will be involved?
20

How will the participants be selected?
THROUGH LOCAL COMMUNITY CONTACTS

Section C - Your data collection
When is your data collection likely to start?
1 2 3 4 5 6 7 8 9 0

What will be your method of data collection?
- In-depth interviews
- Face-to-face surveys
- Direct observation
- Telephone
- Email
- Post

What kind of data will you be collecting?
- Qualitative/written/text
- Images/drawings/maps

Will it be possible to avoid asking for personal data from the participants?
- Yes
- No

Will it be possible to ensure the participants are not being deceived in any way?
- Yes
- No

Will it be possible to ensure the participants remain completely anonymous?
- Yes
- No

Will it be possible to ensure the participants do not suffer any negative consequences?
- Yes
- No

Section D – Declaration
I declare that I will
- give all participants an information sheet conforming to university guidelines
- not contact any participant until my supervisor has approved my information sheet, research questions and methodology
- be sufficiently well-trained in necessary methods of data collection and analysis

Student signature Date

Supervisor signature Date

Module Leader signature Date