DISABILITY AND POVERTY

A GLOBAL CHALLENGE

Edited by Arne H. Eide and Benedicte Ingstad

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Disability and poverty: a global challenge

Benedicte Ingstad and Arne H. Eide

Disability and poverty

This book is about being disabled and being poor and the social, cultural and political processes that link these two aspects of living in what has been characterised as a 'vicious circle' (Yeo and Moore, 2003). It is also about the strengths that people show when living with disability and being poor: how they try to overcome their problems and make the best out of what little they have. It is a book about those who we will call 'the heroes of everyday life'.

The book aims to provide cross–cultural – and cross–national – perspectives on the situation of living with a disability and being poor. Through this we hope to illustrate how barriers to participation manifest themselves differently – and similarly – in different contexts, and how the coping strategies of people involved (the person with a disability and their family members) emerge in different settings. We hope to bring forward the necessity of culturally sensitive approaches to disability studies and rehabilitation, and to counteract some of the cultural arrogance that Europeans and North Americans tend to bring into this field, assuming that what seems important or relevant for them is the same all over the world.

A new focus on poverty has arisen with the United Nations (UN) Millennium Development Goals (MDGs) (UN, 2000), and with the establishment by the World Bank and International Monetary Fund (IMF) of various new aid instruments and procedures designed to reduce poverty. However, disability was not explicitly included in the MDGs and Yeo and Moore (2003), for instance, state that poor people with a disability have been left out of the MDGs and such poverty–reducing efforts. While this may have hindered a focus on disability and poverty initially, disability and poverty have since been included in the monitoring of MDG implementation, possibly due to the more recent UN *Convention on the Rights of Persons with Disabilities* (UNCRPD) (UN, 2006). The UN report on MDGs and people with disabilities (UN, 2009) states very clearly that 'MDG related policies and programmes have not fully addressed or specifically included disability and persons with disabilities' (p 20). Although a review of 80 MDG country reports revealed that about half of these reports made some reference to disability (p 5),

lack of sufficient and appropriate data on the situation of people with disabilities continues to hamper inclusion of disability and individuals with disabilities into the MDG monitoring and evaluation process.

Except for the absence of disability in the MDGs, a global commitment to ensuring people with disabilities equal access to social and economic opportunities is nevertheless largely in place (Albert, 2005). This is expressed by the UN in the World Programme of Action (WPA) concerning people with disabilities (UN, 1982), in *The standard rules on the equalisation of opportunities for persons with disabilities* (UN, 1994), in the 1996 Resolution by the European Union (EU, 1997), and in the World Health Organization (WHO) resolution on disability (2005). These international documents are all part of the same global commitment which is further underlined through the UN Convention (2008). With the Convention, ratifying states are legally bound to ensure the realisations of a number of fundamental rights that, taken together and supported by official documents at national level in high-income as well as low-income countries, represent a political framework for breaking the disability–poverty link. Furthermore, disability issues in relation to poverty and development have for some time been acknowledged by the World Bank, as demonstrated in the following citation:

> People with disabilities in developing countries are over-represented among the poorest people. They have been largely overlooked in the development agenda so far, but the recent focus on poverty reduction strategies is a unique chance to rethink and rewrite that agenda.
>
> One of the Millennium Development Goals is the eradication of extreme poverty and hunger, a goal that cannot be achieved without taking into consideration a group of people that is so disproportionately represented among the world's poorest people. (Wolfensohn, 2004)

With the Convention and the remaining political framework in place, the crucial issue now for reducing poverty is knowledge-based implementation and service delivery. The need for high-quality data about the situation for people with disabilities has been underlined by many authors (Elwan, 1999; Metts, 2000; Yeo and Moore, 2003; Eide, 2010) as well as the UN report on MDGs and disability (2009). For instance, we do not know whether the reduction in number of poor people in many emerging economies particularly in Asia has benefited people with disabilities, and we do not know how the situation for people with disabilities has developed in stagnating economies, in particular in Africa. The effect of globalisation on the living conditions among people with disabilities is a key area for disability–poverty research that needs to be better understood. However, a mapping and monitoring system is simply not in place in low-income countries, yielding a weak knowledge base for including people with disabilities as well as other vulnerable groups in research that can effectively inform poverty alleviation programmes.

The uniqueness of the disability perspective is that it has to do with poverty within poverty. In low-income countries and areas people with disabilities are among the most vulnerable. They are often the first to die when sanitary and food conditions become critical. They do not get to the hospital because transportation cannot be paid for. They are the last to get jobs when employment is scarce. They are often the last in a group of siblings to be sent to school if the parents can only afford shoes and school uniforms for some of their children, or they may simply be blocked from any education due to lack of resources in the schools or other poverty-related barriers in their environment (see Chapter Four, this volume).

The UN Development Programme *World Development Report 2000/01: Attacking poverty* (UNDP, 2002) lists the following main causes of poverty:

- Lack of income and assets to attain basic necessities – food, shelter, clothing and acceptable levels of health and education (opportunity).
- Sense of voicelessness and powerlessness in the situations of state and society (empowerment).
- Vulnerability to adverse shocks, linked to and inability to cope with them (security).

The above points describe the situation of a range of vulnerable groups, including people with disabilities. They are already struggling with barriers in their societies that are not easily overcome when faced with a disability, thus conditions such as those listed above hit them doubly hard. Living in a poor environment exacerbates their condition. Even in countries where there are national poverty reduction strategies, these do not necessarily benefit people with disabilities who tend to be 'invisible' to the eyes of the planners and administrators. Thus, the problem of poverty and disability is not only linked to the small size of the 'cake', but to the sharing of the small 'cake'.

Poverty dimensions

Poverty is a multidimensional concept that cannot be narrowed down to economic measures alone. According to Wolfensohn and Bourguignon (2004), 'poverty is now seen as the inability to achieve certain standards', poor people 'often lack adequate food, shelter, education, and health care' and 'they are poorly served by institutions of the state and society', p 4.

There are three aspects of poverty that must be taken into consideration. They are embedded in the concepts of absolute poverty, overall poverty and relative poverty. *Absolute poverty* is poverty as measured by global standards and compared across countries and population groups. Income per capita is one such measure and 'one dollar a day' is the international indicator most often used. By such measures, about 1.2 billion of the world population may be characterised as absolute or extremely poor (UD, 2005). Absolute poverty was also defined by the World Summit for Social Development in Copenhagen (UN, 1995) as '… a condition

characterised by severe deprivation of basic human needs, including food, safe drinking water, sanitation facilities, health, shelter, education and information. It depends not only on income but also on access to services'.

Overall poverty takes various forms, including:

> … lack of income and productive resources to ensure sustainable livelihoods; hunger and malnutrition; ill health; limited or lack of access to education and other basic services; increased morbidity and mortality from illness; homelessness and inadequate housing; unsafe environments and social discrimination and exclusion. It is also characterised by lack of participation in decision making and in civil, social and cultural life.... (UN, 1995)

Relative poverty is a poverty measure based on a poor standard of living or a low income relative to the rest of the society in question. Unlike overall poverty it does not necessarily imply that physical human necessities like nutrition, health and shelter cannot be met, but rather that the standards achieved by some people are comparably less than what is common in that particular society (Nielsen, 2009).

In this book we will approach different dimensions of poverty, by exploring the experiences of people with disabilities, and also through a comparative design with unique data on living conditions among people with and without disabilities.

The disability concept

The International Classification of Functioning, Disability and Health (known more commonly as ICF) officially endorsed in 2001, represented a culmination of a discourse on disability manifested as a medical or social phenomenon. ICF changes the balance in this discourse from bodily and individual shortcomings, to the sociocultural and physical barriers to participation. It is questionable to what degree the ICF model of disability is still embedded in medical thinking, but according to Shakespeare (2006), ICF is an attempt to establish a 'biopsychosocial' model that can be said, to some extent at least, to integrate two previously conflicting models of disability, that is, the medical and the social models. With the establishment of ICF, disability is now defined as 'the interaction between the environment and the person with an impairment' (WHO, 2001). In biomedical contexts, where individual diagnoses and decisions of treatment are made, the medical model, with its individual focus, will still prevail. But the fact that the net of attention is being cast wider than before will gradually also influence the medical focus. ICF clearly has limitations in not giving subjective aspects of participation sufficient attention (Imrie, 2004; Hammel et al, 2008), and this book attempts to meet this challenge by exploring the subjective experiences of disability and participation.

The social model is well suited for analysing the problem of disability and poverty in that it pays attention to the *context* in which the life of the poor person

with a disability is lived, and thus makes it possible to focus on the relative as well as the relational aspects of poverty. The weakness of the social model has recently been discussed by Shakespeare (2006), pointing to the lack of balance and thus the absence of the individual and his/her experience in the discourse. The new and interesting aspect of ICF is the possibility to downplay the medical–social model distinction and rather to view the individual with a disability as a whole person with individual and contextual/social differences that contribute to the manifestation of the discrimination of human beings globally.

The vicious circle of disability and poverty

The fact that disability may create or make poverty worse is obvious. With often limited access to education and physical barriers to overcome, people with disabilities are most often severely disadvantaged on the employment market and, if employed at all, often get low-paid jobs and even lower salaries than their non-disabled colleagues. There are many examples of the extreme economic exploitation of individuals with a disability, for instance through organised begging.

When poverty is widespread, persistent disability may be an additional dimension rather than a fundamental cause (Yeo and Moore, 2003). Thus, the mechanisms linking disability and poverty may differ between contexts depending on the character of poverty, and thus also between high-income and low-income contexts. This will also apply to strategies for poverty alleviation. It is, for instance, clearly indicated that the recent introduction of a disability grant in South Africa has given individuals with disabilities and their households a better economic situation than many households without members with a disability (Loeb et al, 2007) (see also Chapter Six, this volume). When poverty is endemic, even a limited grant may constitute a major step forward and not least reduce income security among people living on the outskirts of the modern economy. In developed countries disability grants or pensions may, on the other hand, be regarded as a poverty trap as they contribute to exclusion from the labour market and result in a comparably low life income. Level of living and participation in society is closely linked to work in developed countries, while social life and participation is less dependent on work and income in developing contexts.

What is sometimes less obvious is the way that poverty influences, or creates, disability. Being poor may delay people in seeking help with health problems that are normally curable. Thus, for instance, eye or ear problems may lead to permanent blindness or loss of hearing. Difficulties in labour may be brought to medical attention at a stage where it is too late to save the baby from permanent brain damage, leading to cerebral palsy and/or mental disability or epilepsy. Such delay is usually caused by long distances to health facilities combined with lack of money for transport. Lack of knowledge about where and when to ask for help may also play a role. Poor people also live under worse hygienic conditions (lack of sewage systems, lack of access to clean water) than the wealthier part of the population and have less access to nutritious food. Thus they are exposed to

bacteria and viruses that may cause lasting impairments and have less resistance to them because of malnutrition. Malnutrition in pregnancy may also cause developmental delay and/or make the newborn more vulnerable to infections (see Chapter Nine, this volume).

Often people are aware of the dangers they are exposed to, but poor people have fewer opportunities to change their habitat or way of life in order to avoid such risks to their health. Thus, mothers in the squatter areas near Nairobi feel that the low-hanging high voltage electric power lines that cross the valley may be the cause of (what they feel is) a high incidence of epilepsy in children. They have, however, no way of avoiding them since they need to live close to the factories that employ day labourers on a 'first come' basis, and cannot afford to pay for better housing (see Chapter Eight, this volume). Similarly the poor farmers in Cambodia are quite aware of the danger of mines when they go out to plough their fields or clear new areas of land, but they have no other choice but to do so. Areas already cleared of mines have been taken over by politicians and rich landowners; mines are plentiful in the uncleared areas (see Chapters Ten and Eleven, this volume). Other types of dangerous and disability-causing working conditions also tend to be the fate of poor people. In the often poverty-stricken rural areas of Botswana and South Africa there are many young men in wheelchairs – casualties from dangerous and insecure work in the mines that bring wealth to state treasuries in the same countries, as well as to companies and individuals nationally and internationally (Ingstad, 1997). Poor people also tend to live in the most polluted areas, and are the first victims when accidents occur, such as the Bhopal disaster in India in 1984.

Cultural beliefs and attitudes also tend to have more bearing on the life situation of the poor than on the wealthy. In a study from Somalia comparing the life situation of two boys with comparable intellectual impairment, Helander (1990) has shown how the boy coming from an affluent and respected family was accepted by community members and treated differently (better) than the boy who was a poor orphan. This also had a bearing on the labels placed on their impairments, and the explanations given for them. Thus poverty and low social standing are factors that interplay with cultural beliefs, and have a bearing on the way a disability is culturally labelled and the way stigma (Goffman, 1963) may, or may not, be applied. This, in turn, affects opportunities for participation in the daily life of society.

Poverty may also affect the marriage chances of people with disabilities, which, in many societies, affects their standard of living and their possibilities of being considered fully respected members of their communities. In countries in which bride prices are paid, girls with a disability, if married at all, may bring less cattle (or similar value), if any, to their families than non-disabled girls. While in countries with dowries families may have to pay more for their disabled daughters to be married off, or alternatively marry them considerably below their social standing in order to find a partner and family willing to take them. Thus, disabled girls from a lower middle-class background may be married into poverty. In most

cases, however, people with disabilities, especially girls, have problems finding marriage partners – with or without money (Sentumbwe, 1995). For instance in Yemen, while practically all young men with a disability plan to get married in the future, no girls with a disability consider marriage an option (see Chapter Seven, this volume). For girls with a disability from well-off families education may be considered an equally attractive option, while girls with disabilities from poor families foresee a future remaining for the rest of their lives in their parental home or the home of a sibling, and risk being considered a burden.

Religion may also be an important factor when it comes to influencing the lives of poor people with a disability. It may provide an explanation for why disability occurs, for instance by stigmatising it as a 'sin' or less stigmatising, as 'fate' or 'karma'. It may also give rules for the behaviour of men and women respectively, and the consequences of such rules may be more severe for the poor than for the more affluent person with a disability. In Yemen, men and women are supposed to live in separate spheres of life, secluded from each other in space; women wear a black veil that fully covers their body and their faces (*abaya*), with only the eyes being visible to men other than their father and brothers. Women cannot go outside the house on their own, and must be accompanied by their father or a brother. Poor disabled women are for the most part housebound due to lack of money for transportation and limited accessibility for wheelchairs (if they have one) on the rugged streets of the poor housing quarters or steep hillsides of the villages, while economically better-off disabled women may participate in the social life of the family and neighbouring women by being driven in cars or pushed in wheelchairs (see Chapter Seven, this volume).

Finally, poor people, and especially poor people with a disability, are particularly vulnerable in times of war and in connection with major disasters. We hear about the impacts on civil societies in war-torn places such as Iraq, Syria and Palestine, to name but a few, but rarely about what happens to people with disabilities who are trapped in the fighting. It seems reasonable to assume that poor disabled people lacking the means or ability to get away, and often living in poorly constructed houses, are especially vulnerable (Kett et al, 2005; Eide, 2010; see also Chapters Five, Ten and Eleven, this volume).

Overcoming poverty for people with a disability

In discussing how to overcome poverty in general the following three points have been made which also have a bearing on the situation of poor people with a disability:

- opportunity
- empowerment
- security.

Poor people with disabilities need to find opportunities to get out of poverty. This may be done through education, employment or through loans, often in the form of micro-credit (see Chapter Ten, this volume). It is often not sufficient to give them the same opportunities as everybody else; there must be a positive differential treatment that gives preference to people with disabilities to employment, to education or to other arenas for social participation. People with disabilities are disadvantaged from the outset, thus they need to be given something *more* to be *equal*.

Important sources of empowerment for people with disabilities are their own organisations or interest groups. Often, however, the headquarters of these organisations are located in the cities, and the extent to which the leaders of the organisations identify themselves with, and work for the interests of, the poor and often rural people with a disability vary greatly. It is also a problem that these organisations most often rely heavily on funding from international non-governmental organisations (NGOs), and thus are more subject to their priorities than to the needs and requests of poor people with disabilities. In order to overcome poverty by empowering the poorest disabled, these people too must be given a voice. Another important source of empowerment is education, which is often inaccessible to poor people because of lack of money for transport or barriers caused by the physical or social environment (see Chapter Four, this volume).

Security is a basic requirement for all people, and even more so for those who face limitation in their mobility, in the use of their senses or in their intellectual capacity. People with a disability often lack such basic security, and those who are poor even more so than others. They are at risk, even in the womb, by selective abortions; the danger continues into childhood with infants and children with a disability being especially vulnerable to malnutrition, infections and early death (see Chapter Nine, this volume), and as adults, by discrimination, abuse and exclusion from various arenas of life.

Poor people with disabilities need special considerations but they also need to be part of a general development of their country and community to lift individuals and households out of poverty (see Chapter One, this volume). A person with a disability is unlikely to fare better than the average of non-disabled people he/she is living with or among (see Chapter Three, this volume). Thus, disability as a cross-cutting theme must be brought into all poverty reduction work and research (Yeo and Moore, 2003).

Research on poverty and disability

Poverty-focused research looks at factors that directly inhibit poor people with a disability, and produce or reproduce conditions of deprivation and inequality. We are today far from the ideal goal of seeing disability as a cross-cutting theme in all poverty reduction work and research, and what little research has been

done so far on the link between 'poverty and disability' has been done from two different perspectives:

- macro perspective, mainly in the form of prevalence studies and comparative surveys on key indicators of level of living;
- grass-roots perspective, giving people a voice and bringing forth experience near narratives.

Macro perspective

Research on disability and poverty faces two major problems. First, relatively few researchers have taken an interest in and published in this field, particularly regarding developing countries. Second, a lack of standardised definitions and research instruments on disability provides a meagre basis for comparative studies, even in developed countries. With the introduction of ICF we have a better basis for developing international comparable disability statistics that may also contribute to research on disability and poverty (Üstün et al, 2001). The Washington Group on Disability Statistics[1] has been tasked to develop standard measures on disability based on the ICF framework and has so far produced a set of screening questions that may be applied globally. The debate about disability prevalence and the methods for screening for disability has recently been challenged by Loeb and Eide (2006; Loeb et al, 2007) who, in applying the screening questions developed by the Washington Group, have demonstrated that even with a tested standardised instrument there is still the same problem of where to draw the line between disabled and non-disabled. The authors suggest responding to this challenge by applying different prevalence measures based on the Washington Group screening questions. Eide and Loeb (2006; Loeb and Eide, 2006) also argue that in viewing disability as a continuous rather than dichotomous variable, new possibilities arise for disability statistics and for analysing the relationship between disability and poverty.

Several authors have pointed to the lack of data to analyse the disability–poverty relationship (Elwan, 1999; Metts, 2000; Yeo and Moore, 2003). While a number of studies have shown that people with disabilities in developing countries are worse off than their non-disabled counterparts on a small number of economic and social indicators, few of these studies offer an opportunity to study the relationship further. Recently, several national representative studies on living conditions among people with disabilities have been undertaken in the southern African region (see Chapter Three, this volume). These studies offer an opportunity for comparative analyses of differences between disabled and non-disabled people on a number of indicators of level of living, and also the opportunity to generate new statistics on disability and poverty.

Grass-roots perspective

The 'grass-roots' perspective is often taken in studies based on qualitative, mainly anthropological, methods. So far we have few such studies focusing specifically on poverty, but two anthologies edited by Ingstad and Whyte (1995, 2007) present in-depth studies of the lives of people with disabilities, many of them from poor rural settings, as does a monograph by Ingstad (1997) on the implementation of community-based rehabilitation in rural areas of Botswana struck by drought and poverty.

One of the most promising theoretical approaches to analysing the links between disability and poverty is through the use of the concepts 'social suffering' and 'structural violence' (Kleinman et al, 1997; Farmer, 1999, 2004, 2006). *Social suffering* is imposed on people by conditions outside their control. These may be political, economical, ecological or others. By seeing suffering as *social* in its basic character, the blame and guilt is taken away from those who are suffering and placed on these outside forces. For instance poor farmers in drought-stricken rural Zimbabwe are not to be blamed for the early death of their disabled children, but rather the politics that forced them to move from their fertile lands, and gave them no kind of support when drought struck or when thirsty elephants invaded their land to eat their crops (see Chapter Nine, this volume). By focusing on social suffering we take the responsibility for the consequences of poverty away from the poor. *Structural violence* is the violence of everyday life that causes social suffering, as well as the extraordinary violence of war and other disasters that are beyond the control of the individual person with a disability and his/her family. By using these two concepts in (some of) the analyses of this anthology, we seek to give a voice to poor people with disabilities by bringing forward experience through narratives.

Ethics

The contributors to this book have different reasons for entering into the field of studying the lives of poor individuals with disabilities in the so-called developing countries. It is our intention that the content of the book reflects our deep respect for people who struggle with poverty and are faced with discriminatory practice. It is a great loss to society that millions of individuals in developing countries in particular are not given the means to fulfil their desires or to contribute fully to the societies of which they are a part. It is of the utmost importance that research in this field has an emancipatory strategy in being an active part in the continuous struggle for improved living conditions for all individuals with a disability. We believe that this requires the involvement of people with disabilities in research and researchers who see the value and necessity of sharing and handing over power in the research process to the people with disabilities themselves. Only in this way can research be instrumental in building the capacity among people

with disabilities and be able to influence political processes and shape the society of tomorrow.

Note

[1] The Washington Group on Disability Statistics was formed as a result of the UN International Seminar on Measurement of Disability that took place in New York in 2001. The National Center for Health Statistics authorised the formation of a city group to address some of the issues identified in the International Seminar. See www.cdc.gov/nchs/citygroup.htm for further information.

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Social inclusion of people with disabilities in poverty reduction policies and instruments: initial impressions from Malawi and Uganda

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Introduction

This chapter reviews the importance of people with disabilities being included in the process of national and international development, and of them being substantial beneficiaries of this process. We begin by briefly considering the case for social inclusion in international development work in low-income countries. We then review the internationally agreed targets set out in the Millennium Development Goals (MDGs) and how these targets may be restated in terms that are more inclusive of people with disabilities. Next we describe an important policy instrument – the Poverty Reduction Strategy Paper (PRSP) – that has a critical role in achieving these goals at the level of individual countries. Our major analysis is then drawn from initial impressions of the extent to which people with disabilities have had a meaningful role in the formulation of PRSPs in Malawi and Uganda.

Disability and social inclusion

The degree to which people with disabilities are weighed down in their daily lives by illness or impairment determines the extent to which they experience social inclusion or exclusion. The more they are weighed down, the greater the disadvantage they experience in accessing health, education, communication, housing and other social services. The purpose of the United Nations *Convention on the Rights of Persons with Disabilities* (UNCRPD) is to promote and ensure the full enjoyment of all human rights and fundamental freedoms by people with disabilities, who currently represent 10% of the estimated six billion of the world's population. It is estimated that 20% of the world's poorest people are disabled (Thomas, 2005), and that up to 80% or more of an estimated six hundred million

people with disabilities throughout the world live in low-income countries (Mandesi, 2004).

Disability also has a disproportionate burden on women and children. Unicef (2002) estimates that 30% of street children have a disability, while UNESCO states that 90% of children with disabilities in low-income countries do not attend school. The UN Development Programme (UNDP) also estimates that globally only 3% of adults with a disability are fully literate (UNDP, 1989). While we recognise that the definition of disability is contested, this chapter adopts the view expressed in the International Classification of Functioning, Disability and Health (ICF), that '… a person's functioning and disability is conceived as a dynamic interaction between health conditions (diseases, disorders …) and contextual factors' (WHO, 2001, p 10). However, we also want to stress the strong participatory element of the right to 'involvement in life situations' (p 191) that is also recognised. The UN Convention seeks to safeguard and advance basic rights and human dignity with the ultimate aim of improving the social life and development of people with disabilities on an equal basis with others in society.

The concerns of many governments and representatives of disabled people's organisations (DPOs) often include general principles such as non-discrimination, equal opportunities, equality, reasonable accommodation, positive measures, affirmative action, treatment, accessibility and universal design, self-determination, full participation, full inclusion, independent living, international responsibility/ cooperation, disability inclusive development, empowerment of people with disabilities, as well as human dignity and respect for difference and acceptance of disability as part of human diversity and humanity (UN Enable, 2007). These concerns and a commitment to establish equal rights for people with disabilities are now enshrined in the UNCRPD. Article 32 of the Convention states that development programmes should be inclusive and accessible to people with disabilities. This is because disability is regarded as a mainstreaming issue that should be considered in all development programmes rather than as a stand-alone issue (UN Enable, 2007). The Convention calls for organisations for and of people with disabilities at international, regional and national levels to participate in all development programmes.

Other aspects of the UN Convention include general obligations of states such as the need at national level to undertake all appropriate steps to eliminate discrimination based on disability; to promote international cooperation; and to undertake measures for the progressive realisation of economic, social and cultural rights for the benefit of people with disabilities in each country that has ratified the Convention. Thus mainstreaming disability issues into all economic and social development policies and programmes has been included in the UNCRPD under the provisions of general obligations. Equality legislation includes requirements in relation to making reasonable accommodation for people with disabilities and allows positive action in relation to people with disabilities. It is important that these requirements are fully respected and integrated into international development initiatives and strategies.

Disability and the MDGs

The MDGs and targets emanate from the Millennium Declaration, signed by 189 countries, including 147 heads of state and government (UN, 2000), and from further agreement by member states at the 2005 World Summit (UN, 2005). The goals and targets are interrelated and should be seen as a whole. They represent a partnership between low and high income countries to create an environment – at the national and global levels alike – which is conducive to development and the elimination of poverty (Thomas, 2005). However, these goals are incomplete if they do not explicitly address the aspirations and rights of people with disabilities. To this effect, the former World Bank president, James Wolfensohn, remarked:

> Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 or to give every girl and boy the agreed to goals by more than 180 world leaders at the UN Millennium Summit in September 2000. (quoted in Thomas, 2005)

The failure of the international community to explicitly incorporate disability in the MDGs is problematic in that it may be taken as reflecting the neglect and exclusion of people with disabilities from the major international development instrument of our time. However, we prefer to see this as an opportunity to illustrate the relevance of disability across all these goals, rather than to argue for the seclusion of disability into a new additional MDG. This recognises the importance of disability as an interdisciplinary, intersectoral and interministerial issue and of the experiences of people with disabilities being a good probe to evaluate how well services are integrated in this 'inter-land' (MacLachlan et al, 2009a). We now consider how the eight MDGs may be reinterpreted in terms of people with disabilities.

Goal 1: Eradicate extreme poverty and hunger for people with disabilities and their families
Qualitative evidence suggests that people with disabilities are significantly poorer in low-income countries than their non-disabled counterparts. Many people with disabilities are denied or have limited access to healthcare, education or jobs; their impairment may require continuing care and support, which may drain already scarce household resources.

Goal 2: Achieve *inclusive education*
Very often there are insufficient provisions for children with disabilities to be included in education; they get frustrated with school and may drop out. Children who repeat classes or drop out of school may have emotional or intellectual disabilities. It is impossible to achieve the goal of universal primary education unless educational institutions become more inclusive.

Goal 3: Promote gender equality *for women with disabilities*
Women with disabilities are more likely to be victims of sexual abuse. Violence against women causes psychological disabilities, and some disabilities – such as those affecting the female reproductive system (obstetric fistula) – are particularly stigmatising.

Goal 4: Reduce *the mortality of children with disabilities*
Many children with disabilities are at higher risk of dying because of associated health conditions, but also because of a lack of access to public services, and intense stigma – even within their own homes.

Goal 5: Improve maternal health for women with disabilities *and achieve the rights of children and families*
This is important for disability prevention. Women with disabilities have less access to public health information, which would enable them to make informed decisions about health promotion, including preventive interventions. Lack of information places them at greater risk of unwanted pregnancies and HIV/AIDS.

Goal 6: Combat HIV/AIDS, malaria and other diseases to which people with disabilities may be more vulnerable
AIDS and other contagious diseases can, in and of themselves, be disabling. However, most significantly, efforts to halt the spread of these epidemics frequently do not encompass people with disabilities, putting this group at higher risk of contracting such diseases.

Goal 7: Ensure environmental sustainability and accessibility for people with disabilities
Environmental dangers can lead to the onset of many types of disabilities, and inaccessible environments prevent people with disabilities from taking part in economic and social activities.

Goal 8: Develop a global partnership for development that is inclusive of DPOs
Partnership implies inclusion, which means everyone.

Each of the above eight goals are guided by specific targets and indicators for monitoring progress for the general population. Yet there are no similar targets and indicators set for people with disabilities. The disability-specific MDGs described above are a result of a draft memo on mainstreaming disability in MDGs and other development goals tabled for debate in the UN Assembly (GPDD, 2009). We have made some modifications to these to further emphasise disability.

The MDGs are seen as key goals to strive for, but they do not indicate how they should be achieved. A critical step in the 'how to' process is creating national development policies that are inclusive, both in how they are developed, and in

what they recommend should happen in practice. We now consider one of the major policy instruments used for poverty reduction and national development planning in low-income countries, PRSPs.

Policy instruments for addressing poverty

In low-income countries realising the rights of people with disabilities, as stipulated by the UN Convention, presents a significant challenge. International aid assistance is often directed at achieving the targets set out in a document, drawn up by governments in consultation with others that indicate a country's development priorities, the PRSP. However, disability issues rarely feature in PRSPs. Without getting disability on the agenda of these documents it is hard to channel funding to address the particular challenges faced by people with disabilities.

The World Bank has contributed significantly to putting disability on the development radar particularly through its recognition of the double imperative of human rights and the economic potential of people with disabilities. Translating the MDGs into action requires an operational framework at the national level. In more than 70 low-income countries, this operational framework is increasingly being provided by a country-led PRSP. In designing these strategies, individual countries should incorporate those aspects of the MDGs that fit their own situations and reflect the aspirations of a broad range of the country's citizens.

After several cycles of PRSPs, there is still scant evidence of disability being meaningfully incorporated into national plans. Nonetheless, in some African countries disability has a higher profile than in others, including ministries specifically addressing disability issues. However, even where this is the case, disability has not necessarily permeated into PRSPs in a satisfactory way. On occasions DPOs, whose participation in the PRSP consultation may have served to legitimise the process, have been frustrated by little, or no, subsequent inclusion of disability in the resulting PRSP; elsewhere this consultative process has not even been undertaken.

Getting disability on the policy agenda

The obvious challenge of the stated instruments lies in who formulates them and the consultative processes involved, in terms of how widely civil society and in particular the disability community were consulted or asked to contribute. It becomes difficult to get disability on the policy agenda, and subsequently, to achieve poverty reduction, sustained economic growth and social development, if the prevention of disabling living conditions and the participation of people with disabilities are not explicitly addressed in poverty reduction strategies (Barnes, 2009). Mainstreaming steps are required to ensure that people with disabilities are able to participate fully in the development process and claim their rights as full and equal members of society (Butler and McEwan, 2007). The involvement of people with disabilities from grass-roots level up to the policy implementation

level cannot be an option, but an obligation for both national and international development. We now consider our initial impressions of the social inclusion of people with disabilities in PRSPs in Malawi and Uganda, arising from a study entitled 'African Policy on Disability and Development' (A-PODD) (www.a-podd.org).

A-PODD brings together three partners: the Secretariat of the African Decade of Persons with Disability, the Centre for Rehabilitation Studies, Stellenbosch University and the Centre for Global Health, Trinity College Dublin, and benefits from the input of a number of leading international advisers, across civil society, government and academic research. It is a three-year project (2009-11)focusing on Sierra Leone, Ethiopia, Malawi and Uganda, and is funded by Irish Aid, through the Health Research Board (Ireland). The project is documenting and analysing factors and processes that contribute to realising the rights of people with disabilities, promoting their health and well-being and unlocking their economic potential, within governmental strategies aimed at poverty alleviation, in particular PRSPs.

PRSPs have become the planning tools and catalysts used by most low-income countries to fight poverty. They are used to describe the country's macroeconomic, structural and social policies as well as related external financing requirements and key sources of financing (ODI, 2004). They design programmes that run for three years or longer to promote broad-based growth and poverty reduction. Without getting disability on the agenda of these documents it is hard to channel funding to address the particular challenges faced by people with disabilities. This implies that people with disabilities should not be targeted, but also actively engaged in poverty reduction processes (MacLachlan and Swartz, 2009).

In 2005, government ministers from low, medium and high income economies met in Paris to reform the way in which aid was delivered and managed to achieve the MDGs. One of the recommendations of the resulting 'Paris Declaration on Aid Effectiveness' was that donor countries base their overall support on their recipient partner's national development strategies (AFRODAD, 2002). National development strategies usually take the form of PRSPs, mechanisms designed by the World Bank and the International Monetary Fund (IMF), by which highly indebted poor countries (HIPCs) can get debt relief, and become eligible for renewed financial aid (Dube, 2005). Countries receiving aid and loans have to develop national PRSPs – a plan that provides a framework for IMF lending, and for the World Bank's Country Assistance Strategy (CAS) papers, which cover the World Bank's medium-term business plan and its projected lending options (AFRODAD, 2002). This plan has to articulate the government's commitment to, and strategy for, poverty reduction, showing how the government would utilise the savings created by debt reduction. A comprehensive PRSP includes poverty diagnostics based on good indicators of poverty (AFRODAD, 2002). Donor countries would then base their financial aid on these PRSPs. Hence anything that is not written into the PRSP is difficult to subsequently get funding or resources for. Thus, the development of policy instruments such as PRSPs constitutes a

critical challenge for the disability community to get its agenda included – PRSPs present a nexus for the inclusion of disability in 'development'.

PRSP process in Malawi

Malawi is a landlocked country and considered one of the poorest in the world. Like most low-income countries, the PRSP has been used to guide the country's poverty reduction programmes. Malawi has followed its own process of formulating a PRSP and subsequent policy documents, and the PRSP has evolved into the Malawi Growth and Development Strategy (MGDS), reflecting the country's economic and political environment. The MGDS document can be considered a variation of the generic PRSP process, described above. However, it is not clear what processes were followed to include and/or exclude disability issues in the stated policy documents.

Discussions with some key stakeholders suggest that the PRSP in Malawi was first conceived by international donors, such as the IMF and the World Bank. Others suggest the PRSP was actually inspired by the Malawi 'Vision 2020' document, which, they assert, had little to do with international donors. It was clear that Malawi's economic and political course and its relationship with external donors played a major role in shaping the PRSP process. The development of Malawi's PRSP started in the latter part of 2000. Initially, the process was not consultative as civil society and a number of bilateral donors were excluded from the exercise (Booth, 2003), let alone DPOs. Booth (2003) suggests that there were territorial battles between the National Economic Council and the Ministry of Finance Economic Planning, now known as the Ministry of Development Planning and Cooperation (MDPC) as to who would be the custodian of the document. It now seems clear that the MDPC is the custodian of the MGDS. The initial process of the PRSP formulation relied on previous policy framework papers, which were poorly assembled into a PRSP under the direction of a small group of officials working with World Bank staff members.

When the government began the PRSP preparatory process in 2000, it ran into resistance from civil society almost immediately. The organisational structure for developing the PRSP was perceived as government-dominated, and led by MDPC and the National Economic Council. The consultation process was designed as a series of one-day workshops, to which various 'sectors' of civil society were invited so that they would voice their views.

PRSP Thematic Working Groups (TWGs), formed to draft sectoral and issue-based components for the PRSP, were launched. These included representatives from civil society and donors; however, notably, disability groups were excluded from this process. Some TWGs included Members of Parliament (MPs) from relevant parliamentary committees.

The background documents distributed to TWGs contained a reasonably clear statement of the key objectives of the PRSP approach. International donors and the government agreed that the key feature of the PRSP would be its

implementable, prioritised plan of action. District consultations were planned by the PRSP Technical Committee, with input from the National Steering Committee (principal secretaries), who formed three teams that covered between them the 31 districts in Malawi. The district workshops were dominated by local officials, such as district councillors, the police, district health officers, traditional authorities, as well as other influential people within the districts. The first PRSP was formulated between 2001 and 2002 for a four-year period. After the 2004 General Elections, the Ministry of Economic Planning and Development was given the task of formulating the MGDS. This time, there seems to have been wider consultation between ministries, non-governmental organisations (NGOs) and the private sector. During the formulation of 'Vision 2020', the Ministry of Women and Child Development was responsible for disability and they had one sweeping statement regarding their commitment to disability issues. Consequently, the initial PRSP did not include anything on disability.

The government established a Ministry of Persons with Disabilities in 1998, which is now known as the Ministry of Disability and the Elderly, whose main aim was to oversee the implementation and mainstreaming of disability in policy and development programmes in all government ministries. The formation of this ministry was also inspired by 'Vision 2020'.

One informant suggested that when considering issues of disability inclusion, the first point of discussion and contention should be the Constitution of Malawi, which is largely silent on disability issues except for some guidance it gives on the rights of people with disabilities. As the situation stands in Malawi, the same key informant stated: "frogs and grass have more rights than people with disabilities." This is because the protection of wildlife and natural resources is enshrined in the constitution of Malawi, while the rights of people with disabilities is not. The section where disability is included in the Constitution is not enforceable by law. By implication, people with disabilities may not be defended by the laws of Malawi. Thus, it is likely that the minimal inclusion of disability in the MGDS may have been influenced by the Constitution of Malawi, which barely incorporates the subject.

A common theme in our discussions with key stakeholders was that people with disabilities and DPOs, including some statutory organisations such as the Malawi Council for the Handicapped (MACOHA), were significantly marginalised in the formation of Malawi's initial PRSP and the subsequent MGDS paper. Despite this, some people from representative groups were invited to participate during the review process of the MGDS. Disability seems to have been included at the last minute, and its presence in the document reflects the 'charity model', characterised by a provision of handouts; thus failing to meet the aspirations of people with disabilities in Malawi.

A World Bank official who was interviewed in this study suggested that the PRSP was never implemented fully before it was changed to the Malawi Growth and Economic Strategy (MGES) and later to the MGDS, which was launched in 2007. The aim of the PRSP was to try and get government and NGOs to focus

on medium and long-term development goals. They created 16 working groups to carry out annual reviews of the MGDS. As disability is a social protection policy issue in the MDPC, perhaps this is where it will be most strongly reflected. The role of development agencies is to provide financial and technical support to manage the PRSP process using various development partners and experts who assess the impact, challenges and gaps.

Disability seems to be grouped together with other vulnerable groups in the review meetings, and disability-specific issues seem to be rarely raised. It was suggested that the Federation of Disability Organisations in Malawi (FEDOMA), which is the umbrella body of all DPOs in the country, needs to develop a clear strategy on how to meet the needs of people with disabilities. However, there are few data or statistics for/on people with disabilities, perhaps a pre-requisite for FEDOMA to undertake this task. Our initial analysis suggests that DPOs and minority groups are not sufficiently proactive in advocating for their inclusion in government development plans. However, it is also the responsibility of the parent ministry to involve FEDOMA, and the strengthening of this link should be supported.

In conclusion, some of the reasons expressed for the exclusion of disability in the PRSP/MGDS include that people with disabilities themselves are not empowered enough to understand what they are striving for and to be consistent in their efforts. Another challenge is that people with disabilities are not present at senior levels in the Ministry of Disability and the Elderly. Furthermore, the government does not look at disability policy for guidance in implementing development programmes; rather, it is informed by its own policy priority areas, as stipulated in the MGDS paper and the MDGs, especially Goal 1 on poverty reduction. The government does not seem to appreciate that disability mainstreaming means increasing funding to central ministries to enable them to implement disability-specific programmes as well as increasing funding to DPOs to facilitate programme implementation at that level. Therefore, there is a need for disability policy awareness-raising activities among both civil society and government in Malawi. The proposal for a national coordinating committee on disability issues could play an important role here by addressing how to translate policy into programmes.

PRSP process in Uganda

Uganda is also a landlocked agrarian country, located in East Africa, bordered by Sudan to the north, Kenya to the east, Tanzania and Rwanda to south and the Democratic Republic of Congo to the west. Out of its estimated total population of 29.6 million, about 31% live on less than US$1 a day (in 2006); the population is predominantly rural (about 85%) and agrarian, with up to 70% of all economically active Ugandans working in agriculture and fishing (World Fact Book, 2009).

In 1997, Uganda adopted the Poverty Eradication Action Plan (PEAP) as the overall development framework, aimed at reducing income poverty and

inequality, improving human development and increasing gross domestic product (GDP) growth. The PEAP, which aims to reduce poverty to 10% by 2017, has four fundamental goals of: creating a framework for economic growth and transformation, ensuring good governance and security, directly increasing the ability of the poor to raise their incomes and directly increasing the quality of life of the poor (MFPED, 2002). The PEAP's ambition is beyond the MDGs' target of halving the proportion of people living below the poverty line in 1990 by 2015. Since the launch of the PEAP, GDP growth has averaged about 6% per year, and it is claimed that the country is well on course to meet the MDG targets on poverty reduction.

The PRSP consultation process in Uganda started in December 1999 and ended in May 2001. This process coincided with the tabled revision of Uganda's own PEAP, which was developed with the active participation of civil society organisations (CSOs). Consequently, the Uganda PEAP was endorsed as the PRSP by the executive boards of the World Bank and IMF in May 2000. During the PRSP process, a clear timetable of events and activities were developed and CSOs developed a work plan for that purpose. The Ugandan Debt Network (UDN) was invited to participate in the PRSP process as one of the three national networks and was subsequently selected by CSOs to be the lead organisation to coordinate civil society inputs into the process.

Gariyo (2002) confirms that UDN mobilised more than 60 national NGOs, research institutions and other civil society groups to participate in the consultation process. Furthermore, approximately 600 individuals representing farmers, women, youth, elders and opinion leaders participated in district consultations organised to collect inputs from the people at grass-roots level, at numerous workshops held for that purpose. Other interested stakeholders, for example, those involved in human rights and conflict resolution, and environmental groups, organised their own stakeholder meetings and submitted their contributions through the UDN for inclusion in the PEAP process.

Approximately 600 individuals representing farmers, women, youth, elders and opinion leaders participated in district consultations organised to collect inputs from the people at grassroots level, at numerous workshops held for that purpose. Other interested stakeholders, for example, those involved in human rights and conflict resolution and environmental groups, organised their own stakeholder meetings and submitted their contributions through the UDN for inclusion into the PEAP process. Furthermore, Gariyo (2002) confirms that UDN mobilised more than 60 national non-governmental organisations, research institutions and other civil society groups to participate in the consultation process. This was done through workshops, seminars and media events. These platforms were used to solicit information from the public and to inform them about progress of the PEAP process. UDN reported that all written reports from these consultative forums were submitted to the PEAP technical drafting team in the MFPED (Gariyo, 2002). This allowed stakeholders to establish direct links with the PEAP

committee so that all additional information received was immediately passed onto this committee.

The implementation of the PEAP has been aided by the decentralised system of governance adopted in the mid-1990s, in which administrative responsibility is shared between the central government and the local government at district and sub-county levels (MFPED, 2008). Uganda is divided into 81 districts and 897 sub-counties, giving a total of 978 local governing bodies, which undertake much of the delivery of social services using resources allocated from the centre, while the central government takes care of policy formulation and resource mobilisation. The decentralised system has been useful in accessing and expanding key services, including primary healthcare, universal primary education, water and sanitation services, community policing and feeder roads to remote locations.

The PEAP was revised in 2000 to bring the voices of civil society, particularly the poor, who had been left out of the initial document. Thus, the government, NGOs, academic institutions, donors, and civil society participated in the revision process. This was informed by the sector-wide approaches and the Uganda Participatory Poverty Assessment Project (UPPAP). The second UPPAP was conducted in 12 districts, under the theme of deepening the understanding of poverty gained in the first UPPAP, and gathering people's experiences with government policies (MFPED, 2002). Therefore, the 2000 PEAP process was highly participatory through general consultative forums, with wide circulation of PEAP drafts supervised by a steering committee.

The revision process went into more than the 1997 document on the actions that promote private sector development, and therefore contributed indirectly to poverty reduction. The preparation of the 2000 PEAP was highly participatory, with a wide circulation of drafts supervised by a steering committee, strong involvement from civil society, general consultative workshops, the receipt of written comments and regional and political consultations.

Despite the efforts described above, it is of great concern that the disability movement did not participate in the preliminary PEAP formulation until the second revision in 2002. The disability movement then made a coordinated effort to ensure that people with disabilities were incorporated in mainstream poverty eradication programmes (NUDIPU, 2003). During the process of revising the PEAP, the government invited various stakeholders, including DPOs, to participate in the process. This invitation resulted in the National Union of Disabled Persons of Uganda (NUDIPU) mobilising DPOs to participate and input into the process. Nonetheless, due to a lack of resources and capacity, not all of them participated. This is to be regretted because it is crucial for NUDIPU to bring all the voices of various DPOs to ensure that the government takes their concerns into consideration and to give legitimacy to the role of NUDIPU as an inclusive and nationally representative body (Dube, 2005).

Currently, disability concerns in Uganda have reached a level where they are part and parcel of the country's general concerns, which have to be addressed in national policies and programmes. A number of legal provisions, such as the

Parliamentary Elections Statute 1996, the Children Statute 1996, the Local Government Act 1997, the Land Act 1998, the Uganda Communication Act 1997, the Traffic and Road safety Act 1998, the Uganda National Institute for Special Education (UNISE) Act 1998 and the Movement Act 1998, attempt to address the needs of people with disabilities (Dube, 2005). Each of these pieces of legislation mainstreams disability and provides regulations aimed at improving access of services to people with disabilities. However, the fact remains that many DPOs are not well equipped to engage at all levels in these consultation processes and so the extent to which their contribution is taken on board varies considerably (NUDIPU, 2003).

In June 2008 PEAP was replaced by the National Development Plan (NDP). As part of implementing some poverty reduction strategies under NDP, Uganda is currently at the planning stage of introducing social protection provisions for its poorest citizens. As a proactive measure, NUDIPU organised a workshop in March 2009 where various stakeholders, including DPOs, CSOs and NGOs, met to raise their concerns over the proposed government scheme on social protection in relation to people with disabilities. A-PODD researchers attended this workshop. It was clear that there was inadequate involvement of DPOs in designing the social protection scheme. Most delegates at this workshop were not aware of social protection plans, particularly for people with disabilities. The discussions raised a number of issues and concerns that were to be fed into the proceeding workshop on the next day, where representatives from the Ministry of Gender, Labour, and Social Development (MGLSD), the ministry that is also responsible for disability issues, would be present to presumably take on board the recommendations from the workshop. However, some delegates were pessimistic regarding the impact their workshop's deliberations would have on the government officials and ultimately on the social protection agenda. This impact remains to be seen.

The preliminary visit to Uganda brought to light some of challenges facing DPOs in the participation of PRSP processes. These were identified through informal discussions with DPOs, individual people with disabilities, CSOs, the Department of Disability and the Elderly Affairs, and in disability–related research reports. The common constraints highlighted included human and financial capacity, time, DPOs' access to information and their ability to influence decision makers (Dube, 2005). Countries undertaking PRSPs are both poor and profoundly indebted. It is therefore predictable that they will be severely limited in their competence to undertake a comprehensive, participatory consultation exercise, bearing in mind the need for human and financial resources. Although civil society can add to government efforts if called on to do so, it is also most likely that CSOs and NGOs in poor countries are among the most poorly resourced to do so.

There is a need to build the capacity of DPOs if they are to have a greater impact on policy planning, implementation, monitoring and evaluation. Capacity building entails having adequately trained personnel to execute any strategic programmes. Those working in relevant government ministries should also have their capacity

built, particularly regarding their knowledge and competence around disability advocacy, and they should have the ability to form sustainable partnerships with DPOs (Gariyo, 2002). DPOs must also build the capacity of grass-roots people to participate in monitoring policy implementation.

The need to get the PRSP to meet set deadlines so that debt relief can be applied certainly creates considerable pressure that is likely to undermine the quality of the process itself. As indicated earlier, PRSPs are developed in circumstances marked by inadequate funding, insufficient human capacity, insufficient research-based evidence and insufficient time, among many other constraints. Participatory approaches require thoughtfulness and interpersonal sensitivity, they are naturally expensive and time-consuming, and the quality of their outputs is no doubt related to the quality of their inputs.

In the case of Uganda, there was pressure to quickly complete the PRSP process and to produce the document for funding. As a result, the PEAP process, in which civil society had been meaningfully involved, became constricted and civil society found themselves, to some extent, squeezed out (AFRODAD, 2002). The whole process that clearly had good intentions ended up being 'microwaved' in order to meet deadlines.

Given the diversity of the DPOs needing access to information regarding PRSP and related processes, the means by which information is transmitted is highly relevant. Relevant documentation that informed the PRSP process was not in accessible formats or multiple languages (Uganda has multiple different ethnic languages). In Uganda, as in many other countries, illiteracy and language differences present barriers when disseminating information, particularly to people with disabilities (Dube, 2005). Even for people who can read, printed documents may be expensive and difficult to disseminate widely, while internet access is still quite narrowly confined. Television or radio usually reach more people, but are not accessible to the majority of people with disabilities. As a result, this communication challenge can seriously compromise the PRSP process.

Another challenge to increasing the influence of DPOs may be that some government officials still regard DPO and CSO participation in policy development as a means to legitimise the PRSP process, while viewing their criticisms with distrust. While DPOs need capacity building to influence government policy, they also need to fully understand and analyse the agenda of donors contributing to such processes. Donors have a very strong influence over budgetary and other policy plans in Africa because in many cases they contribute a large portion of the government budget (Gariyo, 2002). In the case of Uganda, the activities of NUDIPU (and other CSOs) to date illustrates that DPOs have the capacity to influence governments in planning poverty alleviation programmes and in developing policies.

Conclusion

The idea of inclusive development is widely accepted in theory, but in practice there are many challenges to achieving it. The absence of disability in the MDGs is a stark example of the invisibility of perhaps the most impoverished and disadvantaged group in society. We cannot leave social inclusion to good intensions, even when these do exist. It is important to identify how disability can be put on the development agenda by understanding the factors that have affected its inclusion or exclusion from PRSPs, and related development instruments. A-PODD seeks to explore the extent to which evidential factors (for instance, research evidence initiatives; see MacLachlan et al, 2009b) and non-evidential factors (for instance, advocacy, networking or time pressure) influence what gets on the development agenda. Through the initial impressions of the PRSP process in Malawi and Uganda described above, along with further work in each of these countries and in Ethiopia and Sierra Leone, we hope to identify the most effective tactics that the disability community can use to influence development so that people with disabilities are clear beneficiaries of it and it does actually help them to move out of poverty.

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Disability, poverty and healthcare: changes in the *canji* ('disability') policies in the history of the People's Republic of China

Heidi Fjeld and Gry Sagli

Introduction

The Chinese economy is one of the fastest growing economies in the world today, but the growth is to an increasing degree unevenly distributed. Large parts of the population in rural areas, especially in the western provinces, remain economically marginalised and poor, while urban coastal centres prosper (Ravallion and Chen, 2004; Dalen, 2006; Fan and Sun, 2008). International statistics point to three particularly vulnerable groups in the economic development in the People's Republic of China (PRC) today: minority ethnic groups, women and people with disabilities (ADB, 2004; Edmonds, 2005). This chapter concerns the latter. Lack of access to adequate healthcare and impoverishment due to healthcare expenses are currently perceived as crucial issues causing poverty, particularly in the poor rural areas. Earlier studies have shown that the causes of poverty for many Chinese households were related to family members' health problems (Wang et al, 2005). Such medical poverty traps manifest particularly in households with people with disabilities as their extra needs of rehabilitation and healthcare services constitute a substantial economic burden (see, for example, Wang et al, 2008).

The Chinese authorities have in recent years launched new welfare programmes to address some of the new problems of inequity and poverty (Liu and Rao, 2006; Li et al, 2008). Since the late 1980s, the Chinese authorities, through the China Disabled Persons' Federation (CDPF), have addressed the poor living conditions of people with disabilities through several major plans of actions (CDPF, 1998; Shang, 2005). More recently, from 2002, the New Rural Cooperative Medical System (NRCMS, *xinxing nongcun hezuo yiliao zhidu*) has been piloted (Wang et al, 2005; Liu and Rao, 2006; Zhang et al, 2006). This scheme addresses the general rural population, and not specifically people with disabilities. The NRCMS has nationally, as internationally, been presented as a very positive development with regard to poverty alleviation in rural areas (You and Kobayashi, 2008). The question remains whether or not it can also be expected to create a positive

impact on the economy of poor households with disabled members living in rural areas in the PRC.

This chapter aims to provide an overview of the development of disability policy in the history of the PRC. We argue that seen in the perspective of the PRC's political history, the new health reform that was launched in 2002 indicates a significant turn in the party–state's[1] disability policy. This recent phase is characterised by a focus on general welfare services, rather than preferential treatments, and reintroduces the party-state as a major agent in the field of disability. In the 60 years since the founding of the PRC in 1949, China has undergone a series of dramatic changes, from revolution, socialism and collectivism, to de-collectivism, implementation of liberal market economics and privatisation of welfare services. The political organisation of these different periods altered the everyday life of Chinese citizens extensively, penetrating all aspects of life, from family relations and household organisation, to healthcare and access to services. In this chapter we describe some of the ways in which these political changes have influenced the lives of people with disabilities and their families, particularly in terms of care, health and access to rehabilitation.

Our focus is primarily on the interconnections of health, poverty and disability. Other interesting and important issues, such as the history of special education, the development of the legal framework for employment and education and the work for human rights for people with disabilities will not be included.[2] The material is drawn from literature on healthcare and social welfare for the general Chinese population, from family policy, from literature on the development of the disability movement, as well as literature focusing specifically on people with disabilities in the PRC.

Our starting point is the double-way relation between impairments, disability and poverty that has often been described as a 'vicious circle' (Yeo and Moore, 2003, p 572). International studies point to poverty and disability being mutually constituted in the sense that people with disabilities are often trapped into poverty because of exclusion from social, economic and political opportunities, as well as the financial burden related to their impairments, while poor people, with limited access to adequate services, often risk illness, injury and impairment (Yeo, 2001; Yeo and Moore, 2003). By looking first at the direct and indirect implications of the political-economic organisation of the situation for people with disabilities and the development of a particular disability movement, we discuss the new welfare reform and its potential implications of poverty relief for people with disabilities and their families.

Interconnectedness of statistics and disability definitions

According to a recent national survey (2006-07), there are nearly 83 million people with disabilities in the Chinese population of 1.3 billion (CDPF, 2008). Seventy-five per cent (62 million) of the 83 million live in the countryside and

21% (13 million) of these live in poverty with an income of the total household of less than ¥2.5 (US$0.37) per day (Ministry of Health et al, 2007).[3]

According to the 2006–07 survey, the population of people with disabilities thus constitutes 6.34% of the population.[4] In comparison, the first national survey conducted in 1987 established that there were in total 60 million people with disabilities in the PRC, which at that time made up 4.9% of the Chinese population. Although the disability rate in the recent survey is higher than in the 1987 survey, from an international perspective, it is still low. The Chinese authorities themselves report that although a 10% rate is commonly accepted internationally, the rate is lower in the PRC due to a more stringent [sic] disability criteria used in the Chinese national surveys than elsewhere (CDPF, 2008).[5]

Chinese authorities currently define a 'disabled person' (*canji ren*) as:

> … one who has abnormalities or loss of a certain organ or function, psychologically or physiologically, or in anatomical structure and has lost wholly or in part the ability to perform an activity in the way considered normal. The term "a person with disabilities" refers to one with visual, or hearing, or speech, or physical, or intellectual, or psychiatric disability, multiple disabilities and/or other disabilities. (Law of the PRC on the Protection of Persons with Disabilities, 2008)[6]

This definition reflects the strong medical focus in disability policies in the PRC. Disabilities are understood as defects, that is, 'impairments', perceived to be located in an individual person's body–mind. Such medical understanding is also reflected in the Chinese term used in the official definition. *Canji* consists of two words, where *can* denotes 'incomplete', 'deficiency' and 'injury', while *ji* refers to 'disease', 'suffering' and 'pain', thus indicating a closer link between impairments of the body–mind and disability than that conveyed in the English translation (Guo et al, 2005, p 51).

Canji is one of many words that have been used to denote people with disabilities in Chinese societies in the past and the present. It is increasingly used in public and in the discourse of everyday life and found to be less stigmatising than terms that were more common earlier, such as *canfei* ('useless', 'disabled' – *fei* denotes 'waste', 'useless'), *quezi* ('crippled'), *bu quan de* ('deformed', 'not complete') and *wuguan bu zheng* ('the five sense/organs – not orderly').[7] Although perceived to be less stigmatising than, for instance *canfei*, *canji* is not neutral, however. The *canji* term has a long recorded history in the vocabulary of the Chinese bureaucracy – it has been found in records that date back to the legal and administrative codex of the Tang dynasty (618-907 AD), but is probably even older (Ho, 1959; Stone, 1999; Kohrman, 2005). In the Tang bureaucracy, *canji* was used in contrast to the administrative category *ding*, denoting 'normality'. *Canji* was one subcategory of those 'not *ding*', that is, all those who differed from the administrative norm, including childless widows and widowers, orphans and those who were unmarried. Also 'not *ding*', *canji* referred to those partially disabled, while those seriously

disabled were classified as *feiji*, and those totally disabled as *duji* (Stone, 1999, citing Twitchett, 1970). Thus, although new medical meanings have been attributed to *canji* in the modern disability discourse, the term has a long history of negative connotations reflecting abnormality.

Despite the lack of neutrality, *canji* has, since the 1980s, been the term promoted by the powerful CDPF. While *canji* is an historical term, it was not until the development of a disability movement and a disability policy in the 1980s that the term took on its present encompassing characteristic. The need for an official definition of disability became apparent throughout the 1980s, when preparations for the first national survey on disability were ongoing. Kohrman (2005) has offered a detailed account, demonstrating how the decision on the set of disability criteria that was finally applied in the 1987 survey was a result of complex, highly politicised processes. He argues that it was a prime concern for the researchers conducting the survey that the result would demonstrate an acceptable disability rate of the Chinese population. If the rate was too low, they feared that the international scientific community would hold the researchers to be incapable of conducting surveys. At the same time, if the rate proved to be too high, this would indicate that the quality of the Chinese population was poor. These, as well as a broad range of other concerns, were negotiated in a politically tense atmosphere in which the national pride of the PRC as a modern, scientific, civilised nation was felt to be at stake.

In addition to the concern of status of the Chinese population, budget consideration is another obvious reason to keep the disability rate low. By obtaining disability status, a person may access preferential treatment such as poverty loans, special employment and tax reduction, etc.[8] As the size of the Chinese population is large, slight adjustments of disability criteria may have a tremendous impact in terms of numbers with the right to access to such privileges.

Initially developed in the 1980s, the narrow disability definition focusing on certain impairments has remained fundamental to the Chinese disability discourse and policy making. This is also reflected in the continued use of the categories of impairment applied in the recent (2006-07) nationwide survey on disability. Being contested in the international disability movement, the medical model has also been criticised in the PRC. In the report following the 2006-07 survey it was stated that: 'It is inadequate to conduct disability identification and classification with the focus on physiological structure of individuals alone. Attention should be given to functional barriers and social adaptability' (CDPF, 2008). However, it is difficult to see how a social model of disability has been applied in the actual survey.[9] With the use of such a so-called 'stringent' definition, a large population of people who experience reduced opportunities to participate in society are being excluded from access to disability privileges.

Since the 1980s, the main agents with regards to responsibility for provisions of care and services for people with disabilities have been the individual households with disabled members, the CDPF and the party-state. In the following we discuss

some of the ways that the roles of each of these agents have changed throughout the various political periods following the establishment of the PRC in 1949.

Disability and the family in the PRC

Disability policy in the PRC is, as elsewhere, a recent phenomenon. Throughout Chinese history, people with disabilities remained the responsibility of the household, perceived much in the same way as care-taking for the sick and the elderly. Although the role of the household has varied throughout the political periods of the PRC, there is a clear continuity in the morality of care-giving within filial relations found in households with members with disabilities in today's PRC.

Although little has been published about disability in the periods before the establishment of the PRC, all indications suggest that care was provided through the family (Zhou, 1997; Miles, 2000). Traditional Chinese families were often organised into larger households in which several generations shared the house and economy and where the distribution of rights and obligations were defined by relational statuses (Davis and Harrell, 1993). Within these households, the rules and practices of filial piety were most important and strictly followed (Kohrman, 2005, p 150). In the filial relations, care-taking was a central duty, so that parents were obliged to take care of their children and later, when the parents grew old, their offspring would return their duty and care for them.[10] Some literature suggests that the value of taking care of all the children, independent of ability, was emphasised within this morality (Phillips, 1993; Callaway, 2000). However, most likely there were great variations in how filial obligations were practised in the cases of disability. Until recent times, families with members with disabilities had very few options available outside the household, and widespread informal welfare arrangements for people with disabilities were very limited in traditional Chinese communities. There were, however, some special schools for blind and deaf children set up, first by Christian missionary groups in the 19th century and later by a few Chinese philanthropists at the beginning of the 20th century, but these were limited both in numbers and in their social and geographical distribution (Epstein, 1988; Yang and Wang, 1994). The distribution of these schools reflects the lack of a common policy at the time as they were available to very few people and in very few places. Before the establishment of the PRC, 'disability' was thus not a category relevant for policy making, and people with disabilities remained primarily the responsibility of their parents and secondarily their natal household.

The revolution and the following formation of a communist state in 1949 marked a dramatic shift in the ways in which the state handled the health and well-being of its citizens (Saich, 2004). While there had been little contact between the individuals and the state before 1949, the communist government introduced a new totalitarian regime, bringing all individuals close to the new state. From the end of the 1950s, the collective period not only completely redefined the economic and social organisation of the country, but also introduced new criteria for classifying the population. Social class and political attitudes were the

fundamental categories, while individual characteristics such as disability were an irrelevant criterion in this new political organisation (Kohrman, 2005, p 151). Thus, in terms of policy making, disability remained outside the interests of the party-state, and people with disabilities were perceived as citizens of collective units, much in the same way as people without disabilities.

The collective period brought suffering, famine and conflict to large parts of the Chinese population. The dramatic political and socioeconomic reorganisation also intended to undermine the role of the family, as the main unit to which the individual belonged was now the collective brigades. However, looking at the role of the family and its care-giving practices for members with disabilities, the implications of collective organisation seem to have been largely positive. First and foremost, the collectives were part of an economic organisation in which individual productivity was given less importance and where the needs of all citizens were guaranteed by what was called the 'iron rice bowl'. Access to collective goods was not solely based on work ability but also decided by the cadres based on the individual's needs, political attitudes and social class. Hence, the households of people with disabilities did not manifest as economically destitute compared to other households. Moreover, as mobility was restricted and household members were forced to remain within their natal village, demographic conditions 'conducive to large multigenerational households with extensive economic and social ties to nearby kin' were formed (Davis and Harrell, 1993, p 1).[11] Within these extensive kindred networks, providing for people with disabilities, as well as elders, remained an integrated and important task.[12]

Invisibility of disability

The birth of the PRC thus redefined the categories for social classification in China. During the three first decades of communist rule, disability was not one of the categories of political significance. People with disabilities were seen as members of the masses and disability was handled in much the same ways as other particular needs, that is, by the morality of mutual assistance in filial relations primarily, and the network of kin and community secondarily. The lack of an organisational disability category was also reflected in the lack of a disability movement and, moreover, a disability policy.

With the political changes following de-collectivisation, the new leadership of the Chinese Communist Party (CCP) concerned themselves with disability for the first time. The new development of a disability policy is, nevertheless, founded in the idea that the immediate family, that is, parents, remain the central care-taking social unit in the PRC, although in a different context from that of the collective era. With the development of a market economy and, in that, a new emphasis on productivity and economic success as well as the privatisation of welfare and healthcare, the traditional family ideal has increasingly been challenged, not only for households with disabled members (Phillips, 1993), but for Chinese families in general.

Birth of the *canji* ('disability') policy of the party-state

The consequences of the dramatic turns in policy effectuated by Deng Xiaoping (1904-97) and the new leadership that came into power after the death of Chairman Mao Zedong (in 1976) comprise radial changes also concerning aspects related to disability and poverty. The policy of de-collectivisation, privatisation and increased international contact initiated by Deng Xiaoping, and continued under the leadership of Jiang Zemin (president from 1993-2003) and Hu Jintao (2003-), has been extremely successful with regard to economic growth for a large part of the Chinese population (Naughton, 2007). However, how the new sociopolitical conditions resulting from these new policies influence the lives of people with impairments and the households to which they belong is far more complex and uncertain.

Importantly, during the 30 years with economic and political reforms, impairments have emerged as an issue to which the Chinese party-state has paid attention and in the same period *canji ren* ('disabled people') has appeared as a category in use, both in political and public discourse. People with body-mind variations were no longer simply perceived as members of the masses classified on the basis of their class background and political attitudes, but rather as a group with particular characteristics. The establishment of the category of *canji ren* led to a new classification of people as able/disabled on the basis of their forms of impairments. In this same period, a disability movement developed, in the form of the CDPF, along with the birth of a disability policy adopted by the party-state. Both these developments have dramatically shaped the perceptions of what it means to be *canji* in the PRC today.

A new population policy: reducing quantity and enhancing quality

The establishment of the CDPF has sometimes been seen as the start of disability policy in the PRC (Kohrman, 2005). This is true in the sense that its establishment marks the start of explicit policies for protecting and rehabilitating people with disabilities. However, the disability policy of the party-state consists of two widely different approaches, of which protection and rehabilitation is only one. The first policy dealing with disabilities to be introduced in the PRC was the new population policy already implemented in 1979 (Stone, 1996; Greenhalgh and Winckler, 2005; White, 2006).[13] This population policy programme had two main aims: to reduce quantity, through the one-child policy, and to increase quality, through eugenics. While the one-child policy is much researched, the extensive use of eugenics in the PRC is less well known internationally. The implementation of this population policy inevitably nourished the growth of an awareness of impairment as something undesirable and unwanted. During the early 1980s, 'disability' was thus coming into being in public discourse, accompanied with negative connotations.

The distinction between measures aiming at prevention of disabilities and policies with a focus on protection and rehabilitation is well known in many nations (for example, Abberley, 1987; cited in Stone, 1996, p 480). Nevertheless, the PRC is a different case in point, as the policy of prevention of impairments has been so powerfully enforced as an essential component of the national 'one-child policy'. Under Chairman Mao, the great Chinese population size was perceived as a contribution to the strength of the nation, and Mao encouraged families to have many children. It was only after the change in leadership following Mao's death that population growth was perceived as a serious threat to the modernisation and economic development of China, and birth planning became one of the central concerns in the overall national policy.

Eugenic ideas that had reached China from Europe at the end of the 19th century had already been popular among leading intellectuals in the 1920s and 1930s. At that time, eugenics was thought to offer an explanation for the backwardness of China, and birth control through eugenic methods was considered as a way for the nation to regain vigour and strength (Dikötter, 1992, 1998; Stone, 1996). These ideas were rehabilitated and put into practice by the new leadership in the 1980s.

Both the quality and quantity aims of the one-child policy have recently been re-confirmed by the new Law on Population and Birth Planning (2001).[14] It states, in Article 11, that its aims include 'not only the protection of the health of mothers and children but also the enhancement of the quality of China's population' (Palmer, 2007, p 689). The one-child policy has seriously affected and continues to affect individual families in the PRC. Disability is an explicit concern in certain aspects of the practice of the one-child policy, and the birth of a child with an impairment is one of the particular circumstances in which a married couple is allowed a second child (White, 2006, p 200; Palmer, 2007, p 688).

Detecting impaired foetuses requires advanced prenatal test technologies, which is both costly and, at the end of the 1970s, was hardly available in the PRC. Public resources were supplied for the development and later massive distribution of such technologies. Today, extensive use of prenatal testing aimed at preventing impairments and serious genetic conditions exists throughout the country, even in the most remote corners of the Chinese countryside. The vast distribution of this technology coincided with the privatisation of health services in the 1980s and prenatal testing became one of the ways for the health institutions to secure their income. In addition to the use of prenatal testing, abortion and sterilisation are important means in birth control campaigns. In cases where impairments are found during pregnancy, abortion is strongly recommended to the mothers. Moreover, sterilisation is used in certain cases (White, 2006).

In addition to general campaigns, birth control efforts focus specifically on childbirth among people with disabilities. Although people with disabilities are allowed to marry, they are only allowed to have a child as long as there is no risk that their impairments are hereditary (Stone, 1996, p 474).

The one-child policy thus introduces the explicit concern with disability from the party–state in the PRC. It does so by developing policies that seek to prevent the birth of children with disabilities, and later to prevent those with hereditary genetic conditions to reproduce. This is, however, only one of the aspects of disability policy in the PRC and we now turn to the second aspect, namely, the policy concern with the protection and rehabilitation of people with impairments.

CDPF and the formation of the canji policy

During the same period as the Chinese party–state allocated huge resources for the prevention of unwanted impairments, a state-supported disability movement developed. CDPF was established in 1988 and has, during the course of 30 years, developed to be a significant influence in Chinese social and health policies. Thus, on the one hand, with CDPF as the main agent, a policy of protection and rehabilitation of people with disabilities was developed, and on the other hand, a policy of prevention of impairments was implemented. However, although these two policies seem to approach 'disability' quite paradoxically, the two seem to go hand in hand in China. Arguably, what the two widely different policies have in common is that they demonstrate that 'disability' is taken seriously as a phenomenon and a category by the party–state (Stone, 1996).

There seem to have been three main factors that both enabled the establishment of the CDPF and, more importantly, led to its extremely powerful position within Chinese power circles. Matthew Kohrman (2005), in his extensive study of the CDPF in the 1980s and 1990s, shows how CDPF is a product of, and at the same an answer to, a complexity of the sociopolitical conditions resulting from Deng Xiaoping rising to power in the late 1970s. The three factors are all connected to Deng's introduction of a new policy: first, to the new socioeconomic conditions within the country; second, to the new increased communication with the international community; and last, the access to power through the kinship between the founder of the CDPF and Deng Xiaoping.

With the economic reforms following de–collectivisation, the individual's ability to be economically productive, and thus to contribute to the economic growth of the Chinese nation, was again emphasised. With the new economic organisation it became apparent that some were less able to produce, such as households with members with disabilities, and that these could not benefit from the opportunities offered by the new economy. Many of these households then became poor or were stuck in poverty. Thus, the new economic reforms within PRC produced needs for assistance for disadvantaged groups, among them people with disabilities and their families.

This new awareness of disability as a concern within the new Chinese economy coincided with an international focus on disability policy, exemplified by the United Nation's (UN's) International Year of the Disabled People in 1981 and, later, the UN's Decade for Disabled Persons, 1983-92. Deng's open-door policy provided increased opportunities for international contact and influence, in

particular for the Chinese elite who, from their international contacts, became aware of this focus on people with disabilities held by the international community at the time. The international discourse clearly held a nation's capability of providing necessary assistance and care for people with disabilities and other groups of disadvantaged people central in development into a modern and civilised state. At the time the prime concern of the new leadership was the transformation of the PRC into a modern state. Kohrman argues that the ability of CDPF leaders to situate disability assistance as useful to the nation and to the CCP was part of CDPF's success (2005, p 32).

Yet, even more than the two above factors, the role of *one* person was instrumental in the development of the CDPF. This person is the son of Deng Xiaoping, Deng Pufang (1944-). His personal history is very important. During the Cultural Revolution, he was paralysed after falling down from a fourth floor while being interrogated by the Red Guards. After his father came to power, it was arranged for Deng Pufang to travel to Canada where he was offered help from modern, high-technology medical care and rehabilitation services. Back in China, and inspired from what he had experienced in Canada, he eagerly promoted the idea of developing similar opportunities for people with disabilities in the PRC. Deng Pufang was a main actor in the establishing first, the Foundation for the Disabled Persons in China in 1984 and then the CDPF in 1988, and was the influential chairman of CDPF for 30 years.[15]

With Deng Pufang as its leader, CDPF benefited from the power attributed to him as the son of the prime leader of the party-state. CDPF's close interconnectedness with the party-state makes it stand out as special case compared with disability associations in other countries. CDPF has commonly been described as a semi-non-governmental organisation (NGO) and a semi-ministry. In the course of a 30-year period, the Federation has increasingly become an integrated part of the central state administration. Today CDPF is commissioned by the CCP to supervise affairs relating to people with disabilities in China, and it is the responsible organ for the development, as well as the implementation, of many of the disability policies in general. Today, CDPF presents itself as a nationwide umbrella network, reaching every part of China with about 80,000 full-time workers (CDPF, 2009).

CDPF's services and the promotion of the 'the able disabled'

As an integrated part of the development of CDPF, *canji* ('disability') as a category has been clearly defined as an organisational category, and *canji ren* ('disabled people') have become an increasingly visible part of society (Stone, 2001; Dauncey, 2007). However, in the process of making disability visible, the 'able disabled' and those disabled who can become 'able' through proper care and rehabilitation have dominated public space.

Initially, Deng Pufang and his staff in CDPF concentrated on the establishment of rehabilitation medicine services, first and foremost by the founding of modern, Western-style, high-technology rehabilitation medical facilities. The China

Rehabilitation and Research Centre in Beijing (established in 1988 as the first of its kind in China) is the model example of this development. Most of the activities in CDPF's early phase were urban programmes that did not target the majority of the population living in rural areas. Even with the later introduction of community-based rehabilitation (CBR), the CDPF could not, due to limited funding, provide substantial assistance to people with disabilities in the rural areas (Kohrman, 2005, p 163).

Throughout their history, CDPF establishments have primarily hired and served male urban people disabled with physical impairments, those referred to by Kohrman as the 'the most able of the disabled' (Kohrman, 2005, p 109). CDPF services reflect the goals of the state- promoted economic liberalisation, as they assist people with impairments to become able, that is, 'able' to contribute to the economic growth and prosperity of the nation. Deng Pufang himself embodied this ideal way of being 'disabled'. During the last decades, 'able disabled' have also become more visible in other arenas. People with impairments have enacted roles as patriotic heroes in Chinese films (Dauncey, 2007) and disabled champions from the international sport arenas have added to Chinese national pride (Stone, 2001).[16]

CDPF activities focus on medical rehabilitation, both in the form of centralised hospital services and as CBR. These continue to be based primarily in a medical understanding of disability. However, CDPF has more recently expanded its focus and is presently involved in a broad spectrum of issues and sectors beyond medical rehabilitation. These include legal work for protecting the rights of people with disabilities,[17] education and employment programmes, cultural and sport activities, as well as poverty loans and other economic preferential treatments (Shang, 2005; CDPF, 2009). Yet, even with these new services and programmes, the idea of rehabilitation, although in a broader sense, continues to be an explicit focus for the CDPF (CDPF, 2009).

Importantly, the narrow definition of disability used in official classification as well as a focus of effort towards 'able disabled' excludes a large population of people with disabilities from access to preferential treatments. Thus, until now, CDPF's services and preferential treatments have targeted a small group of the Chinese population of people with disabilities. Reflecting the encompassing power of the party–state, as well as the integrated position that the CDPF has in the political organisation, it was after a turn in national policy that CDPF recently started to emphasise services for people with disabilities within programmes for the general population.

Limits of market economy and the new welfare reform

Following the period of a strong belief that economic growth would eventually release the population from poverty, we see a turn in the focus of the CCP at the beginning of the new millennium. By that time and for over two decades, official statistics had already shown grim numbers about the health situation in rural areas. In 2002, 96% of the rural population was reported to lack any form of health

insurance and 38% was found to never seek medical help during sickness (You and Kobayashi, 2008).[18] Liu and Rao argue that it was precisely the magnitude of medical impoverishment in the countryside that finally motivated the CCP to develop a new rural health reform (Liu and Rao, 2006).

In 2002, the China National Rural Health Conference was arranged in Beijing. National conferences are of utmost importance in Chinese politics as they are the arena where the CCP announces new large-scale policies and reforms. The Conference in 2002 was the first national conference on rural health in the history of the PRC, another indication of the limited focus on medical poverty and health inequity during the period of economic liberalisation in the 1980s and 1990s. The Conference marked the start of what we argue to be a new orientation in the health and welfare politics of the CCP's governance. Focusing less on productivity alone, the new health reforms are, to a larger extent than before, based on the idea that the state should provide welfare support to the population in need.

Although a reform primarily designed to target the poor rural population, it arguably also alters general policies on disability. Within the new health reform, the needs of people with disabilities are placed side by side with the needs of the general population in ways that share some similarities with the collective period. CDPF's policy today holds that people with disabilities should be encouraged to participate in those welfare schemes designed not specifically for the *canji ren* but the general population. At the same time, CDPF aims at influencing the formations of health reform to include medical services important to people with disabilities, such as rehabilitation. So far, they have not succeeded. However, while the CDPF's disability policy in the previous period focused on preferential treatments only, thus marking people with disabilities out as an exclusive group, the new welfare programmes include people with disabilities in the general schemes. As such, the new reforms might be seen to contribute to a mainstreaming of disability as a phenomenon.

The New Rural Cooperative Medical System (NRCMS)

Following the National Conference in 2002, a new health insurance reform was finally launched from Beijing.[19] The insurance reform is called the New Rural Cooperative Medical System (NRCMS, *xinxing nongcun hezuo yiliao zhidu*), and was implemented in chosen pilot counties throughout the country from 2003. By the end of 2008, the NRCMS was intended to cover all the rural population in the PRC; however, its actual distribution remains to be seen (You and Kobayashi, 2008).

While the original Cooperative Medical System was financed by the welfare fund of the communes, this new reform is a voluntary health insurance system that is financed partly by the central government, partly by the local government and partly by the individual citizen. In 2008, the overall insurance per citizen in the poor rural areas was set to 100 yuan,[20] of which the central and the local government subsidise 40 yuan each, while the individual citizen pays 20 yuan. The

fees paid by the individuals are kept in a commercial state-owned bank account, while the contribution is registered in a booklet kept by each person. The insurance is designed as a voluntary mutual assistance among farmers and covers primarily in-patient services and expenses related to what is called 'catastrophic illnesses'.

There have been several evaluations of the implementation of the NRCMS in the pilot counties and they all indicate a remarkable widespread participation, with numbers at around 86% (Wagstaff et al, 2008; You and Kobayashi, 2008). With the well-established practice of over-reporting statistics from local to central government, these numbers should be seen as indications rather than objective figures. Because the insurance is based on voluntary participation on the one hand, and the administrators cannot refuse participation based on health conditions or elaborate needs on the other, the risk for adverse selection is high. The degree to which participation is voluntary also varies. The minimum participation in the poorer provinces is defined by central government to be 80%, and some reports show that local governments have exercised pressure on its population to reach high participation numbers (Hofer, 2009).

The insurance is designed to provide reimbursement for those medical expenses defined within the NRCMS. The reimbursement rates vary, according to a ceiling set for the various levels of treatments, that is, all expenses above the defined ceiling must be covered out-of-pocket by the patient. Due to the limited financial subsidies from the central government, the local authorities need to narrow down the medical conditions that the insurance can cover according to authorities' financial abilities. So far, the majority of the pilot counties have reimbursed expenses from in-patient care for what is defined as 'catastrophic illnesses', such as heart attack, cancer, stroke etc, and have not covered any out-patient care, including rehabilitation.[21]

The intention of the reform was to secure poor farmers from being impoverished due to costly out-of-pocket medical expenses and to increase access to healthcare. However, because of the limited means allocated to this reform, the reimbursement categories of medical conditions and the more general financial system of the health sector in the PRC, so far there has been limited impact on poor households in rural areas. Recent evaluations of the NRCMS have reported two main effects: first, that the use of medical services has increased in the NRCMS counties and second, and more surprisingly, that the out-of-pocket expenses of the individual patient have increased (Wagstaff et al, 2008). Moreover, the same evaluation shows that the effect, both negative and positive, of the NRCMS among the poorest 20% of the rural population has been very limited. Another evaluation states that for the poorest 10%, the NRCMS has not increased their use of health services at all (You and Kobayashi, 2008). For the poorest households, the upfront co-insurance rates are too high, and thus the rates exclude them from participating. For those who have managed to pay for the insurance, the reimbursement ceiling is too low for them to be able to use the health services without risking further impoverishment.

The surprising increase in people's out-of-pocket expenses after the implementation of the NRCMS relates to a larger and more general field of problems, namely the privatisation of health services in the PRC. Starting in the mid-1980s, the financing of health services is now based on the 'fee-for-service' principle. De-collectivisation led to a change in the public spending on health facilities, and recent numbers from the Ministry of Health suggest that less than 5% of county hospital budgets and 10% of the township health centres' budgets are covered by the central government (You and Kobayashi, 2008). Limited funding leads to a potentially moral hazard on the side of the health provider as its main income will have to come from treatment and drug prescription. Various Chinese studies have shown extreme levels of over-treatments, both in the use of costly technology and drug prescription. One study concluded that in the investigated townships, less than 2% of the drugs prescribed were what they term 'rational', while only 0.06% of the drug prescriptions in the village clinics in the same townships were what they call 'reasonable on medical grounds' (Zhang et al, 2003).[22]

The fee-for-service system has led to a shift in the services offered by health clinics of various levels, from basic healthcare to more high-tech treatments. Basic healthcare is cheap and does not generate income for the health providers, so in many cases, basic treatments are therefore replaced with more expensive treatments, often including high-technological diagnosis and prescription of antibiotics. Moreover, the fee-for-service system has led to a continuous increase in prices charged for treatments, primarily because the health providers can define the prices of drugs and treatments without central governmental control. These factors raise the price of each medical encounter for the individual that, of course, has dramatic consequences for the poorest population.[23]

The new health reform, as manifested in the NRCMS, have so far not provided better healthcare to the rural, poor population. The NRCMS has been successful among those farmers and nomads with some economic means to pay the co-insurance fee, in the sense that their expenses have been cut in the cases of hospitalisation (related to catastrophic illnesses).[24] In addition to the potential exclusion from the insurance programme due to the upfront co-insurance costs, poor people with disabilities and their household also lack a financial support system for rehabilitation and related medical and social services. Chronic illness and disability are not included into the category of 'catastrophic conditions', and rehabilitation expenses are therefore not reimbursed through the NRCMS. So far, the NRCMS has not challenged the vicious circle of poverty and disability.

Conclusion

In the PRC, as elsewhere, people with disabilities have proved to be among the poorest of the poor. The growth of the Chinese economy over the last four decades has been stunning, but groups of the population have not been in a position to benefit from the developments or to participate in the increasing wealth. The

divide between China's 'haves' and 'have nots' has become increasingly visible (Shue and Wong, 2007, p 1), and people with disabilities are over-represented among the 'have nots'.

Our point of departure in this chapter has been the hypothesis of the 'vicious circle' between impairments, disability and poverty (Yeo and Moore, 2003, p 572). Much literature has pointed to the double-way process in which impairment leads to poverty and poverty leads to impairments, both in industrialised societies, such as Germany and the USA (Burkhauser and Daly, 1994; Berthoud et al, 1995), and developing countries, such as India (Harriss-White, 1999). Within this literature, access to adequate healthcare is emphasised as a significant and powerful policy to decrease the force of this vicious circle, both by reducing the financial burden of medical and rehabilitation treatment and thus enabling poor people to seek medical help in cases when risking illness or impairment and by limiting the development of disabilities for people with an impairment (Ingstad and Whyte, 1995; Yeo, 2001; Bonnel, 2002).

We hold that although the ways in which the interconnectedness between disability and poverty manifests and how related policies are developed and implemented in China obviously share some common ground with how such interrelatedness appears in other places, there are, as we have demonstrated, some features that must be seen as unique for China. One major characteristic for the Chinese situation is the series of political campaigns, reforms and changes carried out during the period of 60 years since the establishment of the PRC in 1949. We have highlighted the impact of the political changes for people with disabilities and the changing role of the major agents involved in the care and provision for them – the households, the party-state and the CDPF. Our aim has been, on the one hand, to focus on healthcare during these various political campaigns and on the other hand, to underline the disability policy (or the lack of one) of the party-state in the same periods.

The organisation and financing of healthcare services have also been highly influenced by the changing policies since 1949. More importantly, our emphasis on healthcare, and in particular on economic access to healthcare, reflects the importance of this issue in the present sociopolitical situation in the PRC. First, healthcare expenses have proved to be a main cause of poverty among the population in rural areas in general. Second, access to adequate healthcare and rehabilitation services are particularly critical for groups of the population with special needs for such services, and among them are many people with impairments. Without proper medical and rehabilitation services, acute illnesses may cause chronic, disabling conditions and without rehabilitation services, treatable conditions may remain disabling. Third, after decades neglecting problems related to healthcare and rural poverty, the central government has recently launched new forms of schemes, most importantly new forms of rural medical insurance, aiming at poverty reduction caused by healthcare expenses.

However, the new schemes have not yet benefited the poorest of the poor. Limited financial support from the central government is one main inadequacy

of the present system. Moreover, although the ongoing initiative is regarded as important and necessary, scholars have pointed out that 'access is significantly influenced by modes of health financing and provisions that are closely tied into wider local governance systems and practices' (Duckett, 2007, p 61). Thus, in addition to the current top policy initiatives, changes also have to be implemented at the local level.

As we have shown, the state policy towards disability has changed quite radically during the political history of the PRC: from being an almost non-existing issue in political discourse in the period of collectivism (in the 1950s, 1960s and 1970s), to the period of the economic reforms and opening up from the late 1970s until the 1990s, when the party-state developed a *canji* policy and the CDPF was established. More recently (from the beginning of 2000), the central government has begun to address the problems of the inequality of access to healthcare as well as education, security and other opportunities, with new programmes addressing the general rural population, for people with and without disabilities alike.

CDPF is an association worth paying attention to in the context of disability and poverty in an international perspective, not only because it has grown to be so powerful and massive in size in a relatively short time, but also because in important respects it differs from the disability associations known in other parts of the world. While many of the internationally known disability associations are NGOs with influential grass-roots engagement, a strong involvement of the central state administration remains a characteristic feature of CDPF in the PRC. Moreover, because the PRC is a one-party system and the state *in facto* equals the CCP, the CDPF's close connections with the party-state makes CDPF stand out as special case in an international context. CDPF has an access to power that is rare for NGOs. Furthermore, although CDPF aims at representing people with disabilities in China and has elected people with disabilities as leaders, they constitute only a small proportion of the CDPF staff. Hence, in terms of numbers, CDPF does not represent people with disabilities. Moreover, with the strong links to the party-state, CDPF is not in a position to represent viewpoints that do not correspond to the state policy. Thus, while internationally it is not uncommon that disability associations express resistance to, for instance, eugenic methods aiming at the prevention of impairments, the CDPF is not a likely agent for promoting critical voices towards such fundamental state policies in China.

CDPF has been a powerful agent in defining disability in the PRC and has practised allocation of preferential treatments on the basis of a strict definition of what it means to be disabled. In contrast, the new welfare programmes address the general population, people with and without disabilities alike. We therefore suggest that the new welfare programmes may turn out to be the start of a new orientation in what it means to be a person with disabilities in China. These new health reforms may constitute less static frames for the understanding of disability. Presently, the new medical schemes only cover acute catastrophic diseases, but in the future this system might be expanded to include a broader repertoire of care such as rehabilitation services currently promoted by the CDPF. This would

mean that services for people with disabilities will be mixed with other types of services. In this sense, the new programmes arguably carry the potential to blur the strict distinctions between what it means to be a *canji ren* or not in the PRC today. Although *canji* will continue to be based on a medical understanding, the boundaries of the present *canji* category may open up to new ways of being a *canji ren*. The implications this may lead to with respect to the vicious circle of poverty and disabilities remain to be explored.

Notes

[1] As the PRC is a one-party system, the state is *in facto* equivalent to the Chinese Communist Party (CCP).

[2] For an overview of the development of special education in China, see Yang and Wang (1994); Epstein (1998); Callaway (2000); and Deng et al (2001).

[3] The Chinese poverty line is defined as less than 2.5 yuan per day, that is, about one third of the international poverty line of one dollar a day (Liu and Rao, 2006).

[4] The report explains the increase in disability rate due to four main factors: (1) growth of the Chinese population; (2) ageing of the Chinese population; (3) revisions of the disability criteria; and (4) socio-environmental factors. The population aged 60 years and over reached 11% in 2005, up from 8.5% in 1987 (CDPF, 2008).

[5] Obviously, the low official disability rate must be kept in mind when reading official Chinese statistics concerning the interrelatedness of disability and poverty.

[6] Adopted at the 17th Meeting of the Standing Committee of the Seventh National People's Congress on 28 December 1990, and revised at the 2nd Meeting of the Standing Committee of the Eleventh National People's Congress on 24 April 2008.

[7] In general, Chinese conceptualisations of body–mind variations are primarily perceived as undesirable and frowned upon. In her analysis of the language of impairments that is in use in Chinese society, Stone (1999) shows that both impairments and illness, which she explains are not understood as distinct categories in Chinese texts, are seen as products of imbalances that indicate separation from the regular order. Impairments are negative signs that signify disturbed relations in the interconnected domains of the body–mind, family, society, nature and cosmos. They are construed as in opposition to what is *zheng* (proper, regular, orthodox) and *quan* (complete, entire, whole).

[8] For detailed descriptions of preferential treatment in the PRC, see Kohrman (2005).

[9] This 2006-07 survey was the second national survey on disability issues to be carried out in the PRC. The major revisions from the classifications used in the first national survey conducted in 1987, were the differentiation of hearing and speech impairments

and the classification of these into two separated categories. Moreover, the category *jing shen bing canji* ('mentally ill disability', used in 1987) was changed to *jing shen canji* ('mental disability', in 2006-07), and the category *zonghe canji* ('multiple or complex *canji*', in 1987) to *duochong canji* ('of many kinds/multiple disability', 2006-07). Although claimed by the CDPF to be based on a social model of disability, we cannot see how these changes indicate a turn from a medical model.

[10] Filial piety was closely linked to the rules and practices of ancestor worship, and children's duties to respectfully care for their parents also lasted after their parents' deaths (Kohrman, 2005, p 150).

[11] There was a remarkable change in the size of the families following the open-door policy in 1978, when individuals gained the right to seek employment outside their natal village. Many young men, in particular, left and we saw the beginning of the enormous floating population of migrant workers spread out in the urban, eastern areas of the PRC.

[12] Moreover, this was the period before the implementation of the one-child policy in 1979, thus parents were not totally dependent on the abilities of each particular child.

[13] Law of the PRC on the Protection of Persons with Disabilities, Article 11: 'The State shall undertake, in a planned way, disability prevention, strengthen leadership and publicity in this regard, popularise knowledge of maternal and infant health care as well as disability prevention, establish and improve mechanisms for the prevention, early detection and early treatment of birth defects, and mobilize social forces to take measures in dealing with disability-causing factors such as heredity, diseases, medication, accidents, calamity and environmental pollution, to prevent and alleviate disabilities.'

[14] First, by joint decision by the Central Committee of the CCP and the State Council Decision on Strengthening Population and the Family Planning Work (2000), and in the following year the by the Law on Population and Birth Planning (2001).

[15] In November 2008 Zhang Haidi was elected the new chair of the CDPF. Zhang, presented on CDPF's homepage as a wheelchair-bound female writer, replaced Deng Pufang (CDPF, 2009).

[16] Recently, following the demonstrations related to the Olympic torch before the Beijing Olympic Games, the wheelchair-bound torch carrier who was attacked by demonstrators became a national hero celebrated throughout Chinese media.

[17] CDPF has played a crucial role in ensuring that a legal framework protecting the rights of people with disabilities is now basically in place in the PRC. The Law of the PRC on the Protection of Disabled Persons was established in 1990 and has recently been revised (2008). In 2007, Chinese authorities signed the UN Convention on the Rights of Persons with Disabilities. The Regulations on Employment of People with Disabilities

(also 2007) aims to further strengthen the legal frame for people with disabilities in the PRC (Shen, 2007).

[18] The negative development of poverty and lack of health services in the 1990s was a rapid process. From 1994 to 1998 the percentage of those categorised under the (Chinese) poverty line increased from 2.5% to 22%, and medical expenditure raised the number of households below the poverty line by 44.3% (You and Kobayashi, 2008).

[19] There had been several minor attempts to re-introduce the Medical Cooperative System from the collective period earlier. However, these all failed, mostly due to lack of political will, insufficient funding and poor management (Liu and Rao, 2006).

[20] 100 yuan is equivalent to €10.45 (18 November 2010).

[21] There are five models for distributing reimbursement funds that the counties can use: (1) in-patient reimbursements and household savings accounts; (2) certain proportions of in-patient reimbursements and out-patient reimbursements; (3) in-patient reimbursements and household savings and reimbursement of catastrophic conditions covered by out-patient departments; (4) in-patient reimbursements and reimbursement of catastrophic conditions covered by out-patient departments; and (5) only in-patient reimbursements; 62.5% of the pilot counties preferred model 1 (You and Kobayashi, 2008).

[22] 'Rational' and 'reasonable on medical grounds' is not defined in the report, and it remains unclear whether, for instance, traditional medicine is understood as 'irrational'. Despite the unclear definitions, these numbers are extremely low and indicate the seriousness of over-treatment (see also Zhang et al, 2003; Hofer, 2009).

[23] The excess use of drugs is also creating new health problems, such as children's deafness due to over-use of antibiotics (Callaway, 2000; Hofer, 2009).

[24] However, even with the new health insurance, the cost of hospital treatment remains high, as the reimbursement rates vary from only 15% to 60% of the total cost. Brown et al provides examples of hospital costs of around 20,000 yuan for catastrophic illnesses (referred to in You and Kobayashi, 2008).

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Living conditions among people with disabilities in developing countries

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Introduction

Living conditions and *poverty* are two common quantifiers or parameters of socioeconomic status and both have evolved from rather narrow economic and material concepts to encompass broader and more complex understandings.

According to Heiberg and Øvensen (1993), studies on *living conditions* have evolved to include individuals' capabilities and how they utilise their capabilities. Likewise, the concept of *poverty* has expanded beyond a derived level of income or accumulation of material goods whereby 'poverty is now seen as the inability to achieve certain standards', poor people 'often lack adequate food, shelter, education, and health care', and 'they are poorly served by institutions of the state and society' (Wolfensohn and Bourguignon, 2004, p 4). The two concepts are not interchangeable, however; they stem from different research traditions and differ in use both for research and for practical purposes. While poverty research has focused on defining poverty and establishing poverty profiles, identifying poor populations and strategies for reducing poverty, studies on living conditions are based on more loosely bound sets of indicators that are applied to measure, for example, level of income, education, access to information, access to healthcare and social participation in a population, and to establish differences between population sub-groups for descriptive, comparative and monitoring purposes. Poverty is both a more general and complex phenomenon than living conditions, and the field of poverty research has recently been characterised as 'polyscopic', indicating that we are dealing with a multifaceted umbrella term and a conglomerate of perspectives and methods (Øyen, 2005). Surveys of living conditions in a population can, however, provide indicators on poverty and disability, and, if properly designed, they can be applied to study poverty mechanisms, poverty development and trends in a population, as well as contributing to decisions that may be applied to poverty alleviation. In this chapter data collected on the living conditions among people with and without disabilities in the southern African region will be utilised to assess the disability–poverty relationship.

There is considerable support in the literature for the close, dependent relationship between disability and poverty (Palmore and Bruchett, 1997; Turmusani et al, 2002; Yeo and Moore, 2003). According to Beresford (1996, p 553), 'the relationship between poverty and disability is close, complex and multi-faceted'. Barnes and Mercer (1995) argue that the economic and social deprivation experienced by disabled people is hardly experienced by other sections of society. It has, for instance, been estimated that over 60% of people with disabilities in the US and Great Britain live below the poverty level (Beresford, 1996). Studies in Norway have shown a gap in living conditions between disabled and non-disabled individuals and that the disadvantaged position of those with a disability is also maintained in times of continuously increasing prosperity among the general population (Hem and Eide, 1998).

There is, however, less evidence to be found supporting the disability–poverty relationship in low-income countries (Elwan, 1999; Metts, 2000; Yeo and Moore, 2003; Loeb et al, 2008). This is primarily due to the lack of relevant and reliable data; however, there is also a possibility that the relationship between poverty and disability is different in contexts where poverty is a reality for the majority or large segments of the population. The discourse on the relationship between disability and poverty in developing countries is, on the other hand, clear; most people with disabilities live in developing countries and they are among the poorest of the poor (Yeo and Moore, 2003).

> Despite the obvious relationship between impairment, disability and poverty, there is little international comparable statistical data on the incidence, trends and distribution of impairments and disabilities, and much nation-level data, particularly in the developing world, is unreliable and out-of-date. (quoted in Erb and Harriss-White, 2001)

The *World Programme of Action concerning disabled persons* (UN, 1982), *The standard rules on the equalisation of opportunities for persons with disabilities* (UN, 1994) and, most recently, the UN *Convention on the Rights of Persons with Disabilities* (UN, 2006) comprise explicit formulations that reflect the need for information, data collection and research on the situation of people with disabilities, particularly in developing countries.

Studies on living conditions in southern Africa[1]

SINTEF Health Research has, in collaboration with the Norwegian Federation of Organisations of Disabled People (FFO) and the Southern Africa Federation of the Disabled (SAFOD), national Central Statistical Offices and relevant ministries, carried out large and nationally representative studies on living conditions among people with disabilities in Namibia (Eide et al, 2003a), Zimbabwe (Eide et al, 2003b), Malawi (Loeb and Eide, 2004) and Zambia (Eide and Loeb 2006a).[2] The

questionnaires developed for these surveys were based on existing designs that had previously been applied in the region (Schneider et al, 1999; NPC, 2000). A particular feature of all these studies has been extensive involvement of disabled people's organisations (DPOs), individuals with disabilities and a continuous development of the researcher–user relationship[3] into a model whereby DPOs have been in control of the entire research process. In each country stakeholder workshops were important in order to adapt the design to local contexts before carrying out the studies, and reference groups ensured broad influence in the research process. This ensured not only a contextual adaptation of a general concept ('living conditions') and the relevance of the surveys for individuals with disabilities, but it was also a strategy for ensuring application of the data. For further discussion about the user aspect, see Albert (2006).

Sampling was carried out by the Central Statistical Office in each country, based on national sampling frames, and involved a two-stage procedure: first, a representative sample of geographical areas (enumeration areas [EAs]) was drawn, followed by a disability screening exercise in each of the areas. Screening was inspired by the International Classification of Functioning, Disability and Health (ICF), and was thus based on activity rather than impairment, as for most previous censuses in low-income countries (see Eide and Loeb, 2006b; Loeb et al, 2008). Households with a disabled family member were later revisited and interviewed using a comprehensive questionnaire. Neighbour households without disabled members were interviewed as controls to enable comparative analyses. The questionnaires applied in each country differ to some extent due to local adaptation, but they are largely comparable.

Interviewers were given extensive training in order to prepare them for data collection, to avoid interviewer bias and to establish a common understanding on the core concepts involved. It was particularly important to make sure that an ICF-based understanding of disability was shared among the enumerators, as opposed to an impairment-based understanding that still prevails. In all countries efforts were made to recruit interviewers who themselves were disabled; they were often recruited through the collaborating DPO.

Screening for disability in surveys or censuses is a critical issue and the development of screening questions follows developments in the discourse on disability definitions. Comparability between disability data has for a long time been hampered by the lack of a standard procedure for measuring disability and for distinguishing people with and without disabilities (Eide and Loeb, 2006b). The discourse on disability and its definition during the last 20–30 years may be reflected through the revision of the first World Health Organization (WHO) classification on disability (International Classification of Impairments, Disabilities and Handicaps) (WHO, 1980) and the final adoption of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). With the ICF a model of disability has been made available that attempts to merge two clearly different ways of defining disability, that is, the medical model and the social model. Rather than focusing on physical impairments, activity limitations

and restrictions in social participation are regarded as core components in the process of functioning that also include bodily functions, health conditions and environmental and social factors. According to this logic, disability is conceived as the outcome of the interaction of a person's functional status with the physical, social and political environments in which he/she lives (Mont, 2007). This has a direct impact on the screening and measurement of disability, shifting in principle from measuring impairments to functioning by means of measuring capacity (activity limitations) and performance (social participation). ICF provides the framework by which sets of questions may be developed and utilised to quantify capacity and performance in surveys. Following the acknowledgement of problems related to international disability statistics and the adoption of ICF in 2001, the Washington City Group on Disability Statistics[4] was tasked with developing standard ICF-based screening instruments for censuses and surveys. The ICF has been operationalised through the development of disability screening procedures based on functioning in the studies on living conditions among people with disabilities in southern Africa, and in one country (Zambia) directly on the work of the Washington City Group (Loeb et al, 2008).

Results from the national representative studies

In addition to allowing for comparisons between individuals with and without disabilities, and between households with and without disabled members, the coordination and design of these studies also allows for comparison between countries (see Table 3.1).

Table 3.2 shows the mean size of households with and without a person with a disability.

Table 3.1: Size of survey samples

	Namibia		Zimbabwe		Malawi		Zambia	
	With disabled	Without disabled	With disabled	Without disabled	With disabled	Without disabled	With disabled	Without disabled
Number of households	2,286	1,356	1,943	1,958	1,521	1,537	2,885	2,886
Number of individuals in household	16,459	6,855	11,460	10,252	8,038	7,326	15,210	12,979

Table 3.2: Some demographic comparisons

	Namibia		Zimbabwe		Malawi		Zambia	
	With a disability	Without a disability	With a disability	Without a disability	With a disability	Without a disability	With a disability	Without a disability
% female	52.7	51.8	51.8	52.4	51.2	50.2	49.8	50.7
Mean size of household	7.2	5.1	5.3	4.8	5.9	5.2	5.3	4.5

There are no real differences in terms of the percentage of females. The most outstanding demographic difference between the two groups of households (with and without members with a disability) is the higher mean size (number of members) of households with disabled family members. While the explanation for this lies outside of the scope of the surveys, other literature on disability and poverty (see Ingstad and Grut, 2006) suggests that when there is a disabled member in a household, in many instances the task of caring for that person requires extra hands – a task that will often be given to non-disabled female children or other female members of the family. However, regardless of the explanation, the consequence of having a higher mean size of these households implies that direct comparison of households with and without disabled members on poverty-related measures will tend to under-estimate the differences, because these households will have more mouths to feed.

With regards to access to education and literacy there is a consistent pattern across the four countries, as can be seen in Table 3.3.

The results clearly indicate that individuals with disabilities are to a much larger extent (mostly between two and three times) denied access (for a variety of reasons) to the educational system than individuals without disabilities. It should be noted here that treating individuals with disabilities as one group implies that individuals who could not have utilised 'normal' schools are also included in the results. This group is, however, marginal in the overall picture, and not excluding them from these analyses does not have a strong influence on the demonstrated differences.

The urban–rural dimension in Table 3.3 clearly demonstrates that access to education is significantly lower in rural areas. Between 25% and 40% of individuals with disabilities living in rural areas in these four countries have never attended school, while the corresponding figure for urban areas is between 15% and 30%. The same pattern of differences between disabled/non-disabled and urban/rural is also found with regards to literacy.

While the basic trend is similar across countries, Table 3.3 also illustrates the differences in the level of non-attendance in the region, with highest levels of

Table 3.3: Education and literacy (age five years or older)[a]

	Namibia		Zimbabwe		Malawi		Zambia	
	Disabled	Non-disabled	Disabled	Non-disabled	Disabled	Non-disabled	Disabled	Non-disabled
% never attended school								
Urban	29.9	11.2	20.0	7.7	15.8	6.4	19.2	5.3
Rural	39.1	17.1	31.0	10.4	37.7	19.3	26.7	11.1
% unable to write								
Urban	40.8	14.3	36.6	15.0	39.5	26.5	35.7	28.3
Rural	48.5	23.8	43.5	19.0	64.3	53.8	53.1	46.5

Note: [a] These results concern ordinary primary, secondary and higher education and do not include special education institutions.

non-attendance observed in Namibia and Malawi and somewhat better but far from equitable results in Zimbabwe and Zambia in particular. Reasons for regional differences are not immediately evident; however, each country has experienced social development (pre-colonial, colonial and post-colonial) differently, and the results may be a reflection of that history. For example, under colonial rule Zimbabwe experienced the development of a well-functioning social infrastructure, and in particular, the development of facilities specifically designed for those with disabilities (such as the Jairos Jiri Association). Today, or at least before the current political and economic downfall of the country, an extended network of institutions served people with disabilities (Devlieger, 1995). The relatively higher level of school attendance among non-disabled in Zambia and Zimbabwe may also contribute to explaining differences in accessibility to education for individuals with disabilities.

Literacy, or written languages, is another indicator of living conditions, and the same pattern as observed in school attendance between disabled and non-disabled is again demonstrated. Between 40% and 60% of those with disabilities (five years or older) may be classified as illiterate, that is, not able to write. In Namibia and Zimbabwe the difference between disabled and non-disabled are particularly pronounced, while Malawi comes out with the highest figure for both groups.

Interestingly, as illustrated in Table 3.4, once given the opportunity to attend school, individuals with a disability achieve largely the same level of education as non-disabled, and in some countries a higher level, as is the case with Zimbabwe and Namibia.

Table 3.4 shows that fewer complete secondary school level in Malawi and Zambia but also that a higher proportion of students take higher education in Zambia as compared with the other countries. At the level of higher education, there is no significant difference between disabled and non-disabled students. In

Table 3.4: Highest grade achieved (age five years or older)

	Namibia		Zimbabwe		Malawi		Zambia	
	Disabled	Non-disabled	Disabled	Non-disabled	Disabled	Non-disabled	Disabled	Non-disabled
Urban								
Primary	67.3	53.8	65.4	51.0	60.8	60.4	57.9	56.4
Secondary	30.6	44.0	32.5	47.1	33.6	35.0	32.0	35.3
Higher education	2.0	2.2	2.1	1.9	5.6	4.7	10.1	8.3
Rural								
Primary	78.9	67.4	78.3	69.8	88.7	87.7	73.1	70.5
Secondary	20.3	31.3	20.6	29.9	10.4	11.9	23.5	25.9
Higher education	0.9	1.3	1.1	0.3	0.9	0.4	3.4	3.6

general, the differences between disabled and non-disabled are not very high, but there is, to a larger extent, a tendency for individuals without disabilities to reach as far as completing secondary school.

Barriers that hinder children with disabilities from attending school may vary. Often schools and classrooms are not adapted to the special needs of children with disabilities. Beyond the obstacles of gaining physical access to the facility itself, other barriers can include a lack of suitable teaching materials (Braille, sign language interpreters, large print textbooks etc), or a lack of teachers trained to deal with the needs of children with disabilities. Even if children with disabilities gain access to schools, many do not attend because toilet facilities at the schools are inaccessible. Matriculation rates are also lower among students with disabilities. In South Africa, for example, it is claimed that disparities in school attendance and completion are 'informed by attitudes within the schools that reinforce the notion that disabled students do not have a future in higher education and thus it is not in their own interests or in the interests of the school to support that career path' (Howell, 2006, pp 165–6).

Challenges related to school attendance are closely related to type of impairment. A separate analysis on impairment type and school attendance is presented in Table 3.5.

The pattern of type of impairment among those individuals who were identified as being disabled and who never attended school (see Table 3.5) is quite similar among the four countries included. Individuals identified as having a disability using the screening questions were asked to indicate the type of disability or impairment they had. The majority of those who never attended school had sensory impairments (vision, hearing and/or communication) as their primary impairment, followed by physical impairments and mental/emotional impairments. (Other impairments include, for example, age-related impairments, albinism and unspecified impairments.) Comparing the results in Table 3.5 with the distribution of types of impairments among those who were identified as having a disability[5] indicates clearly that individuals with sensory and mental/emotional impairments run a much greater risk of being excluded from education compared with those who are physically impaired.

Table 3.5: Type of impairment among those who never attended school (age five years or older)

	Namibia	Zimbabwe	Malawi	Zambia
n	869	519	403	582
Sensory*	43.6	39.5	42.4	43.6
Physical	34.9	41.4	40.7	35.2
Mental/emotional	19.3	11.0	12.4	15.5
Other	2.2	8.1	4.5	5.7

Note: * Includes communication difficulties.

Unemployment in sub-Saharan Africa is high (Teal, 2000), regardless of the disability status of a household, and this is illustrated in Table 3.6. Despite regional high unemployment rates, households with disabled members are less likely to have an income than households without a disabled family member (with the exception of the data material from Zambia). It is worth noting that the ratio of 'not working to working' is much higher in Namibia and Zimbabwe. In the surveys presented here 'working' has been operationalised as 'working outside the household and bringing cash into the household'. In all four countries informal employment is common and often encouraged without strict enforcement of laws and regulations governing work environments. Subsistence farming and barter trade are other important factors influencing household income. Although the way 'working' has been defined in these studies also covers the informal economy, it is limited to the cash economy and may thus under-estimate the level of activity required to secure a living for the household.

Second, the results demonstrate that unemployment as defined in these surveys is significantly higher among disabled members in three of the four countries, Zimbabwe being the exception in this regard.[6] As mentioned above, unemployment is high in the entire region and even more so among individuals with disabilities. Figures on employment rates in these contexts are problematic due to the relative importance of the informal sector, with many individuals having marginal and insecure income. The figures in Table 3.6 may thus differ from other available statistics as definition and understanding of unemployment will vary.

As an indicator of living conditions, *access to information* was captured according to the level of access or availability to various communication/media sources in a household: telephone, radio, television and newspaper. A household could own or regularly use the source of information, have reasonable access to the source or have no access to the information source. Table 3.7 shows the percentage of households *without* access to the specified information source.

Accessibility is not uniform across the four countries surveyed – different degrees of accessibility are demonstrated, particularly in terms of telephone and

Table 3.6: Employment situation

	Namibia		Zimbabwe		Malawi		Zambia	
	Disabled	Non-disabled	Disabled	Non-disabled	Disabled	Non-disabled	Disabled	Non-disabled
Is someone in the household working?								
% No	56.3	40.9	55.0	49.7	18.1	13.5	16.4	16.3
% Yes	43.7	59.1	45.0	50.3	81.9	86.5	83.6	83.7
Are you currently working? (age 15-65 years)								
No % unemployed	90.1	77.8	78.4	78.3	57.7	53.2	54.5	42.0

Table 3.7: Household access to information: % of households *without* **access to information by disability status of household and urban/rural location**

	Namibia		Zimbabwe		Malawi		Zambia	
	With a disability	Without a disability	With a disability	Without a disability	With a disability	Without a disability	With a disability	Without a disability
Telephone								
Urban	11.2	8.7	14.0	11.7	16.2	12.4	40.7	37.7
Rural	42.0	39.0	14.8	15.0	48.8	46.0	75.3	72.9
Radio								
Urban	7.6	5.5	15.3	14.7	4.4	3.9	16.5	15.2
Rural	13.1	11.1	28.3	24.4*	10.8	8.6	38.9	36.4
Television								
Urban	23.1	18.4	34.9	30.5	25.9	18.5	34.4	34.4
Rural	70.1	65.8*	67.8	68.5	64.5	60.0*	77.1	73.9*
Newspaper								
Urban	23.1	13.2†	35.2	27.5*	25.9	18.1	46.8	46.1
Rural	72.4	63.3†	52.7	50.5	67.6	59.8†	84.1	84.1

Notes: * $p<0.05$; † $p<0.01$.

radio. This may reflect true differences in the living standards of the countries at the time of the survey.

Not unexpectedly, rural areas have poorer access to all forms of information (telephone, radio, television, and newspaper). While differences between households with and without a disabled family member reached statistical significance in only certain types of information in certain countries, the general pattern was similar across the board. This is true for all forms of information, and it follows the same general pattern as was seen in terms of mean number of possessions. The above media for communication are considered a luxury, to the extent that they have to be continually paid for, especially among the poor and disabled households. However, most households tend to buy/procure them as one way of ensuring that those with a disability are entertained and connected to the outside world as and when they need it.

Differences between households with and without a disabled family member, when statistically significant, are generally in the direction of households with a disabled family member on average having fewer possessions than households without a disabled family member (see Table 3.8). Only in Zimbabwe were households with a disabled family member found to have more possessions than households without a disabled family member. Rural households were on average found to have fewer possessions, regardless of the household's disability status, than urban households. Possession in Malawi and Zambia was more evenly split between rural and urban; in Namibia and Zimbabwe the list of possessions is biased towards urban dwellers.

Table 3.8: Mean number of household possessions by disability status of the household (weighted by size of household) and urban/rural location

	Total number of possessions considered	With a disability	Without a disability	*p* value
Namibia	30	4.2	5.2	<0.001
Urban		7.1	8.1	<0.001
Rural		3.5	4.3	<0.001
Zimbabwe	30	5.8	5.7	0.007
Urban		7.1	7.2	ns
Rural		5.3	5.1	<0.001
Malawi	41	10.6	10.9	<0.001
Urban		14.1	13.9	ns
Rural		10.1	10.5	<0.001
Zambia	40	10.3	10.3	ns
Urban		11.4	11.4	ns
Rural		9.6	9.6	ns

Table 3.9 provides an overview of services that are considered to be important for individuals with disabilities, in particular with respect to their level of functioning and degree of social participation.

Table 3.9: Gap in service delivery

	Namibia		Zimbabwe		Malawi		Zambia	
Service	Needed[a]	Not received[b]	Needed[a]	Not received[b]	Needed[a]	Not received[b]	Needed[a]	Not received[b]
Health services	90.5	27.1	93.7	8.0	83.4	39.0	76.7	20.7
Welfare services	79.5	76.7	76.0	76.4	69.0	95.0	62.6	91.6
Counselling for parent/family	67.4	58.3	49.2	54.6	50.5	80.5	47.3	78.1
Assistive device services	67.0	82.7	56.6	63.4	65.1	82.1	57.3	81.6
Medical rehabilitation	64.6	73.7	68.2	45.2	59.6	76.2	63.2	62.5
Counselling for disabled	64.6	84.8	52.1	59.2	52.7	89.3	51.2	85.7
Educational services	58.1	72.6	43.4	48.8	43.9	79.7	47.0	82.2
Vocational training	47.3	94.8	41.1	77.3	45.0	94.4	35.1	91.6
Traditional healer	33.1	53.2	48.9	9.9	57.7	40.3	32.3	37.1

Notes: [a] Percentage of total number disabled; [b] percentage of those claiming they needed the service.

The first column, for each country, indicates the importance of the different services, that is, the proportion of the total number of individuals with disabilities who stated that they needed the respective services. Although there are slight variations between the countries, the order of the services in the table largely also reflects the rank order of importance. Also presented are the percentages of those who did not receive the service (from among those who claimed that they needed it). Few services have small service delivery gaps (services not received but needed), although it is somewhat encouraging that health services are among those most often received in all countries. The largest gaps are found for vocational training, welfare services, assistive device services and counselling, and generally the smallest gaps are observed in Zimbabwe; this again may be a reflection of the (then) rather well-functioning (in regional terms) social infra-structure inherited at independence.

Conclusion

The results presented here are unique in representing the first generation of a thorough comparative mapping of the level of living among people with and without disabilities in the southern African region. The strong involvement of DPOs throughout the entire research process, as well as the efforts to recruit interviewers with disabilities, have positively influenced the relevance and applicability of the data.

Although DPOs have limited resources and experience with doing research and coordinating complex national data collections, they received good support from the collaborating universities as well as the national Central Statistical Offices in each country. These surveys comprise an important element in a planned and strategic organisation capacity building programme being carried out in collaboration between SAFOD and FFO. The overall operations of the surveys thus rest within the national organisations themselves. Combined with a parallel capacity building programme designed to empower organisations with the ability to understand, interpret and apply research results, the exercise has given DPOs in each country the ability to inform policy as it affects the lives of people with disabilities.

While there are many positive aspects to these studies, it is nevertheless the case that they have been carried out under difficult circumstances with regards to infrastructure and capacity in general, and many individuals previously inexperienced with research methodology and data collection were involved. To some extent this may have affected the quality of data, and it is possible that some of the differences between countries may be explained by variation in understanding of certain questions and concepts (compounded by the fact that the four countries included here each have many local languages). We attempted to counter this, however, by teaming inexperienced research assistants with those who were more experienced and recruited through the local universities, by continuously improving selection criteria for and training of interviewers as

well as quality assurance during data collection by employing highly qualified supervisors and a standardised system for the control and flow of questionnaires in the research process.

There is strong support for a close relationship between disability and poverty in the literature. Data to support this is particularly weak in low-income countries due to the general lack of statistics in poor countries as well as the problematic quality of the few data that exist. The surveys in the southern African region provide a first broad, systematic approach to living conditions among people with disabilities in developing countries that enable comparison between groups as well as across different contexts. Results from the surveys have demonstrated a consistent pattern of differences between people with and without a disability, in rural as well as urban areas, and between households with and without disabled family members.

The proportion of those with a disability who have not attended school is about twice as high as the corresponding figure for those without a disability. Close to half the population of people with a disability are illiterate. Unemployment is in general extremely high, but clearly higher among individuals with disabilities. Access to information is lower among households with disabled family members.

The studies have further identified large gaps in service delivery, in particular with regards to vocational training, welfare services, assistive device services and counselling. The gaps in delivery of these services are among the largest and are indicative of some of the environmental barriers that restrict the full social participation of disabled individuals. In each country such figures could be applied to guide policy development, priority setting and resource allocation in order to ensure the effective use of limited resources. In many of the countries in the region disability policies are in place that are based largely on international documents such as *The Standard Rules for the Equalisation of Opportunities for People With Disabilities* (UN, 1994). Unfortunately, these policies are at the same time based on rather limited or no research based knowledge concerning the situation of people with disabilities in the countries in question. This will clearly affect the relevance of policies and thus also the quality and outcome of policy implementation. With the existing data material, more informed policies might be possible in the future.

The majority of the differences shown in the tables presented here are statistically significant, implying that there are real differences on the level of the population of disabled people. Several of the indicators included in the analyses are also valid poverty indicators, and thus the studies have contributed with data that confirm the disability and poverty co-dependency.

Although the general pattern is confirmed in all four national surveys, and in both urban and rural contexts, there are also pronounced differences between countries, for instance, in terms of employment. As mentioned in the introduction to this chapter, the disability concept in itself is complex and is further complicated through the influences of regional and cultural differences. Although standard

training was offered, with much emphasis on establishing a common ICF–based understanding of disability, traditional understandings of disability may have had some influence on the final operationalisation of the disability concept in the research presented here.

While it is argued that comparability across countries is one of the possibilities offered by these data, such comparisons are nevertheless problematic. Comparability may be compromised through any of the following actions: minor differences in survey design due to contextual adaptation in each country or inherent cultural differences; changes based on experience in previous countries surveyed; refinements in the understanding of core concepts; differences among the data collection teams; or variations in training procedures. However, since the survey design remains by and large unaltered and the surveys were carried out under the guidance of the same people, it is nevertheless assumed that the differences observed reflect true differences in living conditions between the countries.

Regardless of level of employment, or education, access to information or the availability and acquisition of services, individuals with disabilities and the households in which they live are worse off than those without disabilities and their households. The two indicators that were analysed for urban–rural differences further demonstrate that living conditions measured in this way are better in urban areas, while the difference between households with and without disabled members follow the same pattern for both.

High quality statistical data concerning differences in living conditions, which prove the systematic discrimination against individuals with disabilities, have the potential to contribute to the planning of effective and equitable service delivery, policy development and the establishment of priorities in terms of the rights of people with disabilities. Furthermore, good data provides the foundation for good guidance in designing the specific means to reduce discrimination; for those who are working, good data can provide the means of raising awareness among the general population and for advocating for the rights of people with disabilities. In addition, and due to the strategy of involving and giving control to DPOs, the surveys also provided research skills and training to individuals, employment to disabled research assistants and a much-needed impetus to the organisations involved. It is argued that in many of the countries in the southern African region and in the developing world in general, governments and the public bureaucracy are often weak on the implementation side. It is one thing for a government to adopt a disability policy and to ratify the UN *Convention on the Rights of Persons with Disabilities*; it is quite another to implement it. Supporting civil society, including DPOs, is vital to actualise change. Documented proof of inequalities in the lives of people with disabilities has been a strong force in improving living conditions among disabled people and other marginalised and vulnerable groups in the industrialised world. Building strong DPOs in the South and building alliances between DPOs and researchers may thus provide the same possibility for those with disabilities in the South.

Notes

[1] The Atlas Alliance/NORAD funded all studies.

[2] The studies were carried out in close collaboration with the Universities of Namibia, Zimbabwe, Malawi and Zambia. In all four countries the national Central Statistical Offices were also involved in sampling and partly in data collection. National affiliates of SAFOD have been overall responsible for organising the studies in the respective countries: the National Council for Disabled People in Zimbabwe, the National Federation for Disabled People in Namibia (NFDPN), the Federation of Disability Organisations in Malawi (FEDOMA) and the Zambia Federation of the Disabled (ZAFOD).

[3] For further information about the user perspective in the studies, readers are referred to Eide and Loeb (2005).

[4] The Washington City Group on Disability Statistics was authorised by the United Nations (UN) Statistical Division in 2001 to guide the development of disability measures for censuses and surveys globally.

[5] Impairment distribution in the four countries varied. Approximately 40-45% were found to be physically impaired, 20-25% reported sensory impairment, while 10-15% had emotional or mental problems.

[6] Note that data collection in Zimbabwe was carried out in 2002. Due to the downfall of the economy in the country, living conditions including access to work have deteriorated dramatically.

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"No disabled can go here…": how education affects disability and poverty in Malawi

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> Education … beyond all other devices of human origin, is a great equalizer of conditions of men – the balance wheel of the social machinery…. It does better than to disarm the poor of their hostility toward the rich; it prevents being poor. (Horace Mann)[1]

Poverty is often conceptualised as resulting from a poor economy or as a lack of personal goods and material wealth. Recent years, however, have witnessed a shift in the parameters that define poverty as well as an overall approach to poverty. Wolfenson and Bourguignon (2004) describe this as a shift from poverty defined and measured by the level of income or consumption, to the notion of poverty as the lack of access to food, shelter, education, employment, healthcare and more. This reallocation of the poverty concept is in agreement with the description of poverty put forward by *The World Summit for Social Development, Copenhagen 1995* (UN, 1995), highlighting the importance of addressing both economic/material poverty (described as 'absolute poverty') and social exclusion (described as 'overall poverty') in the attempt to achieve the United Nations' (UN) aim of halving world poverty by 2015 (UN, 1995; Townsend, 2006).

Thus, one of the main predictors of poverty becomes the level of and access to education. It is generally believed that having an education can lift individuals and their families out of poverty, while the lack of an education merely entrenches the individual in a perpetual state of poverty (see, for example, Colclough, 1982; Lewin, 1993; Kadzamira and Rose, 2003). Hence, the Government of Malawi (Ministry of Education, Sports and Culture) emphasises the importance of an educated population for Malawi's development and in an attempt to alleviate poverty. Research from Malawi and other countries in southern Africa have documented that people with disabilities and their families in these countries have poorer living conditions than people without disabilities, and problems include those of economic and material poverty, low levels of participation in education and employment and poorer social and health conditions (Eide et al, 2003a, 2003b; Loeb and Eide, 2004; Eide and Loeb, 2006; Eide and Kamaleri, 2009).

This chapter focuses specifically on the challenges and obstacles faced by people with disabilities in Malawi in obtaining an education. It draws on the results from three studies conducted in Malawi on topics of living conditions for people with disabilities. The first study was a quantitative national representative survey of living conditions among people with activity limitations (Loeb and Eide, 2004). The second study was a qualitative study concerning albinism (Braathen and Ingstad, 2006). The third study, also a qualitative study, focused on living conditions for women with disabilities (Kvam and Braathen, 2006, 2008; Braathen and Kvam, 2008). The analysis of education and poverty in this chapter is based on a complementary and supplementary analysis of the results from these three studies.

Background

The Republic of Malawi is a democratic country, located in southern central Africa, with a population of about 12.8 million people. On the Human Development Index Malawi is ranked as the 13th poorest country in the world (UNDP, 2007/08). Malawi's economy is predominantly agricultural, and approximately 90% of the population live in rural areas (World Factbook, 2008). The school system in Malawi consists of primary school (standard 1-8), secondary school (form 1-4) and university (four years). Primary education has been free since 1994, but students have to pay school fees to attend secondary school and university. In addition they have to pay for school uniforms, books and stationary at all levels of education (SDNP, 2005). According to the Millennium Development Goals (MDGs) Indicators (UN, 2008), the total net enrolment ratio for Malawi in primary education for both boys and girls in 2004 was 96.1% (93.8% for boys and 98.4% for girls), while the percentage of pupils starting standard 1 who reach last grade of primary school in 2004 was 33.6% (32.1% for girls and 35.2% for boys). Primary school completion rates are higher for boys than for girls, as reflected in the 2004 data, which shows that the ratio of girls to boys was 1.02 in primary level enrolment, 0.81 in secondary level enrolment and 0.54 in tertiary level enrolment (UN, 2008). This is also reflected in the literacy rates that are 76.1% for men and 49.8% for women (GAIA, 2009).

Primary education still remains unaffordable, inaccessible (schools are far apart and school buildings are inaccessible to many) and inadequate (poor standards of teaching and teaching materials) for many children in Malawi (National Economic Council, 2000). The national education goal for Malawi, as spelt out in *Vision 2020*, includes increased access to education and improved special education (National Economic Council, 2000). Furthermore, Malawi has established and recently adopted a national disability policy, which has as one of its priority areas to ensure the equal right and opportunity to education for people with disabilities (MSDPWD, 2006). Malawi currently has four special schools for the deaf and two special schools for the blind. In public schools, as well as in the special schools, there is a lack of special education teachers and adequate teaching material, especially in Braille, large print, hearing aids, computers, mobility devices, etc.

Furthermore, schools and public institutions are very often inaccessible to people with mobility limitations, or people who are dependent on wheelchairs. There is a general lack of resources for special needs education in Malawi (Ministry of Education, Government of Malawi).

Studies from 11 developing countries around the world have shown that children and young people with disabilities are less likely to start school and often have lower levels of education. The correlation between disability and poor education outcomes is often larger than those associated with other characteristics, such as gender, rural residence or low economic status (Filmer, 2005). In South Africa, Howell (2006) argues that attendance and completion of higher education among people with disabilities is affected by attitudes that 'reinforce the notion that disabled students do not have a future in higher education and thus it is not in their own interests or in the interests of the school to support that career path' (Howell, 2006, pp 165-6).

Research has shown that people with disabilities in several African countries have lower levels of participation in education compared to their non-disabled peers. In addition, the studies from Malawi, on which this chapter is based, showed that people with disabilities face discrimination and stigmatisation because of their disability, often due to lack of awareness about disability in their society in general (Loeb and Eide, 2004; Braathen and Ingstad, 2006; Braathen and Kvam, 2008).

Methodologies

Living Conditions Survey 2003/04

Beginning in 2003, the Federation of Disability Organisations in Malawi (FEDOMA) in collaboration with local partners (Centre for Social Research [CSR] at the University of Malawi) and international partners (SINTEF Health Research and the Norwegian Federation of Organisations of Disabled People [FFO]) undertook a national representative survey of living conditions among people with disabilities in Malawi.

A national, representative sample was chosen for this survey. The sampling frame used for the survey was obtained from the national Central Statistical Office developed from the (most recent) 1998 Census of population and housing. For the purposes of this survey, enumeration areas (EAs) constituted the ultimate primary sampling units.

The survey was designed to cover 157 EAs (stratified according to urban/rural location) across the three provinces and to provide a cross-sectional sample of approximately 3,000 non-institutionalised, private households in Malawi. Details of the survey design and methodology are available in Loeb and Eide (2004) and at www.sintef.no/lc.

A total of 3,058 households were included in the final sample, 1,521 (49.7%) representing households with a disabled family member and 1,537 (50.3%) representing 'control' households without a disabled family member. The sample

included 15,364 individuals or approximately 0.12% of the Malawian population; 1,623 individuals (11%) of the sample population were identified as having a disability.

The heads of households selected for inclusion in the survey were interviewed regarding the living conditions of the households, including housing standards, composition of the households as well as the education and literacy, economic activity and disability status of individual family members. Subsequently, those individuals identified as having a disability (or a proxy) were interviewed using a separate detailed questionnaire to elicit further details of their experiences as a person with a disability, including details of their activity limitations and participation restrictions, experienced environmental barriers, their awareness, need and receipt of services, their experiences with assistive devices and technology, accessibility in the home and surroundings, inclusion in family and social life and their health and general well-being. Neighbour households without disabled members were interviewed as controls.

Using a methodology proposed by Filmer and Pritchett (2001), an asset index was calculated as a proxy for wealth using principal component analysis (PCA). This index is composed of 18 indicators linked to the possession of certain household or individual items, characteristics of the household dwelling and household ownership. These indicators were determined to be culturally appropriate and contextually based to the Malawian situation. Subsequently, three distinct asset groups were defined based on the first factor of the PCA.

Ten teams implemented the entire survey; each team was composed of a supervisor, four to five enumerators and a driver. In addition, a field coordinator, assisted by study investigators from FEDOMA and CSR, facilitated the survey.

Albinism in Malawi Study 2004

This study used qualitative research methods, individual in-depth interviews and participant observation. The aim was to gain detailed and in-depth knowledge about the lives of people with albinism in Malawi, and to learn from them, first hand, about their views, knowledge and experiences. In this regard, the topic of education for people with albinism was raised on several occasions. The study population included people with albinism as well as their family members. An interview guide was used in all the interviews. This covered the informant's background and current situation, knowledge about albinism, and stigmatisation, discrimination and violation of people with albinism. The fieldwork took place over a six-month period, from June to December 2004.

There were 25 informants in the study, comprising 11 people with albinism, 11 mothers of children with albinism, two siblings of people with albinism and the leader of The Albino Association of Malawi (interviewed about the situation for people with albinism in Malawi in general, and not about himself personally). All the informants lived in either Blantyre district (urban) or Mangochi district

(mostly rural). (See also Braathen and Ingstad, 2006, for more information about the study design.)

Women and Living Conditions Study 2006

The data collection methods in this study were qualitative; more specifically, one focus group discussion with representatives from seven disabled people's organisations (DPOs), one focus group discussion with four hearing impaired women and 19 qualitative individual interviews with women with disabilities. Criteria for inclusion for informants were that they had a hearing, visual, physical or intellectual impairment or albinism. The informants were 18 years or older, and in cases where the girl with the disability was younger than 18, her mother was the informant for the interview. Informants were selected by the local DPOs. The study took place in Blantyre district, which is an urban district and the commercial centre of Malawi. The theme for the interviews was the situation and experience for women with disabilities in Malawi compared to women without disabilities and men with and without disabilities. Education for women with disabilities was a particular focus. The data collection took place over a one-month period, from June to July 2006, and was conducted in collaboration with FEDOMA and the organisation Disabled Women in Development (DIWODE).

There were 23 informants in this study – Malawian women with disabilities, aged 18-61. Nine informants had physical disabilities, four had albinism, four had a visual impairment, four had a hearing impairment and two had an intellectual impairment. (See also Kvam and Braathen, 2006, 2008 and Braathen and Kvam, 2008 for more information about the study design.)

Results

Living Conditions Survey 2003/04

Table 4.1 below reports the scoring factors derived from the PCA of 18 variables used for the composition of the asset index. Each asset variable takes the value 0 or 1 for all individual or household goods. The weights are thus easy to interpret: an increase of 1 changes the index by the ratio of the scoring factor divided by the standard deviation. For instance, a household that owns a radio has an asset index higher by 0.53. Some items are common and have little affect, or even a negative affect, on the asset index. Therefore, their impact on the index is limited. Other items are uncommon and indicate a higher standard of living, such as refrigerators, which increase the asset index by 4.12. Furthermore, individuals were assigned to one of three categories of material wealth according to the index value: the lowest 40% were placed into the 'poorest' group, the middle 40% were placed into the 'middle' group and the upper 20% were placed in the 'richest' group. This categorisation follows the differentiation used by Filmer and Pritchett (2001). The

Table 4.1: Scoring factors and means for variables included in the PCA of the household portion of the Malawi survey

Malawi: *n*=3,046						Means	
	Scoring factors	Mean	SD	Scoring factor/SD	Poorest	Middle	Richest
Own a sewing machine	0.334	0.072	0.258	1.29	0.000	0.065	0.213
Own a cell phone	0.673	0.038	0.191	3.53	0.000	0.000	0.181
Own a refrigerator	0.686	0.029	0.167	4.12	0.000	0.000	0.137
Own a bicycle	0.133	0.379	0.485	0.27	0.192	0.488	0.486
Own a motor bike	0.149	0.015	0.122	1.22	0.000	0.012	0.049
Own a motor vehicle	0.413	0.014	0.119	3.46	0.000	0.000	0.069
Own a radio/tape player	0.261	0.567	0.496	0.53	0.210	0.733	0.858
Own a television	0.756	0.057	0.232	3.26	0.000	0.000	0.274
Drinking water from well	−0.395	0.565	0.496	−0.80	0.772	0.598	0.134
Drinking water from pipe	0.629	0.209	0.407	1.55	0.000	0.102	0.795
Drinking water from open source	−0.144	0.226	0.418	−0.34	0.228	0.300	0.071
Main cooking by biomass	−0.551	0.970	0.170	−3.24	1.000	1.000	0.856
Main light by electric	0.837	0.072	0.258	3.24	0.000	0.001	0.344
Toilet facility flush toilet	0.740	0.047	0.211	3.51	0.000	0.000	0.224
Toilet facility latrine toilet	−0.376	0.850	0.357	−1.05	0.960	0.814	0.730
No toilet facility	−0.072	0.103	0.304	−0.24	0.040	0.186	0.046
Dwelling of all high-quality materials[a]	0.698	0.158	0.364	1.92	0.000	0.078	0.598
Dwelling of all low-quality materials[b]	−0.250	0.253	0.435	−0.57	0.516	0.135	0.032
Asset index					−5.083	−3.868	3.839

Notes: [a] High-quality materials include: windows of glass; floors of concrete/cement; roof of asbestos/iron sheets or tiles/shingles; walls of concrete or bricks.

[b] Low-quality materials include: windows (none); floors of mud; roof of paper/plastic; walls of poles/mud.

difference in the average index between the poorest and the wealthiest group is 9.92, illustrating a different level of wealth inequalities between social groups.

Turning to poverty (as measured by the asset index) and disability, we found that there was not a significant difference in mean asset index between disabled and non–disabled households in Malawi (see Table 4.2). (This finding will be explored further in the Discussion later.)

For the purpose of the analyses of access to education, data were restricted to the group of family members who were five years or older at the time of interview.

Table 4.2: Mean asset index by household disability status

	Mean	SD	*t*	*p*-value
With a disability	−2.81	4.51		
Without a disability	−2.61	4.90	−1.16	ns

These individuals were further categorised into three groups representing three 'generations' of Malawians: those aged 5-18, representing the portion of the population that is currently of school age; those aged 19-35, representing young adults beyond school age; and those aged 36 or older, as the mature or older generation among family members. Among the 12,532 respondents, 49% (6,089) were aged 5-18, 28% (3,515) were aged 19-35 and 23% (2,928) were aged 36 or older. Both genders were equally represented, with 51% female and 49% male. A total of 1,415 respondents (11.3%) were classified as having a disability according to the screening criteria established for this survey (Loeb and Eide, 2004, p 56). Disability was equally prevalent among males and females; however, fewer of the younger group aged 5-18 had a disability (7.3%) compared to the young adults 19-35 (9.3%) or older adults 36+ (22.0%) ($\chi^2 = 448.9$, df = 2, $p<0.001$). Information on school attendance was available for 12,379 of these household members; overall, 2,433 (19.7%) of these individuals had never attended school. Analysis below focuses on this group of non-school attendees and how age, gender, rural/urban locality and disability may impact on school attendance.

Among all age groups combined, those with a disability are less likely to have attended school (34.8%) than those without a disability (17.7%). The same trend is apparent in each of the age cohorts, although there is a clear decline in non-attendance over time. A substantial decline in non-attendance was observed between the oldest and middle cohorts, with relative stability in non-attendance rates between the youngest and middle cohorts. Overall, females were less likely to attend school (23.5%) than males (15.7%); however, that trend appears to be changing. Among the oldest cohort, female non-attendees amounted to 47% compared to 23% for males, and among the youngest cohort the respective numbers were 13% for females and 16% for males. The same pattern is observed among those with and without a disability, although the figure for those with a disability remains inflated.

Regardless of disability status, those living in a rural setting are, on average, three times more likely not to have attended school (21.4% versus 7.5%). Again, those with a disability are clearly disadvantaged: among those with a disability, 16% of urban dwellers had not attended school compared to 38% of those in rural areas; and among those without a disability, the figures were 6% and 19% respectively. The same pattern is also reflected here in the age cohorts, again with correspondingly lower non-attendance in the youngest cohort and highest non-attendance among the oldest cohort.

Among the 433 individuals aged 5-18 who had a disability, 29% had never attended school according to the head of the household or primary responder to this portion of the questionnaire. When asked why they had not attended or left school, almost half (47% of the 62 respondents) claimed that it was because of their disability. Other reasons included not enough money (16%), lack of interest (18%) and illness (15%).

Under the circumstances described above, scholastic achievement, as measured by highest level of education achieved, is of particular interest. Given the

opportunity to attend school (that is, among those who had attended school at some stage) overall, those with disabilities perform at a level that is equal to those without a disability. This observation stands regardless of gender or urban/rural setting. There is a slight age effect, however, that would seem to indicate that, by age, those with disabilities have not attained the same level of education as those without disabilities.

Of the 1,415 individuals identified (through the Living Conditions Survey) as having a disability, 443 were in the age group 5–18, that is, currently of school age. A detailed disability survey was completed for 430 of this age group – either by the people with a disability themselves or by a proxy. These individuals are represented in the major impairment categories: visual (12.1%), hearing (26.3%), communication (6.1%), physical (30.1%) and intellectual/emotional (22.4%). Three per cent fell into a category defined as 'other'.

This portion of the survey also included questions specific to education, access to education and educational services, with particular reference to the person with a disability.

The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) has been instrumental in directing the focus of the survey away from issues of the impairment and towards issues of capacity (activity limitation) and performance (participation restriction). A person's disability is as much informed by their underlying health condition as it is by the environment in which they live, that is, the barriers they face in social participation. In other words, a person with a physical impairment, for instance, who lives in a completely accommodating environment, would not experience disability in the same way or to the same extent as a person with the same impairment in a more inaccessible environment. (Here, environment is inclusive of the physical, social, personal and legislative.)

With respect to education, individuals were asked for a subjective, perceived assessment of difficulty in going to school and/or studying without the use of any personal or technical assistance (a measure of their capacity to attend school or to learn) and the subjective experience of problems associated with going to school and/or studying in the individual's current environment (a measure of their performance or ability to participate in education and to learn). The difference between these two measures may then be an indication of the effect of (all types of) environmental barriers. In addition to physical access barriers, these would include, among others, access to adapted educational materials, specially trained teachers and the attitudes of teachers, school authorities and classmates. Table 4.3 illustrates the variation in capacity and performance, as defined above, based on type of impairment. Focusing on those who experience severe difficulty or who are unable to attend school, it becomes apparent that those with communication impairments experience the highest degree of activity limitation (39%), followed by those with intellectual/emotional impairments (27%). About 20% of those with visual or hearing impairments and 15% of those with physical impairments experience great difficulty in attending school without assistance.

Table 4.3: Experienced difficulty going to school and/or studying (capacity and performance) by type of impairment among children aged 5-18 with a disability

Type of impairment	Capacity: activity limitation			Performance: participation restriction		
	Amount of difficulty			Amount of problem experienced		
	None	Mild/moderate	Severe/ unable to do it	None	Mild/moderate	Severe/ unable to perform
Visual	65	17	18	69	21	10
Hearing	48	31	21	54	35	11
Communication	42	19	39	50	27	23
Physical	65	20	15	69	22	9
Intellectual/emotional	52	21	27	61	21	18
Other	77	8	15	85		15
Total	57	22	21	63	24	13

Turning to problems attending school as experienced in their current environment (that is, with the full range of technical and/or personal assistance), the corresponding proportions of those who experience the greatest difficulty are: communication (23%), intellectual/emotional (18%), visual/hearing (10%) and physical (9%) impairment. While the proportion of those who experience problems remain quite high, they are lower than the corresponding figures for capacity above, and seem to indicate that in certain circumstances environment and/or personal factors aid the individual in being able to attend school.

Individuals were asked to provide their opinion on the need and provision of several public services, among them educational services (Table 4.4).[2] Generally speaking, the majority of respondents (63%) were aware of the availability of educational services and about 64% claimed that they had a need for these services (between 54% and 69% depending on the type of impairment). However, only 14% had actually received the benefit of educational services. By examining the difference between stated need for service and receipt of service, it is possible to

Table 4.4: Experience with the provision of educational services by type of impairment among children aged 5-18 with a disability

Type of impairment	Educational services				
	Aware of	Need	Received	Gap[a]	*n*
Visual	61.5	53.8	7.7	14.3	52
Hearing	63.7	61.1	15.9	26.1	113
Communication	73.1	65.4	19.2	29.4	26
Physical	64.3	66.7	13.2	19.8	129
Intellectual/emotional	58.3	66.7	12.5	18.8	96
Other	53.8	69.2	30.8	44.4	13
Total	62.7	63.6	14.0	22.0	429

Note: [a] Proportion of those who have received educational services, of those who have claimed that they have a need for such services.

describe the gap in service delivery. The majority of those who claimed a need for an educational service had not received the service. Only 14% of those with visual impairments received educational services, while between 20% and 30% of those with other types of impairments claimed receipt of such services.

Looking at the asset index divided into the three asset groups defined earlier (poorest, middle, richest), and whether or not the child (aged 5-18) attended school, the results indicate that the better off (richest) among those with disabilities were more likely to attend school (see Table 4.5). While 87.3% of those children with disabilities in the richest asset group were attending or had finished school, school attendance in the middle and poorest groups were 65.1% and 69.2% respectively (*p*=0.002).

Table 4.5: Asset group by school attendance for children/youth aged 5-18 with a disability

	Poorest		Middle		Richest		Total	
School attendance	*n*	%	*n*	%	*n*	%	*n*	%
Never attended	36	30.8	45	35.9	10	12.7	91	28.0
Attending/finshed/left	81	69.2	84	65.1	69	87.3	234	72.0
Total	117	100	129	100	79	100	325	100

Chi square=12.7, df=2, p=0.002

Albinism in Malawi Study 2004

People with albinism have poor vision, and for many school children this creates significant challenges, as it can be very difficult for them to read what is written on the blackboard and in books. Visual aids are unavailable to most people in Malawi, and none of the informants in this study had eyeglasses. Some schools and teachers had made special considerations for these children, such as making sure that the lighting in the classroom was sufficient, allowing the children with albinism to sit close to the blackboard or transcribing for them on paper what they had written on the blackboard. These simple considerations can make school much easier for a child with albinism, but it requires something extra of the teacher, and it seemed that not many teachers made the extra effort. The informants reacted differently to the classroom situation in the absence of these considerations; some constantly walked to the front of the classroom to see the blackboard, some copied their friends' notes and one simply left school because the difficulties became too big to overcome. There are private schools that cater for children with a visual impairment. These schools, however, cost money, and are therefore unaffordable to most people in Malawi. One 27-year-old man had gone to a private school for the blind for five years, and he felt that he learned much more in that school than in the public school. Due to his visual impairment he felt it was better for him to study at a school where his fellow students were

all blind or visually impaired, and special considerations were made for them all. In public schools, where all the pupils could see, his visual impairment was always a problem and made learning more difficult for him, because the school would not make special considerations for just one blind student.

People with albinism have little or no pigment in their skin, which makes them extremely vulnerable to sunburn. All the informants in this study constantly got sunburnt, and only a few had access to, or the funds to buy, sunscreen lotion or long-sleeved clothing. School uniforms in Malawi are usually short-sleeved shirts and shorts, which presents a problem to children with albinism because they spend much of the school day playing outside, often in the sun. In addition, it is not unusual for school children in Malawi to walk long distances daily to and from school. The result of this exposure is sunburn. Some schools allow children with albinism to wear long-sleeved shirts, trousers and hats, while other schools force them to wear the standard school uniforms. As one mother of two children with albinism put it:

> 'Nothing is done in school to help them protect the skin.'

The children, one boy who had finished standard 8 and a girl in standard 7, both wished to continue with their schooling beyond primary education, but had difficulties both with their eyesight and with money. Their mother – a widow, housewife and mother of six – was finding it difficult to get the money to pay for secondary education for her children.

The parents of a six-year-old boy with albinism had tried to register their son in nursery school, but were told that the school could not accept him because he had too many wounds and blisters (from the sun) on his body. They were told to:

> '… take him back home until those wounds are healed…., and maybe find somebody to help him to get him glasses or hats, or something.'

Due to lack of money in a family of nine children they were unable to buy sunscreen lotion to prevent sunburn, and glasses to help him with his vision.

One seven-year-old boy with albinism, living in Blantyre with his grandmother, had been rejected at birth by his father, and his mother was living somewhere else with his two half-siblings and their father, who was not the same father as the seven-year-old's. His father had rejected him because he did not think the albino child could be his. The 23-year-old mother said that she was bankrupt, and only the stepfather had a job that gave a little income to the family. She had been advised by doctors to buy long-sleeved clothing for her son, but she had not done so because they did not have any money. As a result the boy got sunburn when he was playing outside in the sun at school, on his way to and from school and after school. At the time of the interview the boy was in standard 1, and he liked it at school, but his grades were poor because he was not getting any help

from his teacher in overcoming his barriers due to his poor eyesight. His mother had asked the teacher to help him, but to no avail:

> 'He has problems with eyesight, so when I told the teacher to let him sit at the front the teacher moves him from the front to the back. And so she says that if I want my son to be at the front, I should take him away from that school.'

One 23-year-old woman from Blantyre spoke of her difficulties in getting an education beyond secondary school (form 4) and a job. She had applied for several jobs, but she felt that when she came to the interview and they saw that she was albino, they rejected her. She was unemployed at the time of the interview, living with her parents. She wanted to be a nurse, but felt that she was being rejected due to discrimination and lack of knowledge:

> 'I want to go to the nursing school, and when I go there they say "you can not help us because our medicine is too difficult for your skin".… They say that medicine can destroy my skin … I always get rejected because of my skin.'

Clearly, children with albinism face several challenges in the regular school system in Malawi. However, in addition to the more logistic challenges they face that are surmountable with simple and low-cost considerations, perhaps the greatest barrier hindering the inclusion of children with albinism is in the form of an unaccommodating school system.

Women and Living Conditions Study 2006

For the majority of the informants in the study about women with disabilities in Malawi, the onset of their disability dated from before they started school. All informants had some education – six had finished primary school, four had started but not finished primary school, six had finished secondary school and seven had some sort of higher education (university/college). All the informants lived in Blantyre, an urban district, at the time of the study. The informants of this study may be typical of women with disabilities living in urban areas of Malawi, but they are not typical of the average Malawian woman. Compared to the informants in the Living Conditions Survey among people with disabilities in Malawi (Loeb and Eide, 2004), the 23 women described here are better educated and more have jobs. In spite of the fact that they represent a selected and privileged group of Malawian women, most of the women interviewed had experienced difficulties in accessing and obtaining an education that may be more common to Malawian women in general.

Among the four informants with a hearing impairment, three had gone to schools for the deaf. These schools are privately run, cost money and are therefore

unavailable to most deaf or hearing impaired children. One deaf woman had gone to 'normal' public school, and she had experienced that:

> 'In school people say teachers should speak to deaf children, not use sign language.'

The woman is a teacher herself now, and has been fighting for the use of sign language in schools for many years. She feels that she is more accepted in society because, unlike most deaf people, she can speak.

> 'There is a battle between hearing society who thinks we should speak, and deaf society who thinks we should sign.'

One major problem in using sign language in schools or in society in general is the lack of sign language interpreters in Malawi. The women knew of only two or three in the country. In addition to the lack of sign language interpreters, their services are very expensive, and it is not government sponsored, so most people cannot afford their services.

A woman with albinism had experienced discrimination in public school, both from other pupils and from the teachers. The pupils were afraid of her unusual looks, and thought she was infectious. In addition, one of her teachers had refused to teach her, saying:

> 'I am not supposed to teach a short-sighted pupil.'

Because of this discrimination she decided to change to a private school, where she was treated much better; the teachers dictated to her what they wrote on the blackboard and other pupils sometimes shared their notes with her. This woman was fortunate to have a family that could afford to send her to private school, as private schools are too expensive for most Malawians.

Many of the women told similar stories of being teased or bullied by their fellow pupils, and one woman with a physical disability said that it made her feel unwanted in school. Another 20-year-old woman with a physical disability had been discriminated against by one of her teachers:

> 'I … experienced psychological abuse when I was at school. Once a teacher asked each of the students to bring six sticks [small but hard]. He told each student to break the sticks using the left leg knee – all the sticks at once. Since my left leg is the one which is disabled, I did not break the sticks. The teacher asked me why I did not break them. I tried to explain, but he did not listen and he started shouting at me, saying that I was stupid and that I will get zero marks. I really felt bad in front of the other students, who were also laughing uncontrollably. I felt bad and I could not concentrate anymore in class for two days.'

A 23-year-old woman, who became blind when she was five, had experienced many difficulties throughout her education. In secondary school she went to a private boarding school (paid for by a relative) where there were 13 other blind students. The school lacked adapted materials for the blind (Braille). At the time of the interview, she was in a teachers college, financed through a scholarship by the Government of Malawi, together with 11 other blind students. At the college the students experienced several challenges, including lack of adapted materials for the blind, few examiners who could mark their exams and lack of papers written in Braille.

One woman, who became blind when she was 15 years old, was helped by a special education teacher who taught her Braille, but she was also mainstreamed in the classroom with the other pupils. In her experience she felt that many parents take their children out of school because of lack of money, and if the choice is between removing a son or a daughter, it is usually the daughter who is taken out of school, because boys are perceived to be more intelligent than girls. Similarly, a physically disabled woman had been taken out of school because of poverty in the family, while her (non-disabled) brother continued his education. A blind woman put it this way:

'Men are pushed up – women are pushed down.'

Some of the women had not even been encouraged to get good marks and to take formal education. One woman said that:

'I grew up in a village where people disregarded education. So when
I quit school, no one encouraged or persuaded me to go to school.
But I regret it now. I am glad that my children are at school.'

A woman in her forties became disabled after having polio when she was five years old. Throughout her childhood she had to crawl everywhere because she had no wheelchair or crutches, and therefore she could not go to school. Her mother had taught her to read and write, and when she was 17 years old she received a wheelchair and could attend school for the first time. She started school in standard 5 (primary school), being much older than the other pupils, but she did not mind. Her problems in school were connected to the accessibility of the school buildings. Some classes were on the second floor of a building without a lift, and so she was unable to attend these classes. She was fortunate, however, to have had some friends who shared their notes with her. In addition, she could not access the toilets in the school; the doors were too narrow to accommodate her wheelchair. She mostly experienced acceptance by her teachers and fellow pupils, but some teachers were known to have said "No disabled can go here!" In spite of these difficulties she managed to get a college-level education, with good financial and practical help from her family and friends.

Similarly, other disabled women succeeded in getting an education with the assistance of family and friends. Some rather simple solutions, others involving more effort, have been initiated to overcome the obstacles faced by women with disabilities in attaining an education:

- parents sent a young disabled girl to boarding school, together with one of her sisters, so that the sister could help look after her;
- a woman who was unable to walk had been carried to school every day by her grandmother;
- another physically disabled woman had been driven to school by her father who worked as a driver.

Assistive devices and adapted education have been recorded as breaking some of the barriers that hinder girls from attending school. A woman in her forties became disabled after having malaria when she was one-and-a-half years old and until the age of 15 she was unable to either walk or speak. However, after a series of operations and after being fitted for callipers so she could walk, she started school. She successfully completed primary and secondary school. In secondary school she had to change school once because the steps in the first school were too big.

The family of a girl with Down's syndrome was not aware of her intellectual impairment until the girl was in standard 2. At that stage the child's teacher advised the mother to enrol the girl in a special school for children with intellectual impairments. The girl likes it much better in that school, she has friends, she has learned to write and she is much happier.

Education is perhaps the main key to less discrimination and better integration for women with disabilities. One of the deaf informants was educated as a teacher of special education needs. She was proud of what she felt to be her important job, and felt that education makes women with disabilities more self-confident:

> 'People have changed their attitude towards me because of what I have accomplished.… I have a junior certificate and I also have a teacher's certificate.… I have a house of my own.'

Similarly, a blind teacher said:

> 'The blindness has affected my life, but now I have accepted it because of the work I am doing. Blind people can do anything!… I am a teacher….And I can cook for the family when I am at home.'

Conclusion

In the research presented in this chapter, poverty is addressed through paradigms defined not only by lack of personal goods and material wealth, but in terms of social inclusion, and in particular, access to education. As one of the poorest

countries in the world (UNDP, 2007/08), Malawi faces several challenges in the provision of education to its population.

With respect to the Living Conditions Survey, households selected for inclusion were matched with respect to disability status by location – households without a disabled family member were chosen from the same neighbourhood as the selected household with a disabled family member. It might be expected, therefore, that economic indicators would be also be similar – to a certain extent neighbours might be expected to have similar socioeconomic standards. That finding was confirmed in the analysis presented; there was no significant difference in mean asset index between families with and without a disabled family member. This finding does not mean that such a relationship does not exist – the data and the research design did not allow for that particular finding to emerge. However, it was shown that disparities between those with and without a disability do exist when poverty is measured according to access to education and other indicators of social inclusion. This finding is stronger, in fact, *because* of the design of the survey analyses presented here, that is, all else being equal (age, gender and socioeconomic status [asset index]), people with disabilities are still subject to poverty and its consequences due to the inaccessibility of education. Finally, in low-income countries, and among the households in our sample, poverty is an equaliser, although we find a certain degree of variation in the asset index and can differentiate three rather distinct groups; these groups are more similar than they are different.

Thus one main conclusion can be drawn from the results from the three studies described above – people with disabilities in Malawi face more difficulties accessing the education they are entitled to by law compared to their non-disabled peers, and as a result they are more likely to be uneducated, unemployed and poor. The main challenges, as pointed out by the National Economic Council (2000), are access to education (physical and economic) and poor standards of education (teaching and teaching materials), factors that we have seen from the studies above that affect the vulnerable group of people with disabilities in particular. But, as the studies described in this chapter have shown, the challenges are more than just physical and economic. The examples also show that challenges and barriers to education are created by lack of awareness leading to bad attitudes and discriminatory practices among teachers as well as fellow pupils. Similar findings were made by Howell (2006) in relation to higher education for people with disabilities in South Africa.

People with disabilities in developing countries in general (Filmer, 2005), as well as in Malawi, have lower levels of education compared to their non-disabled peers. Furthermore, several studies have shown that the correlation between disability and poor education outcomes is larger than those associated with other characteristics, such as gender (Filmer, 2005). The Living Conditions Survey in Malawi showed that people with disabilities are less likely to have attended school compared to their non-disabled peers. Women with disabilities and disabled people living in rural areas are among the most disadvantaged when it comes to school

attendance and completion. Among the individuals with a disability who had never attended school, the main reason for this was because of their disability, followed by lack of interest, lack of money and illness. Disability may be a reason in itself and may also include the environmental barriers experienced by the person with a disability. Lack of interest may include problems associated with difficulties in communication and learning experienced by those with visual, hearing or communication difficulties and without the necessary support or technical assistance (Braille school materials, sign language teachers etc) needed to ignite and maintain interest in the classroom.

Much of education is based on communication and it was not surprising to find that those with communication impairment and intellectual/emotional impairment faced greater activity limitations than those with other forms of disability.

People with disabilities in Malawi, given the chance to attend school, perform at a level that is equal to those without a disability. There is, however, a slight age effect that would seem to indicate that, by age, those with disabilities have not attained the same level of education as those without disabilities. This finding is perhaps indicative of the fact that many children with disabilities face greater barriers in attending school, starting later than their peers and often taking more time to complete their studies. Barriers that hinder children and young people with disabilities from attending school may vary. Often schools and classrooms are not adapted to the special needs of children with disabilities. Beyond the obstacles of gaining physical access to the facility itself, other barriers can include a lack of suitable teaching materials (Braille, sign language interpreters, large print textbooks etc), or a lack of teachers trained to deal with the needs of children and young people with disabilities. Many of the children with physical disabilities either have or had problems getting to school and accessing school buildings, and even if they gained access to schools, many could not attend because toilet facilities at the schools were inaccessible to them. Several of the barriers faced by children with disabilities could be overcome with very minor costs involved, such as ensuring physical access to the classroom (making sure it is on the first floor) for people with a physical impairment, adapted learning materials, classroom placement and assistance of classmates for people with poor vision. For children with albinism, sunburn may be overcome through adapted school uniforms (long sleeves and hats), the application of sun block and encouraging and permitting those children to remain in the shade. In addition to the barriers created by poor physical access and lack of special education in mainstream schools, stigmatisation and discrimination of people with disabilities creates barriers to equal access to education for children and young people with disabilities in Malawi. Several of the informants in the studies said that they had experienced discrimination and exclusion by teachers and fellow pupils at school. This discrimination made it very difficult for some to carry on with their education, and as a result many got poor results or at worst, dropped out of school altogether. The qualitative studies also indicate that being a girl/woman with a disability created a double burden,

an indication that is verified in the Living Conditions Survey. The problems of knowledge and discrimination in society in general and in school in particular require an active effort on the part of schools, teachers and others to understand, accommodate, accept and include children with disabilities in the school system.

The Government of Malawi (Ministry of Education) has spelled out that there is a general lack of resources for special needs education in Malawi, both in mainstream and in special education schools. The findings from the three studies above emphasise this shortcoming, but those who had experienced both mainstream and special schools (for the blind, deaf and intellectually impaired) felt that they received much better education in the special schools. The reason for this was that the education was adapted to their special needs and the teachers were trained in special education. In addition to this, the children felt more accepted and less discriminated against by the teachers and fellow pupils. Public schools, on the other hand, do not have the funds, knowledge or means to make special considerations for children with various forms of disabilities and special needs. The issue of integrated special education in mainstream schools versus segregated special education schools is still largely un-debated in Malawi. The overall aim, however, of the disability movement and the Government of Malawi is 'to foster, develop and sustain an inclusive society through clear policies, programmes, legislation and mainstreaming of disability issues in all sectors of development' (MSDPWD, 2006).

There is an observed positive change in education attendance over time (as seen in the Living Conditions Survey), and this change is observed among those with and without a disability, although the attendance statistics for those with a disability lag somewhat behind those without. There may be several reasons for this observed change. One reason may be connected to primary education having been free since 1994, and hence there has been an increased emphasis on the importance of education from the Government. Furthermore, education is the focus of a number of international development projects in Malawi; schools have been built, teachers educated and recruited, and awareness about the importance of education has been spread throughout Malawi. In Malawi, education attendance and level of education appears to be closely linked to both the parents' finances and their level of education – the higher the parents' education, the more likely they are to ensure that their children have a good education. The Living Conditions Survey also showed that the richest among those with disabilities were more likely to attend school. It has been said that children are our future and if that is true, then nothing could be more important than providing our children with an education. Providing an education for children is an investment in future generations.

In the attempt to achieve the UN's aim of halving world poverty by 2015, it is imperative that the notion of poverty be broadened to include lack of personal goods and material wealth, as well as social inclusion and access to public services such as healthcare, education and employment (UN, 1995). Through increased access to education for people with disabilities, an increased self-sufficiency among

this group could be ensured, which would be a more lasting solution to poverty eradication then merely focusing on material wealth.

Children and adults, men and women with various forms of disabilities, all expressed a great wish for people with disabilities to be given the opportunity to get an education. Many felt that education was the foremost way to empower this group of people and to eliminate the poverty among and discrimination of people with disabilities in Malawian society.

Notes

[1] More information about Horace Mann is available at http://en.wikipedia.org/wiki/Horace_Mann

[2] Educational services include: remedial therapist, special school, early childhood stimulation, regular schooling, etc.

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"We too are disabled": disability grants and poverty politics in rural South Africa

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Introduction

This chapter investigates the relationship between disability and poverty in the new democratic South Africa. During this country's transitional period, a new conceptual understanding of disability has mainstreamed disability in new policies and laws. The anthropological material presented here shows how these processes of programme implementation have shaped people's social experiences in rural areas of the Eastern Cape, around Mthatha. The history of apartheid, with its establishment of structural inequalities, has created a specific type of poverty forming people's social experiences as well as their understanding of disability.

The process of implementing disability grants (included in the Comprehensive Social Security System) has shown disagreements between poor people's demands and claims for being disabled and the bureaucratic definitions of who is considered to be disabled. The situation of poverty creates disagreement about what is analytically distinguished as broad (disability as discrimination) or narrow (disability as impairment) definitions of disability. Both these approaches are incorporated into the social change processes, within a human rights framework, that are transforming South African society, yet both approaches entail history differently, which affects how social experiences in poor settings are being interpreted, understood and debated, and hence how people's suffering is being acknowledged and acted on through programmes and new interventions. In this chapter we start with a discussion of the historical production of *poverty*, then we discuss the local conceptualising of disability and *Ubuntu* in the surrounding areas of Mthatha. In this setting, disability grants are a tool of survival for both the person with a disability and the household. In addition, the grants contribute to establishing a commonly shared disability category that people make use of and can act on in the new democratic South Africa.

Broad and narrow definitions of disability

Broad and narrow conceptualisations of disability are embedded in past historical structures of how disability is explained and understood. The broad definition understands disability as discrimination resulting from past injustice and segregation. Embedded within this is a different way of constructing personhood and disability, with a specific emphasis on how society creates barriers and hence disability. New constitutions, laws and policies have been developed from this perspective of understanding disability as discrimination (Office of the Deputy President, T.M. Mbeki, 1997).

The narrow definition classifies disability through bodily signs (impairment). This understanding is embedded in the bureaucratic implementation of the Comprehensive Social Security System that distributes disability grants in South Africa. The narrow definition forms part of a political and professional process of *medicalisation* that, according to Kleinman et al (1996), powerfully shapes the responses and type of social suffering. The Comprehensive Social Security System depends on classifications that are integrated in the political process of knowing how to develop a welfare state for all. This current modernisation process within South Africa requires the state to develop a knowledge system that regulates households, people, their bodies and their network. It also requires population studies and statistics from all over South Africa in order to plan comprehensive health and social services. This process additionally regulates how to define disability and how to formulate questions such as *'who is disabled?'* and *'what constitutes disability?'*. The question *'who is disabled?'* starts with the individual impairment level of classification and the definition leans on a biomedical system of expert knowledge.

The historical understanding of apartheid and the process of producing poverty creates disagreement between broad and narrow definitions of disability. In rural areas of the Eastern Cape, people demand that the condition of '*having fits*' be acknowledged as impairment and therefore covered within the disability grants system. In order to capture the social experiences of those living in poverty and to understand the disagreement that occurs between the broad and the narrow definitions of disability, we find Kleinman et al's (1996) theory on social suffering useful for poverty analysis. Social suffering draws attention to suffering as a social problem, not as an individual condition, but rather as a result of political, economic and institutional structures and forms of power which influence people's responses to social problems as social experiences. According to Kleinman, suffering is a social experience grounded in interpersonal relationships, not only as an individual essence but also in its relation to structure, history and culture (Kleinman and Fitz-Henry, 2007, pp 63-4). Farmer (2004) makes power more explicit in his analysis of social suffering as a direct consequence of the production of poverty. Farmer uses Galtung's concept of structural violence (Farmer, 2004, p 307) to underline social structures as historical processes that create realities of poverty that continuously limit people's possibilities today. Farmer's analysis relates to how

the production of poverty occurs and what political acts and ethical demands are needed to change the 'vicious circle' of poverty and disability. Kleinman et al's use of social suffering draws attention to the cultural responses, including bureaucratic responses, that can intensify social suffering as structural violence. Important questions to ask are how social suffering is produced in societies and how acknowledgements of pain and poverty as cultural processes are given or withheld (Kleinman et al, 1996). In addition to describing the context of social suffering this ethnographic material shows how experiences of disability and local manifestations of conceptualising disability enable people to create meaning in this particular local context. Thus the analysis follows Bourgois and Scheper-Hughes (2004) and Green's (2004) comment to Farmer. In addition Ingstad and Reynolds Whyte's (1995, 2007), and Kohrman's (2005, 2007) ethnographic investigations shows the importance of studying how disability is being manifested and shaped within these particular local contexts.

Poverty and the history of apartheid

The history of apartheid has created a specific form of poverty. Dependence has become a consequence of the segregation policy under apartheid. One of the intentions of apartheid was to establish 'separate development', with independent ethnic 'homelands'/Bantustans which were part of the 'native reserves' (established under the Land Act 1913) for native black South Africans. During the apartheid era, passports (*Dom passes*) and ID documents became central for moving between places. Those who received ID documents from government had been enrolled in labour regulation programmes. The apartheid state distributed labour between farms and towns, and only those who became migrant labourers could travel. Bantustan territories served as migrant systems, functioning as 'labour reserves' for the South African economy. 'Labour reserves' separated the household members living in 'homelands' from the migrant workers who lived on the white South Africans' land located in the cities far from 'homelands' or 'native reserves' (Comaroff and Comaroff, 1987; Ferguson, 2006). Black South Africans could only move in towns with a *Dom passes* which contained their life history and employment story and hence the right to be in the town (Legassick, 1977, pp 181-3). IDs and passports were given to people within a specific age group. The inability to move (due to lack of ID documents) restricted people's access to healthcare and social services that were located in urban places (Bundy, 1977). Today, ID documents are crucial in accessing disability grants, and much effort has been put into registering people who were never given the documents or birth certificates. Past practice has left a huge black population behind due to unfamiliarity with the bureaucratic system and lack of knowledge needed to access the current Comprehensive Social Security System.

Comprehensive Social Security System and disability grants

The Comprehensive Social Security System is part of a programme aimed at reducing poverty, *the war against poverty*,[1] for all South African citizens. In the past, white South African planners did not take much responsibility for living conditions in the Bantustans. The Comprehensive Social Security System, including disability grants, was part of the white-controlled state, serving 'poor whites'. The welfare costs of housing, pensions and social facilities were up to each 'homeland' to facilitate from the domain of the urban workforce and the industrialised centres. The welfare of poor whites was provided for under public works, vocational guidance, health services and housing and social clubs.[2] Pensions for poor mothers and older people and disability grants for the sick were given and provided for whites only (Giliomee, 2003). This system has now been transformed into the new Comprehensive Social Security System, incorporating all South African citizens. This means–tested system[3] is provided to a number of specific population groups such as children, people with disabilities, foster carers, war veterans and older people, according to personal income levels. Biomedical diagnostic tools with medical tests and scientific proof are the basis for accessing grants. Classifications and new definitions are under development and the practice and interpretation of these new definitions are understood differently in various settings within South Africa. The programme's intention is to strengthen the household level and the individual person with monthly distributions. The distribution system has less focus on guidance and advice on how to use the grants for the future. This chapter shows how disability grants are being used as a practice that has constructed the broad concept of disability.

Two phases of development after apartheid

We have chosen to divide the development process of conceptualising disability in the new democratic process into two phases. The first phase (1994–2001) consists of a reconciliation period that was a major issue in the building of the 'rainbow nation'. During this period, discrimination and subjective experience were part of the public discourse on dealing with memories of the past. The strategy for Disabled People South Africa (DPSA) (DPSA, 2001), the Disabled Children Action Group (DICAG) and other actors in the disability movement has been to define disability through subjective discrimination experiences. The disability movement was visible and active in informing and recommending people in disadvantaged areas as to how to utilise disability grants. In this phase, the intention was more or less to distribute services to those who were in need, rather than to ask the question of *who* was in need. People had the right to receive grants to make up for past wrongdoings. Disability organisations run by disabled people were given the task of recommending people for accessing grants and for informing them on how to access disability grants.

The second phase (2001-07) consists of the implementation of new policies and laws. The welfare system was under pressure as high unemployment rates increased the number of applications for disability grants. More people wanted to receive disability grants than those who actually received the grants (De Koker et al, 2006; Nattrass and Seekings, 2005; Nattrass, 2006; Mitra, 2008; Whitworth and Noble, 2008). In order to plan and control health and social services, the government saw the need for better statistics on the number of people with disabilities and the number living in poverty. The need for control was also apparent in how definitions of disability changed in subsequent national censuses – in 1996, 12% of the national population was considered disabled and in 2001 it was 5% (Child Health Policy Institute, 2001; Statistics South Africa Census, 2001). After 2001, the question of abuse and corruption was publicly debated and closely linked to the grant distribution process. The government initiated investigations that ended in reducing the number of recipients and withdrawal of grants from people, and introduced a more narrow definition of disability.[4] However, the distribution process is now, more or less, in the hands of professionals, where disabled people's organisations (DPOs) claim difficulties in participating in the political process of defining disability within the Comprehensive Social Security System. In this political process there is a tendency to fear that too many people will be classified as disabled and as ill. Nattrass (2006, p 2) argues that 'people become ill and remain ill because disability grants become one source of income'. This tendency is enhanced by the lack of unemployment grants in the welfare system that forces people to become ill (Nattrass, 2006, p 2). This has instigated debates about how to define disability, more narrowly, while in practice moving the process away from what really matters, addressing the phenomena of social suffering and the relationships between disability and poverty. Instead, the public discussion is caught up in debating what disability grants represent rather than what disability grants *do* and how people *make use of* these grants locally.

Part of the public debate was focused on the fear of creating state dependency, where too many receive government grants under the category of disease. In the South Africa Human Sciences Research Council study on state dependency it was highlighted that the notion that too many people receive disability grants goes back to the 'undeserving poor' entrenched in pre-welfare state Great Britain. However, more recent roots are to be found in neoliberal thought which emerged in the 1980s, particularly in the US, spreading concerns to any state offering cash transfers as part of its anti-poverty politics with state transfers becoming a strain on national expenditure (Noble and Ntshongwana, 2007, p 6). Interpreting people's demands for disability grants as abuse of the system and further 'blaming the poor' for taking advantage of the system are well-established concerns in South Africa. From this perspective the individual is seen as the recipient of handouts. It is interesting that studies of the contemporary Comprehensive Social Security System on grant beneficiaries made by the South Africa Human Sciences Research Council conclude that no evidence was found for creating a dependency culture (Noble and Ntshongwana, 2007, p 6). From this we understand that the

government wants strong arguments to deal with the rhetoric of abuse, corruption and the fear of *medicalisation*.

The two phases of development described above are connected to the broad definition (1994–2001) and the more narrow definition (2001–07) of disability. Here we have distinguished the phases analytically. In public discourse as well as in experiences among people, these thematic phases are often interwoven and cannot easily be distinguished.

During these phases, a new framework for disability has been developed through the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), moving the medical model towards a social model, with greater emphasis on how the environment creates barriers and limitations. The ICF model deals with bodily impairment as a bodily entity that can be changed or removed. Disability is therefore something a person can move in and out of and the conceptual framework is flexible in defining people with disabilities in relation to the environment. During the same period, people within the South Africa disability movement have played a significant role in developing a global framework of human rights and the process of developing the United Nations (UN) *Convention on the Rights of Persons with Disabilities* (2007). The Convention requires a specific disability focus with a strong focus on discrimination and the responsibility to create a society that incorporates and makes reasonable accommodation for people with disabilities. In this political context South Africa has been used as a good example as to how the government has come far in implementing the Convention in new policies, laws and the constitution. The Convention depicts the proportion of people with disabilities in a population as around 10%, thus creating a space for a focus on barriers and limitations in society rather than on the question of *'how many are disabled?'*. Even though South African disability activists have achieved much, in only a short time, in mainstreaming disability to all levels of society, a call for a clearer definition (narrow definition) and the questions of who are disabled and what constitutes disability are still key aspects in the public debate. Demographic studies and national censuses contribute knowledge to form a basis for how the government sets priorities. Behind these prioritisations emerges a way of thinking that tends to draw the focus towards numbers in research and knowledge production rather than on questioning how suffering is produced in societies and in identifying factors that perpetuate the relationship between disability and poverty.

Disability as discrimination

There is a close relationship between the broad explanation of disability and the theory of social suffering. Disability as discrimination relates to the past and current structures of society, where discrimination is closely related to how people experience the environment. Subjective experiences become crucial in how discriminating practices are defined. The relationship between the individual

person and the environment becomes significant in order to understand how people conceptualise disability. Barriers in society are seen as discrimination due to restrictions in participation. Discrimination in South Africa also relates to the history of past inequalities and apartheid's segregated practices that also explain the cause of disability as barriers created by society.

As a development strategy to address inequalities of the past, the disability movement in South Africa has put cultural representation on the political agenda – representation is understood as people with disabilities being represented in positions of authority/power. Having such a position means that the embodied disability experience becomes significant. From this perspective the movement seeks to move away from seeing people with disabilities as victimised after apartheid, but rather as agents for change. The slogan 'Nothing about us without us'[5] underlines this emphasis. A significant distinction exists between people who are disabled and people who do not see themselves as disabled. This distinction is visible in the division between DPOs that only have members who are disabled (also called organisations *of* disabled people) and organisations run by professionals for disabled people (organisations *for* disabled people). The disability movement (DPOs) in South Africa has made self-experiences and self-representations a political agenda, emerging with the transformational process of creating access for all. These DPOs have created entrepreneurships in order to accumulate specific knowledge on how to mainstream disability in the workforce, organisations, institutions and government on all levels. A nationwide network of people who are disabled has put forward a recommendation to assist each other, and also to make sure that people with disabilities are represented by taking ownership of their own agenda. This network of people has been driven by people who are disabled and who used to be part of the resistance movement and the African National Congress (ANC) struggle against apartheid. In the contemporary transformational process of empowerment, a specific category of disability is acknowledged in laws, policy and the new constitutions. The national network has functioned as an empowerment tool to identify and to include more people who are disabled in activities and events.

The process of empowerment and change incorporates the past injustice of discrimination, and makes the disabled person visible and enabled to act in public. The focus on *I can* and on creating enabling environments has enabled individual performance through self-representations. DPSA have actively negotiated and taken part in developing policies and laws, and facilitated social change in government structures. DICAG has promoted the inclusion of children. This is particularly evident within education, social security and health areas. Disability has been mainstreamed in specific areas such as education, health and social services, buildings, transport and employment (Office of the Deputy President, T.M. Mbeki, 1997). Within the *labour* sector, disability is integrated as part of the affirmative action and equity programme of the Broad-based Black Economic Empowerment Act (South African Government, 2003) and the Employment Equity Act (South African Government, 1998). The law confirms that 2% of employees must be

people with disabilities. Specific units within the government that are established to implement the disability programme are further required to employ people who are disabled. Through these processes of employment positions, social change has been initiated and created places where disabled people are represented. The crucial aspects in these programmes are participation and equal opportunities. The human rights approach of social change has actively worked with empowerment, emancipation, self-representation and participation within the South African state. Disability has become a matter of citizenship, required through cultural representations in the new transformation process.

Conceptualising disability in the rural surroundings of Mthatha, Eastern Cape

The anthropological field study started out with a local key person who collaborated closely with the chief and headman. The local rural village structures were a significant starting point for mobilising and gathering people.[6] We were overwhelmed by the number of people who turned up to our planned meeting and we could easily identify social suffering as a normality among them which had been shaped as a collective form of social experience. The anthropological material was collected through an open question methodology that allowed people to speak for themselves. A total of 10 village meetings were conducted, in addition to 57 individual interviews (some in people's homes) and 15 focus group discussions. The selection methods were drawn from those who had turned up at village meetings and who volunteered to participate in interviews. Among the individual interviewees were both men and women between the ages of 18-60. We purposely did not ask for a specific diagnosis nor had any diagnostic measurements but allowed people to express their understanding of disability.[7] The material presented in this chapter forms one part of a broader doctorial research project in which this chapter is integrated into a broader content. The anthropological material was gathered during nine months of fieldwork where participatory observations enabled a situation in which the researcher moved with and between people in different situations – *following the disability grants*. A multisited methodology is essential for presenting different aspects of how disability grants are variously interpreted among people and made use of locally in different situations and places.

   With this choice of method we asked about people's experiences of disability and created room to allow people's demands and social sufferings to be articulated. The most interesting part was that we met the same statements wherever we went: shared perceptions and agreements about what disability was all about. The general answer was: "You are disabled when you can't do what you want", "We can't find work and we can't work – we are disabled." They were referring to restrictions of mobility as important for understanding disability, inabilities to perform and barriers in the environment. This was expressed and articulated in many ways: "People are dying here because they can't travel to the doctor, we want

to seek medical help and there are no doctors here. People are ill and people are dying"; "Transport costs money and medication costs money, and the distance is too far"; "People experience pain, fits, illness, and a body which cannot do what they want"; "We become sick from the water." All the time people asked, "Why are we not considered disabled?" These articulated demands were the result of huge expectations of the new democratic South Africa. In this situation, people try to talk themselves into disability. This correlates with MacGregor's 2006 findings on how people in Kayelitsha expect the state to provide the means for health, receiving grants from food and the most basic means of sustenance (MacGregor, 2006, p 53). We were faced with a situation where people seldom got the chance to articulate their experience in public hearings. Few doctors, nurses or social workers visited these localities and few development programmes were initiated, except for the event of the monthly distribution of grants in the villages. Poverty was not sufficiently addressed. We positioned ourselves as interpreters of people's experiences and saw it as important to put forward local and inside perspectives on how shared experiences and local understandings of disability and social suffering as a concept were being shaped, learned and constructed as cultural representations. The specific relationship between poverty and disability puts pressure on a medicalisation process, where people demand more people to be included and to be acknowledged as disabled, a process which is mobilised through a culturally inclusive word, *Ubuntu*, in addition to a political process of transforming South Africa into a new democratic society.

Ubuntu and self-representations

Kleinman et al (1996) define social suffering as an interpersonal experience embedded in local words of social experience and morality. Local moral words are significant in how people create networks and are able to share experiences and produce cultural representations of suffering. In this process the concept of *Ubuntu* shapes people's interaction and how they express their experiences in their everyday lives. There is a close link between how organisations of disabled people have worked with conceptualising disability and how *Ubuntu* creates a sociality of sharing perceptions, ideas and a practice of being together in everyday life. The practice of *Ubuntu* is visible in how people express their shared demands, differences, conflicts, disagreements and agreements, the knowledge of disability, the huge expectations that exist among rural people in poverty and the way people manage to organise these experiences as collective demands. *Ubuntu* is not an easy concept to translate. It is embedded in values of how people relate to each other. *Ubuntu* shapes relationships oriented in a sensibility vis-à-vis the other. *Ubuntu's* capabilities are about reaching out to people, showing greatness in order to help and assist others who are in need, sharing food, money or knowledge. It is about building a self in conjunction with others. In South Africa the concept of *Ubuntu* is commonly used in public as part of the reconciliation creation of unity.

The word *Ubuntu* is Zulu, *umuntu ngumuntu ngabantu*, and means 'humanness – a person is a person through other persons'.[8] In a web video,[9] Nelson Mandela explains the spirit of *Ubuntu*: '*Ubuntu* does not mean that people should not enrich themselves. The question therefore is: Are you going to do so in order to enable the community around you to improve?'. Desmond Tutu describes *Ubuntu* as:

> A person with *Ubuntu* is welcoming, hospitable, warm and generous, willing to share. Such people are open and available to others, willing to be vulnerable, affirming of others, do not feel threatened that others are able and good, for they have a proper self-assurance that comes from knowing that they belong in a greater whole. They know that they are diminished when others are humiliated, diminished when others are oppressed, diminished when others are treated as if they were less than who they are. The quality of *Ubuntu* gives people resilience, enabling them to survive and emerge still human despite all efforts to dehumanize them.[10]

In South Africa there is a common understanding of the word as part of an existing humanity. In Xhosa the word *Ubuntu* is the same, you just remove *u* (*umntu ngumntu ngabantu*). Humanity is closely linked to how people understand being incorporated into the new South African state, the interconnection and the way people help and assist each other. We discussed *Ubuntu* with some of the members in the local DPO and one of the leaders always repeated that there was little *Ubuntu* left. This came up instantly when he talked about how people are suffering and that people are more concerned about themselves 'these days'. As outsiders we saw how incredibly important the value of *Ubuntu* is in order to interconnect people and communities, between different hierarchies and the way of sharing information and gathering people in order to help and assist and what people *do* and how people *act*; and, most importantly, how significant such a value system is for making voluntary organisations work.

There is a close relationship between sharing goods and wealth and how disability grants are made use of. In a context of poverty, disability grants easily become integrated into a practice that has to do with sharing wealth and building relationships vis-à-vis others. Expectations to share these grants are embedded directly in values of *Ubuntu* as reciprocity. Around Mthatha ties of interdependence are indirectly maintained through disability grants as the amount of monthly income enables some households to share and create ties of interdependence through the value of sharing food and information. Disability grants also make it possible to sustain activities related to disability, creating meeting places and a common ground for sharing experiences. Local organisations *of* disabled people have developed a common ground for sharing subjective disability experiences and established networks and meeting places where words can be attributed to collective experiences. This network of people has also helped people with disabilities to access the disability grant system in rural areas. The story below is

based on an interview with a woman who used her own experience as a basis for setting up an organisation of parents. Exchanging dialogue created a network where mothers could share their experiences. She narrates.

The first story: *Ubuntu* – sharing experiences and developing organisations

'I became engaged in this work in 1983. I heard from two social workers that there was a national organisation run by mothers who had disabled children. It was after meeting the leader that I started to talk about my son and my life as a mother. Already I knew different villages and the traditional structures with the chief and headman system. Due to my previous working experience I could easily be taken seriously in village meetings with the chief and headman. Personally I found it difficult to express my own experiences in public, but I got used to it. In our culture and our tradition among the Xhosa we still have an understanding of a *community child*. When a disabled child is born in the village it is announced by the family head, usually the man, through the headman's *kraal*. It is well known that it is a misfortune to deliver a disabled child. It is especially difficult for the mother and the family as a whole; that is why they need to announce their difficult situation in their community so that people know their vulnerability. Traditionally it is believed that having a disabled child is a punishment from the ancestors, especially if you as a mother have brought bad luck into the family. The husband usually accuses his wife of bad behaviour. There are many husbands that punish their wives because of this abnormal event and the husband usually leaves the family in the end. You will find many examples of this around here, quite common I would say. When I delivered my disabled son everybody around me was in shock. I started to talk about these experiences, disability issues, in village meetings being a mother and a woman. We established a village committee at the headman's place and we had community meetings. The headman has responsibility for each local area where approximately 10,000 people live. Each local area is run by a chief who is responsible for seven locations. Both the chief and the headman can call on meetings in the *kraal*. In such a way the grass-roots level is easy to reach. At these community meetings it is usually the man who speaks. In order to manage to talk to the women we established separate groups. It was very easy to get acceptance from the headman and the chief. For a long time these mothers have regularly been gathering, talking to each other while they collect firewood or travel to town, etc. Some women have opened their homes as a meeting place; some have managed to start a bakery where they bake bread which they sell to schools; some have started vegetable gardens; and some do basket weaving. At these meetings it has been those who have similar experiences that have come forward to join. We have worked hard with helping people to receive grants, referring people to social workers. All the people who I referred received grants during that time. Now it is more difficult. There are many such voluntary branches in different villages, some more active than others depending on the distance and funds allocated.'

Being able to establish such groups and being open to sharing one's experience is deeply related to values and practices of *Ubuntu* – acknowledging differences

and a willingness to share. Given the amount of people in the area who received disability grants, and the grass-roots movement that developed a network of people sharing disability experiences, the process can be analysed as sharing collective experiences, creating collective political demands.

   The second and third stories below illustrate how disability is conceptualised within the disability grants system, what counts and what does not count as disability. These stories illustrate the disagreement between how people experience disability and the contemporary economic, bureaucratic prioritisation the government represents through a more narrow definition (medicalisation) of who qualifies for disability grants. The bureaucratic response intensifies people's suffering. In the second story we meet the social security officer who takes part in the implementation process of how people are selected for doctor's consultations as part of the process of applying for disability grants. The community is asked to pre-select 10 people. The social security officer, Mr Ngobo, encounters people who have already conceptualised a local understanding of disability related to illness and are able to articulate to him their social suffering as demands. The story shows the local disagreement between the broad and narrow understanding of disability and the kind of morality that is embedded in practices addressing poor people who experience social suffering and poverty.

The second story: "We too are disabled"

'After some months of travelling around in the villages surrounding Mthatha, we managed to get permission to follow one clerk who was appointed by the Department of Social Development to administer the distribution of disability grants. The clerk, Mr Ngobo, was the link between the social department and the villages who was intended to implement services by encountering people in their own environment, and to draw on village citizens to select those who were most in need. Such an approach is a change from past practice when people had to turn up at the offices and stand in never-ending lines. Mr Ngobo was a man with great communication skills. Before we entered the village he wanted to have a small meeting with us to explain that what we now would experience was not a good situation, but that his role was to do his job that was to select 10 people. He had given information to the village through the committee, located at the headman's house, and told people to meet up for the selection process to receive a disability grant. His intention was to collaborate as much as he could with people and ask the people who lived in the village to select 10 people.[11] These 10 were then approved for a visit to the medical officer before they could receive disability grants. He argued that the village people knew who needed the grant most, and he assumed they – the community – would help make the right choices.

'The selection process turned out to be quite difficult and was met with huge resistance from the village due to the fact that only a few people were selected. People in the crowd openly questioned why the community needed to select 10; in their opinion 10 was too few. Mr Ngobo was in a difficult position and such situations are overwhelming. People

feel diminished and see the act of prioritisation as a practice of social oppression remnant of the apartheid system; a situation where the government does not address what really matters to people's social suffering and poverty. People who are impoverished spend a lot of time and energy trying to substantiate claims to these grants, which in turn makes claiming grants part of the vicious circle.

'Around 150 people had turned up. The question that remained was how to select 10.

'It was easy to see that all of them needed help; weariness and fatigue in their eyes, visible signs of too little food were obvious in their bodies. They were very aggressive, demanding a medical doctor to decide rather than this community approach. They also questioned Mr Ngobo's competence as a decision maker. In his introductory speech, Ngobo insisted that they had to select those people who were critically ill. He did not emphasise disability. When we asked him to explain what critically ill meant, he pointed to a blind person and said that you can see that he is disabled. At the same time he said that it was not easy. Some people could be invisibly disabled and that he would not know. It is the role of the community to come forward with those people who are not able to speak for themselves. He said that to be critically ill is about physical disability.'

From this we see how disability was articulated by one gatekeeper, Mr Ngobo. Going through all the clinic cards in the queue we could see that many in the line were people with epilepsy. They had received treatment from the clinics for some years but still had fits periodically. Even though, they explained, the medication had an effect on reducing the seizures, they had not disappeared and for that reason they still regarded themselves as disabled in everyday situations and wanted to apply for a disability grant. In the process few of these people were selected. Thus, the question that remains is, why are seizures not acknowledged as 'impairment' symptoms that can lead to disability? Those who were selected included a young person with skin problems, one deaf and one blind person and others with physical disabilities. With the bases of my nursing experience, I assessed many of those left behind as critically ill. We followed the same selection process in five different villages. Twice a year Mr Ngobo visited the same village and conducted the selection process. Using this selection process was at the time the most common way of assessing disability grants, unless one did not happen to be admitted to the hospital for a longer period. In some cases hospitals issue disability grants, but the new reform refers such cases to the municipality.

Above we saw that Mr Ngobo quickly acknowledged physical signs as impairment in contrast to signs of fatigue, malnourishment, tiredness and fits/seizures. This illustrates a distinction between visible and invisible signs in the selection process that is part of a complicated public bureaucratic system dependent on medical evidence and documentation. To apply for a disability grant, the person needs an ID card, clinic cards and professional medical documentation concerning their disability, such as x-ray pictures, blood tests or other tools for diagnostic justification. However, diagnostic technology is distributed differently

according to where you live due to the establishment of institutions that have such capacity. Urban areas are far better equipped when it comes to such technology and availability of medical doctors. In the past, most black people were denied access to places where such technology existed. They now demand to have medical doctors in places where people are ill. The term 'epilepsy' requires such expertise to acknowledge such a condition as being disabled.

The third story: 'Having fits' challenges of defining disability

In the Comprehensive Social Security System 'having fits' is hard to diagnose as epilepsy, hence people do not receive disability grants for this impairment alone. Looking through 100 rejected cases (up to the year 2006) in the O.R. Tambo DPO, 70 of these cases were rejected with the argument that epilepsy could easily be treated with medication, and hence, since in South Africa medication should be given out free at each clinic, it was not seen that 'having fits' could cause any situation of disablement. This correlates with Segar's (1994) argument of the ambiguity of disability when it comes to epilepsy, and that people from impoverished backgrounds spend a lot of time and energy trying to substantiate claims to these grants, and are rejected due to the morality of drug compliance (Segar, 1994, pp 282–86). The argument of rejecting 'having fits' as impairment for disablement is interesting when we compare this argument with recent epidemiological research findings. These studies show the connection between malnutrion, high unemployment and undertreatment of *taenia solium cysticerosis*, a biomedical infection causing tiredness, fatigue, malnutrition, fits and epilepsy. According to Carabin et al (2006), the former Ciskei and Transkei in Eastern Cape are endemic areas for *taenia solium cysticerosis.* This condition causes serious public health problems and remains uncontrolled due to lack of information and awareness, absence of suitable diagnostic tools and appropriately adapted interventions (Carabin et al, 2006, p 906). Comparing the high prevalence with how people in the study express their subjective experience, we see that the link between poverty and 'having fits' also demands attention within expert groups and professionals who are working within the health and social service system. An epidemiological community-based survey in the area showed that among professionals it was well known that humans acquired tapeworm after eating raw or undercooked pork contaminated through faeces or food but little is done in order to act on such information (Del Rio-Romer et al, 2005; Carabin et al, 2006). From these research findings relevant questions emerge: in which way can the Comprehensive Social Security System relate to people's emerging demands on the ground? Further we illustrate how poverty is continuously shaping a disabling environment, and constituting disability differently in different places.

In rural areas, 'having fits' is quite a common phenomenon among people, and different local explanations exist. People distinguish between those who have regular fits and need constant care from those who have fits once or twice every six months. Rituals where pigs are eaten are significant events such as funerals

and marriages, and some people are fully aware of the danger of eating such meat. But other explanatory models also exist. The 'poison' is not only understood as coming from what the pigs eat but also as evil spirits embodied in the pigs, which later has the ability to be transferred to the person who eats the meat and then the spirits which embody them. In some Xhosa tribes, eating pigs is part of a practice linked to special rituals. It is believed that a person can resist poison if he or she is well protected or has the ability to see whether the meat is poisoned or not. To receive protection, people use priests, faith healers or traditional healers. Some attend regular services and pray every day in order to receive protection from God but also from the ancestors. Different local healers play a crucial role in giving people such specific protection. People see the healer's role as significant. Some people find the healers meaningful and important and tend not to find the clinics useful in the same manner. The current situation is that many people are suffering without being successfully treated and lack of diagnostic tools has resulted in a failure to prevent epilepsy or to cure well-known treatable infections which are not given attention.

When it comes to applying for disability grants within the Comprehensive Social Security System there are several barriers regarding acknowledging 'having fits' as a disability. First, in interviews with both adult men and women, it was difficult for people to remember the prevalence of the fits; they could not easily describe the specificity which is required as vital information when applying for a grant. People with fits would rather talk about everyday difficulties – their difficulties in reaching the clinic, struggle with transport, how to find money for food and medication, the realisation that the help received did not work for long and that it required them to start all over again, their apathy and tiredness. Second, people who attend traditional healers tend to be left out of the whole system. The healers do not have clinic cards and do not register the fits anywhere, and many people who only use healers do not even have the necessary ID card. The word 'epilepsy' was only used by people who had attended the clinic regularly. The use of the word 'epilepsy' put a stronger emphasis on medicalisation, diagnostic equipment and a call for biomedical doctors with expert knowledge who understand the context of poverty. This is how one mother explained her situation:

Subjective experience of having fits

'For three weeks in September 2005 my daughter had fits and I did not know what to do. I went around borrowing money so that I could send her to the clinic. I could not leave her unattended because she had fits: she wanted to hit people and she was not herself. Eventually I did get money and I took her to the nearby Baziya Clinic. I was very afraid. At the clinic they gave her pills but they did not help. We went home and the situation improved slightly. In February she became sick again. She wet herself and white saliva came out her mouth. She did not talk and she was sick day and night. She did not eat any food. I went again to the village and tried to borrow money and they gave me some. I took her to the clinic again; they gave her other pills. Then, in March, she became

worse again because the pills she was given were finished. Then my neighbours lent me money and I took her to the clinic on the 10th of March. At that time there was white saliva coming out of her mouth and she did not want to eat anything. She said her body was tired and very painful. She can't do anything, only stay at home. For over a year now she hasn't attended primary school due to the fits. She doesn't go out often but stays inside the house.'

The financial consequences for the household are huge. Since the mother needs to be with her daughter she is not able to take on paid work. The mother struggles to get money every day, money that is needed to get to the clinic, to get medication and food. There is also the hopeless feeling when she encounters the clinic and is left with a feeling that what she received did not help in the end.

In a focus group meeting with adult men, none had received a disability grant, even though they had regularly attended clinics for years (some of these men were previously mine workers and some had never been migrant workers). The doctors had never mentioned the possibility of applying for a disability grant. As a group, they had started to question why epilepsy or 'having fits' was not acknowledged as a disability. The condition was described as dizziness and they felt that they could not progress in the same manner as others; they were always scared when the next fit would occur. Feelings of pain and fear in addition to the experience of losing their jobs had created the need to do something about their situation. We sat in one of the huts listening to the men openly express their concerns about why 'having fits' was not regarded as a disability. Their hope was that we would pass along their stories. The problem they were facing was related to difficulties in keeping their job because of their pains and weakness compared to others. Many had lost their temporary work in surrounding villages. They expressed how difficult it was for their families when they suddenly had to stop working on the house because of the fits, leaving the work to others due to their inability to perform at the same speed. They felt that they were becoming weaker and weaker, with no money or income, struggling to provide for their families.

In situations where people cannot find work or cannot work due to illness, 'having fits' is an example of how men have gathered these experiences and demand epilepsy to be acknowledged. Their argument draws on the fact that they feel that their fits make them unable to find work or keep work, they are not receiving appropriate medications, and hence they can relate to disability as a concept. The men have been able to gather collective demands, an act of collectivity that would not have happened without a prior process that produced a common understanding of disability. They are developing and expanding the disability concept further as a political demand.

The fourth story in this chapter shows how disability is made use of. Households become totally financially dependent on the grants as their only means of survival for building a future for their families. The poor environmental setting of unemployment creates dependency on the grants system. As we will see, this dependency is not necessarily part of an individual manipulative abuse practice,

but rather the result of a survival strategy where disability becomes a collective positive category people can act on and make use of. Further analysis emphasises how the local DPO and their work is embedded in a practice of *ubuntu*, also referred to in the first story. This is a practice where the family receives a position within the community in the process of naming disability.

The fourth story: Poverty, agency and discrimination

Nowinile (meaning a winning woman) and her husband live in a village outside Mthatha with three children and have been part of the DICAG voluntary rural network. Nowinile and her family have made their own house into a place for community services, where people come for several reasons – some when they need help and advice, and some people who also come for food. There was a general view that this place had also been significant for stimulating knowledge and sharing experiences concerning disability issues. It was in their house that we conducted all focus group discussions. Nowinile managed to gather people together at short notice, which indicated that she was trusted and had some power. The central place and position Nowinile created in the community is closely related to how her family has managed to receive help for her daughter, Coceka (meaning cleanliness). Coceka was born in 1993, one year before the democratic election. There is a close relationship between how Nowinile has experienced her daughter's disability and how her experience has been important for how her family has shared their experience with the community in this transitional time for South Africa:

'When I gave birth to Coceka she seemed normal, and then I noticed that something was wrong with her feet and because I had wrong feet when I was growing up I thought that her problem was hereditary, but I was not sure. I also assumed people were jealous because I had managed to get a girl. The event with the snake made me realise it was out of jealousy and that someone wanted to punish us: One evening the whole family was sitting around the fire. A snake fell from the roof and landed on my daughter's feet. This event was unusual because snakes are usually afraid of fire; you don't find snakes in a house where there is fire, but this black snake was different and it was even difficult to kill; it took time to kill and while we were doing it the snake's head turned in opposite directions. We had to call the neighbours to come and assist us. I used holy water from my church to calm it down and then my husband was able to kill the snake. This is the story of why Coceka has problem with her feet.

'As Coceka grew up her feet began to turn inwards and people said that the flesh under her feet shifted to her heels so she walked as if she was tiptoeing. She also had problems with her hands being deformed. The situation with her feet worsened as she grew older. Coceka could not walk; she could not make use of her feet because they seemed to point towards each other. I took her to the doctor at the local hospital when she was four and they advised me that she must have an operation. I refused because I knew how painful it was. I was scared. I was afraid that if she was operated on she might not wake up again. Some years later, in 1999, I applied for a dependency grant [disability grant] for Coceka, which I received because of her feet. In 2000 I took her to a new doctor,

Dr Hoff, who told me that he was going to remove the excess flesh on her heels and operate on her legs. I was referred to Cape Town. I was supported by others. My son and my daughter-in-law managed to help me to take her to Cape Town where I was summoned to give consent for her to undergo the operation. She was operated on one leg and later the other to remove the excess flesh under her heels in Cape Town where I had to travel with her. After the operation she could walk as she does today. You can see, Coceka is healthy in 2006.'

Nowinile uses her daughter's story to tell us about how she has received help and support, and this experience still keeps the family active in community gatherings as a family who managed. Although they received help for the girl's feet, her arms have no strength, which limits her ability to cook or clean and other 'female' work. After the operation, the child dependency grant (grants given to parents due to disability of a child under the age 18) was not withdrawn. The mother was managing to keep the disability identity through her status and community work. Coceka, her whole family and her mother Nowinile, have created a life around disability. Sharing experiences and establishing working relationships have given Nowinile a position in the DICAG network. The local group initiated the building of a community centre for children with disabilities. Part of this work was made possible due to the fact that Coceka's family receives a disability grant in the village. They save some of the grant money every month for education, but they also share the money among others – to give out food and coffee, for instance. The family is totally dependent on the category of disability in order to receive the grant and hence also keep their position in the community. The story shows how the whole family has managed to identify themselves within a framework of disability and created activities and relationships. Similar processes are also described in Botswana, where Benedicte Ingstad has shown how disability makes an impact on the whole family and how it inflicts the household as a whole, not just the individual person as such (Ingstad, 1997). In this context, it is interesting to question whether disability grants could be accepted as a contribution to the whole family/household as such and not specifically linked to one individual that a human rights perspective requires. Nowinile and Coceka's story shows that disability is also about relationships between people and how this shapes the perception of discrimination. Receiving disability grants becomes a matter of acknowledging being discriminated against in the past but now receiving help. The achievement is especially clear when we compare how differently disabilities are locally interpreted and the amount of attention and physical signs given in the bureaucratic process.

Conclusion: New democracy, poverty and disability agency

The anthropological material shows how the broad definition of disability is embedded in cultural representations perceived and understood as practices of *Ubuntu*. The morality of *Ubuntu* is embedded in cultural practices of sharing. We

have seen how disability experiences are openly expressed in public as *words shared*, articulated as experiences of discriminating practices. Furthermore, the sharing of money and food has created relationships of solidarity. The morality of *Ubuntu* has created a common understanding of discrimination and poverty, explained as a result of the past segregation practice of apartheid. The shared practices of *Ubuntu* have initiated a foundation on which grass-roots organisations for disabled people have developed locally. The production of poverty in the past has managed to gather people around a collective understanding of disability and practices of utilising disability grants. *Ubuntu* as a cultural representation of humanity has enabled citizens to mobilise for change in the new democratic South Africa.

The four stories presented here have shown how disability grants are being *made use of* – implemented in a context where people have a common understanding of the relationship between disability and poverty. People put forward their social experiences – *we too are disabled* – demanding inclusion in plans and policies in the new democratic South Africa. The demands of acknowledging 'having fits' as a disability incorporates aspects of poverty illustrated through people's expression of not being able to find work, of having no money, no food, and in having difficulties in reaching clinics when fits occur – all aspects of social experiences included in the broad definition of disability as well as Kleinman et al's (1996) understanding of social suffering.

In this context, the distribution of disability grants creates local conflicts and disagreements between the broad and narrow definitions of disability. The narrow definition tends to interpret physical impairment, physically visible signs, as a qualification for what disability *is*. These sign interpretation processes are closely linked to similar historical processes. During apartheid, specific visible signs (skin colour as the basis for classifications of different 'race' groups) became significant for structural segregation practices. These physical signs of disabilities can today easily be interpreted as representing double discrimination, adding to previous disadvantage due to skin colour. The current situation shows how these past historical practices, in conjunction with biomedical knowledge and international classifications, are part of the processes that construct what disability *is*. Furthermore, the distribution of disability grants puts forward the question of *who* the disabled are and requires a definition of *what kind of impairment can count for defining what disability is*. These questions enhance historical practices in conceptualising disability as an *essence* embodied in a person's body.

This anthropological material shows that people in the rural Eastern Cape conceptualise disability acted out as demand for acknowledging the relationship between poverty and disability. The broad definition represents the new approach in South African policies and laws, but this definition is interpreted differently among central institutions, organisations and people representing these organisations. The challenge today is to embrace the new broad approach within the contemporary social security system, with disability grants, not only in how to define disability, but also in acknowledging how people *make use of* the grants; in other words, to emphasise how people locally interpret the broad understanding of disability. It is

important to make room to locally discuss this broad understanding in public with the intention of creating a broader acknowledgement of the relationship between poverty and disability. The broad definition manages to explain disability in an historical, cultural and social perspective that is closer to people's understanding and their lived experiences as social suffering. Conceptualising disability becomes deeply embedded in political processes, both in how disability is defined and in how policies are implemented. This is highly significant in the process of defining research questions and in determining what needs to be investigated. In this chapter we have shown how incredibly important these questions become in shaping people's everyday life situations and how their social experiences are conceptualised locally.

Acknowledgements

Notes

[1] The Comprehensive Social Security System (allocating disability grants) of poverty reduction is in line with Amartya Sen's argument that capability/functioning can affect the needs of the person. For instance, a disabled person's capability to function may be lower than that of a non-disabled person. The additional needs disabled people may have in order to achieve similar functions to non-disabled people involve additional cost. Poverty, according to Sen, should be defined as 'the failure of basic capabilities to reach certain minimally acceptable levels' (Sen, 1999, quoted in Lister, 2004, p 16).

[2] The welfare of poor whites including coloureds, a mixed race group with substantial ancestry from Europe, Indonesia, Madagascar, Saint Helena, Mauritius, Mozambique, Malay and southern Africa. Racial segregation in South Africa began in colonial times, but the official policy was introduced in 1948. From 1958 black people were deprived of their citizenship, legally becoming citizens of one of ten tribal based self-governing homelands called Bantustans, four of which became nominally independent states. The government segregated education, medical care, and other public services, and provided black people with services inferior to those of white people.

[3] According to the national policy, the Comprehensive Social Security System is provided in the form of: an old age grant, a disability grant, a war veteran grant, a care dependency grant, a foster child grant and child support grant. The grants are subject to a means test (which means that the South Africa Social Security Agency evaluate the income and assets of the people applying for social assistance) with the exception of the old age grant, where the universal model is used, with a grant to all above the age of 67 (Department of Social Development, 2006). Specific diseases such as AIDS are also covered within the disability grant system when the person indicates seriousness of disease due to a specific blood test (Nattrass, 2005). The disability grant is means-tested and awarded to a person who is unfit to enter employment due to physical or mental disability (Social Assistance Act, number Act 59 1992 or Act number 9 2004). The disability grant is intended to make provision for the person's monthly maintenance with 940 ZA Rand. (The SASSA model can be downloaded from www.sassa.org.za)

[4] The Eastern Cape has a high proportion of disability grant beneficiaries: 18% (Natrass, 2006, p 23). Compared with the other eight provinces, Eastern Cape is second only to KwaZulu-Natal (O.R. Tambo District Municipality, 2008-09). From 2001 work has been done in order to restrict the grant distribution according to the abuses and corruption that were investigated in the Eastern Cape. From 2001 decisions in Eastern Cape were to be made by the medical officer alone, followed by an assessment unit and district medical officer, followed up by guidelines. A person must be significantly impaired, and if treatment is available it is necessary to provide documentary evidence of treatment compliance. In the Mthathta region, the medical officer herself was disabled and a member of DPSA, actively involved in the Mthatha branch. In three out of nine provinces in South Africa assessment panels have been used for implementation. The intention of theses panels was shaped out of interdisciplinary work, whereby a team from the local community, traditional healer organisations and health personnel carry out the assessment, not only the medical doctor. In these provinces the numbers of beneficiaries seem to be high and the methods of the assessment panels have been questioned in that regard. I was told that representatives from the DPSA were satisfied with the panels because the decisions were not only based on a medical judgement but also that of a multidisciplinary team, which in many situations managed to avoid conflict and initiate a more understandable community approach. In interviews with people in the Department of Social Development at national level it was indicated that, to a larger extent, the environment was brought in as an indicator for receiving disability grants when occupational therapists was brought into the assessment.

[5] This was taken up by the South African disability movement. It was first used by David Werner (1998) in describing the development of innovating technologies in developing countries. The term was later used as a slogan within the Disability Rights Movement, especially in the US Disability Rights Movement, and it is also strongly visible in South Africa. It is about power to the people and the demand for control: the quite militant and revolutionary claim is that politically active people with disabilities are beginning to proclaim that they know what is best for themselves and their community. Since people with disabilities have needs, this creates dependency, and further people are born into

powerlessness, poverty, degradation and institutionalisation. 'Nothing about us without us' points towards these power relationships with active representations (Charlton, 1998).

[6] We were three women, two of us foreign to the place (one South African 'coloured' disability activist from the Disability Rights Movement, one Norwegian and one local assistant). The material was collected from two research projects funded from the Norwegian Research Council. The research was conducted in collaboration between the University of Cape Town, the Department of Social Anthropology and Department of Health Science, DPSA and DICAG and the University of Oslo, Section of Medical Anthropology, Department of General Practice and Community Medicine, using multisited methodology, interviews and participant observation over a 12-month period between 2004 and 2007. I use *we* in the text since we were a team who collected part of the ethnography together.

[7] The material in this chapter is drawn from interviews, focus groups and the village meeting and informal and formal conversations. In addition, one of the researchers used participant observations, which here means that she was able to move between different places and situations (urban and rural, between different levels of society), and to meet different people with different experiences and positions, and followed up events that became significantly visible. The situated methods enable the researcher to see connections and to understand people within a local context, to grasp conflict, disagreements and agreements. This position gave a specific insider and local perspective since the researcher participated more in everyday life. This material draws on 12 months of fieldwork, where one of the researchers lived in a household in Mthatha.

[8] *Ubuntu* – African philosophy (www.buzzle.com/editorials/7-22-2006-103206.asp).

[9] Web video of Nelson Mandela explaining the concept of *Ubuntu*: http://youtube.com/watch?v=Dx0qGJCm-qU

[10] Desmond Tutu: *Ubuntu* – African philosophy (www.buzzle.com/editorials/7-22-2006 -103206.asp).

[11] The number of 10 was directed from the Department of Social Development. It was difficult to find out why it was 10 and the distributions process was always under a process of development, so today the number might have changed.

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Displacement, mobility and poverty in northern Uganda

Herbert Muyinda and Susan R. Whyte

Shattered livelihoods and entrenched poverty are pressing issues for people with mobility disabilities in displacement locations in northern Uganda. For over two decades there has been a prolonged civil war in northern Uganda, covering the whole of Acholiland,[1] between the Lord's Resistance Army (LRA) and the Uganda government forces. The LRA war has been characterised by violence and brutality, leading to the displacement of the local population (Finnsrom, 2003; MSF, 2004; Refugee Law Project, 2004; UNICEF, 2004; Allen, 2006). For the period 1996–2004 an estimated 1.2 million people in the region were displaced and in Gulu district alone, over 400,000 people (almost 90% of the population) lived in camps for internally displaced persons (IDPs)[2] and temporary settlements in towns (Refugee Law Project, 2004, p 1; UNICEF, 2004, p 5).

The war and displacement has caused massive losses of the means of livelihood. IDPs lost their livestock and were hardly able to access their agricultural land. Market places and agro-processing plants were destroyed or rendered inaccessible; trade was constrained. The number of those of working age was diminished through abduction and deaths; food insecurity and poverty increased (WFP, 2004, p 7; Allen, 2006). The displacement locations lacked not only sources of income but also other basic necessities such as healthcare, education and day-to-day security.[3] In the IDP camps people survived mainly on emergency relief handouts intended to save life rather than to support livelihoods or to address poverty. Development, which is about building sustainable systems, promoting equity, building systems of governance and eradicating poverty, was put on hold until the conflict could be resolved. The war and displacement have been found to be the single most important factor responsible for the poverty levels in the Acholi sub-region (World Bank, 1998; CARE, 2002).

In these conditions, where hundreds of thousands of people suffered impoverishment and constraints on their movements, we focus on the consequences for people with mobility disabilities – those unable to move around easily because of impairments to their legs or eyes. Our observation is that poverty and physical immobility reinforce one another. Mobility impairment increases poverty while poverty prevents the social arrangements (including assistive devices) that might improve mobility. Yet this vicious circle is not inevitable nor does it affect every mobility-impaired person equally. We show that the policies of government and non-governmental organisations (NGOs) play a role in the relation between

mobility and poverty. The nature of the impairment was significant, with those wounded from the war enjoying most support opportunities, and leprosy survivors least. Most of all, we emphasise that the 'heroes of everyday life', struggling against huge difficulties, seldom stood alone. Nearly all were embedded in kinship relations and these social resources contributed to enhanced mobility for some.

The sweeping changes accompanying the war and displacement constituted a multifaceted jeopardy in the form of entrenched poverty[4] and affected people with disabilities in different ways. Most were unable to access mobility devices and have been unable to develop their livelihoods because it is difficult for them to invest in learning appropriate skills and education, and to effectively participate in activities needed to reduce poverty. The burden is also extended to their families who are forced to divert household expenditure to non-productive expenses such as food purchase, healthcare and extra needs for their family members with disabilities. The few rehabilitation interventions that could be a basis for reducing poverty target certain categories of people with disabilities and not others, benefiting those in urban more than rural settings, men more than women, and those impaired directly by the war rather than by other causes.

To illustrate the experience of poverty and its association with immobility, we compare the life experiences of two polio survivors – one living in a rural IDP camp without mobility devices, the other in an urban setting with mobility devices. From this analysis we show the linkage between physical mobility and social interaction, resource mobilisation, attraction of socioeconomic support and poverty.

Akello: IDP life and mobility constraints

Akello, a polio survivor since childhood, was one of the residents of Unyama IDP camp. She set her age at 23, but according to the details of her life, she must be older. She was married to a fellow disabled person (a man with clubfeet), with whom she had two children. The elder child (seven years) attended school nearby and the youngest was still breastfeeding when we first met them. Like most of the disabled people in the IDP camps, Akello did not have any mobility device; she moved on all fours with her legs straight, bending to reach with her right arm to grab the right foot, which she pulls in front when moving.

Because of how she moved Akello could hardly engage in any income-generating activities; her husband, who worked for subsistence at a sand quarry, was responsible for providing most of the household needs, and supported their older child in school. Just behind her house, Akello had a small garden of maize and some vegetables, where she occasionally did some limited weeding, while sitting. The limited produce from the garden often resulted in food insecurity in her household, which was the reason she gave for the prolonged breastfeeding (close to three years) of her youngest child. "If I wean her now, what will she eat?" The first time we visited Akello, she was still waiting for her husband to bring food for her to cook the first meal of the day when we left her home in late afternoon.

With the help of her paternal aunt, Akello occasionally went to the garden outside the camp to do some weeding in order to produce some supplement to the World Food Programme (WFP) rations and to get some income. But she stopped when they heard rumours of a rebel presence nearby. At such times it was only the aunt who continued to sneak out to the fields to get food to feed Akello's children.

For help in domestic work, Akello depended on her older child, especially with tasks that needed frequent movements. Before she left for school or went away from home the seven-year-old made sure that she gathered all that Akello needed to use in her household work. She collected water, firewood and any other household items that needed to be obtained from outside the home – from the market, shops or other relatives – so that Akello could easily access them. "She is my legs," Akello used to say.

Margaret: challenging poverty through physical mobility

Margaret was 28 years of age, a relatively smart looking resident of Gulu town, who had lost the use of both legs because of polio. She moved on a hand-crank tricycle with her baby strapped on her back. She was a very fast tricycle rider, and she often loaded it with boxes full of pancakes and fried cakes (*mandazi*), vegetables and sometimes jerricans of water, firewood and charcoal. Margaret had never attended school and she was co-habiting with a man who moved on a tricycle too.

Margaret earned her income by making *mandazi* and pancakes. She had different outlets and used her tricycle to distribute her *mandazi*. She put the box of *mandazi* under the seat of her tricycle and went about distributing them before settling at her stall on one of Gulu's streets.

> 'I started this business in Anaka IDP camp but it was limited because I just had a wheelchair and I could not carry many *mandazi* as it did not have enough space. When I came here [to Gulu town] AVSI [Associazione Volontari per il Servizio Internazionale] gave me a tricycle and the first thing I did was to move around to search for places where I could sell *mandazi* and pancakes. I found a few people selling them in different places and some of them agreed to buy from me. Since I now had a tricycle, it was okay for me because I carry as many as I can and distribute to my customers. Sometimes I even fail to satisfy the market when the demand is too high. The main problem usually comes when my tricycle breaks down; then I cannot go to the shops to buy the wheat flour, oil and charcoal, which are the main things I need. Sometimes I am forced to use my husband's tricycle when mine has a problem.'

Off the tricycle, Margaret moves on her knees at half her body height. Her feet dangle backwards as she swings her hands to balance her movements. In fact she can hardly move a long distance without a tricycle.

Margaret got her first wheelchair at the age of 15 from a Catholic priest to encourage her to attend church, and she got a tricycle through her spouse with whom she was cohabiting.

'I used to crawl to church to pray. I would tie cloths on my knees so that I don't get bruises. When the priest saw me so committed to church, he gave me a wheelchair to ease my movements. I got a tricycle through my husband who came to Gulu town in January 2005. He wrote a letter through a taxi driver and informed me that I should come so that I am given a tricycle by AVSI.'

The last time we met Margaret, she was carrying a white polythene bag with about 10 kilograms of maize to the mill to grind it for food. She told us that she also used the tricycle to take her child for immunisation and to hospital when she fell sick. It was clear that the tricycle was central in her day-to-day activities and life.

Displacement and poverty

Before the LRA war Acholi men lived in family-based homesteads surrounded by homes of patrilateral relatives, situated on allocated pieces of land that were owned communally. Wives moved to the homes of their husbands and helped cultivate the land around the homesteads for subsistence food production and the sale of some crops. Ox ploughs were used as well as hoes, and the land was fertile. Between farming, livestock breeding and trading, families were largely self-sufficient. People recalled the past as a time of plenty in contrast to the poverty of life as an IDP.

Yet despite these memories of an abundant past, it can be argued that poverty in the North pre-dated the LRA war. Economic development there had long lagged behind growth in the South, even though the first executive prime minister and later president of independent Uganda, Milton Obote, was himself a northerner. Like the rest of Uganda, the North was affected by Idi Amin's regime, especially after the declaration of the economic war in 1972 in which he nationalised the manufacturing sector and sent away the Asians who were the main lifeline of Uganda's private sector. Economic deterioration continued through the 1980-85 Obote II regime, which was characterised by political instability and insecurity. The National Resistance Movement (NRM) assumed power in January 1986 to face a shattered economy and inflation raging at an annual rate in excess of 240% (World Bank, 1990). The NRM government embarked on a stabilisation and structural adjustment programme in 1987 with the aim of restoring macroeconomic stability and bringing down inflation. Inflation went below 10%,

and economic growth rates averaged 6.4% a year for eight years (UBOS, 2001). While these impressive figures were important in areas without violent conflict, in northern Uganda the poverty situation was continuously deteriorating mainly due to insecurity and displacement. After displacement the rural areas (former villages) became ghost communities. The people were gone, the houses collapsed, the goats, cows, chickens, the food granaries and most domestic property were all gone. Cultivation was also seriously affected since the plough oxen were lost during the war and the government restocking programme had not succeeded.

Especially for the rural populations, the encampment type of settlement organised by the government as part of a military strategy to 'protect' the civilian population largely lacked basic facilities and services essential for subsistence (Finnstrom, 2005; Allen, 2006, pp 56-7). The Ugandan government made no advance arrangements for provision of appropriate health services, sanitation and food in any of the designated locations (MSF, 2004; Refugee Law Project, 2004), resulting in new conditions characterised by lack of access to land, spatial congestion, hunger and entrenched poverty. Means of livelihood were completely skewed, lives of the people profoundly affected, and most people survived on relief handouts.

To deal with the worsening situation, the Northern Uganda Reconstruction Project (NURP) was formed in 1992, with the aim of redressing the imbalance in development in the northern districts. NURP was later followed by the Northern Uganda Social Action Fund (NUSAF), aimed at empowering communities in war-torn northern Uganda by enhancing their capacity to systematically identify, prioritise and plan for their needs within their own value systems. The rehabilitation programmes, however, have been generally characterised as 'too little, too late'. Not enough use was made of NGOs, especially in the rural IDPs, and the programmes fell short of major social rehabilitation reforms (World Bank, 1998). According to the *National Household Survey*, people in northern Uganda live below the average national household consumption level (UBOS, 2001, 2006).

One of the key constraints in the life of people in the IDP camps was access to land. With the large number of people in one place, it was difficult for people with mobility disabilities to find land within the gazetted 5km around the camp to do any cultivation. Movement to more distant areas was restricted due to rebel threats and the 'security' measures put in place by government forces. People were not allowed to leave the camps before 9.00am and they were expected back before 5.00pm. Akello (who had to walk on all fours) explained her experience of the few times she had been to the garden:

> 'One had to leave the camp after nine o'clock as the regulations were. It took an hour or two to reach the garden as the fields were far, and by then the sun would already be hot and one could hardly do a good amount of work before walking back in order to reach the camp within the gazetted time (5.00pm). Then, what you manage to

get is very little, because you work under tension and worried about the distance back.'

Despite all the rules and restrictions, those who did not get a chance to be allocated land around the camps sneaked out to their fields (outside the gazetted 5km radius) to get food, and to carry out many of their other daily activities in a more or less clandestine manner. But most people with mobility disabilities could hardly engage in that kind of venture because of their mode of mobility. This was tough because apart from losing a source of income, many of the people with mobility disabilities could hardly produce enough food for their families and often went without a meal. A few worked in other people's gardens to either get the money to buy food or be given food in kind.

The direct consequence of insecurity, restricted mobility, lack of devices and limited access to land was lack of food. Most people in the IDP camps survived on WFP handouts; the policy of WFP was to provide 40-60% of nutritional requirements on the assumption that people would be able to supplement food rations with crops they grew. However, people with disabilities were given more rations, in principle 98% of their nutritional requirements. Yet the real amount of food they actually got for meals was reported to be inadequate. In the first place, they shared their rations with other members of the household. Moreover, with hardly any sources of income available, disabled people, like others, often sold the WFP food to the 'food aid black market' in order to support their families by buying basic necessities such as salt, soap, paraffin, renting some more land for gardening, taking the WFP maize to the grinding mill and keeping their children in school. This considerably reduced the amount of food at their disposal for actually feeding their families and exposed them to persistent food insecurity and hunger.

On one of our visits to Akello's home, she informed us that they had done without meals for two days because the WFP handouts had been used up and there was no money to buy food since her husband had spent some days without working because of sickness. She had to send her elder daughter to her paternal aunt to get some millet flour for food.

Another socioeconomic effect of low agricultural production and restricted mobility was loss of linkage between the (rural) IDP camps and the urban areas. Traditionally, the main economic linkage between the rural and urban areas was the buying of agricultural produce by business people in urban areas, from the rural producers. With the lack of marketable products due to lack of meaningful agricultural production, there were limited means through which money could flow to and circulate within the IDP camps. Thus, people in the camps hardly had any ability to buy. The few items that were occasionally marketed were expensive due to the low production and the risks involved in transporting them from the gardens, since they were produced outside the camps. With such low economic dynamism, any activities that people with disabilities or members of their families got involved in could hardly help them earn a reasonable income. Occasionally some people with disabilities marketed foodstuffs, handicrafts and WFP handouts,

but people in IDP camps had limited capacity to buy, rendering commodities sold by people with disabilities marketless.

Inappropriate planning

Despite the rapidly increasing numbers of disabled people in Gulu town, the issue of disability did not seem to be a priority. Many political leaders and programme managers struggled for something to say when asked about it. Disability was not perceived as a 'life threatening' condition, and was considered to be more of a long-term, rehabilitation issue. Politicians and planners gave priority mainly to situations or events that were categorised as emergencies or 'life threatening', such as lack of food, water, shelter, clothing and medical services. In the process, work on routine social and economic aspects of life including the extra needs of people with disabilities, domestic violence, AIDS and other health-related problems and household incomes was generally neglected.

On the WFP food distribution day it was common to see people with mobility disabilities together with another person, in most cases a relative, in the queue for food. Akello was always with her seven-year-old daughter. On that day the young girl had to miss school to assist her mother in getting the food and carrying it home. Those with tricycles and wheelchairs, on the other hand, could be seen with sacks of their WFP handouts on the baggage carriers below their seats, wheeling home. Although even those with crutches, sticks, white canes and other forms of mobility devices had difficulties carrying the food home, at least they could lead the way home to whoever volunteered to carry the food for them.

Some planners and programme implementers, including WFP, perceived disability as a homogeneous condition for all the people affected. Disabled people were lumped together as a group perceived to have 'similar' problems and needs: basically food, shelter and emergency medical supplies. The catchword in the policy documents was 'needs'. More specifically, the Ugandan IDP policy document recognises the necessity of attention to the special needs of certain categories of people that it identifies as the most vulnerable – including widows, older people, children and people with disabilities (Office of the Prime Minister, 2004). Such lumping together of the different categories of disabled people ignores bodily differences and leads to standardised approaches to various activities which in many ways theoretically and practically excludes disabled people. Such an understanding also disregards the aspect of multiple disabilities – loss of limbs and loss of sight, loss of limbs and mental health problems, physical disabilities combined with other chronic conditions such as tuberculosis, HIV/AIDS, diabetes and so on – which require extra attention.

The lumping together of the different categories of people with disabilities as one group made it difficult to focus on the particular problems that affect different categories of people with disabilities and to come up with relevant interventions. From our observations, even disabled people's organisations (DPOs) at both grass-roots and national level tended to downplay or even be unaware of the

diversities that existed among people with disabilities. This has implications not only for how to root out poverty among people with mobility disabilities, but also how specific targeting and planning of interventions involving people with disabilities can be affected. We understand the difficult task of differentiating the various categories of disabilities without accepting some similarities, but at least for the important aspect of reducing poverty, the different forms of mobility needs should be considered as a specific issue.

During violent conflict situations, certain aspects of disability are crucial and should be attended to immediately. Physical mobility is critical for people with disabilities to be able to carry out day-to-day activities including ability to access relief services. Many people with disabilities could not effectively access relief supplies without mobility facilities. Many of those with a visual impairment needed white canes, those who had problems with their limbs needed crutches, wheelchairs, callipers, corsets and so on to be able to access other emergency supplies, and therefore to stay alive. All these could hardly be obtained due to policy inadequacies and poverty, especially in the rural IDP camps.

Lack of mobility devices

In situations of poverty and conflict where services are in short supply, communication technology very poor and traditional social support systems weakened or completely missing, physical mobility is a key determinant and crucial to a person's economic status and survival. In a war situation, people need to be 'physically fit', not only to escape danger (running or walking long distances, taking cover in case of shooting, looking for food and staying in undercover hiding for a long time) but also to live a relatively normal life and to fight poverty in such circumstances. This brings into question the nature of mobility technology in protracted conflict situations and displacement locations, the process of accessing it and how all these impact on the livelihood of people with mobility disabilities.

In Gulu town, and to a lesser extent in the IDP camps, one could easily see someone limping, someone missing a limb, a few moving in wheelchairs, walking using crutches or a stick, using a white cane or being guided by a child. Of the 107 people (66 men, 41 women) we interviewed, less than half (44) had any mobility devices, and out of the 37 who lived in the IDP camps, less than a third (only 10) had mobility devices. This was mainly because most of these people could not buy the devices due to lack of reliable sources of income. A wheelchair cost 250,000 Uganda shillings (approximately US$125) and a tricycle was about US$175, which most people with mobility disabilities could hardly afford.

At the same time, most of the NGOs that could assist them had fled, especially from the rural areas, due to the insecure situation. The orthopaedic workshop in Gulu hospital that was being funded by AVSI[5] was the only one that produced mobility devices in the whole of the northern region. Although the mobility devices had been considerably subsidised by the NGO and were even free in some instances, most people with mobility disabilities in the rural areas could not

afford them because of the additional costs on top of what the NGO contributed. Some could not get transport to reach the NGO office in the urban areas, given the insecurity and their modes of movement. Interestingly, many directly linked poverty to their disability since it was because of their immobility that they had failed to address most of their extra needs, in particular improving their livelihood.

In almost all situations, particularly in the IDP camp, the only way that someone could get mobility equipment was through good social connections. Most people accessed them through contacts to an NGO, a church institution or a relative. Margaret got her wheelchair through connections she had with the priest and three others got theirs when we linked them to the district rehabilitation office, at the time of collecting data for this study. In the IDP camps, it could easily be concluded that there were few people with disabilities because they could hardly be seen in public places or moving around.

Apart from the adverse effect on social relationships, the lack of mobility devices influenced the nature of support people with mobility disabilities could get from the community. Most people found it easier to assist those with mobility devices than those without. People helped those in wheelchairs to pump water, pushed them over hills and helped carry something for someone using crutches. However, it seemed difficult to help someone crawling on the ground or a visually impaired person without a white cane. "People just pass as if they don't see me. Maybe it is because I am just on the ground. But they seem to enjoy pushing the wheelchairs of those who have them" (beggar who moved on all fours).

Closely related to mobility and poverty was the difficulty in getting appropriate clothing. With the different modes of physical mobility it was easy to see that the clothes some people with disabilities were putting on were not meant for them. Many could be seen wearing under or oversized clothes and shoes. These were given to the IDPs by relatives, charity organisations and friends without taking appropriate measurements. In some cases this made mobility more uncomfortable for those with a physical disability and the clothes wore out in a relatively short time. Akello often wore an oversize dress, which seemed to have been given to her. Such donations were nevertheless important in the lives of the disabled people because they were some of the very few alternatives available, and could only be obtained by those who had the appropriate social connections.

One of the categories of people who could not access mobility devices due to extreme poverty was that of the disabled former combatants who had left rebel activities without going through the official channels. They did not go through reception centres and they did not have official amnesty (valid documents) and thus missed the accompanying benefits including medical treatment, financial support and mobility devices from the rehabilitation agencies. Many stayed in the rural areas and were 'hidden' by their families because they did not have the 'appropriate papers' to allow them to freely move around, interact with others and to participate in any activities that could earn them an income. The lack of valid documents also made it difficult for this category of people to be targeted by the intervention agencies since most NGOs feared being labelled collaborators.

The poverty levels among the former fighters became more entrenched because of community attitudes toward them. Partly, people feared that the government would term them 'rebel collaborators' if they associated with such former fighters. More generally, there was perpetual suspicion of whatever they tried to do; most people would not work with them unless they did not know that they were former combatants. Many did not trust them; they feared doing business with them because they looked at them as dangerous people capable of anything. As one former rebel returnee in the suburbs of Gulu town recounted: "I had started a boda-boda [motorcycle taxi] business but when the owner of the motorcycle learned that I am a formerly abducted returnee, he removed it from me."

The undercover returnees were anxious about their future and had low self-esteem; they felt discriminated against, and they seemed to struggle in adjusting from their lives as former combatants to fit into a new civilian setting. Their situation was made more complicated by their inability to disguise themselves as non-combatants since they had an impairment that directly connected them to the rebellion and people often asked how and where they got such disabilities. The stigma and their inability to freely interact with others made it difficult for them to acquire mobility devices and/or mobilise and organise themselves to advocate for their other extra needs. They lacked resources to clear their image, which limited their socioeconomic interaction and further perpetuated their poverty.

Sanitation and reduced personhood

Personhood is about the cultural recognition of an individual's social value and dignity. The combination of disability and poverty impinged on personhood in many ways. Not being able to support oneself and provide for others, not being able to get to social functions easily, and for some, not being able to find or keep a spouse diminished their standing in the eyes of others. One of the most overlooked yet deeply felt sources of humiliation was access to latrine facilities. This intimate and fundamental aspect of everyday life was largely perceived as a private and personal problem.

Sanitation facilities were generally poor in the camps. The small grass thatched huts had hardly a metre between them. Due to the large number of people in one place, there were latrine facilities, rubbish collection points and water sources very close to the homesteads. There were not enough latrine facilities for the number of people. Most were built with mud and wattle and many were either open to the elements or had a roof with inadequate grass covering, and therefore leaked. The latrines typically had a bad stench, flies and a wet surrounding, indicating that most were shallow. They consisted of a simple hole in a dirt floor; most did not have concrete slab floors as is recommended. In many cases they were surrounded by faeces, both inside and outside, because some people, especially children, did not use them properly.

Families of people with disabilities lacked resources to build modified latrines suitable for their disabled members; they could not afford to buy slabs to make

Some latrine facilities in Unyama camp

them more useable, or put up doors and lock them to keep them clean. Some of the latrines were in waterlogged or bushy areas, which were difficult for people with mobility disabilities to reach. People without mobility devices had to move through these contaminated places on their four limbs; others scooted on their buttocks. Sometimes they could not make it by themselves and they had to be physically lifted, especially during the rainy season when most of these places were soaked. Akello's sisters-in-law (the wives of her brother-in-law) physically carried her to the latrine because it was in a waterlogged place. This was in many ways embarrassing and sometimes she had to starve herself to reduce the number of times she had to go to the latrine, or wait for night time when less people would see her being carried:

> 'Sometimes I am like a child because people have to lift me to the latrine and wait for me. Can you imagine? But what can I do? I cannot use any latrine; the specific one I can use – the one with a slab – is in a place which I need help to reach, especially when it rains, because it gets waterlogged.' (Akello)

With no modified seats, accessibility to latrines was very difficult for people with disabilities. Using a latrine, especially those in the camps, needed strong legs that could support someone squatting over a hole for some time. And many of

the amputees or those with weak limbs had to move long distances to look for appropriate latrines they could actually use.

So, the lack of mobility devices and the failure by the authorities to build appropriate latrine facilities left families and individuals with physical disabilties to deal with an everyday need that was experienced as a source of humiliation. Poverty made it impossible for families to provide decent latrines. Ultimately this meant a reduction in personhood: instead of adults who could manage their private needs, disabled people were reduced to a helpless state, who had to be assisted in going to the latrine.

Stigma and aid policy

Poverty, disability, discrimination and stigma are influenced by policies of government, donors and NGOs. Some categories of people with disabilities were affected by poverty more than others, which forced them into stigmatising conditions. This was a result of selective investment in particular target groups, particularly in the urban areas. A few international agencies, government departments and NGOs launched interventions aimed at reducing the effects of the war and improving the conditions of people with disabilities. Although the official policy was to serve everyone who needed extra assistance regardless of the type of disability, the plans, whether intentionally or unintentionally, favoured particular categories of disability, leaving others in extreme poverty.

Most NGOs and government departments supported mainly people with war-related impairments, leaving out those who were impaired due to other causes. In particular polio and leprosy survivors and those with a visual impairment were hardly targeted. Attention was given mainly to those whose impairments were a direct result of the war: landmine, bullet and bomb blast survivors. The risks they confronted as war victims and the challenges of reintegration faced by (officially processed) abducted returnees and former combatants were of considerable concern to the intervention agencies (AVSI, 2004a; Refugee Law Project, 2004: World Vision, Uganda, 2004).

Of all the categories of people with mobility disabilities leprosy survivors were the most affected by stigma, reflected in the avoidance, fear and outright hostility they suffered in the community even if they were cured of the disease. Discrimination was compounded and reinforced by poverty. The activities in which they could engage to earn an income were limited. They were supposed to avoid certain activities and places because they were prone to injuries through burns and wounds. At the same time, because of stigma, they could only do work that did not require them to be in direct contact with other people (repairing shoes, selling charcoal, digging people's gardens and so on), which limited their levels of income. Therefore, it was difficult for them to acquire the devices and medical treatment they needed and they ended up stuck in a poverty cycle.

Forced urban life

Studies in Africa have shown that disabled people are attracted to urban centres because of new livelihood possibilities (Van den Bergh, 1995; Silla, 1998; Whyte and Muyinda, 2007). In the case of northern Uganda, the attraction of towns was reinforced by insecurity in the rural areas. With the destruction of agriculture, which was the main source of income, and because of persistent insecurity in the rural IDP camps, people with disabilities moved to Gulu town for alternative livelihoods and relative safety. Most of those who left their rural homes to stay in Gulu town were men, apart from a few women who were caught up in the urban settings due to the insecure situation and were unable to go back to their villages. Most women were tied to their life in the rural areas mainly because of family obligations of looking after children and/or protecting their marriages. If they went to town and left their partners in the camps, they expected that their husbands would find other women. Most men, on the other hand, had no fear of losing their spouses if they left them in the rural areas; instead, many used this as an opportunity to get some source of income in town to support their families in the rural camps.

Unlike their colleagues in the rural IDP camps, many people with disabilities in urban areas mobilised themselves into organisations to advocate for their needs and to fight poverty by devising ways of improving their lives. In town there was a greater density of people with disabilities, so it was easier to mobilise, and there was easier access to potential sources of aid and support because government offices and donor organisations were located there. All of the informants we talked to in Gulu town, with the exception of the leprosy survivors, were members of disability support organisations through which most of them had acquired mobility devices that facilitated their engagement in income-generating activities and helped them fight poverty. For instance, visually impaired people formed the organisation called Gulu Agriculture and Handicraft for the Blind on their own, without donor support. They staged drama and theatre performances at various locations; these were aimed at encouraging visually impaired people to participate in handicraft making and agriculture activities for improvement of their incomes and life conditions. Another initiative was the formation of the Gulu Disabled Cooperative Society, which specialised in leatherwork, making and repairing shoes and bags. Others, with support from Pact Omega (a US aid-funded NGO), formed the Alokolum Kilombe disabled group in the suburbs of Gulu town and initiated a grinding mill project.

Most of those in the urban settings (more than two thirds of all those interviewed) had mobility devices and they could be seen engaged in various activities: operating sewing machines, petty trade, cleaning vehicles, repairing shoes, making charcoal stoves and small oil lamps and doing casual labour (mainly collecting rubbish in public places such as markets, car parks and along the streets). Thus the poverty levels of people with disabilities in urban settings were lower than those in the rural areas.

Some disabled people, however, were not able to get the necessary social contacts to any source of income in their new urban lives. Poverty and hunger forced them to resort to the much-despised economic activity of begging. Many of them, especially the leprosy survivors and those with visual impairments, could be seen at the Holy Rosary Catholic Church in Gulu town, where the priests gave them some food and small amounts of money on Wednesdays. They also begged on the streets, at entrances of restaurants, banks and shops, and from passers-by. On Fridays they went near the mosque to get alms. Many of them knew that the activity they were involved in was disdained by society but said that they had no alternative because they had no one to help them. In Acholi culture begging is seen as a dehumanising activity and a family's integrity could be seriously undermined if one of their members was a beggar. But in the circumstances, staying in the villages would lead to worse life conditions than being a beggar. One of the beggars on the street in Gulu town preferred life in town to that in the village:

> '… yes, here in town I get something although I hate it and everybody hates it. In the village people are very few and it is hard to get kind people that can donate. Here, although most people seem to hate it, they give you money and they tell you not to go to them again. Shopkeepers sometimes hide away from us, you can see them running away the moment they see us going to their shops, and at times they openly tell us that there is no money, but still we can get something for survival.'

Some of the beggars who had mobility devices used them to attract attention by demonstrating the extent of their disability and levels of poverty. Apio parked her ramshackle wheelchair beside her, with its dry grass cushion, pressure-less tyres tied on the wheels with sisal string and wooden back wheel, to attract the attention of people who might give him money. Omac dismantled his prosthesis and waved it to whoever passed him as a way of asking for money.

However, the relatively better livelihoods in the urban areas were undermined by the severe lack of food due to lack of cultivation in the rural areas that had previously fed people in the towns. The situation was made worse by the lack of relief food provision in urban settings. The WFP relief policy was to provide food only in rural IDP camps, excluding people in urban and semi-urban settings. This was mainly because the towns were perceived as relatively secure compared to the rural IDP camps; urban people were expected to earn some income to buy food and to cater for their other needs on their own. However, in Gulu town, the majority of those with mobility disabilities lived in the 'urban IDP camps'. These were displacement settlements within Gulu town with all the characteristics of an IDP camp, particularly congestion, poor hygiene and lack of livelihood opportunities. Because they were not administratively categorised as 'camps', people did not 'qualify' for relief services, in particular food from the WFP.

The lack of food made life conditions very difficult for people with mobility disabilities in urban areas. They could only get food by having a source of income, which was precarious for many of the leprosy survivors and those with a visual impairment, who often ended up begging. The few who had a source of income spent much of their earnings on food, paying for healthcare, support for their children in school and on household requirements. They hardly had any resources left to meet their other needs, especially maintaining and replacing their mobility devices.

Conclusions

Different people in different situations experience disability differently (Murphy, 1987; French, 1994; Bruun, 1995; Petryna, 2002; Kohrman, 2005). Because of these different experiences, Coleridge (1993, p 28) notes that disability leads to different life pathways, different mindsets, different ways of looking at the world and what life means. One of the ways this manifested itself in northern Uganda was in the form of poverty.

We chose to focus on the relation between poverty and physical mobility among people with disabilities in conflict and post-conflict situations. We did this by examining how people with mobility disabilities are exposed to entrenched poverty through the effects of displacement: inaccessibility of land, lack of basic necessities, forced urban life, lack of mobility devices and poor priority setting by planners and political authorities. We have shown that poverty can be both a cause and a result of physical immobility. Illustrating the relationship between physical mobility and poverty in such circumstances is one of the ways abilities and disabilities of people with disabilities can be analysed, and appropriate interventions developed.

As in the case of Akello, many people with mobility disabilities in the IDP camps were stuck in the mobility–poverty cycle: they were not able to get the mobility devices they needed due to poverty and at the same time they could not engage in any activities to reduce their poverty due to immobility. The lack of resources to acquire mobility devices affected their ability to engage in economic activities and made it difficult for them to advocate for their extra needs. They were often unable to develop their livelihoods because they could not invest in education and in learning appropriate skills.

The effects of poverty were particularly evident in the lives of those left out by the intervention agencies. Most of those whose impairments were not due to the war lacked mobility equipment, did not participate in disability organisations and activities and were not provided with credit facilities to start income-generating activities. The lack of such socioeconomic stimulants forced most of those who were not targeted by intervention agencies to remain in the rural areas, where it was easier for them to be supported by their relatives.

Disability has been given deserved attention in most of the developed countries in the form of favourable policies followed by effective interventions (Ingstad,

1995; Barnes et al, 1999; Stiker, 1999). In the developing countries, on the other hand, it is seen as a problem for tomorrow. Since the promulgation of the 1995 constitution, Uganda has tried to improve the welfare of disabled people through a policy of affirmative action, where the representation of people with disabilities is embedded in national sociopolitical structures at all levels. The aim was to improve the welfare of disabled people through active participation in decision making at various levels. Much as these efforts indicate that improvement of the life conditions of disabled people is one of the national priority areas, unlike in developed countries, lack of adequate resources to deal with the more persistent and seemingly overwhelming problems of HIV/AIDS, conflict and political stability make disability a low priority.

Further, disabled people are seen as a minority group that lack the numbers necessary to have a broader political impact beyond choosing their own representative in an election, so politicians, planners and implementers pay negligible attention to their condition. Because of their condition, many are not educated and therefore not employed. They lack the financial and organisational ability to bring pressure for an effective response to their condition, which further perpetuates their poverty.

In general it is difficult to draw a line between poverty and emergency conditions in conflict situations. Poverty and disability should therefore be looked at in terms of balancing relief and rehabilitation concerns in the short term, and development (reducing poverty) in the long term. Focusing on mobility is important because it facilitates specific attention to people with various levels of mobility disabilities and helps avoid lumping them together, which makes it easy to target specific cases with the necessary interventions. Examining the various aspects of mobility also creates a linkage between the objectives of the emergency relief programmes in the short run and the long-term plans aimed at sustainable development and reducing poverty. We have shown that it is easier for a person with mobility devices to benefit from the emergency programmes, which are usually the basis for participating in the long-term development activities.

Therefore, examining how poverty in violent conflict situations makes people with disabilities unable to acquire the necessary mobility devices is central in informing policy on disability. It is important to re-emphasise that provision of mobility devices to those who need them in violent conflict situations should be treated as an emergency, to reduce the short-term effects of immobility and to set a basis for long-term developmental programmes including poverty alleviation among the affected individuals. Focusing on mobility can help restore or strengthen not only 'physical fitness', but also the socioeconomic interaction and regard for the personhood of people with mobility disabilities in violent conflict situations.

Notes

[1] The Acholi are situated in the four districts of Gulu, Kitgum, Pader and Amuru, east of the Nile, in northern Uganda, with an estimated population of 1.5 million (Uganda Population and Housing Census Report, 2002).

[2] There has been a distinction made between IDPs and refugees. IDPs are those who have been forced to flee their homes as a result of war, natural or man-made disaster or generalised violence, who do not cross an internationally recognised border but remain in their country of origin. Refugees, on the other hand, are those who leave their homes for the same reason, but cross the border and enter another country (United Nations, 1999). Differentiating between the two terms is important because each of the terms define certain identities and entitlements.

[3] The government of Uganda has always argued that the reason for establishing IDP camps since 1996 was to provide security to the civilians. Most people in the camps felt, however, that they were being inadequately protected and there was a very high sense of insecurity in the camps. Some camps were attacked and people were abducted by rebels (Refugee Law Project, 2004, pp 29-30; Finnstrom, 2005, pp 110-11; Allen, 2006, p 54).

[4] Generally, poverty in Uganda (including the northern region) is defined as the 'lack of basic necessities and services such as food, clothing, beddings, shelter, basic health care, roads, markets, education, information and communication' (UBOS, 2001).

[5] An Italian organisation that has been doing disability work in northern Uganda since 2000.

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Where culture really matters: disability and well-being in Yemen

Benedicte Ingstad, Arwa Baider and Lisbet Grut

Introduction

Since the early 1970s so-called 'disability studies' has been a growing field of interest in anthropology. There are several reasons for this. First, a focus on the disabled body links up to themes of interest in mainstream anthropology such as 'the body', 'normality and deviance', 'stigma' etc. Second, it has to do with the medically or mentally *impaired* body, and as such, with the growing field of medical anthropology as a sub-discipline. Third, a group of scholars have recently come together and made an interesting anthology on the fruitful use of Foucault's theoretical perspective on the topic of disability (Tremain, 2005). This brings it right into the mainstream of professional interest. And finally, 'disability studies' links up to traditions of activism by groups of disadvantaged people that – especially in the USA – has had a major influence on the field of anthropology.

Lately, in the field of disability studies and activism there has been a strong move towards substituting a *medical model* – with a focus on impairment and its consequences – with a *social model* – focusing on the *disabling environment*. The concept of 'disabling environment' implies an emphasis on how structural, sociocultural and physical conditions constrain people and make it difficult for them to function to the extent that is considered 'normal' in a given society. This change of focus – from the individual body to the surrounding society – links up to recent interests in mainstream and medical anthropology in *social suffering* and *structural violence* (Farmer, 1999, 2003; Kleinman, 2000; Daas, 2006). This also links to applied perspectives in anthropology such as community development, empowerment of disadvantaged groups and so on.

In academic writing about people with disabilities in poor countries it has often been claimed, by academics as well as aid workers, that these people are hidden, neglected and sometimes even killed by their families, and that such behaviour has to do with 'attitudes' and 'culture' (Helander, 1993). Ingstad has, however, on several occasions and through research argued for the fact that 'attitudes' towards people with disabilities is as much – and often more – the result of social circumstances of which poverty is an important factor. She has also demonstrated that circumstances which, seen from the outside, may look like hiding and neglect most often may

be explained by the life situation of the family who are responsible for the care of the child/person with a disability (Ingstad, 1991; Ingstad and Whyte, 1995, 2007).

The study from Yemen, on which this chapter is based, shows a situation in which culture does make a real difference – the difference in the life situation of poor disabled women and men.

Methodology

This chapter is based on a multi-country study on 'disability and poverty' which so far includes two countries[1] – Kenya and Yemen[2] (Grut and Ingstad, 2006, 2007). This chapter concentrates on the data from Yemen, mainly qualitative interviews with 35 individuals and one group interview with young physically disabled girls in an orphanage.[3] The interviews were conducted in a variety of different sites, all from poverty-stricken areas, rural as well as urban. The interviews followed a checklist of key words, but were flexible to the extent that the person being interviewed was free to take the lead in the conversation. The informants were primarily people with disabilities, but they were substituted by close kin if the person with a disability was too young or too impaired to speak for him/herself. The interview sessions were of one to two hours' duration, and were conducted by two teams consisting of one researcher, together with one local counterpart. The two counterparts served both as translator(s) and partner(s) for discussion of the findings.[4] One of them is a co-author of this chapter.

Disability and poverty: a theoretical approach

Several academics have pointed out that disability and poverty are linked together in a 'vicious circle' (Yeo, 2001; Yeo and Moore, 2003; Grut and Ingstad, 2006, 2007). Disability creates – or contributes to – poverty by people with disabilities not being able to get an education, to participate in the labour market and so on. Similarly, poverty increases the risk of becoming disabled through malnutrition in pregnancy, increased exposure to hazardous work situations, unavailability of health services, lack of money to buy medicines etc. In a clinically controlled study from Haiti it was shown that of those tuberculosis patients who received free medicine, home-based follow-up, food and vitamin supplements plus money to cover travel expenses, as much as 100% of all patients were cured. However, in the group receiving free medicine only, the recovery rate was barely half that of the other group (Farmer, 2003, pp 149-50). Thus we see that compliance to a treatment regime, or rehabilitation, is not only a question of availability but also about ability to – or a barrier against – utilising it. For instance, the availability of a clinic for delivery is not enough if a woman in difficult labour does not have the means of transport or money to pay for it.

Kleinman (2000) talks about 'the violence of everyday life', and this is precisely what is present in the link between disability and poverty. The violence is structural and comes from the individual's surroundings, from the local community, state

legislation and even the international policies and economic forces that contribute to creating wealth in some places, and for some people, and poverty for others. This leads to suffering that is not primarily linked to impairments and individual shortcomings, but that is *social* in its character and generated by forces outside the individual. While all people in a community may be victims of such suffering, people with disabilities are hit the hardest, because of their problems in reaching even the small resources that are available, and having to turn to unsatisfactory – even degrading – solutions to survive. For instance, in Ghana, Dennis found that a significant number of children who work on the streets in the city of Tamale were supporting disabled adults at home (Dennis, 1997, quoted in Yeo and Moore, 2003).

Structural violence – or barriers – is also to be found in the environment, in the houses that are constructed that are inaccessible to wheelchair users, elevators without Braille writing, or schools without facilities for children with hearing difficulties. It is also to be found in the constraints given by nature – sand that is too deep for wheelchairs, mountains that are too steep to climb for a person with an impairment to get to the field etc. Such natural barriers do not represent structural violence in themselves, but become so when nothing is done to overcome them and to give people with disability equal opportunities (or alternatives) to participation.

Farmer (2003) argues that if problems are caused by structural violence, then the solutions also have to be structural and sustainable. Our task as (critical) medical anthropologists is to identify the structural forces as well as the social and cultural barriers that create and sustain 'the evil circle of disability and poverty'. This brings us to a revival of Fredrik Barth's (1960) 'generative model' from the early 1960s, which seems like a suitable analytic tool for this purpose. Barth looks at *social forms.* These are the aggregated results of people's choices, made under specific constraints and possibilities in a given situation. The issue in the model is to understand how social forms are generated by identifying the constraints and possibilities under which choices are made.

Such a perspective brings anthropology and disability activism close to each other. The new emphasis on a 'social model' focusing on barriers to integration and participation – instead of a definition of disability based on individual shortcomings (impairment) – in many ways resembles a generative model put into practice.

"This is my life": barriers to integration in Yemen

Background

The Republic of Yemen was established with the merging of former North and South Yemen in 1990. Previously South Yemen was a socialist country. Yemen is located on the tip of the Arabian Peninsula, bordering on Oman to the East, Saudi Arabia to the North and surrounded by the Gulf of Aden to the South and the Red Sea to the West. The ocean route across to Somalia on the Horn

of Africa is short, and the influx of boat refugees is an increasing social problem. The language spoken is Arabic and the religion is Islam, but there are also small communities of Jewish people.

The main income comes from agriculture. Small farms in terraces cling to the steep mountainsides, requiring hand-held tools, harvesting by hand and carrying products on people's backs. In the fertile bottoms of the valleys more advanced machinery may be used, but this is often limited by lack of money to buy them. The main agricultural products are grain, vegetables and fruit. The climate is warm, and while the temperature is bearable on the mountain plateaus at about 2,000m, it becomes desert-like and very hot towards the South. Other ways of getting an income are fishing and small industries. Yemen is facing rapid urbanisation and a growing economy, but is still rated as the poorest country in the Arab world. The United Nations Development Programme (UNDP) *World Development Report* ranks Yemen as 151 out of 177 countries in the world (UNDP, 2005).

Islam is practised strictly according to the Qur'an, and religion plays a large part in most people's lives. This had an implication for gender roles and relationships. Women, for the most part, are completely covered in foot-long black cloaks and black veils that cover everything but the eyes. Such a way of dressing is said to be voluntary, and some younger women are seen with only a headscarf above their long dress, which may also come in other colours than black. The extended family is the centre of social life. Girls live in their father's house until they marry – most often with their cousin or another close relative – after which they move to the husband's family's home, often to live in the same house as his parents, married brothers and unmarried siblings. For the well-off families this necessitates building very large mansions; for the poorer families it often leads to very crowded quarters. For a nuclear family to live on their own may be a sign of poverty, of having had to move out because of lack of space. The man is the head of the household, and women are not supposed to travel or walk the streets alone without being escorted by one of the male family members – even a young boy may do. If a woman breaks the rules of behaviour or clothing it may be seen as bringing a great shame on the family, and thus damaging the family's honour. Women and men occupy separate spaces within the home (if big enough), celebrate weddings and other festive occasions separately, and in some restaurants there are even separate rooms for men and women. Thus men and women move in separate spheres: the women's sphere is one of public seclusion and close individual relations, and unveiled companionship only with other women and at home. The men's sphere is the public arena, with an emphasis on strength and manliness. Ideally, during his lifetime a man should not see the face of any other women than his mother, his sisters, his wife (or wives) and nieces, and a woman should only see the men with whom she is prohibited from marrying (father, brothers, nephews).

Gender and disability

Against this background of religiously prescribed gender segregation, it is interesting to see how this cultural trait, which permeates all areas of life, influences the lives of people with disabilities. Consider the difference between these two cases:

> A young woman, dependent on a wheelchair because of polio in her youth, lives in a very small house with her parents and two adult siblings who are also disabled. She has no particular assignments outside the household and claims that she only gets out twice a year when her brother takes her to festivals. When asked why she does not go to the day care centre for disabled people like her sister, who is able to walk, we are told that the road conditions are too rough for the wheelchair and the bus stop too far away to carry her, and that her father and brother do not want to get up early enough to take her there.

> A young man has quite severe cerebral palsy which affects his arms, legs and to some extent his speech, but not his ability to understand and communicate. The family has arranged to have three beds for him – one in the living room where he can spend time in the family as well as sleep at night, one in the yard outside the house so he can be with them when they work or just sit outside, and one outside the fence were he can communicate with neighbours and passers-by.

It would be wrong from this to deduct that the woman is 'hidden' in the house. Obviously her existence is known by neighbours and relatives outside the immediate household. The same is the case with her more mobile sister who gets to go to the day care centre. Thus 'hiding' as such is not an issue. However, the custom of gender segregation combined with the constraints of the physical surroundings and a somewhat unconcerned father makes her situation far worse than that of the man with a much more extensive impairment.

Another cultural trait that is important for the lives of people with disabilities is the strong emphasis on beauty and bodily fitness for both men and women. Thus an impairment which affects the beauty and working ability of a woman is seen as an impediment to marriage. Similarly, men with an impairment may risk being considered 'less manly'. Two men, one blind and one a wheelchair user who had moved to a city, stated that they preferred not to go to their home village because there they were treated as inferior by other men. This was in spite of the fact that the man in the wheelchair had succeeded in getting an academic degree.

It was striking among our informants that several of the men were married, and the others hoped to get married, while the women did not even consider the possibility of marrying. When we asked about marriage in the group interview with physically impaired young women, it created spontaneous laughter and they

said that this was something they had not considered as a possibility at all. Another young woman, in a wheelchair as a result of polio, said jokingly that she would marry if she found a rich man who could afford to keep a maid. A young man, also a polio victim, had proposed to her father to marry her. She had refused, however, and said: "He is even more disabled than I am and does not have a job. What would we live on? It is not enough just to like each other."

Divorce is relatively easy to obtain in Yemen for both men and women, provided the bride price dowry is returned to the man's family. Separated women usually move back to their father's household. We did, however, encounter a few examples of divorced women staying alone with a disabled child, if possible with the help of a younger sister or older sibling, on the grounds that she was afraid her family would not accept the disabled child. The group interview with young girls in the orphanage showed that many of them came from broken homes. Thus in a situation of divorce the disabled child, and in particular the girls, seem to be vulnerable, especially if the mother remarries. As said by one girl in the orphanage: "First I was kicked out by my father, then by my mother and then told to go to my grandmother." She felt unwanted by her family and preferred to live in an institution with her disabled friends.

To acquire a disability as an adult is especially painful for a woman who thereafter is no longer able to fulfil her duties as a woman and as a housewife.

> Khort is a woman in her fifties. She is married as a second wife and has 10 children. They live in a poor area that was rebuilt some years back after an earthquake disaster. The husband operates a small grain mill from home that they live from. About a year before we met her she had been run over by a truck, and had one leg amputated at the hip after numerous infections and hospitalisations. She was now sitting in a wheelchair. She has not tried to use crutches (which has got) or tried to get a prosthesis for walking. She spends her day-time in the family's common room which has big windows, and her duties have been taken over by a daughter who is consequently not likely to get married. Khort is very depressed and cries a lot. She says that her heart has died, meaning that she is not interested in anything, and that she only wants to die. She feels useless, her husband has lost all interest and concern for her, and the first wife resents that she is occupying the common room as much as she does these days. Khort has a sewing machine but says she only knows how to mend clothes. Although some training in sewing might have made life more meaningful for her, and contributed to the family income, there is no way they would be able to send her to the training centre in Sana'a.

We see that although Khort's household duties are taken care of and she still has small children who depend on her love, it is not enough for her to feel accepted and worthy as a woman. The fact that she feels that her husband has rejected her because of her damaged body, and the co-wife is unsupportive, is an added pain to the physical phantom pains she has to live with daily.

Disability in the household

The occurrence of a disability tends to make a poor household even more crowded than it would normally have been. The reasons for this are that a disabled girl does not marry but remains in her parents', and later her eldest brother's, household for the rest of her life. In addition, such families often keep another non-disabled sibling from marrying in order to stay at home to take care of a disabled brother or sister, and if the brother eventually marries it is usually too late for the sister to have any 'value' on the marriage market:

> A family has three disabled boys suffering from muscular dystrophy and gradually getting worse. One son with a similar condition died some years back because he was not able to move fast enough away from a lorry and was run over. The father is weak from a heart condition and diabetes. The mother is the only one with an income from selling quat. The three boys get 1,000 YER [about US$5] a month in social support. A non-disabled young daughter is taking care of the whole family and doing all the housework. She went to school for five years but has had to quit. The father says there is no possibility for her to marry because she has to remain home and take care of all of them.

> Amin is 14 years old, hyperactive and may be intellectually impaired. He is totally dependent on his daily rituals. Life has to be very regular, otherwise he becomes aggressive. The whole family is involved in caring for Amin. To keep him calm, the father comes home in the lunch break every day and takes him for a ride on his motorcycle. The same procedure is repeated every afternoon. His mother and the elder sister have the main responsibility for him during the day. Amin needs help to dress, wash himself, and eat. The two younger sisters take their turn as well. Amin's aunt comes every now and then to take him for a walk so that the family can get some rest. He receives no medication for his hyperactivity.

It is useful to analyse the situation of the household with a disabled member in Yemen from the perspective of the 'disabled household' (Ingstad, 1997). When an impairment occurs in a family, whether from birth or by accident later in life, the family has to reorganise their resources of labour, time and capital in order to meet the new needs. Thus in this way we may also say that the family becomes disabled, and therefore rehabilitation of the disabled individual should also be concerned with the family unit. In some cases, the best help a 'disabled family' may get could be for a non-disabled household member to get a job. There seems to be a tendency for non-disabled sons in such families to leave school early to get a job in order to contribute to the family's income. We see from the case above how poor Yemeni families with no money to hire help have few other ways of meeting the demands on their time and working capacity but to keep adult daughters from continuing school and/or getting married and involve them as lifetime caretakers for disabled family members.

We also met people with disabilities who did not live in large family households. In these cases breakdown or physical distance to the supportive family network was part of the reason for living in poverty. The forced return of Yemeni families from Gulf countries after the first Gulf war was one example. Some of these families had only weak family networks remaining in Yemen, and with a person with a disability to care for it was easy for them to end up alone. In other cases families choose to live alone for various reasons. In one case a blind man chose to live in a small town with his wife and children because he had been to school for the blind there and had friends. They lived under poor conditions, in a very small rented house. Neither he nor his wife had a job, but they did get some support from his family in the village. This was the same man who felt that he was seen as inferior by other men when returning to his home village. In another case an elderly woman, bound to a wheelchair, lived alone with a son in the poor areas of Sana'a. The son was married but his wife refused to come to the city. It seemed that the old lady spent the day begging, an activity which could only be profitable in the city, and probably the main reason why they were there.

Religion and the meaning of disability

Religious activities in Yemen organise the day into five prayer times and give meaning to everything that happens in life – such as having a disabled child or becoming disabled oneself. People strongly believe that everything that happens to them or their loved ones comes from God, that he will help them and give them the strength to cope with any problem, and that they will be rewarded for being patient with what they got. The Qur'an has a verse that says 'great and good things will happen to enduring people'.

Disabled people are considered to be vulnerable, and looking after them and being kind to them is a religious duty which people will also be rewarded for. There is a story in the Qur'an about a blind man who called on the Prophet, but the Prophet was busy and did not give him much attention. The blind man went away unhappy, and that made God angry. There is also a saying that 'one is blind when his heart is blind, not his eyes'. We saw many examples of how religion played a role in giving meaning to a life with a disability/disabled child:

A family that already had a girl with a visual impairment one day found an abandoned newborn baby on their doorstep. They took the child in and kept it as their own. The fact that the child had hydrocephalus, cerebral palsy and eventually became intellectually impaired (because they could not afford an operation) made no difference. According to the father: "God gave this responsibility to us, we have never even thought about not taking him into our family. God put mercy in our hearts."

While this seemed to be the most prevalent attitude within families with disabled members there was, however, as in many areas of life, often a gap between learning and practice, especially when it came to people outside the family. It was said to

be common occurrence for people with disabilities to be teased and even have thrown stones at them. Several parents therefore chose to keep their disabled children at home and away from school. One mother had complained to one of the teachers, but was told that "they are just children and nothing can be done about it."

> Amar, 17 years old and deaf, finds it very painful when other people express negative attitudes towards him and his deaf friends when they use sign language on the street. He can feel people staring at them, and that makes him angry. He is looking for a job, but no one wants to hire him because of his communication problems.

Fear of ridicule or mistreatment may also keep disabled individuals and their families from seeking help from family members outside the immediate family. Such is the case of a teenage girl who is deaf in one ear, and her divorced mother. They live under very poor conditions, but the mother is afraid of moving back to her own family because she thinks they may mistreat the child. Other parents kept their disabled children from meeting strangers in order to protect them from negative reactions. The girls in the orphanage preferred to spend most of the day inside the house because strangers would call them names and shout at them in the streets.

  Adults may also prefer to spend most of the time at home because of their disability:

> Nasser lives in the city. He is blind due to measles as a child. He tells us that children call him names when he goes out, but he does not care even if it hurts his feelings. He says to them 'May God forgive you.' He goes to the shop and to the mosque to pray and he communicates with neighbours and knows them all, but most of the time he does not go out because of epileptic fits, for which he has no medication.

In some respects it seems that the village life, in close-knit communities where everybody knows each other, may be easier for a person with a disability then life in the city. But on the other hand, if villagers reject them and discriminate against them, life in the village becomes very hard.

Employment

The majority of the people in Yemen live in villages that are scattered around the mountains. Village life is based on employment in the agricultural sector that produces both cash crops such as quat and crops for home consumption. Some families have their own piece of farmland; poorer families are employed by others and sometimes paid only in kind. In rugged terrain farming is obviously almost impossible for people with a physical impairment and the only place they can make themselves useful – if at all – is around the house.

Self-employment based on special skills is another option. Some centres for people with disabilities give training in special skills such as sewing, basket making, leatherwork etc. But this requires a market to be profitable and capital to get started on their own. The market is rarely sufficient in rural areas, thus this requires a move to the town or city, and micro-finance or similar loans are hard to obtain for people with disabilities:

> Aisha had the opportunity to learn basket work at a training centre. During the three-year training period she could sell her products at the school's shop. When she finished school she was shut out from this opportunity. She had no resources to start a business of her own and is now back to the same situation she faced before the training. She is totally dependent on her parents again, a situation that increases her feeling of being useless.

But even a small capital may make a lot of difference:

> In Sana'a we met two young brothers, both impaired by polio, one using crutches, the other a wheelchair. One brother was going to school, and one was running a small business selling matches, cigarettes, sweets and soft drinks from a basement window in their home. They had inherited a small house in the poorer parts of Sana'a when their father died, thus they have no rent to pay, and live there with their mother, unmarried sisters and the wife and children of the eldest brother. Their economy is very marginal, but they hope for better days when the younger brother finishes school. He has a friend in a wheelchair who works in a factory, and hopes to get a similar job himself.

We learn from this example that (self)employment is difficult but not impossible for people with physical impairments in Yemen, especially men. There are some employers who are willing to take them on if they can perform the necessary tasks, and even a small capital opens up opportunities to be self-employed.

Education

Basic education is not yet compulsory in Yemen, but there is a major effort going on to increase the enrolment rate. Girls go to school, but at a lower rate and for fewer years than boys. Not every village has a school and many children have to walk long distances in rugged and hilly terrain to get to one. This of course makes it difficult for children with disabilities to attend if they are not able to get there on their own. Transport facilities exist in some places, but these cost money, and if poor people can afford it at all they are likely to make priorities among their children – with non-disabled boys most likely to come first.

Training of teachers in special education is still at an early stage in Yemen, and ordinary schools rarely have staff who are able to give extra help to children with hearing, visual or intellectual impairments. Parents tend to be aware of this and see little point in spending money on transport and uniforms if it is considered to be of no use. Facilities for special education tend to be found in cities, and

many parents are hesitant to send their children off on their own. In some cases they choose to move the whole family:

> A father who used to work as a carpenter in the city passed from time to time a centre for children without disabilities without giving it further thought. As it happened, some of his sons developed a muscular disease, and he remembered this centre. He realised that the only possibility for his children to get an education was for the whole family to leave the village and move to the city. In this way the boys could get day care and schooling at the centre and at the same time be taken care of within the family.

Although it seems that the parents are particularly worried about the education of their disabled boys, the fact that disabled girls are not considered likely to be married gives them a chance of education that they probably would not have had if they were not disabled. Some caring fathers of disabled girls paid particular attention to the education of their disabled daughters on the grounds that they should have a different chance in life, and be able to develop their intellectual skills.

Gender issues may also become relevant in other ways. A 15-year-old boy, Mahmud, with an intellectual impairment, was brought by his mother to a centre that teaches illiterate adults. But after a short while the female teacher refused to teach him on the grounds that she did not teach male students. The mother was very sad about this because he was beginning to learn for the first time in his life: "He is a child inside and a man on the outside" she argued.

Healthcare and rehabilitation services

In most rural areas people do not have access to healthcare and schools, and since transport costs money, these services are in any case inaccessible for the poor. Consequently disability-causing conditions, such as difficult child labour and severe infections, are, to a large extent, dealt with outside the professional healthcare system. Yemen has had one of the worst epidemics of polio worldwide, with around 485 cases in 2005-06. The epidemic has been stopped now and there have been no more new cases of polio for more than a year (WHO, 2004, 2006). There is a widespread rumour that the vaccination shot in itself causes the disease, thus making parents hesitant to accept such services.

Similarly, existing possibilities for (minor) economic support for disabled people[5] can only be applied for at an office in Sana'a and is thus unavailable for many poor people in remote areas.

> A father of six small children used to work in a stone quarry and used to be a respected man in the village. Probably due to this hard work he suffered from thrombosis in both legs with amputation as a result. Similar symptoms have started to develop in his hands as well. As a result of the amputation he has phantom pains and is not able to move around anymore. He has no assistive devices such as crutches or wheelchair. The family

> has no income and survives on charity from villagers. He knows about the possibility to get financial support, but no one is willing to take him the long way to Sana'a to apply for the grant.

To apply for financial support people have to go to the office in Sana'a, fill out a form (which of course requires writing skills) and get the necessary signatures. They have to appear at the office several times during the application process, which may take up to two years. This means long and costly travel for poor people in remote areas:

> A father in a village outside the town of Dhamar had been striving to raise money to pay for hospital treatment for one of his sons. He worked for three years to get the application through. Finally he got a reply that he had to wait until the boy got older. He has given up the application process because it is too demanding.

We see from this example that although there are possibilities for (very limited) social support for people with disabilities, the process for obtaining it disfavours the ones who need it most – poor people who are often illiterate and without the means to pay repeatedly for transport to get to the right office(s).

Environment

A rugged and hilly environment, like that to be found in (parts of) Yemen, does, as we have already seen, in itself represent an obstacle for people with disabilities, especially those who are physically impaired or even blind. However, the environment as such only becomes part of a picture of 'structural violence' when nothing is done to overcome it for people with physical limitations. When nothing is done to make buildings accessible, when transport to school or education close to home is not provided for, thus leaving disabled children and adults disadvantaged compared to others, when alternative income opportunities to agriculture on steep hills does not exist, then we may talk about 'social suffering'.

Conclusions

The 'evil circle of poverty and disability' is in many ways confirmed in this study from Yemen. Poverty gives people less access to healthcare and preventive measures, education (knowledge) and money to buy nutritious food and medicines. Thus poor people are more at risk than others to develop impairments. Similarly, education, social services and employment are less accessible to a disabled person in Yemen than those who have full use of their limbs, senses and intellectual ability. In addition to this, the gender issues of segregation and male dominance play an important role in making girls/women with an impairment more disadvantaged in many ways than boys/men. Poor girls with a disability, even more than other girls, are stuck in a traditional family pattern. There is, however, an exception to this, in that the presence of an impairment and thus few chances of getting married

may give the girl a chance of being educated if she has a caring and 'enlightened' father. Economy is a critical factor here, thus girls from poor families are very unlikely to get such a chance, unless they are lucky and find a sponsor.

Speaking in terms of Barth's generative model, we may say that we have in this study identified some important factors that generate the 'social form' of inequality and lack of integration for poor people with disability in Yemen. The constraints under which people make their choices are those of poverty in general, but made worse by limitations in the ability to utilise natural resources, or obtain the services of healthcare, education and social security. The options they have are those provided for by a (more or less) caring family, non-governmental organisations (NGOs) providing for special education and skills training – and in some cases the luck of finding a sponsor.

The life situations faced by many of the poor people we interviewed in Yemen demonstrates what Kleinman (2000) called 'the violence of everyday life' creating a situation of 'social suffering' (Farmer, 1999, 2003). These concepts are useful in that they remind us of the fact that discrimination and lack of integration is not so much a question of personal shortcomings or bad will, but a result of political, social and cultural constraint imposed on the suffering individual. Thus when a poor 'disabled family' is not providing the optimal opportunities for their disabled family member, it is not so much because they do not want to, but because they are not *able* to and/or have not been given the necessary information and options. In Yemen, however, we have seen that cultural factors, especially religion and its impact on gender segregation, play a strong role in making the life situation for disabled women and men very different from each other. While the culturally constructed role of men allows for participation in social life, work and even marriage and fatherhood, the traditional role of women adds an extra constraint to the life of those who have a disability and may easily leave them isolated, unemployed and unmarried. Thus Yemen differs strongly from several other studies in which it has been shown that 'culture' and 'traditional beliefs' play a fairly minor role in determining the life situation of people with disabilities compared to the influence of social and political factors (Ingstad and Whyte, 1995).

Turning to the 'social' and 'rights-based' model of the disability activist, we can clearly see how this may feed from the analytical approaches indicated above. A generative analysis may help identify the barriers to integration that need to be overcome in order for the rights of people with disabilities to be fulfilled. There are, however, aspects of 'equal rights' to be considered. One is that of comparing the life situation of people with disabilities with that of people without disabilities. Another is the more difficult issue of achieving equal rights for disabled girls/women and disabled boys/men. In Yemen this is probably a very slow process since it is linked to the religious and cultural values that generate the situation of Yemenite women and men in general. Equality in the Western sense of the word may, at least for the time being, have to be replaced by a more culturally appropriate way of thinking of equality within the separate gendered spheres of life.

Notes

[1] We are in the process of applying for funding for similar studies in South Africa, India and China.

[2] Two studies on 'disability and poverty' were carried out in 2006 by Grut and Ingstad in Yemen and Kenya, commissioned by the World Bank (Grut and Ingstad, 2006, 2007).

[3] They were in their teens and early twenties. They were all physically impaired, but not all were true orphans. Some had been abandoned and some had just left home.

[4] We thus made two teams consisting of one Norwegian and one Yemenite. After each day we would change partners. The Norwegians are both female, one anthropologist (BI) and one qualitatively oriented sociologist (LG). Our counterparts, Dr Arwa Bader and Dr Mahdi Nasser, are both medical doctors. Arwa is a pediatrician. We thank both of them for having contributed to this study. The responsibility for the content of this chapter rests solely on us as the authors, however.

[5] The Social Welfare Fund and The Disability Foundation Fund.

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Disability and barriers in Kenya

Lisbet Grut, Joyce Olenja and Benedicte Ingstad

People with impairments encounter many barriers in their daily life. In this chapter we describe the variety of barriers and see how the collected sum of many barriers influence access to what is considered essential and indispensable for all humans: healthcare services and education. We illuminate some of the mechanisms that create and maintain a difficult life in a resource-poor context by describing the particular challenges people living in poverty with disabilities encounter. We also describe some of the given options of coping with these challenges. We argue that a family perspective should direct actions that are implemented in order to reduce barriers as well as to develop coping strategies.

Interrelationship between poverty and disability: a double exclusion

People with functional impairments are often disabled not so much because of their impairment, but because of being denied access to education, labour markets and public services. This exclusion leads to poverty and in a vicious circle, poverty can lead to more disability by making people more vulnerable to malnutrition, disease and unsafe living and working conditions (Elwan, 1999; Yeo and Moore, 2003). The situation of disabled people living in poverty can be understood as a double exclusion as they are hindered in social and political participation and the opportunity to develop abilities because of poverty, which is a situation that is worsened due to the impairment.

The understanding of both disability and poverty has undergone changes during the last decades. Poverty is a complex and multidimensional phenomenon, covering a range of aspects such as income, education, health, social and political participation, environmental quality, security and freedom, as well as social justice and human rights (Eide and Loeb, 2004; Wolfensohn and Bourguignon, 2004). This has led to increased interest in micro-level decisions and instruments and measures intended to improve poor people's access to food, shelter, education and healthcare. Focus has been directed both towards improving service delivery to poor people and to ensuring increased influence on important decisions affecting their lives (World Bank, 2000). Health, education and work are decisive factors in this respect and considered fundamental human rights (UNESCO, 2006).

Disability, similarly, places its focus on participation and activity, thus expressing disability as a complex process involving a number of different elements at

individual and societal level (Grönvik, 2007). Disability arises when the individual's ability to do daily activities, to participate in local and communal activities and to carry out social roles that are considered normal or common by the individual and the community is limited or hindered because environmental barriers do not take into consideration the individual's bodily, sensory, mental and/or intellectually reduced functional ability.

Living conditions among disabled people in high-income countries are low compared with non-disabled people, (Hem and Eide, 1998), and a similar pattern seems to be the case in low-income countries (Eide et al, 2003; Loeb and Eide, 2004). There is, however, scant information on the dynamics of how the presence of impairment combined with poverty affects the daily life of the individual in a resource-poor setting. And there is scant information on individual coping strategies. However, there is sufficient knowledge to conclude that people with disabilities are at risk of being and remaining among the poorest. Among the most prevailing exclusion mechanisms are illiteracy or low education (O'Connor, 2006; Jandhyala, 2007, Wedgwood, 2007); low priority for access to limited resources such as food, health services, clean water and land; unemployment and limited social contacts; lack of support for high costs associated with the impairment; and exclusion from political and legal processes (Yeo, 2005). In addition to lack of money, which is only one of many barriers for access to services, limited awareness about available services and bureaucratic obstacles are significant barriers (Saloojee et al, 2007).

The exclusion is not necessarily intentional. As we show in this chapter, exclusion easily happens when people's different functional abilities are not taken into consideration when developing services that are intended to be accessible for everyone. Lessons learned from this study are to recognise that people's functioning level varies significantly. It is necessary to account for individual functional differences when designing programmes and services that are meant to promote economic and social well-being for all. In resource-poor settings it is important to focus on the situation for the whole family group.

Methodology and empirical basis for the study

The empirical basis for the study draws on fieldwork in Kenya conducted during two weeks in 2005 and in 2006 (Grut and Ingstad, 2006). The work was commissioned by the World Bank as part of a larger effort to focus on the intertwined relationship between disability and poverty. The focus was to gain a deeper understanding of people's daily lives and the challenges and coping mechanisms in place. Given the focus of the study, a qualitative approach with visiting local settings and carrying out semi-structured interviews was selected as the most appropriate methodology.

The informants and the sites visited were chosen for their diversity, representing a variety of ethnic groups and ecological zones as well as covering the urban–rural dimension. The idea was to capture a variety of causes of disability and poverty

in its different manifestations. We had to choose accessible places and at the same time obtain as complete data as possible. To meet the requests of adequate samples, we chose populated and also multicultural areas.

The sample comprised different types of impairments: bodily, visual, hearing and intellectual. The principle of variety also concerned congenital and acquired impairments, and impairments due to accidents and disease. The sample comprised a variety of ages: parents of children (newborn to youth), adults from 18 up to older people. The preferred place for the interviews was the informant's home, as this represented an opportunity to focus on the total situation of the person and the viability of the household. In all, 91 interviews were conducted during the two field visits.

The sample was strategically chosen among people who represented a wide variety of life situations (Miles and Huberman, 1994; Kvale, 1996). Our pre-conception of the challenging relationship between disability and poverty led us to seek the poorest areas, whether this was the city slums or poor, remote, rural areas. While urban poverty in Kenya may be of the extreme kind, rural poverty is sometimes met by having a small plot with vegetables for a family's own consumption and perhaps a goat and a few chickens. Proximity to relatives and established networks ensure that there are some coping mechanism at hand if a crisis occurs. The urban poor, on the other hand, are often alone, with their families living far away; the much sought after freedom and independence can become a liability when there is dire need.

It must be considered a possible bias that some areas as well as some cultures and tribes were omitted from the study. We did not have the opportunity to visit every district in Kenya nor to interview every person in each area visited, but had to pick a sample that could give information covering as many relevant aspects of the research questions as possible. Due to limitations in time and resources we chose not to visit the more remote areas. As we were dependent on local assistance to identify informants, we chose places with organisations working for the benefit of people with disabilities, disabled people's organisations (DPOs) in particular. This implies a possible bias in only reaching people benefiting from these activities and services and not those who do not benefit from any kind of assistance. On the other hand, we discovered that many of the informants, even if they were known by the organisations, did not benefit from any services and were not informed of the possibilities for assistance. People with mental ill health were not included in the study. This implies that this study could be less suitable to throwing light on the situation for people with mental ill health.

Disability in a Kenyan context

Kenya is a low-income, food-deficient country with a population of 34 million and with great ethnic diversity. About 43% of the population is under 15 years of age and about 58% live below the poverty line. Approximately 75% of the workforce is engaged in agriculture, mainly as subsistence farmers. Most city workers retain

links with their rural, extended families and leave the city periodically to help on the family farm (MPND, 2003a).

Knowledge on disability prevalence and living conditions of people with disabilities is scant as well as knowledge on the impact of the available services. According to a health and demographic survey in 2003, Kenya is expected to have a population of over three million disabled people, which is about 10% of the total population (MPND, 2003b). The occurrence is expected to vary from district to district, due to diverse living conditions and the conception of impairment and disability. Trauma, particularly due to road traffic accidents and violence, is a growing public health problem and a significant cause to impairment (Masiira-Mukasa and Ombito, 2002). Screening in Bondo District in the Nyanza Province among children between the ages of two and nine found that 64 (16%) out of 399 children had a disability (Muga, 2003). There is indication of a considerable burden of moderate/severe neurological impairment (NI) in Kilifi District in Kenya, with prevalence for moderate/severe NI of 61/1,000 (Mung'ala-Odera et al, 2006). Epilepsy, cognition and hearing are the most common domains affected.

Issues of particular relevance to this study

Many of the diseases that are significant causes for morbidity and mortality are widespread in Kenya as in many other low-income countries. Malaria, infections, untreated epilepsy, malnutrition, diarrhoea, HIV/AIDS and tuberculosis are all strongly related to poverty and impairment. All these diseases were identified as major causes during the fieldwork for this study. Pregnant women and their unborn and newborn children are particularly vulnerable to malaria, which can have a critically damaging impact on children's cognitive development (WHO, 2005, 2006). In Kenya all those suffering from malaria have been entitled to free treatment at health facilities since the end of 2006, and pregnant women are entitled to malaria prophylaxis in the weeks around the delivery. Still, the disabling consequences of malaria infections confronted us when visiting the areas at Lake Victoria and the areas around Mombasa.

HIV/AIDS is believed to infect one in every 18 adults in Kenya. Although Kenya has made significant progress in preparing for institutionalising care and treatment (WHO, 2004), knowledge of treatment is very low due to high levels of stigma among health workers and the general population. Although an estimated 11,000 people are receiving antiretroviral therapy, systematic monitoring and evaluation is lacking. Kisii District, included in this study, had its first AIDS case in 1987. The extent to which HIV/AIDS has infected or affected disabled people in Kenya has not been determined. The combined effect of disability and HIV/AIDS has received little attention, but it is anticipated that the situation is similar to many other African countries. People with disabilities are more vulnerable than the rest of the population, therefore it is to be expected that they suffer the same level of prevalence, or even higher, as the rest of the population (Groce, 2004;

Yousafzi and Edwards, 2004; Thomas, 2005). Women with disabilities encounter various barriers to accessing safe motherhood and reproductive healthcare services in particular regarding HIV/AIDS. A generalised assumption among healthcare service providers is that women with disabilities will not be sexually active, and thus do not require reproductive healthcare. This leads to increased vulnerability to sexually transmitted infections. Traditional beliefs about the transmission of disabilities can create barriers to integration in ante-natal clinics. Furthermore, midwives' fear of delivery complications in women with physical impairments can result in over-referral to a tertiary maternity facility which is outside the locality and difficult to get to (Smith et al, 2004). A special focus on HIV/AIDS and disability is also important because HIV/AIDS weakens the family group, on which the disabled family member is particularly dependent.

Polio has been a major cause of impairment in Kenya as in many other countries in the world. There have been no reported cases since 1984, but recently the risk is appearing again, as polio has been found in the refugee camps in the north east (Dolan, 2006). Today many of the adults affected as children are living with the consequences of the disease – as they grow older many are facing postural dysfunctions from an early childhood infection.

A study of children with hearing impairments in Kisumu District showed that the mean age of identifying hearing loss was 5.5 years (Omondi et al, 2007). The median travel distance to the preferred healthcare centre was 2km, but with great variations. Despite the parents being aware of the child's impairment, health facilities were underutilised and parents seldom sought help for their hearing-impaired children.

The limitation in attainment of education and challenges to economic development and self-support is a critical challenge. Unemployed people with disabilities have difficulties in contributing to family income and welfare and this may put a strain on the limited resources as their families attempt to provide special care. Thus, education is considered the most important tool for participation in the socioeconomic life. Achieving education for all is one of the Millennium Development Goals and Kenya is committed to this. Education in Kenya has been based on a system with eight years of primary, four years of secondary and four years of university education since the late 1980s. Primary education in government schools became free and compulsory in January 2003, 40 years after it was first promised. The importance of money for sending children to school was clearly demonstrated when free primary schooling was introduced as the number of children and adults enrolled in school increased dramatically. There is an obvious lack of teachers to deal with the demand. In spite of school fees waiver initiatives, parents have to pay for books, school uniforms and meet other requirements as the demand for them arises. It is estimated that less than 10% of all disabled children in developing countries go to school, and less than 3% of children with physical or mental impairments. Studies from other low-income countries show that teachers in the mainstream schools are reluctant to help learners who have functional and/or learning limitations (Sharma et al, 2006),

findings that are also supported from this fieldwork. A number of low-income countries have adopted inclusive policies, as is the situation in Kenya. However, no country worldwide has as yet implemented a fully inclusive educational system (Jonsson and Wiman, 2001).

Organised care for people with disabilities

Kenya has had a history of organised care for disabled people since the Second World War.[1] Stakeholders offer a wide range of services, mainly based on charity. There has been a certain governmental contribution to establish public bodies for the benefit of people with disabilities. However, the services reach only a small percentage of the people in need and they are unequally distributed regarding types of impairments. The volume and quality of services are marginal and reach out to only a small proportion of those in need. Ten rural vocational rehabilitation centres have been established countrywide, offering artisan courses such as carpentry, dress making and leatherwork. A special education section was set up in 1975 within the Ministry of Education to coordinate education for children with special needs. In 1981, the National Fund for the Disabled was set up as a trust, making available direct assistance to both individuals and institutions. The Ministry of Education introduced the Educational Assessment and Resource Services (EARS) in 1984. EARS has enhanced the inclusive education delivery strategy that promotes placing children with disabilities in integrated programmes. DPOs exist both as national associations[2] and as community-based groups. Kenya has a Persons with Disabilities Act brought into effect in June 2004, with the establishment of a National Council for Persons with Disability whose mandate is to implement the rest of the Act on the rights, privileges and protection of people with disabilities.

Barriers: lessons learned from the fieldwork

Encountering barriers when seeking health services

The primary healthcare system is not sufficiently developed to cover all of Kenya. People in rural areas live across the region while health facilities are centralised in the towns and cities. This implies that rural people have to travel long distances to get to the healthcare services. Many disabled people have considerable problems with walking long distances, which means that healthcare facilities are only accessible for those who can afford to pay for transport causing a considerable expense for poor people. Consequently people do not seek healthcare treatment or they are brought to the hospital too late. Take, for instance, Edna, who lives in a small village, a two-day walk from the nearest healthcare centre. She did not manage to get to the hospital to collect her malaria prophylaxis when she was pregnant – a prophylaxis that is free of charge for pregnant women. She got sick and was in difficult labour for several days with the child. The family did not

seek emergency help in time because money for transportation was not there. This unhappy situation caused brain damage to her child. Despite the fact that she has later taken the child to both modern doctors and traditional healers, she has not received any counselling on how to deal with a child who is severely mentally impaired.

But even when the family manages to raise money for transport, the effort sometimes is in vain. When they get to the hospital there is no guarantee that there are healthcare personnel present to help them. They could just as well be told to come back another day. Several families mentioned how they got appointments to see doctors and managed to mobilise family and friends to raise the money to go, only to be told when they got there that the doctor was not in and asked to come back several months later. Not knowing how to raise the money a second time, they might easily give up at this stage. This is the situation for Aisha and her family:

> Aisha is 12 years old and was born with deformed legs. She lives with her parents and three younger siblings on a small farm in a rural area in western Kenya. The settlement pattern in the area is scattered, with each family living on a small plot of land. The mother works in the fields and the father is a day worker, spending most of the day in the nearby town looking for a job. Aisha has never been taken to school. There is a local school in the village nearby but it is too far for her to walk and her parents are not able to carry her. She is the first born and there is no elder brother or sister to assist. The poor family has no spare money for a boarding school, and even if they did, the parents do not wish to send her away to let strangers take care of her. When she was a baby, her parents took her to several hospitals to ask if something could be done about her condition. They applied to the APDK (Association for the Physically Disabled of Kenya) for funds to pay for an operation five years ago. The operation enabled her to walk with a wooden stick made by her father, but it is difficult to walk and she gets tired easily. She should have had another operation, also paid by the APDK. The parents managed to mobilise relatives to raise money for transport. They went to the hospital, but this was in vain because the doctor did not show up. When we visited them they had been given a new appointment for the end of the year. In the meantime, they must raise money for the bus once again, which is quite expensive.

We see from this that even if services are in place, as both a local school and a health clinic are in the area, they are not necessarily accessible for the people in need. This situation illustrates very clearly some of the consequences of healthcare services depending on foreign medical personnel who visit on an irregular basis. Children with treatable conditions are not treated because the health facilities lack sufficient personnel and there is a lack of both knowledge and medical equipment. Because of this situation, conditions that would be considered rather trivial in developed countries will worsen the situation for a disabled child in a low-income country.

By using the wooden stick Aisha is able to make herself useful by helping with the household work and looking after her younger siblings. Assistive devices are vital to lessen the consequences of the impairment. However, there is a severe lack of adapted assistive devices in low-income countries, representing important barriers in themselves. The available devices, such as crutches and wheelchairs, are old and worn out and rarely adapted to the individual. When visiting people who had a wheelchair, we noticed that very often it was not used. The explanation given was either the difficult terrain or that there was no one to push the disabled person. Modern wheelchairs work well on a city street, but are not fitted for terrain with rocks, fine sand and ditches. Wheelchairs and crutches are typically not adapted to the individual's body. This causes in particular severe consequences for children as the child grows and the impairment becomes aggravated. Crutches that once were given to the small child do not grow with the child. Wheelchairs fitted to adults will trap the child in passivity as they are too big and heavy to manoeuvre. The result is a paradoxical situation where the aid that is intended to minimise the consequences of the impairments instead increases them. This was the situation for many of the people we met with polio, as, for instance, Grace, a young woman in her twenties. As a young girl she got callipers and crutches. As she has matured, both the calliper and the crutches have become too short. Still, she is dependent on the devices in order to move around. When she walks, she has to bend down and this has caused postural related dysfunctions that also give her pain in her back and hips. She needs to have the crutches and callipers adjusted, something that should have been done several years ago. Adjustments are expensive and must be done at a rehabilitation workshop. In order to have this done she must go either to Nairobi or to Kijabe, which is far away from her town. She constantly postpones this because she is not able to raise the money. When we sit and talk she says hopefully: "Maybe I will get some next year." But after a short pause she adds: "But I am used to these ones so will manage," indicating that she does not really believe in it.

Obviously, it is challenging to get to a hospital or medical clinic. But even when a disabled person manages to get there, the clinic itself creates many obstacles. The medical personnel might not be in place or the routines at the clinic do not take into consideration the particular needs of people with functional impairments. Several of the people with physical impairments we met told us that they had to queue up like the other patients in spite of difficulties connected to walking and standing. If they left the queue to sit down, they risked losing their place in the queue. Benado, a young man, told us about his difficulties when he visited the hospital to get treatment for postural dysfunctions from polio. He always asks for an appointment to avoid queuing up and every time the hospital refuses, claiming that they must treat everybody the same way, "… but to treat me the same way as the non-disabled is to discriminate me because I am not able to line up in the same way and if I go and sit I lose my place in the queue," he said. In this way the clinic's requirement for equal treatment creates barriers, leading to inequality.

Encountering barriers to education

Free education in Kenya is not free in the sense that the parents do not have to pay. Parents have expenses for books, uniforms, shoes and transport and in some schools the children also have to pay for meals. These expenses represent a considerable amount for poor families with many children. Let us have a closer look at the situation of Frida's family. Frida is widowed and has three children. Wilson, the youngest one, at 13, is mildly mentally impaired. Frida works all day as a very low-paid housemaid in a better-off area on the other side of the city. Two years ago, a special class for children with learning difficulties was opened at the local school. This was very fortunate for Wilson who has since followed this special class. Frida has many reasons for sending Wilson to the local school. First and most importantly, it represents an opportunity for him to learn. He likes being in school and has started to learn how to write his name. He is also taught social skills by the teacher who is a specialist in working with children with mental impairments. Second, being in school means that he is looked after properly while she is working. The school is free, but they have to pay for a food programme. The children who are not able to pay for the food programme are sent home at lunch time and not allowed to come back that day. Frida cannot afford the food programme, so Wilson is missing the opportunity of a nutritious meal as well as half a day's education. He gets less training than his classmates from better-off families. Thus, he is only looked after during the mornings and from lunch time on he strolls around the streets begging for food until his mother finishes work.

Many local schools do not accept disabled children at all. Special schools and boarding schools for disabled children are expensive and dependent on donors. Consequently, the expenses connected to having a disabled child in school easily exceed the expenses for the non-disabled one. Faced with such expenses, many poor parents still have to make priorities among their children and often end up sending the non-disabled children to school before the disabled children.

Many parents try hard to keep a disabled child in school, selling a goat and some chickens to keep up with the school fees. Still, many end up having to withdraw the child after some time because they are unable to raise money to continue paying the school fees. Poor parents have to have a year-to-year perspective when it comes to sending the disabled child to school.

We have already described some of the challenges disabled children face in getting to school. For many children, transport to and from school by public buses or simply by walking along the road is not possible. Many disabled children are not sent to school because they are not able to walk that far and there is no possibility for transport. But even parents who can pay find that the transport is inaccessible. The father of an autistic boy told us that his son could manage to take the bus on his own, but he needed assistance to get off at the right stop. The parents were unable to accompany him themselves as they both had to work in order to make money for the family, among other things, to be able to pay for the boy's special school. The bus drivers refused to help the boy, as did the other

passengers. After several traumatic incidences where the boy did not get off the bus at the right stop and therefore got lost, the parents decided to take him out of school.

Lack of education for a person with a disability is not only a question of being able to get to school or to afford the school, but also of accessibility and suitability of the school itself. Very few schools have classrooms that are accessible for children with physical impairments and very few have teaching materials that are adapted to either mental, hearing or visual impairments. If a disabled child needs assistance during the day in a 'normal' school, the other learners are the ones who are asked to help. If they refuse, the child is most likely left on his/her own. We met several parents who had taken their disabled child out of school because classmates or teachers were reluctant to assist during the day. This was the situation for Mildred, who is bodily impaired and uses a wheelchair. She only went to the local school for a short time before her parents took her out. The wheelchair is big and heavy and she has to be pushed by someone. Her mother brought her to school every morning before she went to work and collected her every afternoon. To enter the building she needed to climb the stairs and therefore the chair had to be left outside. She crawled to take herself to the classroom and managed fairly well inside the classroom. But the school day was long and she needed to go to the toilet during the day. The toilet is a hole in the floor, as is quite common, and therefore not accessible to her without adult assistance. However, the teachers were not willing to assist outside the class. Faced with these obstacles the mother saw no other option but to take her out of the school: "When she moves around in the buildings she has to crawl and nobody is willing to help her when she needs to go to the toilet. I do not want my child to crawl in the other children's droppings."

Parents of disabled children often make very realistic assessments and conclude that their child will not be able to cope in such an environment.

The number of teachers with special education is slowly increasing in Kenya, but there is still a real lack of teachers with skills in teaching children with hearing and visual impairments, not to mention children with mental impairments. To be in a so-called 'normal' school for a child in need of adapted teaching will most likely lead to no skills at all. The most common solution by the teacher seems to be to let the child sit in front of the class and then let him/her manage as best as he/she can. Irene was born deaf and attended the local school for four years. Then her mother could not afford it any more. Anyway, the mother says, it was a waste of money: "She did not learn anything. She does not know how to write and read. She just sat there learning nothing."

Coping in the context of disability and poverty

Poverty and disability is intertwined in such a way that sometimes poor families seem to have lost what we may call a 'fighting spirit' and have given up. Faced with the many losses and obstacles that poverty creates, the care for a disabled family member is one burden too many and just becomes too much. The fragile

family is tipped off balance and there is just not enough labour capacity, resources or time to give the disabled person proper care, to seek help or to receive help that is available. This was the situation for a family we visited in the poor outskirts of Mombasa. The father is a day worker, and the mother was severely injured from burn wounds. The children include four girls and a 14-year-old boy with cerebral palsy and epilepsy. The doctor suggested amputation of the mother's leg, but she refused, afraid that this would make her even more impaired than she already is. The boy was able to move around with callipers and crutches until about a year ago when his seizures started to increase because his family could no longer afford to pay for his medicine. Within a fairly short time he was no longer able to walk. We found him lying on a plastic sheet on the concrete floor of the family's small house. His legs had become spastic and to keep them from crossing the family had kept his callipers on. This had given him big sores on his knees and heels on which flies were feeding, and he cried desperately in pain when we tried to turn him around. He was very dirty and smelled of urine. We suggested getting him up from the floor and onto softer bedding but the parents only gave us a blank, helpless look. They only had one mattress to share among the family members and could not afford to have it soiled by urine: "We have one and that one is shared among the other ones. Where shall we get money from to buy one for just him to use?"

This case could reasonably be interpreted as one of extreme abuse and neglect. What we saw in the eyes of the parents was not lack of love and interest, but desperation over a situation in which they were no longer able to cope; they were unable to care for the disabled boy or with his four other non-disabled siblings. The father was unemployed and only occasionally got small day jobs. On days without work they often had to go without food. The mother was in severe pain because of her infected leg and it was difficult for her to walk around and manage her household duties. So how can we accuse them of neglect? We find it more useful to see this family as the victim of poverty created mainly by social and political forces outside their control and by a weak social security system that is not able to detect and prevent situations like this. Thus, the best way to help this boy would first of all be to help his family regain a viable way of life in which fulfilling his needs is only one challenge out of many in the daily struggle to cope.

Often we were told about disabled people who were kept at home, apparently 'hidden' by their family. When visiting these families we learned that there was always a reason for keeping the disabled family member more or less inside the house or the compound. Looking only superficially into these cases, we could have easily interpreted them as cases of 'hiding' the disabled family member. Our interpretation, however, is that of coping with a difficult situation. Wherever we went, parents told us not only about bad treatment and stigmatisation from others, but also and often about fear of such treatment. The risk of mistreatment and abuse is particularly present for girls but also for disabled young boys when they are exposed to the world outside the close family and the village, or when they move into the big cities to seek more opportunities. Several of the boys

with mental disabilities had encountered negative reactions from neighbours who had hit and kicked them because they had failed to behave in a manner to be expected from a child of that age. Young disabled girls living in the more crowded areas of the cities were vulnerable to strangers' abuse, risking early pregnancy and possible HIV infection. Thus, fear of stigmatisation and actual stigmatisation is linked within a vicious circle.

A typical example was Makot's situation, a boy with a mental disability. Makot wanted to go to school, but he was not accepted at the local school and his family could not afford a boarding school for mentally impaired children. Makot suffered from epilepsy and his social behaviour sometimes caused conflicts with the neighbours. He had an urge to take long walks away from the village and this had caused great concern for his parents. He needed to be looked after constantly. He is both "strong and determined and he needs a strong person to control him", according to his father. The father decided to stay at home in order to take care of the boy who was kept inside the house most of the day while the mother worked in the fields. The fact that the father stayed at home caused a severe strain on the family's economy. No one had ever offered counselling to the family on how to deal with the boy's behaviour and the father was exhausted and worried about Makot's and the family's future.

Often a majority of the poor households we visited were not viable entities to the extent that although innovative ideas could be made with regard to addressing the problems of the disabled member, it was often almost impossible to realise this given a poor resource base. Someone could suggest that the neighbours should contribute in such cases. We discussed this in a group interview when talking to family members and neighbours of disabled people in a village. The neighbours defended their non-involvement by saying that they too had little to spare. They already found themselves in a strained situation looking for work, fetching firewood and water, or farming their small piece of land. Poor families very often have poor relatives and there is not much to spare. During the past few years, social security systems, with basic disability-related grants, have emerged in some low-income countries. There are indications that the take-up of these grants is increasing, albeit slowly (Booysen, 2004; Loeb et al, 2008). Still, we lack knowledge on how these grants contribute to the benefit of the particular individual and the family.

In some families relatives played an active role in raising money for either school or health services for the disabled family member. Another way luck can strongly contribute to resilience was the luck of running into an organisation and sponsors who would help a disabled person through operations, school or vocational training. Disabled children from poor families who are at boarding school or in vocational training often had experienced such luck. This was the situation for Josef, who was functionally deaf as a boy, due to middle-ear inflammation on both sides. He was detected by some missionaries who offered to send him to Europe for an operation and the opportunity to get an education. This has changed his life dramatically. From being a possible burden to his family he has

become a resource to them all as well as to the community. But donors come and go. We met several young people who had been in school because the school had sponsors from abroad. But they had to leave when the school introduced high school fees as the sponsors decided to withdraw.

Poverty and lack of education lead to reduced self-confidence and limit knowledge on where to go for help, no money to buy a radio to listen to informative programmes and fewer opportunities to utilise the help that is actually offered. In this matter DPOs play an important role in sensitising people about the possibilities that may exist. It was very encouraging to see the role that some local representatives of DPOs played in relation to other disabled people. In several of the districts we visited they worked closely together with the officers of the Social Development Office in detecting cases, offering advice and counselling and referring them when severe needs were detected. "They know everything about the disabled people here," some of the district officers said when we were introduced to the representatives of the local DPO.

Engagement in the DPO gave volunteers an opportunity to contribute to coping with their own situation and to helping other people with disabilities. Some young people in the towns and cities join a DPO and build groups to support each other, whether this is emotional, practical or financial support. This could easily be interpreted as a 'peer family' – a replacement of the family that is not around. The 'peer family' could be understood as a way of building a social security network in a society where family ties are about to weaken and public social security is almost absent. This added qualities to a life that otherwise could easily have been without meaningful activities. However, DPOs work for idealistic reasons and only rarely do they have sponsorship. There was consequently a limit to how much they could achieve and how much time they could spend on the task.

Collected sum of the many barriers that influence daily life

Looking on each barrier separately without understanding the connection between them can easily make us think that some are quite trivial. By taking a deeper look into the situation of poor people with disabilities and their families it is evident that many different elements appear together and operate in synergy to influence each other, creating a situation with significant obstacles. Through this fieldwork we have demonstrated the necessity of conceptualising the complexity in the interaction of the many barriers that influence people's daily life. The study shows that disabled people meet different kinds of barriers in many areas in their everyday life. From the person's point of view everyday life is about handling situations that are characterised by the intertwinement of barriers. Such situations lead to systematic exclusion from life areas that are considered important. Key barriers are evident, notably the lack of resources, inaccessible infrastructure, social barriers and weak or non-existent policies that prevent people with various mental, physical and sensory impairments from participating in the economic and social endeavours within their communities as they strive to better their lives. The

intertwinement of the many barriers in the various arenas of social life and during different stages of the life cycle represents almost insurmountable hindrances.

An example of how the sum of many barriers creates a life of passivity and helplessness is Mary's situation. She lives in a small village together with her parents and three older siblings. They live in a small hut made out of soil. The place is quiet and nice and a large mango tree offers protection from the sun. A couple of hens and chickens move freely around in the courtyard. Her father is a day worker and her mother does the household work. According to her parents, Mary was born normal, but two years ago they discovered that she had started to lose her eyesight. She apparently has a progressive eye disease and her sight is gradually growing worse. She is in first grade at school and her eye disease makes it difficult to keep up with her lessons. The only option in class is to sit in the front that does not help much as it is still difficult for her to read from the books. Without an eye operation she most likely will have to leave school before completing primary grades, facing the prospect of being blind before she reaches adult age. Her parents have taken her to the doctor and they have been told that the disease is curable through an eye operation, something that would be manageable for a family that is well off. And once a year medical experts from Europe visit the regional hospital, so there is a possibility for an operation. But there are many in need of the family's scarce resources and even if the operation was not expensive, by any standard it still costs money that the family can ill afford. A way out for the family is to find a sponsor in order to pay for the treatment. Until now, however, they have not succeeded. In the meantime, Mary is gradually losing her sight. Another option for Mary is to stay at home and make herself useful to the family by helping her mother with the household work and looking after the animals. The hut is small, with only a small hole in the wall to let the day light in, and the oven is an open fire on the floor in a corner. Because of her eye impairment Mary cannot see to work in the dim light inside the hut and her mother is reluctant to make her cook as there is a risk that she could stumble and fall into the open fire. Outside she is blinded by the bright sunlight which makes it difficult for her to manage. Consequently, there is not much she can do. She is slowly becoming more and more passive. Her prospect is to remain dependent on her parents, or maybe her siblings, for the rest of her life.

The household as a resource system

Like most other low-income countries Kenya does not have a comprehensive public welfare system that grants protection when an individual is not able to care for him/herself, which, for instance, is to be found in most European countries. In general, the family is the social security system that tends to the individual. Many of the informants in this study have supportive families. In addition to the parents, elderly brothers and sisters devote themselves to lifelong care for a disabled sibling. In the wake of the HIV/AIDS epidemic, many grandmothers

have been left to take care of their orphaned grandchildren, with a disabled child representing a particular challenge and cause for concern.

By focusing on the complexities of the difficult situation for poor people with disabilities we have seen the importance of applying a family perspective and a focus on 'the disabled household' (Ingstad, 1990), whether this be the spouse or the extended family. By focusing on the complexity of the many barriers and the situation of the household of which the individual is a member this enables us to better understand the pattern of elements that creates what is called the 'evil circle of poverty and disability', thereby also, hopefully, enabling us to propose how this circle could be broken.

We look on the household as a system in which resources are distributed in relation to the needs of the members in order for the household as a whole to be viable (Ingstad and Saugestad, 1987). Viability of the household means coping in a way that takes care of the needs of every member. With an impaired household member, the resources of labour capacity, time and capital – income, land and livestock – have to be redistributed. This redistribution affects every member of the household. Thus, rarely will a person with an impairment fare better than the average household member. Generally, regardless of the kind of rehabilitation efforts made, poor households make poor disabled people. A household with a disabled person will call for a rearranging of the resources in order to cope with the challenges of care and to restore viability. There is a real risk that the vulnerable viability of an already poor household will tip the balance.

So the situation of the family group must be reflected in all initiatives that are carried out to improve the situation for people with disabilities. The initiatives, whether policies for people with disabilities, implementation of activities directed towards the individual, or sensitisation of the general public, should be founded in a comprehensive perspective in order to be sustainable. When implementing specific activities directed towards individuals it is necessary to recognise that the family is the social security net for the individual. In countries without, or with poorly developed, public welfare systems, initiatives to help the individual should target the family as a unit. This perspective should accompany public welfare policies and initiatives by DPOs as well as other NGOs that are engaged in this field.

Notes
[1] Further information is given in Grut and Ingstad (2006).

[2] In 1989 the DPOs in Kenya came together to form the United Disabled Persons of Kenya (UDPK) in order to build their negotiation capacity to champion disability advocacy work.

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Disability and social suffering in Zimbabwe

Jennifer Muderedzi and Benedicte Ingstad

Poverty and politics

Zimbabwe is a land-locked country in southern Africa. It shares borders with South Africa, Botswana, Zambia and Mozambique. It has a population of 13 million people, 348,861 of whom are people with disabilities (CSO, 2004). Half of the people with disabilities are children (Government of Zimbabwe, 2004). Zimbabwe is mostly a rural country and there is a higher poverty incidence in rural areas (63%) than in urban areas (53%). Most rural households in Zimbabwe are located in drought-prone provinces, for example in Matabeleland North (Binga District). They are subsistence farming households that mainly depend on dry land farming and are therefore affected by drought. It has been noted that although there has been a higher increase in poverty in urban areas, rural households remain worse off. Matabeleland North Province has been found to have the highest poverty incidence, of 70% (PASS, 2006).

In contrast to the development achievements of the first 10 years of independence (1980-90), the 1990s witnessed a turnaround of economic fortunes as economic decline set in and structural problems of high poverty and inequality persisted. Some of the explanations behind this turnaround include recurring droughts and floods, as well as the non-realisation of the objectives of the Economic Structural Adjustment Programme (ESAP, 1991-95).

The period 1996-2005 was marked by accelerated deterioration in the socioeconomic situation. The non-realisation of ESAP resulted in a number of 'homegrown' reform packages. The Enhanced Social Protection Project (ESPP, 2000) was launched in response to worsening social conditions that were causing the poor to suffer deepening multi-shocks of escalating prices of basic commodities, high unemployment rates, high number of drop-outs of school-aged children and high interest and inflation rates. The government also embarked on a land redistribution programme (in 2000) as one of the major strategies for poverty alleviation (PASS, 2006). Its potential has yet to be realised.

Despite all the economic policy-making efforts, Zimbabwe has continued to experience severe macroeconomic instability, characterised by nine digits hyperinflation (231,000,000% and it continues to soar endlessly upwards; see

The Standard, 26 October 2008). Other challenges faced by the government include general international isolation, the devastating impact of the HIV/AIDS pandemic, high poverty and unemployment (at 80%) levels. The *Report on the global AIDS epidemic* (UNAIDS, 2006) indicates that Zimbabwe has 1,700,000 people living with HIV.

Poverty in Zimbabwe has increased considerably from 1995 until the present. The proportion of households below the food poverty line increased from 20% in 1995 to 48% in 2003, representing an increase of 148%. This shows that more households shifted into the 'very poor' category rather than moving out of poverty. There are now reported cases of people dying from hunger-related illnesses. Nyati (2007) reports that, 'eight people have died of malnutrition in Bulawayo where hunger-related medical complications have been identified in suburbs previously considered affluent.… Bulawayo resumed publicizing malnutrition deaths last year after it suspended the service in 2004 following threats by the government'. Despite recurrent government denials, there is little doubt that hundreds are perishing weekly as a direct consequence of undernourishment as well as inability to access healthcare. There are good reasons to believe that people with disabilities, even more than non-disabled people, are among the victims.

Sadly, constructive efforts by the government to contain inflation are not visible. It is the magnitude of Zimbabwean inflation, which is fast collapsing all economic sectors, that is the biggest trigger of the nationwide poverty. A Zimbabwean economic commentator, Bloch (2007), states:

> The tragedy is that the appalling deterioration in the living circumstances of most Zimbabweans is not due to uncontrollable circumstances, to acts of God, to the ravages of nature, or the sequences of fate. The pronounced poverty that is now near endemic in Zimbabwe has undeniably been occasioned by government, and is being intensified and exacerbated by government's arrogant rejection of culpability, its continued pursuit of destructive policies, and its rigid resistance to any changes of policy which are either recommended by others, or which could be construed as an admission that prevailing and past policies were erroneous and ill advised.

Aims, objectives and methodology

The study on which this chapter is based took place from August to November 2005 in Binga District, located in North West Zimbabwe towards the border of Zambia. As one of the poorest districts in the country it has been struck especially hard by recent economic developments, and poverty is prevalent. The major aim of the study was to gather knowledge on the situation of rural families with disabled pre-school children in Zimbabwe. The study also gathered information on traditional beliefs about the causes of impairment, as well as on attitudes and behaviour towards children with disabilities in the past and present. It was of

particular importance to determine the coping abilities of these families in general and the link between disability and poverty in particular.

The methodology used was in-depth interviews with 30 mothers and two grandmothers, participant observation in the villages and at the district hospital and clinics and three focus group discussions. Content analysis was used for secondary data.

The Tonga: past and recent histories

The mighty Zambezi River used to run through the north and south settlements of the Tonga. They were separated by what was then the Federation of Northern and Southern Rhodesia (now independent Zambia and Zimbabwe). According to the old men and women, the river was then known as 'Kasambabezi' meaning 'it was only those who knew the river who could bathe in it despite the presence of crocodiles', giving respect to those who knew the waters. In other words, the river belonged to them. Sadly, the river no longer belongs to them since they were forcefully evicted from the valley by the Rhodesian government in 1957 to make way for the Kariba dam (approximately 280km long and 25km wide), which provides electricity for both Zambia and Zimbabwe.

The Tonga is one of Zimbabwe's smaller ethnic groups. They are found in the north west of Zimbabwe near the Zambezi River in Matebeleland North Province, Binga District. For many generations they lived by the fast flowing Zambezi River which connected them to their relatives and friends, known as 'bamutala' – those living on the other side of the river. When they were moved from the riverbanks the bond between them was broken and this meant that traditional ceremonies to honour ancestral spirits and other ceremonies came to an end.

In her novel *African Laughter* (1992) Doris Lessing describes the misery of the Tonga as observed by her during a visit in 1989 (pp 379-87). Since then, the situation of the Tonga has deteriorated. Tremmel and the River Tonga People (1994) state that their life near the river was a time of 'splendid isolation'. This description needs to be understood in its historical context. They state that the Tonga were basically isolated from the rest of the people of southern Rhodesia and lived a very traditional life of farming as well as catching fish. The absence of government involvement left them free to honour their ancestral spirits and keep their traditions alive. It also resulted in them not having schools, clinics or hospitals, even as late as 1957 (which was unlike the rest of the country at that time). Tremmel states that they relied on traditional medicines, which were effective for some illnesses but not for major illnesses like malaria, tuberculosis, leprosy, measles and others. As a result, life expectancy was low, with 60–80% of children dying from malaria and diarrhea before the age of five.

Binga today is one of the most underdeveloped districts in Zimbabwe. It is approximately 12,500km^2 of which 9,000km^2 is habitated. It has a population of 300,000. The whole district is a malaria endemic area in which all the population

is affected. Some areas are more affected than others. Malaria accounts for 60% of total admissions at the district hospital (Ministry of Health, 2005).

'We had a good life. The soil was fertile and we had more water than we needed. We grew maize, sweet potatoes, bananas, pumpkins, vegetables and other crops – we also herded a large number of cows and goats – life in the valley was good' (quoted in Muderedzi, 2006). These were words from the old men and women who are now scattered in the villages as well as the Chizarire mountains. A tearful mist could be detected in their eyes as they said the above words. Apparently when the Tonga asked the 'white man' how they were going to survive on the dry mainland, they were told to continue moving inland and that 'the water will follow'. Sadly, the water did not follow them as promised. The Tonga in their new homeland came to suffer from persistent droughts, but the government has not brought piped water to the villages. The Tonga stated that they remember old people, children and those with disabilities getting sick and dying from lack of food, diseases of the mainland and attacks by wild animals. Some died of grief.

The lives of the Tonga since they were taken from their land, their shrines and the graves of their ancestors have been hard and painful, a struggle year in, year out and from season to season (Lessing, 1992). From being able to produce two or more crops a year, they now do not produce anything most of the time. The Tonga are currently on the verge of starvation and have to beg or borrow in order to survive. They are not able to fish as before, quelea birds eat the little that is produced in the fields and elephants just love to eat their maize. It is sad to note how they have had to scatter to look for means of survival such as water, fertile fields and wild animals for food.

The Kariba dam, which deprived the Tonga of their homes, has not benefited them. The lake does not irrigate the land along its long shoreline and the electricity it generates does not benefit the villagers. Their skills in such crafts as carving and basketry are well known but this is of no benefit to them due to the political situation that has brought fewer and fewer tourists to visit the area. Little social progress has taken place among the Tonga. The illiteracy rate is still very high. Health facilities are inadequate as well as clean water and sanitation facilities. Malnutrition is rife. Poverty is not a new phenomenon; the colonial government found it and left it after its rule. The present regime found it and still has not managed to do much about it. Their present situation of poverty includes realities such as excessive drinking, a high unemployment rate, household food insecurity, a high mortality rate, witchcraft accusations, poor health, a low literacy rate, poor self-image, infidelity and AIDS, among other things.

Immediately after independence, Zimbabwe recorded an upswing in quality of life as seen in a declining infant mortality rate (IMR) and maternal mortality rate (MMR) in the 1980s by focusing on primary healthcare (PHC). With the introduction of the 'pay per use' cost recovery policies as well as poor services in the 1990s, all these gains were reversed. Programmes like prevention of diseases through immunisation, malaria prevention, water and sanitation, family planning as well as information, education and communication (IEC) have suffered due

to lack of the required equipment, medicine, limited resources, 'brain drain' and other challenges. In terms of child illnesses such as acute respiratory infections (ARI), fevers and diarrhea, only 29% of the children were treated in a health facility (CSO, 2006). The rest supposedly used the 'alternative' healthcare system. Such a situation results in suffering and deaths of many children, especially those with disabilities.

Disabilities: Tonga beliefs and attitudes

There were no indications during this fieldwork that present-day Tonga families are purposely hiding or neglecting their children (Ingstad, 1997). We did, however, encounter the *assumption* that disabled children are left to die or are hidden away in rural areas. This is rooted in early ethnographic accounts. The village elders narrated stories of how people in the past used to dispose of children born with disabilities because they believed that such children would bring bad luck to the village community. This is no longer practised. In spite of being one of the most economically deprived groups of people in Zimbabwe, the Tonga do their utmost, displaying much love for their disabled children.

When expecting a child, the Tonga were more worried about whether or not the child would survive rather than a visible disability. Bodily imperfections were seen as important only to the extent that they impaired normal functioning in society, and life was seen as superior to death. Disability was seen as secondary, as seen in the proverb, '*kocilema kunywigwa maanzi*' ('It is better to be disabled than death. Thus, it is better to have a disabled child than a dead one'). This was noted when asked to state their reactions on discovering their child's disability; most of the mothers stated that "it was a life event … one of those things that happen in life.… I was happy but sad for the baby" etc. With the high mortality of children among the Tonga, the sentiment among the mothers was that they should be grateful to have a living child than a dead one. Similar findings have been made by Ingstad (1997) among the Tswana.

The Western concept of disability seeks to improve the lives of people with disabilities. In many African societies, the primary interest is in explaining why these people have become as they are (Devlieger, 1995; Talle, 1995; Ingstad, 1997). The most important issue concerning a disability becomes answering the question '*why*' rather than the idea of rehabilitation. When misfortune or illness strikes, the traditional healer is the first port of call. The Tonga believe causes of disability to be witchcraft (*kuloyiwa*), an ancestor's sorrow or anger (*mizimu*), the will of God, natural reasons or that it 'just happened'. The first two causes can be termed 'Tonga diseases' as they have a Tonga name and can be identified as originating in disturbed social relations, and the rest are caused by external forces.

This results in the immediate family not being blamed for the child's disability. Since the question 'why' is central, less attention is given to the person with the disability as an individual. That person is integrated into normal life in an indifferent way, without ceremony, without much medical attention, but without

being hidden. It is clear that these beliefs function as a strong social control mechanism, as well as a restoration of relationships in the community. This makes disability a condition related to culture and religion.

Tonga attitudes towards disability varied in the study according to whether it caused problems for others and took the mother away from carrying out other household chores. For example, children with cerebral palsy and other neurological disabilities were considered more disabled for being solely dependent on other people for their basic needs compared to deaf children who could carry out chores like herding cattle and other errands. In addition to the above perceptions of various types of disability, each family would have their own constructed notions of disability that might influence the treatment of and relationship with the disabled child. Unlike the Hubeer of southern Somalia (Helander, 1995), looking after children with disabilities was not seen as a religious duty of showing mercy.

As noted before, the child with disabilities as well as the immediate family is not blamed for the disability/misfortune. More importantly, the mother does not blame herself. Family ethno-medical beliefs, childhood experiences, personality factors as well as attitudes were seen to play an important part in coping with a disabled child. We found among the Tonga a kind of 'natural integration' of these disabled children in the sense that the families did their best to look after them without reservation. If the child died, it was a result of the family as a whole not having enough food and lack of healthcare. This is in contrast to Scheper-Hughes' (1992) description of Alto mothers from Brazil who perceived disabled as well as weak babies to be predetermined to die, resulting in them withdrawing nourishment as well as care and leaving them to die.

One of the strengths of an African understanding of disability is the recognition that it is not simply an abnormality of the individual body but also a disruption in the family. Thus, attention should be paid to the relational context in which the person with a disability exists and greater efforts should be made to involve and support other family members. An African approach to disability is concerned with the meaning that biological deviations have for society, for the family and for the individual.

Talle (1995) states that in order to understand the concept of disability, one needs to look at cultural beliefs as well as a contextual analysis in order to grasp the phenomenon in its full social and cultural setting. This is in contrast to the modern Western biomedical approach that is more technical, with a focus on the improvement of functions and activities of daily living.

Consequences of poverty for people with disabilities

Human poverty is commonly defined as the deprivation of basic needs or various social and economic entitlements such as income, health, nutrition, knowledge, water, shelter, security, equity, human rights, freedom of choice, religion and participation in decision making (UNDP, 1990). However, poverty is not simply

the consequences of a lack of resources. Some people are unable to access existing resources because of who they are, what they believe or where they live. Such discrimination is a form of exclusion and a cause of poverty (DfID, 2000b). Yeo (2001) states that not only do disabled people experience disproportionately high rates of poverty, but being poor dramatically increases the likelihood of getting an impairment, for example due to the hazardous nature of the job. Those living in chronic poverty often have limited access to land, healthcare, healthy food, shelter, education and employment (Despouy, 1993).

The links between poverty and disability are strong and go in both directions. Poverty causes disability through malnutrition, poor healthcare and dangerous living conditions. Disability can cause poverty by preventing the full participation of disabled people in the economic and social life of their communities, especially if the proper supports and accommodations are not available. The United Nations (UN) estimates that at least 10% of the poor in developing countries are people with disabilities. The adverse consequences of disability fall heavily on the poorer sections of the community.

Eide et al (2003, p 27) state, 'A large majority of people with disabilities live in developing or low-income countries, very often living without optimal technical, medical or social support that could have improved their level of living conditions considerably. Disabled people are often marginalized and belong to the poorest segments of society'. The above statement rings true of the situation of people with disabilities, but for the Tonga with disabilities, this is an understatement. It is among the Tonga that one perceives the symbiotic relationship of disability and poverty. The challenges that they face in their everyday lives must be witnessed.

The majority of people with disabilities find that their situation affects their chances of going to school, working for a living, enjoying family life and participating as equals in social life. Poor nutrition, dangerous living conditions, limited access to vaccination programmes, and health and maternity care, poor hygiene, bad sanitation, inadequate information about the causes of impairments, politics and natural disasters all cause disability. Also, children may be disabled as a result of malnutrition and HIV/AIDS. In turn, disability exacerbates poverty by increasing isolation and economic strain, not just for the individual but often for the affected family as well. Breaking out of the vicious cycle of poverty and disability becomes more and more difficult (DfID, 2000a).

The direct costs of disability impact the rest of the family that makes it reasonable to talk about the 'disabled family' (Ingstad, 1997). We found that the burden of care often fell on mothers or other female relatives and siblings. There was a trend of schoolgirl drop-outs looking after their disabled brothers and sisters. Caring for a child with a severe disability further increased the workload of women living in extreme poverty, like the Tonga. This took their valuable time away from the daily struggle to make a living, thus they could not work in other people's fields for food, money, clothes or seeds.

Disability and social suffering among the Tonga

The study of the Tonga families and how they coped with the care of children with disabilities brings about a picture that makes the concepts of 'structural violence' and 'social suffering' useful tools for analysing their situation. Benatar (1997, p 1634) defines social suffering as 'a collective and individual human suffering associated with life conditions shaped by powerful social forces'. He further states that unlike physical suffering or mental illness, social suffering is largely unrecorded. It is the result of what political, economic and institutional power does to people, and reciprocally, how these forms of power themselves influence responses to social problems. Included under the category of social suffering are conditions that are usually divided among separate fields: health, welfare, legal, moral and religious issues. They destabilise established categories (poverty, war, torture etc). Social suffering is at the same time about the collective and the individual (Kleinman et al, 1997; Kleinman and Farmer, 1998). Structural violence is the negative impact – beyond their control – of social structures (political, religious, cultural etc) on the lives of individuals and groups. 'Social suffering' and 'structural violence' bring in a new perspective in that they take politics down to the household and individual level.

The Tonga situation is very similar to that of the Haitians described by Farmer (1992). Both were uprooted from their land and forced to leave behind a culture that was built around their closeness to the river. Both were moved to poor land where they could no longer make a proper living from agriculture. For the Tonga as well as the Haitians the structural violence of the past has been aggravated by the structural violence of recent years' politics. Adding to the suffering for both these people is the AIDS pandemic.

In Zimbabwe, as in Haiti, young people leave the villages in search of work in the nearby towns of Victoria Falls, Bulawayo and Hwange. On getting to the cities, they find that jobs are not easy to get (as they are generally illiterate) and so they end up taking demeaning, low-paying jobs just to survive. They find housing in the slums where alcohol, drugs and prostitution are the order of the day. After contracting AIDS, they cannot afford hospital fees or pay for anti-retroviral medication. When they get very sick, they return home to be taken care of by parents or relatives until they die. The village mothers and grandmothers take on all the 'home-based care', leading to loss of income-generating activities, which in turn results in a family ending up in a situation of chronic poverty.

McDowell (2005) states that displacement disproportionately affects the poor, those who are distanced from the centres of power, who often live outside the formal economic system, are members of minority populations speaking a different language and who generally do not fit a metropolitan national identity. The Tonga fit the above description. Poverty is the central fact of life for most of the people in Binga today. To live in their villages is to witness their struggle as they confront the deepening economic crisis that is currently gripping Zimbabwe.

Food and elections

At the time of research, Binga had not had good rains for the past four years, a common situation for the whole of Zimbabwe. This has led to severe food shortages since 2001. This, as well as the barring of international relief agencies from feeding the hungry, has worsened the situation of the Tonga. At the time of research, the government had stopped non-governmental organisations (NGOs) from participating in the distribution of food aid in fear of NGOs' use of the exercise as a pretext to mobilise support for the opposition party. In the case of the Tonga, politics has resulted in starvation due to previous forced displacement, and the government's current withholding of food aid from the people.

According to Tonga informants, the government stopped NGOs from supplying them with food in 2004, before the parliamentary elections. In an article, 'No food before elections – Mugabe', Didymus Mutasa, a government minister, stated: 'Most of these NGOs play politics with food and they might as well use the food handouts to influence our people to vote for the imperial lapdogs, the MDC. We are busy with the Senate elections and after that we will look at the situation. But it should not be lost that we have the capacity to feed our own people' (*The Zimbabwean*, 14 October 2005). Government supplies of grain were erratic: not enough, expensive and not available to those who voted for the opposition parties. From their claim of having plentiful food as well as a good social life in the valley, the Tonga are now on the verge of starvation and have to beg or borrow in order to survive.

Part of the problem seems to be that the Tonga were displaced to resettlement areas that could not support them. Drought has always been a major problem for them because no efforts have been made to supply the resettlement areas with piped water. In some parts of the district, elephants have been known to destroy the crops as well as food in the granaries. These elephants are stray animals from the nearby Hwange National Park. The poor national economy has led to unrepaired pumps for the waterholes in the park, leaving the elephants to seek water and food elsewhere.

On visiting the village of Dumbwe one morning, I (JM) found a village of 'defeated' people. The elephants had just visited the night before and wiped out the gardens. This was supposed to be food for the next few weeks before the river dried out. I looked at a disabled child who was already malnourished and wondered what would become of him in the next few days, weeks or maybe months, if he was lucky. 'We were not threatened by elephants before, but now they are everywhere … we no longer bang empty tins to scare elephants away lest we anger them, but just watch as they descend on our fields and graze on our crops' (allAfrica.com, 2006). At Siyabuwa village, the villagers told sad stories of school children being attacked and killed by the elephants.

It is indisputable that hunger and famine are largely the result of drought, but in Africa and the developing world there is an evident correlation between hunger and politics. Action Contre la Faim (Action against Hunger) (2001) writes 'Yet

hunger and malnutrition are by no means dictated by fate or a case of nature; they are man made. To die of hunger is equivalent to being murdered: while chronic and serious undernourishment and persistent hunger are violations of the fundamental right of life'. It was an insult to human dignity to see so many people starving to death or dying from hunger-related illnesses.

Starvation today mainly occurs when a nation is disrupted by wars or political upheavals and economic crises such as in the case of Zimbabwe or Ethiopia. A nation does not have to starve if drought alone is the cause of famine. For instance, Botswana, Zimbabwe's neighbouring country, is also usually hit by the same, or more severe, drought periods, yet they do not experience famine in the same way. This is because a well-functioning draught relief programme is in place. In the case of Zimbabwe, the European Commission has continued to provide the Zimbabwean population with food and other humanitarian aid exclusively through international and non-governmental structures. However, these food aid efforts are hampered by politics.

On Friday, 1 June 2007, one of the Tonga chiefs was heard on national television (News at 2000hrs) lamenting the poor road infrastructure that has led to families starving due to the long distances that families have to walk to get to the Binga 'growth point' where they can purchase maize when available. Women were walking long distances and staying in makeshift shelters on people's homesteads in order to work for food to take back home to their families. Mothers of children with disabilities found this very difficult due to the child's constant sickness and so many stayed at home. Some mothers stated that some employers refused to employ them because the children often died on their premises. It is a Tonga belief that a non-relative's death on one's premises can result in bad luck for the host family. Such a situation meant a shortage of food leading to more problems for the 'disabled family'.

Some of the households who had seed put aside had mixed the seed with sand. The explanation behind this was so that they did not consume the seed that was meant for the next planting season. Young women climbed huge trees to collect wild okra leaves. These were pounded, boiled and eaten with *sadza* (thick maize porridge). They also collected a dried sour fruit (*busika*) that would be sold for cash or exchanged for other foods like vegetables or fish. The dried fruit was mixed with porridge to make it palatable as they did not have sugar for the children's porridge. A daily diet of porridge in the morning and *sadza* with okra in the evening does not constitute many nutrients. The villagers admitted to drinking boiled ashes when food was scarce. Apparently, this was done just to take away hunger pains, for it is neither palatable nor nutritious.

It was common to come across cows dying by the roadside due to lack of pasture and water. This has resulted in the Tonga today having few or no cows at all. Hungry cows would disturb villagers during the night as they slept out in the courtyard. The cows would come to eat the grass on the newly thatched huts (Muderedzi, 2006). The animals that are seen most frequently scattered around the villages are the drought-resistant goats. Still, many families do not have any

goats left because they have exchanged them for food or sold them for purposes like cash for hospital fees. One family who no longer had any goats stated: "If someone gets sick in the family, we know that they are going to die because we have nothing left to sell to get them treated."

Evidence of recklessness on the part of the government of Zimbabwe can be deduced from statements such as Didymus Mutasa's (ZANU, PF Organising Secretary, 10 August 2002) 'We would be better off with only six million people, with our own people who support the liberation struggle. We don't want all these extra people'. The government's apparent lack of concern for the Tonga speaks for itself

"Go … the water will follow"

The Tonga do not have adequate water for personal use, let alone for other uses. Piped water was only be found in a few villages near the river. The villagers could only get water early in the morning and evenings. At the taps, women had to compete for water with goats that would visit the taps in the evening for a drink. The villagers were being made to pay a monthly fee that they stated they could not afford. When asked what would happen if they were unable to pay, they stated that the council would take a cow as payment. Those who had no animals left simply drew water from dug-up wells in the riverbeds.

Water continues to be a major problem for the Tonga women. Driving along, it is common to see women carrying large containers of water on their heads as well as on their backs so as to have enough water for the day. In some cases, mothers of disabled children brought home less water because they would also be carrying a child on their backs, and yet it is the disabled family who needs more water for the child's constant washing and changing due to diarrhea or vomiting. Women had to go to the river or borehole at least twice a day, around half past four in the morning and four in the late afternoon. Each trip would take an hour or more each way, thus four hours a day was spent just collecting water. Such a situation makes life more difficult for the women who have to work in the fields after this as well as collect firewood, cook and look after the children. To an outsider, these women seemed to spend half their lives collecting water and firewood. Local access to water would mean that the women would have more time with the children as well as time to rest and socialise.

Bathing seemed a luxury in such instances. When it came to toddlers' soiled pants, the mother would shake the faeces out and put the pants out to dry without washing them. Lack of soap and water was a common phenomenon, creating a health hazard. Lack of sanitation facilities was noted among all the families visited. In one village, the villagers used salty water for domestic purposes. They could not grow vegetables because the water was too salty. The village children were noted to have yellow corroded teeth due to the water.

Some parts of the district had boreholes that were functioning, while others were not. The rest of the district did not have any boreholes and people depended on

dug-out waterholes in the river sands, where women competed with cows, goats and wild animals for drinking water. In the middle of the hot summer, the drop in water supplies in dams and rivers affects the quality of water and this can lead to cholera outbreaks. On record is the cholera outbreak of 2003-04 that claimed several lives in Chunga Ward. This was followed by the August 2008 cholera epidemic that affected the whole country but mainly the urban poor, and left more than 1,100 people dead and more than 20,000 infected (by December 2008) (WHO, 2008). Outbreaks remained high or increased into 2009 (*The Zimbabwe Herald*, 3 June 2009). The Millennium Development Goal (MDG) 7 (UN, 2000) to halve by the year 2015 the number of people without sustainable access to safe drinking water and basic sanitation seems a far-away goal to achieve in this area. Lack of water for fields, gardens, animals, drinking and sanitation shows how water is connected to poverty in a broader sense in rural Zimbabwe.

Access to healthcare and education

Binga is one of Zimbabwe's most underdeveloped districts. It is linked with Bulawayo by one tarred road; the rest are dust roads in deplorable conditions. As a result, the district is not popular with bus owners who find their repair costs prohibitive. Normally, only two buses alternately ply the main road, resulting in people having to walk distances of up to 30km to get to the district hospital or nearest clinic (Langhaug et al, 2003).

Maternal deaths in Zimbabwe are increasing and continue to be a major problem. Officials in the Ministry of Health and Child Welfare stated that maternal healthcare has declined deplorably, as seen in the increase in the maternal mortality rate, which is up to 684 per 100,000 births in 1999 from 283 per 100,000 in 1994 (Government of Zimbabwe, 2004).

In Binga, lack of family planning, HIV/AIDS and women having children in their teens results in more women dying of pregnancy and birth-related problems. Stories of pregnant women giving birth by the roadside on their way to the nearest clinic were common. Pregnant women are not monitored for conditions such as diabetes, hypertension, malnutrition, bacterial and viral infections, which can complicate pregnancy and affect fetal development. Supplements such as folic acid and iron, which can prevent some deformities in unborn babies, are not available. Such a situation exacerbates the number of children born with disabilities. Economic constraints lead to home births, which in some cases puts the mother and baby at risk, making child disability, such as cerebral palsy, a byproduct of unsafe delivery. In this case, the relationship between poverty and disability is very apparent.

In 2005 *The Zimbabwe Herald* (14 December 2005) stated: 'Hospital goes without doctor for six months'. A reporter wrote that Binga rural hospital had been without a doctor for more than six months, forcing thousands of patients to travel as far as Bulawayo, about 450km away. The reporter's interview with Binga District administrator, Mr Cephas Mutale, said that the situation was further

compounded by a critical shortage of qualified nurses at clinics throughout the remote district, noting 'Our clinics are being manned by unqualified nurses; mainly school leavers, who are elevated to nurse aides after sometime – the situation is particularly difficult for women as they often develop complications during pregnancy'. In the same paper the Minister of Health's response was: 'We are fighting at least to have two doctors in the district – It pains us as a government to have such a situation, but we are trying our best to address the situation'. A year later the situation had worsened.

Binga has an exceptionally high infant mortality rate as well as other deaths from otherwise preventable causes. Giving birth by the roadside on their way to the nearest clinic was a common cause of child disability and infant mortality. This usually took place after delivery complications at home. Respondents accorded malnutrition as the number one cause of deaths in children and remembered the food hampers that they used to receive from NGOs. This has resulted in child rights organisations stating that 'nearly one in three children has stunted growth' (*The Standard*, 27 May 2007). The second cause of death was lack of health services. Fuel shortages had stopped or made erratic the provision of the Expanded Programme of Immunisation (EPI), which may have caused deaths and disabilities due to measles complications such as encephalitis, pneumonia and diarrhea.

Malaria is rife and results in 60% of hospital admissions per year. Most parents who had received mosquito nets from NGOs and the government admitted to having sold them to get treatment for their sick children or to buy food for the family. Appropriate dressing of long-sleeved garments and socks as well as repellents was a luxury, making malaria a social disease or a 'disease of poverty'. Due to the shortage of malaria drugs, cerebral malaria was seen to cause disability as well as deaths, especially among the under-fives and pregnant women. The Zimbabwe Demographic and Health Survey (CSO, 2006) reports that 50% of pregnant women in the rural areas access anti-malaria prophylaxis, while only 6% of children in rural and urban areas receive it. Children with disabilities were reported to suffer most due to perpetual opportunistic infections and malnutrition. It was common to come across children suffering from diarrhea and skin problems. Epilepsy was another condition that went untreated due to financial constraints.

Traditional medicine was the treatment readily available, whereby families could pay in installments and did not have far to travel. Despite the installment scheme, some families could not afford this due to lack of chickens and goats to pay for the medication. A few families were turning to Christian interventions such as prayers, laying of hands and 'holy' water.

Access to education is a key poverty indicator. The Convention on the Rights of the Child mandates that states should make primary education compulsory and available free, for all children. It also requires that children with disabilities should have access to and receive education in a manner that will help each child to achieve the fullest possible social integration and individual development. However, the current situation for children with disabilities from developing countries is not encouraging (Price, 2003).

In Zimbabwe, the major reason for non-enrolment at both primary as well as secondary school is financial constraints (PASS, 2006). The second most important reason for non-attendance is long distances to school; third comes ill health.

Situated in a high poverty rural province, Binga has a higher proportion of households further away from primary and secondary schools. Primary schools were as far apart as 14km, whereas secondary schools could be 25 or more kilometres (there are fewer secondary schools). This fact alone prejudices the child with disabilities who has mobility problems. Save the Children UK (2002) stated that 50% of Tonga disabled children did not attend school. The ones attending school at the time of this fieldwork were those living near a school where they either walked or were escorted by parents or siblings.

Tonga girls get married at an early age, for example from 12 years onwards, resulting in fewer girls enrolled at secondary school.

The age of starting school ranged from five to sixteen years, with the majority starting grade 1 between six and nine years. A fraction of children with disabilities as well as other vulnerable children have their school fees paid for by the government's public assistance scheme, the Basic Education Assistance Module (BEAM), whose funds constitute a small proportion of the full fees. Parents have to pay the difference, especially at the present moment, whereby school fees can be increased twice or more per term. For a disabled child coming from a poor family, a place in a day care centre was out of the question unless donations could be found. This meant that mothers of children with disabilities had to care for their children for 24 hours of the day with no respite at all. These children were also losing out on early learning as well as stimulation activities. The district does not even have one special school. Only one primary school was said to be practising 'inclusive education' without specially trained teachers to handle disability. This was a class with children of all ages and different abilities.

The numerous problems faced by the Tonga have made them one of the population groups least likely to have educated children. The children have no role models and their parents still do not appreciate the importance of education due to lack of education on their part. The socioeconomic and political situation leads to the denial of educational opportunities for girls as well as disabled children. Poverty among the Tonga gets passed on from one generation to the next. The implication of lack of education is a tragedy in a community let alone a matrilineal society, seeing that education is the vital tool not only to empower women and girls but also to eradicate poverty.

In Binga, disability-related needs such as assistive devices, physiotherapy, special education and social involvement were disrupted because their basic needs of food, shelter and survival were not being met. There were no community-based rehabilitation activities in the district and the families had to make food and survival their first priority. They could not afford to travel to get such services.

Conclusions

Almost all the causes of disability were seen to be present among the Tonga. Some of these were malnutrition, poor child health, poor maternal health, ill-conceived policies and illnesses such as tuberculosis, malaria, measles and HIV/AIDS, among others. The two-way causality between disability and poverty was clear, thus in order to alleviate poverty it requires taking people with disabilities into account.

As noted among the Tonga, poverty is an attack on human rights. It is morally and politically intolerable that basic human rights are being violated in such a massive and constant way. People need to be empowered so as to make positive changes in their situation. Investment in education and health is one of the most effective measures for combating poverty, which is why any government have strong policies in these areas. In the light of the current economic and political crisis, it is evident that Zimbabwe currently does not operate on the basis of medium-term development plans. Rather, short-term economic stabilisation plans have become the hallmark of development planning.

A look through the lens of history shows the way a people – a social group, a subculture, a community or a whole country – is laid open by the course of important economic, political and ideological changes to new patterning of behaviour and belief, new ways of seeing what is happening to them (Mintz, 1960, p 253). On entering the villages, both the violence and the vulnerability that characterises the life of the Tonga are apparent. They are pawns in an economic and political scheme that has left them laid open. Their suffering is associated with life conditions shaped by powerful social forces. 'Government pushes out NGOs in Binga' (*Zimbabwe Independent*, 8-14 June 2007): 'the government has ordered three quarters of NGOs operating in Binga district Matabeleland North to pull out as they are accused of influencing people to vote for the opposition during the elections … they do this every time when we are heading towards elections', stated Ngirande, advocacy officer for the National Association of Non-Governmental Organisations (NANGO).

Achieving the international development targets for economic, social and human development will undoubtedly reduce the levels of disability in many poor countries. However, general improvements in living conditions will not be enough. Specific steps are still required, not only for prevention, but also to ensure that people with disabilities are able to participate fully in the development process, to obtain a fair share of the benefits and claim their rights as full and equal members of society. An integrated approach is required, linking prevention and rehabilitation with empowerment strategies and changes in attitudes (DfID, 2000a). This shows the significance of disability as a key development issue and its importance in relation to poverty. The MDG of reducing poverty by half by 2015 is unlikely to be achieved in Zimbabwe, and especially not in Binga, unless the rights and needs of people with disabilities are taken into account.

The case of the Tonga brings forth a situation of social suffering due to structural violence. They have been the victims of such violence for a long time, since the

building of the Kariba dam and their forced move from fertile to unfertile areas. The division of their tribe between two countries has added to their suffering by dividing kinsfolk and making important traditional rituals difficult to perform. The present-day politics of Zimbabwe, and especially the lack of interest in relieving the suffering of the poorest of the poor, has added further to their suffering and created a situation where the Tonga people of Binga are close to starvation. Being harassed by stray, thirsty elephants from Hwange, only one of many consequences of political and economic disasters, only adds to this picture.

In the midst of this, people with disabilities, especially children, are double losers. On the one hand, in many instances their medical impairments are a direct result of the failure of the government to secure healthcare and proper nutrition to vulnerable groups. On the other hand, they are the ones to suffer the most and die first. Thus any programme to alleviate suffering in Zimbabwe and countries in similar situations should make it a priority to prevent disabling conditions and give people with disabilities the best possible care – supporting not only them but also their struggling families.

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"My story started from food shortage and hunger": living with landmines in Cambodia

Merete Taksdal

Cambodia is one of the countries in the world most contaminated with landmines and explosive remnants of war. The mines are not deployed in what we would traditionally call 'minefields', visualised by barbed wire and warning signs. Nearly 90% of victims in 2006 reported that there were no mine signs in the vicinity of the accident (CMVIS, 2007). In addition to the extensive placement of mines by all armies, the US dropped nearly three million tons of general-purpose bombs and cluster bomblets[1] on Cambodia during the Vietnam War (Owen and Kiernan, 2006). During the Khmer Rouge period, mines were used along the Thai border to seal off agricultural cooperatives. Mines were never systematically cleared, overgrown with vegetation and immersed in water, but no less lethal (Davies and Dunlop, 1994). During the Vietnamese occupation, and later in the internal conflict, new mines have been placed as late as the end of the 1990s.

The majority of people living with landmines in Cambodia are poor subsistence farmers. One of them is Sok,[2] a farmer who lost his leg in an explosion while clearing farmland in the forest. In this chapter, his story will be used extensively along with other survivors' stories in order to illustrate life inside the minefields. Although the rural population is aware of the danger of mines, they have to face the threat in order to avoid starvation. In a country without a social safety-net, the vicious cycle between poverty and disability becomes visible through the high number of people with disabilities seen in the poor villages. After losing a leg and going into debt to pay for medical treatment, the disabled survivor or the family members will have to enter the mined area again and again, as they depend on farming, collecting wood or using other natural resources to sustain the family.

Sok's story

"The accident happened three years ago, I was out in the jungle on my plot of land clearing the bush. I was not working for anyone else, I was trying to expand the farmland." Sok lives with his mother and young son in a thatched-roof bamboo hut in a remote village in Samlot district in northwestern Cambodia. He is a strong man in his mid-thirties, used to hard labour as the breadwinner in the family. Initially he seems a bit shy during the interview, performed by fieldworkers from

Trauma Care Foundation (TCF–C), a Cambodian non-governmental organisation (NGO) engaged in improving survival of trauma victims in landmine-infested areas. Sok is in distress because his wife recently left him and he has more difficulty talking about the disruption in the family than the dramatic accident when he lost his leg. "I had been there many times before and I was not thinking of any danger. I was just thinking of the good and fertile land we would be able to cultivate if we got rid of the trees and the bushes. Of course we know that this used to be in the fighting area, but I had farmed the land for some time without any incident and thought it might be free from explosives by now." He is indicating the size of the tree trunks with arm gestures while talking. He was chopping down the trees while his mother was clearing the shrubs and bushes.

After felling two trees, he stepped backwards and triggered an explosion: "When it suddenly exploded, I looked at my leg and told my mother that my leg was cut off. I was still standing up as usual and I looked at my missing foot, and then I searched around the ground and I moved slowly and sat down in the pit of the explosion. I was afraid there were still more dangerous mines than I managed to discover, but my mother took the chance to reach me and sat close. She cleaned the dirt from the wound. She tore her scarf into pieces, and applied a tight bandage on my leg. The other leg was also bleeding, just from cuts and wounds, and my foot was still intact. A few minutes later a man shouted to me. He came because he heard the explosion from a distance. I asked him for help and he came to carry me home. My leg was cut off!" The helper proved to be one of the neighbours and Sok instructed him where to walk to help him safely. The neighbour carried him on his back, as Sok explains that his body had gone numb and he was unable to stand up. "I was even unaware that my legs existed and I had to use my hands to lift my body and climb up on his back."

The accident had happened less than a kilometre from his house and he was taken across the river on an inflated inner tube tyre and then carried home. The village medic was notified and he was transported by motorbike to the local health centre and later transferred by vehicle to the surgical hospital in the provincial capital. Sok had to have his left leg amputated. Many amputees describe immediate thoughts of suicide in what they see as a hopeless situation, but Sok denies having any thoughts like that. "When I was injured I felt sorry for my kid and wife. I was thinking about who would take care of my family. My wife had just delivered our baby and now I was amputated. I did not want to die or kill myself. I was willing to move on and earn money to feed my son so he would not suffer from starvation. I told my wife not to cry, and that I would find a job." Sok stayed alone in the hospital for three weeks. Then he asked to be discharged and went home, worried about the well-being of his family. A relative had visited him at the hospital and encouraged him by saying that he could not be blamed for what had happened and that he did not deserve it. In accordance with Buddhist belief and local tradition, there is a tendency to see things that happen in life as a cause and effect of actions in earlier incarnations. Sok thinks about this sometimes and assumes that he may have committed sins in a previous life.

His wounds were not healed when he left the hospital and it would be months before he could be fitted with a prosthesis at the ICRC[1][3] workshop in the provincial capital. But he had to find a solution to plant the seeds. Three days after coming home, he started making his own artificial leg from local wood. He saw no future in lying idle at home in pain. He used light wood from the forest, cut it to the appropriate length and carved out the inside in order to reduce the weight. He filled in the hollow area at the top with cloth to soften the pressure against his newly operated stump, and fixed it with a rubber strap. He used wood with a piece from a rubber tyre at the end as a foot. After seven days of wearing it, moving around and working, the pain disappeared. He even managed to cross the river although with more difficulty than before, as he could not feel the slippery stones at the bottom of the river. Another problem was that he could not farm while using crutches – things took longer time and he was not as strong as before. "I am the person to earn the money for the family and I have to farm even if it is painful," he said. When asked if it was difficult to make the artificial limb, he said: "People here have always created what they need by themselves. So we just do it!"

Sok showed great determination and will to find solutions. But the family was struggling very hard and was periodically living with the risk of starvation. Sok's lack of mobility means that he is unable to take additional jobs as a daily worker or to collect wood or use other resources in nature as he could before. He is also spending money on healthcare services, travelling to fit his prosthesis, buying painkillers and paying others to do tasks he could manage himself before. In addition, the family still lives in danger of the landmines in the same forest area. He is worried about the safety of his son and he continues farming the land where he lost his leg. A new worry is that he is unsure about his formal rights to the land which he put his life in danger to clear. There are rumours among the villagers that the authorities now classify the area as an environmentally protected area and that his traditional right of using land that he has cleared himself may be challenged. When his wife abandoned him, his elderly mother had to take responsibility for more of the daily household chores. Sok finds himself under a lot of strain, despite his hard work and efforts to manage.

Sok is one of many landmine victims in Cambodia who takes the continual risk of being exposed to landmines because of poverty and who is becoming even poorer because of his disability. As most landmine victims, he lives as a poor man in a poor neighbourhood with the least access to services in the society. He is too poor to hire others to do the dangerous tasks and he is too poor to avoid using the dangerous land himself.

Mine Ban Convention

In September 2007, state parties to the Mine Ban Convention, along with humanitarian agencies, marked the 10-year anniversary of the key negotiations in Oslo, Norway. The treaty, signed by 122 nations in Ottawa in December 1997, was a result of intense lobbying from individuals and humanitarian agencies, and also resulted in the Nobel Peace Prize being awarded to the International Campaign to Ban Landmines (ICBL). Unlike other weapons, landmines continue maiming and killing long after the conflict has ended. The signatories to the Convention are committed to ban production, transfer, storage and use of landmines, as well as clearing mines from the ground, destroying stockpiles and assisting the survivors of landmine accidents, all within well-defined time lines. However, because of the vast number of landmines already placed, people in many countries around the world still face the problems related to living in a mined environment. Anti-tank mines and other explosive remnants of war are not banned and may have exactly the same effect on civilians as anti-personnel landmines. Even if the ban potentially saves people from being injured in the future, huge numbers of disabled people live in misery through injuries already inflicted.

The health of the whole family is at risk when a member becomes a burden in poverty-stricken households in marginalised societies. ICBL (2004) defines a victim of landmines as: 'Those who either individually or collectively have suffered physical or psychological injury, economic loss or substantial impairment of their fundamental rights through acts or omissions related to mine utilisation'. All community members could, by this definition, be seen as victims of landmines when they limit their possibility of using resources in the forest, farming land in safety, contributing to poverty and psychological stress. However, disabled survivors in the same communities suffer an even larger burden of hardship than the general population with limbs and functions intact. For villagers living in the minefields, the legal definition of anti-personnel landmines in a convention is irrelevant. In this chapter, the word 'mine' is used when describing all explosive war remnants that have the same effects as devices formally defined as mines.

The Kingdom of Cambodia signed the Mine Ban Treaty on 3 December 1997, and the treaty entered into force on 1 January 2000. Although real progress has been made in the areas of mine clearance, stockpile destruction, research and data management, further improvements and reforms are needed if Cambodia is to meet its objectives and the goals of the Mine Ban Treaty. Victim assistance in particular calls for more support in all stages of their needs, from the emergency situation, their hospital stay through to rehabilitation to a functional life in their families (ICBL, 2006). Nearly all mine casualties now occur along the K5 mine belt and in the border provinces of Battambang and Banteay Meanchey, reflecting the demand for land. Almost all landmine victims have received mine risk education prior to their accidents. The boards from NGOs along the roads and in clinics warn villagers against chopping fire wood, harvesting bamboo, hunting game or ploughing their fields. Although the villagers are aware of the dangers, they have

no choice if they want to survive. "I can sit at home and starve to death, or I can plough my fields in danger," a farmer said, requesting 'real help' from NGOs and the authorities. "If I had land without mines, of course I would not plough these fields. Everybody here has to take risks to survive."

"People with power and guns can do as they like"

Ownership of land is a complicated issue in Cambodia and the cause of many local disputes. Historically, farmers living from slash-and-burn cultivation in the jungle obtained an informal user's right to the land they cleared and did not need any written contract as proof. During the French colonial period, the French implemented a Land Act, and by 1930 most of the rice growing fields were registered as private property, but all free areas and unoccupied land were still available for customary rights (Ramamurthy et al, 2001). During the Khmer Rouge rule, all private property was abolished and all land belonged to 'Angkar' (the community). The population was forcibly moved from the cities to become rural farmers. After the fall of the Khmer Rouge regime in 1979, displaced and starving people returned to their previous homes. The new government established collective property rights for land and housing. In 1989, the government established a free market economy, including the re-introduction of private property rights. Land was redistributed to rural households in established communities in an egalitarian manner. Those who continued living in border camps until 1989 and after, however, did not necessarily get land from this distribution, and agricultural landlessness was estimated at around 5% (Williams, 1999). Ownership prior to 1979 was invalidated. Land markets have evolved and much land has changed hands more than once in the last decade. Land trade was formally permitted in the early 1990s (Sophal and Acharya, 2002). Distribution of land ownership is highly unequal. Landless households have fewer assets and earn lower incomes compared to landholders, and the near landless are only marginally better off than the landless. Around 80% of the population lives in rural areas where there are few alternative income sources, and owning land is an important prerequisite for a life without degrading poverty. Demographic forces are influencing the balance between supply and demand for land. Rapid population growth since the end of 1979 has created a large demand for food. There are many people in the young age group and the plots the parents divide between their children are too small for a sufficient livelihood for each of the new families.

The commercial value of good agricultural land is increasing. Land that has been cleared by a professional landmine clearance agency has, in fact, had substantial investment, sponsored by the international humanitarian community. The intention behind humanitarian demining is to save lives and reduce disability, as well as improve livelihoods in poor countries. But in Cambodia, the poor subsistence farmers who already cleared the land 'informally' leg by leg and family member by family member, may be 'pushed off' their land by economic or other pressures. I witnessed this process when seeing a district under clearance

by international deminers in 2000, a village settlement area of bamboo huts along the road which housed around a hundred families. When passing the place three years later, the whole cleared area was occupied by a privately-owned chilli plantation and the previous inhabitants dispersed. People said that some of them were in the city looking for jobs and others had moved deeper into the forest in order to clear new land. That means breaking land in old minefields. This places the family at risk again of death and disability, as a result of poverty and lack of other options for a decent livelihood.

Irrespective of the presence of mines, poor farmers are at risk of 'distress sales' of land usually related to inability to pay back loans. The most important single cause of losing the land is debt caused by illness and payment for medical treatment (Williams, 1999). Money lenders demand extortionate interest rates from people without collateral and in the situation of acute needs of cash, the family with a mother in obstructed labour or a son bleeding from the loss of a leg, does not have negotiating power. Losing land is a first step in a downward economic spiral, as most people are fully aware at the time of the sale. Before selling their land they have usually tried all other options, from selling other assets (if any), sending family members as migratory workers to the city or Thailand, taking children out of school or mobilising financial resources through their extended family network. It is not difficult to force someone off their land if you belong to what the rural Khmers call 'the power people'. "The people with money and guns can do what they like," an old villager said.

So what some reports call 'the process of land concentration' is accelerating in Cambodia under the unregulated market economy from the 1990s. In reality, this means that some people become increasingly poorer while at the same time the economic indicators reflecting the progress of the economy in the country are improving (Weggel, 2007). The figures of economic performance are probably influenced favourably by chilli export sales, while landless families disappear without a trace, not only from their small houses and plots, but also in the gross national product (GNP). Landlessness increases by 2% per year (Sophal and Acharya, 2002, p 2) and despite favourable economic indicators, Cambodia continues to be among the world's least developed countries (Weggel, 2007). 'Cambodia remains a minefield full of social constraints. One in three Cambodians still lives on less than 2,000 Riel ($0.50) per day' (Weggel, 2007, p 145).

The deforestation of Cambodia has occurred rapidly. Between 1985 and 2002 the loss of forest was estimated at almost two million hectares. The pressure from environmentalists is strong when it comes to the need to preserve the natural habitat for wildlife and plant species, as well as for climatic concerns and flood protection. However, rural farmers have experienced that land that is placed 'under protection', which in turn causes them to lose their plots, still continues to be exploited but under the operation of bigger companies, or even logging or mining companies with concessions from the authorities. So Sok's worry about losing the user's right of the land he cleared is quite real, but whether it protects the forests for future generations in Cambodia remains to be seen. It is

well documented that 'considerable areas of common property resources, such as forests, rivers, lakes and agricultural land (not redistributed in 1989) have become *privately controlled*. For example, millions of hectares of forests have been granted as concession forests to private companies and many large plantations have been developed' (Ramamurthy et al, 2001, p 37).

"The only safe thing to do is to sit and die"

Sann, a mine victim from Pailin, has survived two different landmine accidents. He is a double amputee and previously supported his family by combining farming sesame seeds and running a small business. He had to leave his village because of a land dispute; he was not able to defend himself as a disabled person and he feared for his life. He is currently living what he calls a "miserable life" with the risk of starvation every month, together with some of his wife's relatives, in "the jungle". The land he has access to in the new area has some bunkers on it, indicating that it was a previous front line and subsequently probably infested with explosive war remnants. His reluctance to enter that area is understandable, having suffered two life-threatening incidents before. But if his alternative is to sit at home and starve to death, facing the risk of the minefield may be less after all.

Many of the mine victims were injured when working as daily workers on other people's land. Ploughing a mine-suspected rice field in the wet and soft soil is very risky compared to just walking across the field in the dry season. If you can pay someone else to do it, you reduce your own risk. There are always destitute people, landless or migratory workers in need of a day's wage. In the district hospitals in northwestern Cambodia many of the injured mine victims come from other provinces. Sann is aware that his children will have a poor future if they stay where they are at the moment and he is hoping that they can move to some distant relatives in a city or at least in a more structured place than this "new" commune. The children have irregular attendance at the school and barely learn to read. According to Sann's wife, the teacher only shows up a day a week or so, and the rest of the time the children are dismissed. They do not have books or trained teachers. There is no clinic. The nearest clinic is almost always closed as the underpaid staff usually go home before lunch to treat patients at their private homes or dispensaries. The cost of hiring a motor taxi to get there is too much for them to pay anyway. Other public services in this area hardly exist. The village is inaccessible by road through the rainy season and for a double amputee a prosthesis can easily get stuck in the mud, so Sann is housebound for weeks at a time.

The health condition in the village is poor even within a Cambodian context, with high rates of malnutrition, dengue fever and malaria, and water-borne diseases. Many babies die as newborns because the mothers deliver at home and the mothers also risk dying. Cambodia has high maternal mortality compared to other countries in the region. An elder woman in Sann's village assists at deliveries on request, but she is not formally trained and is unable to make a difference

Access in the rainy season

when the mother is bleeding or the delivery is obstructed. When the midwife cannot come to the house due to landmines, floods or lack of communication, the same problems restrict the mother from reaching the clinic.

The social indicators in Cambodia are substantially worse than in its neighbouring countries. Around 20% of children do not attend primary school. Only one girl for every three boys attends secondary school. One baby out of 10 dies before reaching the age of one. Only around 30–35% of births are attended by skilled health personnel. There is a high prevalence of HIV/AIDS and only one third of the population in the countryside has access to clean water (Weggel, 2007). In the cities the situation is better; the national statistics do not reflect the unjust distribution of resources inside the country.

Poverty is a significant cause of disability, as pointed out in the examples of landmine accidents caused by lack of alternatives to making a livelihood. In addition, lack of access to basic healthcare means that simple infections, illnesses and injuries often result in permanent disability because they go untreated or are even mistreated. Poor nutrition is another cause of disability. By the age of two, half of all Cambodian children are stunted and malnourishment is a major cause of developmental delay and long-term intellectual disability. Iron and iodine deficiency can reduce intelligence and Vitamin A deficiency is the leading cause of childhood blindness. The United Nations (UN) concludes that 'Cambodia's tragic and recent history of war has left it with the highest proportion of disabled people in the world' (UN ESCAP, 2002, p 15). The benefits of national economic

growth have not had a major impact on reducing poverty, and rural communities have in particular been neglected. The situation for the poorest of the poor shows a downward spiral over the last 10 years: 'the share of real per capita household consumption for the poorest 20 percent fell from 8.5 percent to 7 percent of total per capita consumption' (WFP, 2007, p 16). The fact that inequality has been expanding rapidly while a significant proportion of the population experience absolute deprivation makes it unlikely for Cambodia to reach the targets of the Millennium Development Goals (MDGs).

Thavy

Thavy, a soft-spoken, 16-year-old female, was waiting for us at the health centre in Samlot. She had been notified by the local medic that we wanted to talk to her. "We" were a delegation of two foreigners with a translator and a fieldworker from TCF-C. However, we wanted to see her in her home environment and following a discussion she agreed to come with us in our car. We drove through the forest on a dusty path as far as it was driveable. From the car we walked through fumes of smoke and charred tree roots protruding from the burnt soil where the settlers had cleared land for slash-and-burn agriculture. The area had been in the war zone and had never had any professional mine clearance. It was a chilling feeling as we walked uneasily through the area, taking guidance and keeping our feet strictly on the path the villagers were using every day. The last three days they said that they had heard explosions from mines spontaneously detonating because of the fires in the grass. Luckily no one had been injured. The interview took place in the shade below the house, built in traditional style on stilts. Together with Thavy, the other seven people in the household were present: her parents, two sisters, a brother-in-law and two infants. The family had planted rice, beans, peas and pineapples on the new farmland surrounding the house. Her father limped to the scene, a result of a stroke that had weakened his left side and, as Thavy said, had affected his brain. He sat quietly, listening, but not adding to the conversation. The family moved into the forest and started clearing the plot in 2000 and the father had cleared most of the forest with his one normal functioning hand. Lately, his son-in-law had assisted him. They had also removed numerous "objects" from the ground with the utmost care. These were presumably different explosive remnants from the war.

   Thavy was injured at 9am in the morning when walking on the road in the heavy rain. She was about a kilometre from home on her way to buy medicine from a local vendor and there were no adults around. She was not worried about mines because "everybody" was using the road regularly. There was heavy lightning and thunder and she didn't understand what had happened in the unexpected explosion. She was confused and didn't realise why she had fallen. When she understood that her leg was gone she tried calling for her sister. But nobody heard her cries. Around half an hour later, a man passed by, saw her and carried her on his back towards the health centre. He stopped at his house on

the way as she was in shock from the loss of blood. She had tried (unsuccessfully) to stop the bleeding with her own scarf. It was raining heavily and she felt very cold. She also described her emotional state as "in panic". She was unconscious on arrival at the health centre where the medic bandaged her leg, wrapped her in a blanket and gave her intravenous fluids. She was transferred to the surgical hospital in the provincial capital escorted by three relatives, her mother, sister and brother-in-law, and stayed more than one month in the hospital. She was fitted with a prosthesis six months later but it was too loose on the stump and needed adjustment as she grew. She got another one fitted a year later, still in use at the time of our visit, although by now it was too tight and had caused blisters on her skin in the heat. The prosthesis was a bit shorter than her remaining leg so she walked with a limp. But she had no chance of doing anything about it until her school holidays. Then she might be able to go to town again, depending also on her parents' finances at the time.

Thavy explains that she feels frustrated and angry when walking with the prosthesis and that she cannot do the same as she could before. She cannot carry water. Activities are more complicated and painful now. But she is able to use a bicycle and can cycle to school. She knows another girl who is disabled from a mine accident who is also an amputee. They used to meet on the way to school. They talk about ordinary, daily things like other young people, but sometimes they talk about living without a leg. They feel worthless and ashamed about how different they are from other girls. Thavy used to play with the other girls before but when they play they run, and now she can't. So she tends to withdraw socially from interaction with others. It is no problem at school but others call her names and tease her because of her "unnatural" leg. This makes her shy. She is in grade 6 at school. She dreams of continuing until grade 12 but does not know if that is possible. She will most likely have to start earning her own money. As a disabled female she believes she will have to manage on her own and is unlikely to get married. She is interested in being trained as a tailor or in setting up a bride grooming beauty saloon, but will need assistance from an aid agency to be able to do that. There is no governmental support. Everybody has to manage their own lives and her family is very poor. She hopes that she will be able to earn a living as a tailor, even though she and her family live in the forest, quite far from the market.

Every time she walks in the area where her family lives she is afraid. She is worried that this might happen again and that she could risk losing her other leg. She is also worried about her sister's children or her father when he is clearing the land. She seems a bit surprised about our questions as everybody knows and it is obvious that "living in a mined area means living with fear". But they have no other place to live and as a daughter of the household she is fully dependent on the decision of her parents.

The Cambodian social system is generally hierarchical. The main determinants for placement within the society are age and sex. Culturally and socially defined gender roles traditionally place men higher than women in the hierarchy. This

could also be explained as part of Buddhism where being reborn as a male is believed to be better. But symbolic markers also include a range of other factors such as wealth, reputation of the family, political position, individual character and employment. The traditional division of work in a farming family may be changed as a result of disability and impairment and many families show much flexibility when solving daily problems. But some spouses leave when their partner becomes "powerless". It is hard to determine how pervasive beliefs related to destiny and ill deeds are and to what extent disruption of a traditional family is caused by the fact that it just becomes too much to bear. Many victims describe feeling guilty about the accident and that they worry about other people's perceptions of them. Informants in an interview study (Taksdal, 2002) seemed convinced that exposure to risks and protection from harm were linked to a person's inherent qualities. While some people seemed to see themselves as "resistant" to the impact of mines, others were more prone to accidents. It was also possible to improve resistance by "magic", such as protective tattoos against bullets and mines. The explanation of "karma" as a predestined quality that can hardly be influenced by current actions, is described by words such as "luck", "unluck", "faith" or "destiny". Clearly, some did not see it as arbitrary who was injured. If many people chop wood in the same place, why did the mine explode on one of them in particular? The victim may suspect that they have done something wrong in a previous life to deserve this ill faith of living as a disabled person suffering chronic pain. This perception may account for some of the problems disabled people have in getting back to a life with dignity and also when they complain about discrimination and social exclusion. They, as well as their social environment, may conclude that they have 'bad karma'.

The head of the pagoda in one of the villages explained his understanding of the Buddhist interpretation:

> 'The Buddhist faith mentions some explanations for the disability. First it may be *karma*. If in a previous life you have acted badly, you may suffer in this life. If you have previously acted well, you will receive good. You can be born into this life as a healthy person and become well educated because of the good you did before. This is Buddhist understanding. If you are bad and know you have behaved badly you can do something good. But you cannot mix good and bad. If you mix, you will receive both good and bad in the next life. If your bad actions are serious, you get the bad first. Those who share the conviction that you face bad results sooner if you have performed particularly bad actions in a previous incarnation, will feel that an injured child has worse karma than an adult victim.'

Some of the victims try their best to improve their chances in the next life. Doing 'good' is related to helping other people in need or supporting foundations in Buddhist wisdom: helping to build a temple, giving food to the monks on a daily

basis and giving clothes for the monks during religious festivals can improve your merits. There is a widespread use of offerings to small Buddhist shrines that most people have in their house or garden. Incense, fresh flowers and fruit are placed there to soften the spirits for a positive outcome of daily activities or for special events like weddings, travel or transactions. In a belief system with an holistic perspective of forces influencing each other, it may be unjustified to draw too rigid conclusions of one aspect. Even if the Buddhist faith explains things as the result of previous lives, the person who is suffering in this life has to struggle. Individuals with special needs place a burden on their family, a burden some families would not be able to absorb, irrespective of beliefs. Most families do their utmost to take care of the needs among the family members, as the family constitutes the first line of care. With the high proportion of disabled people in Cambodia where so many people know someone disabled or have a disabled relative or neighbour, this is probably altering the understanding of previous beliefs. A key factor seems to be to what extent the victim manages to re-establish a normal life as well as his/her ability to not lose contact with their family and social network. In daily activities, people make choices according to practical possibilities and limitations caused by poverty, rather than from faith.

Self-help groups

TCF-C, with the slogan 'Save lives, save limbs', is assisting trauma victims in reaching the clinics alive. Through networks of first aid-trained lay villagers and medics at health centres, TCF-C has built a 'chain of survival' from the minefields to the surgical hospitals in the city. However, the medics, although pleased with reducing the pre-hospital deaths, reported that the disabled survivors suffered from chronic pain and depression, and lived 'hopeless' lives in their villages after discharge from the hospital. Could something be done to help them, besides distributing analgesics? A study was conducted in cooperation with Tromsø Mine Victim Resource Centre (TMC),[4] and concluded that the only correlation to the severity of chronic pain in the survivors was poverty (Husum et al, 2002). The hypothesis that poverty itself acts as chronic trauma was the rationale to initiate the self-help programme aimed at improving the economic situation and subsequently to act as a 'painkiller' for the victims.

   Sok from Sam Lot was selected to become a member of a self-help group which included five members, all male subsistence farmers, who had all lost (at least) a leg. Sok tells how he joined the group: "One day soon after returning from the hospital, my uncle went to collect bandages and medicine for me. The medic remembered that I was newly injured and told my uncle that a poor, disabled man like me could be offered the chance to join the cow bank project. My name was registered by the medic from the time when he helped me and I was very happy to be informed that I would receive a cow. I really did not want anything else, just the cow!" Some of the others in the group wanted a loan, but for Sok the cow was very welcome. There was plenty of grass around the house and his wife or

his mother looked after the cow when he was at the farm. The first calf was born the first year and another one the next. Sok had become emotionally attached to the cow and had difficulty in deciding whether to keep the cow or the two calves, which was what he ended up doing. (The returned cows were then given to new members.) When Sok decided to keep the calves, he said he was sorry to give the cow away. "I love the cow and feel that it belongs to me and I hope that the other family will take care of it. It brought a lot of luck for me and I feel sorry to separate the calves from the mother." Unlike a pig, which partly feeds on the same food as people, the cow eats grass, leaves and banana stalks. The main benefit of a cow is its reproduction. A cow can be used as a guarantee for a loan and can be sold very easily. When a cow produces a calf every year or two calves in three years, this helps pay for the building of a house, paying for education or social ceremonies, the bride price for arranging a wedding or covering the costs of medical treatment. A cow is valuable property in the household, Sok says, adding that many people have asked him why he got the cow when there are so many poor people in the area. His understanding is that TCF-C only helps the poor disabled, as they are not able to conduct business in the same way as those with their bodies intact.

The members of the group try to have regular meetings. They have a group leader and usually the medic also participates. Sok explains: "We meet with each other to discuss our problems and how to look after the cow or the business. We also have fun and laugh together, and try to meet once a month. But all of us cannot meet all the time, because we are busy with our lives and work hard with the farming. During the busy months we go to the farm early in the morning and return late in the evening and there is no free time to go out just to meet." In his group they also tried to start a savings system, so that the group itself creates a buffer for unexpected expenses. But only two members of the group have had any surplus to save, so it has been put on hold. Sok sees the benefit of helping each other financially to avoid the money lenders and their high interest rates. He even thinks about other poor people in the village. When they are in trouble, they may borrow money from the group at a lower interest rate than the money lenders. In that way, the group member may get a slight return of their saved money, a tempting idea in a country where there is no real access to a bank account for the poor.

Although he has friendly relations with the other members, he has not shared the problems related to his divorce. He feels it would be a loss of face and the others couldn't help anyway. He understands that his wife had to take on many extra tasks because of his diminished strength and that he was moody and frustrated. "I get angry quicker than before because there is nothing I can do. I get angry quicker because of the difficulty in being an amputee and because I have to ask people to do things I used to do myself. When I asked my wife and she refused I was very angry, and I was more tired than before I was amputated. I was working harder with fewer results and I felt pity for my wife who had to do so much. Before I used to carry the water if there was no rain and I had to fill the water

jar at the house. Before, I could go to the river 20 times to refill the jar but when my stump aches and I lose my balance, fall down and come home with a broken container and no water. My wife said that she wanted to help when I was very tired, but I felt useless."

In some of the self-help groups, the meetings seem to create friendships among the members. They share experiences on being disabled in a country with many prejudices against people "who are not whole" and practical tips on how to avoid problems or treat muscle spasms and blisters on their stumps. They talk about signs to look for in the health of the cow, how to contact the veterinary service and arrangements for breeding. They discuss aspects of improving the business for those who have loans and occasionally the medic and TCF-C field workers attend the meetings as a follow-up. Thavy, as a young woman, is a member of a group with adult males only and they live so dispersed that it takes a day to arrange a meeting. They use the health centre as the meeting place. One of the members of her group said that "We have to work all the time. We are clearing, ploughing, tilling, all the time doing something. We have no time just to meet." A girl like Thavy has no influence over savings in the group, as long as it is her parents who control the family's income. Thus the medic is an important contact person for the group members. He comes to see them at their homes individually and Thavy describes the medic now as a friend of the family. The ability of the group to function depends on the geographical distance between the members, the age and gender and their 'free' time.

The head of the group in which Sok is a member has taken an active role. He is a father of four, grows rice, cashews and fruit and used to fish and catch snails and frogs in the rainy season. He is concerned about the emotional state of the returning amputees, remembering his own despair when he lay bleeding in his garden and felt that he would be better off dead than as a burden on his family. He says that people fall sick from "thinking too much" when they are inactive. Then they feel every ache and pain, worry and become depressed. "When I am busy I do not even think about being an amputee. With the prosthesis I can use my hands and I can do everything like before, but with some more difficulty." He has started visiting the new mine victims when they come back, whether they are members of the group or not. He tells them, "I was like you." He supports their emotions, their spirit and the feelings they have and encourages them to accept what has happened. He knows it is difficult because he has been through it himself, but he stresses the importance of having a focus. "What is gone is already gone, think about the things you can do!" He also shows them his own mobility with the prosthesis. Sok feels that the group leader has been a strong supporter in his own healing process.

Through TCF-C new victims have access to locally produced walking aids to help them get up and start moving. While waiting for a fitted prosthesis from the rehabilitation workshops in the city, which can take up to six months, there is plenty of time for pain and depression to grow and for debt to accumulate. "In Battambang city you see amputees as drunkards and beggars, but here in the forest

we take care of each other," Sok says. There is no difference in value between ordinary and disabled people, he adds, and he does not believe that mine victims deserve what happened as a punishment. "We did not lay the mines and we are hard working, but life is very strenuous. There should be a system to help the needy. Those with full limbs can easily move as they like but in the rainy season we cannot move with wheelchairs or crutches and our artificial limbs get stuck in the mud. We cannot go to the market to sell our products and we are stuck." The notion of the limitations it brings to be living in a mined environment can be summed up as "living in a prison without walls".[5]

In Cambodia there is no social safety-net granting a pension or compensation to the civilian disabled, a system some interest groups are lobbying for. After the demobilisation of soldiers in 1998, veterans, according to certain conditions, got a monthly pension based on their military background, or because of disability. One of the group members is an ex-soldier with both legs amputated above his knees from two different accidents. He is entitled to a pension of nearly US$30 per month. This pension had to be collected personally at an office in the city, which made it a two-day journey every month. In connection with an incident concerning illness, he had to mobilise cash rapidly and the lender demanded double the amount back. The lender has taken over the right to his future pension until the end of 2009 (nearly three years). Now he is trying to feed his family through a soup kitchen at the roadside, financed by the micro-credit scheme of loans from the TCF-C. Many of the members focus on the value of getting interest-free loans with a reasonable pay-back time, as it gives them a fair chance. "The interest-free loan is a real help" and "this is helping and not just business", are some of the statements from the members. Whatever income-generating activity they start with the loan – tailoring, battery charging, a local cinema or motorbike repair – the income is unpredictable and seasonal. Tying up the return payment in fixed monthly rates may be too inflexible. Typically the households are in deficit before the harvest and some people even talk about "the hungry season". The effect of the loans on the family economy in a three-year perspective shows positive results, and preliminary results of ongoing research[6] indicate that the pain problem is reduced. As long as the family has a standard of living on the same level as others in the community, the disabled family is seen as the same as any other family. The stigma of disability seems to be attached to being a burden on others. But if you behave like the social norm dictates, self-reliant, polite and friendly, the disabled person in the village is invited to social ceremonies and lives an ordinary family life as before.

Conclusions

"My story started from food shortage and hunger," said Soda, a self-help group member from Baval. Now he is feeding his family through repairing engines and bicycles from a repair stall at the roadside. His son is an apprentice in his business, a business based on a vocational training course when he was newly amputated

and a workshop equipped through a micro-credit loan. He had no chance of farming for a living because of a permanent joint injury in his remaining leg. His loan is now paid back and although he is bothered with muscle stiffness and occasional cramping in the amputation stump, he sleeps well at night. He does not worry about his livelihood: "I earn a surplus these days," he says. "My kids go to school and my wife wants to start a small shop in the village." The road and a stretch of land on each side towards the clinic have been cleared professionally. He is hopeful that his children and grandchildren will manage well. "Maybe in the future children will not even know what landmines are," he wonders. Soda doesn't say much spontaneously, neither does he say much about his life when asked. Often he responds that he doesn't remember or doesn't know. Like most Khmers he prefers to leave what has happened behind, tries to forget the bad things and looks ahead, not to re-experience trauma! He has lived through too much, as anyone with a minimal knowledge of Cambodian recent history can imagine: external and internal war, heavy bombardment, running through a burning jungle, losing all property, being displaced and at the mercy of others, living in a suppressive political environment and barely surviving from day to day; starting a family and almost losing everything because of a landmine; and an explosion shattering his body when he was giving the draft animals he borrowed to pull the cart a cooling bath in a pond when collecting bamboo in the forest. "You cannot understand the lives of the poor disabled in Cambodia," he says. "It is a miserable life."

Narratives in this chapter, stories from landmine victims in rural Cambodia, have illustrated aspects of the vicious cycle of poverty and disability. Because of a lack of a decent livelihood, people living in the minefields have to expose themselves to continued risk of traumatic accidents. In addition they have less access to healthcare and rehabilitation services, making the outcome of accidents worse. Living in poor areas with lack of proper education and alternative livelihoods, the possibility for the next generation to create a better future is limited. The children in poor households with a disabled breadwinner are at risk from dropping out of school and having to work at a young age. The vicious cycle is not limited to the individual person but continues to include the whole family and into the next generation.

Notes

[1] 'Bomblet' or 'bombie' is the term for small bombs inside the 'mother bomb' in cluster munitions or cluster bombs.

[2] The names used in this chapter have been changed, as well as some of the details in their stories and location. The people mentioned are members of self-help groups supported by Trauma Care Foundation (TCF-C) in Cambodia

[3] International Committee of the Red Cross. They operate an orthopaedic centre in Battambang city.

[4] TMC is an action research centre aiming at improving local communities' resistance to the impact of war and suppression. It develops teaching material in advanced first aid, and trains local instructors in the countries where they carry out their projects. See www.traumacare.no

[5] This was a quote from one informant in an interview study conducted in Battambang province in 2000, resulting in a Master's thesis with the same title (Taksdal, 2002).

[6] Qualitative interviews with members who finished the intervention before 31 December 2006.

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Poverty as trauma: methodological problems when reality gets ugly

Hans Husum and Odd Edvardsen

Rehabilitation means re-building my habitus, my home, the position where I am I. By this we are face the unpleasant question: *who am I?* Like it or not, we are taken deep into the field of identity politics where three basic questions have to be answered: first, accounts of reality depend on position in space – the account of reality as seen by the insiders, the downtrodden poor, is different from accounts set up by privileged outsiders of brief transit study missions. So, what are the voices we hear in research reports from oppressed communities? Second, knowledge is also situated in time – places, people and identities are in process and carry a history (Haraway, 1991). Do we find it convenient to study this history? A lecturer in international health once opened her presentation about a field mission in Africa by a beautiful landscape slide, saying, "And here was I, in the middle of nowhere." She had spent some months exactly where one of the East-African old cities – now destroyed – was located some 3,000 years ago. Third, if it is so that differences of class, human rights, gender and so on have been disguised by privileged readings by outsiders, what are the conditions, then, for making the invisible visible, to hear the voiceless speak?

We can dance around these questions in the field of philosophy and theory of science, and we can probably also find some plausible answers by which we can comfort ourselves and guide our students. But when reality becomes ugly, the sympathetic nerve system makes our heart beat hard; muscles contract, we start sweating, our brain shrinks its focus, we stare out as through a tunnel; the back skin contracts just like a cat caught in the corner. We can agree with Sartre that 'the Other' is a threat to our own experience of 'Self'. Minefields and massacres are ugly; they catch us at point blank range and by instinct we protect ourselves from danger.

In this chapter we want to use the examples of minefields and aerial bombing to reflect on some methodological problems in research on poverty issues. Here is a typical case story as told by one of the research informants.

Abdul's story, told by mine medic Hikmat

I am Hikmat, a medic from Tawela, a mountain village in Halabja District close to the Iranian border. My village was a battlefield between the Iranian and Iraqi armies. For that reason a lot of mines have been placed; some are removed, but many are left in

Abdul. Photo documentation from field studies in 2001

the mountains and in the gardens. After the Uprising in 1991, the villagers went back to the villages because life in the city was bad due to the embargo. Their main source of income in Tawela was farming and cross-border trade from Iran. For that reason many people were killed by the mines. At that time I worked in the small health centre in Tawela. We were short of gauze, of intravenous fluids and most other equipment. And we didn't know how to manage the mine injuries. Anyone injured by a mine was taken by the villagers into a car and rushed to the city hospital on long and bad roads while bleeding and in pain. As a nurse in the health centre I faced this problem daily. In 1996 I was selected to participate in Trauma Care Foundation's training programme for mine medics.[1] They called it the 'Village University'. The course was hard, 15 days of training and lectures day and night. When we completed the course we got the certification and a medical kit, the Burma-pack as we say, and returned to our villages to implement the Village University lessons for our own folks. We collected common villagers and taught them basic life support. After that, we selected some as our first aid helpers in order to inform us when any accident took place. We told them that from this day we would not wait for the injured to come to the health centre, we would rush to the site of the accident and start to treat them there. We also collected the drivers and told them that after this day they shouldn't take the patients directly to the hospital; the victims should be treated by us first and then we would follow them to the hospital. We showed the Burma-pack to everybody and told them that we now had all the medical necessities for any emergency case.

Let me tell the story of one of the patients that I treated. It happened a very cold winter night; I think it was in 1999. The snow was falling and most villagers were sleeping or sitting around the stoves talking about life and hardships. At that time there was an embargo on Iraq and we were short of everything. At night time some men used to cross over to the Iranian side to bring back flour and other food stuffs. Border crossing was illegal so those people had to operate during the darkness. Abdul was one of those people, a young guy, 20 years old. He was living with his parents in a very small cabin. Abdul had to care for his parents because his father had psychological problems after his village was destroyed by chemical bombs; he never came out of his house. That winter night Abdul and Massoud, one of his friends, were carrying flour from the Iranian side. It was snowing heavily and they lost the way in the high mountains. Around midnight, one hour from Tawela, Abdul stepped on a Valmara, a jumping fragmentation mine. Massoud had participated in my first aid helper training so he packed the wounds and placed Abdul with legs up in order to reduce the bleeding. Then he ran to Tawela to warn me. After one and a half hours we got to the site of the accident. I found Abdul with both legs blown off and severe injuries to the upper limbs. He was unconscious, but responded to pain stimuli. Most of the people from the village training course came with me to the site of the accident. One of them brought warm water; three of them compressed the femoral artery and the brachial arteries; some of them helped to prepare intravenous fluids, and some helped to pack the wounds.

When we were working with Abdul that night, I remembered all the advice of doctor Hans and doctor Torben from the Village University. I placed two large intravenous cannulas and gave him painkiller and warm IV fluid. We packed all the wounds with gauze and I put the pressure dressing with elastic bands criss-cross from the amputation stumps up to the groins. To keep him warm we placed plastic bottles with hot water over his chest and in the arm pits, and covered him with four blankets before taking him back to Tawela. There we found a car and I went with the Abdul and some of his relatives to the hospital. Because there was a local war going on between Talabani and the Islamic Movement we had to pass many military checkpoints so the transport took time. Abdul's relatives were very worried for him but when they saw that I cared for him all the way they calmed down. I told them that he wouldn't die. In the morning we arrived at the Suleimaniah hospital.

The job we did for Abdul gave us self-confidence. Back in Tawela I told the villagers that I could manage any emergency case. Abdul did survive. In the hospital they amputated both legs over the knee. He is still living in Tawela where he makes local Kurdish shoes for sale. His father died, unfortunately. He is now supporting his mother and his wife; he got married just some months ago. Now Abdul and I are very close friends because he knows that I helped him survive.

Finally I want to say that this is just one example of patients managed by the knowledge from the Village University. And that's all. [2]

'The illusion of objectivity has a protective function' (Habermas, 1979)

Our own routes to studies of poverty as a trauma has not been easy. We grew up with radio news from the bloody victory of the Algerian revolution and the US marines' massacres of Vietnamese peasant villages. When the Soviet army smashed rural Afghanistan in the 1980s we went there to study war from the point of view of 'targets on the ground'. The Afghans taught us two lessons.

First: modern warfare is worse than 'we', the manufacturers of 'smart' bombs and jet fighters, can think of. The pain and fear of children torn to pieces at home – in their habitus, inside their safe harbour with the smell of boiling rice in their nostrils – is beyond imagination. How can we understand the hopelessness of a mother who has lost children to land mines, and still has to wait for the next bang with more children mangled or dead? And it is even harder to understand the price of endurance the poor peasants have to pay – for there is not just one bomb, but many; not one land mine, but thousands; not one war, but repeated wars of colonialisation fought by 'us' against 'them'. Guernica, Dresden, My Lai, Gaza, Helmand, Fallujah, Abu Graib: structural poverty is killing millions of children yearly. In this dirty context 'few' and 'many' represent different qualities because each massacre modifies conditions for recognition. Herein lays the urgency of giving voice to the voiceless if we are to seek a serious understanding.

The second lesson told by the Afghans was this: "We will never give in!" On the one hand, this standing is based on Afghans' deep-rooted distrust and hatred of 'us' as Westerners – for good historical reasons. But this attitude – 'we' and 'you' are different – was as much a foundation for coping. We met the Afghan 'we': the Afghan patient was not a passive recipient of medical attention; rather his family and the entire village were active parts of the medical team as surgical assistants, blood donors, nurses and cooks. We thought that villages bombed to saturation level or caught inside minefields would stand no chance of survival. Instead we learned how scores of villagers rescued their wounded even under fire, organised forward clinics, built makeshift training centres and made us feel confident and 'at home' inside the war zones. That was during the 1980s. Now, more than 20 years later, we see in the paddy fields of Cambodia and the plains of Mesopotamia that the war is still going on. The banners and the rhetoric of the perpetrators have changed, but war is still the condition. Gradually we came to realise that the nice desktop concept of over-lapping hermeneutical circles learned in university libraries – 'our' world and 'theirs', connected by some sort of empathetic measures – breaks when it comes under fire. In war there is no safe position from where you can contemplate on 'their' representations of the world: either stay or leave;

either inside or outside; either with us or against us. There is no third space for 'objective' reflections here.

Saving lives – for what?

We are professional trauma care providers and teachers. Having learned in the war theatres of Lebanon and Afghanistan in the 1980s that at least one patient had died on the way for every patient reaching the operating room alive, we left the hospitals to set up rural chains-of-survival with some colleagues from the University Hospital Northern Norway. We deliberately sought out the world's worst landmine areas and found two of them, one at the Iranian border in Iraqi Kurdistan and the other along the Thai border in northwestern Cambodia. This was where we set up the 'laboratories', where we met the medic Hikmat from Tawela. The research question at that time, in 1996, was: 'The victim starts dying at the time of injury. If half of war and mine victims die on the way and most of these deaths are avoidable, are we able then to reduce deaths by teaching somebody along the roads how to stop bleeding and how to keep the airways open?'. In a systematic massive medical intervention we set up makeshift training centres – 'village universities' – inside the minefield areas, where groups of carefully selected local nurses, midwives, ambulance drivers, farmers and teachers learned basic life support techniques and were certified as medical instructors. Within three years 5,000 villagers were trained by these instructors under bold slogans such as 'Khmers teaching Khmers'. More than 1,000 victims of war and landmines were carried by a network of warm hands towards the hospital, all injuries and treatment being carefully registered, coded and computerised. When we eventually pushed the button 'multi-factorial analysis' in 2001, the graph came out nicely (see Figure 11.1).

  Many lives saved; we seemingly had good reason to celebrate (Husum et al, 2003). However, chilling information soon started to come from partners inside the minefields of Cambodia: "Doctor, what can we do for the survivors with chronic pain? We have tried all kinds of analgesics and tranquillisers, but nothing works on them. Some of them have even killed themselves." We were obviously facing an important problem, not previously recognised by us outsiders. Consequently we undertook a study of 57 landmine accident survivors in Cambodia and Kurdistan. All study patients had been injured at least one year ago, and all of them had severe injuries. The findings were shocking. One of the case reports goes like this:

> RK, 16-year-old male farmer from Penjwin, close to the Iranian border. Before the actual injury RK had seen a neighbour die in a mine accident. He had also sustained a bullet injury himself during the Iran–Iraq war. Having lost his mother and father during previous massacres RK now takes care of his sister who is severely handicapped. While herding in November 1997 he stepped on a blast mine. After one hour he was found by neighbours

Figure 11.1: Death rate in land mine victims, by year
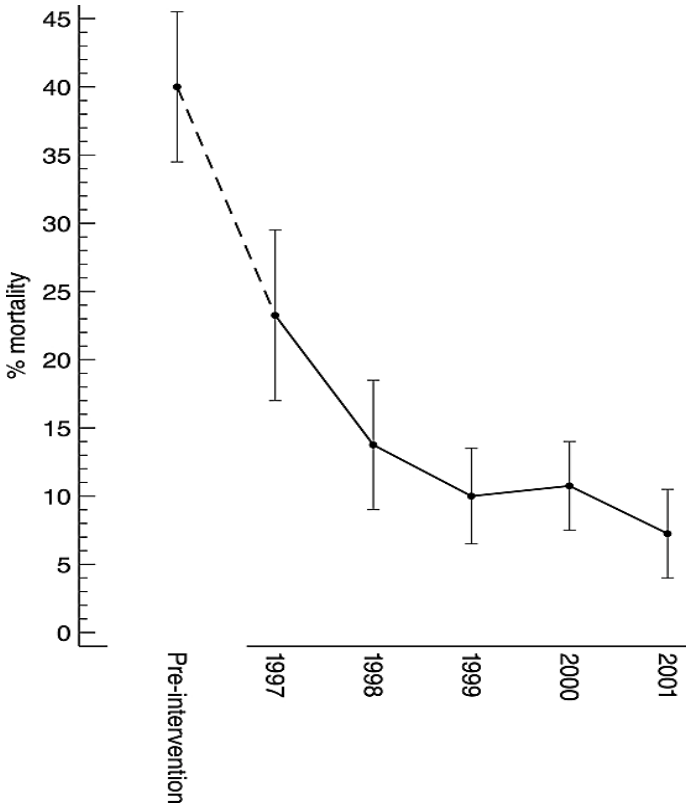
and carried to the local medic. His blood pressure was low, 80mm Hg, and he was breathing rapidly. The medic controlled the bleeding, gave four litres of intravenous fluid and four doses of painkiller before taking him to the hospital. He arrived at the hospital more than five hours after the accident in reasonable shape. His right leg was amputated below-knee and his fractures managed by external fixation. Due to postoperative wound infections he had four re-operations and stayed 50 days in the hospital. Prosthesis was fitted five months after the accident. He is now herding cattle again in the same grasslands where he was injured. He looks far older than his age.

In the study of survivors we used clinical pain examination, visual analogue scale self-rating and interviews to examine the pain problem. Three quarters of the mine accident survivors had chronic pain syndromes to such a degree that they could not carry our daily duties, socialise or wear prosthesis. Half of the patients felt that their pain was still increasing more than one year after the accident. The levels of pain carried no correlation to the quality of primary trauma care for the actual injury. However, levels of pain correlated strongly with poverty. Most

study patients belonged to poor families in work-intensive households – in those families where times became even harder after the accident – due to debt caused by medical expenditure or inability to attend their farms – we found the survivors with most pain (Husum et al, 2002).

We started to understand that pain is the price you have to pay when hardships are chronic. We can stop bleeding and heal wounds, and should, of course, do our best to heal more wounds. But poverty acts as a trauma beyond our control. This had a dramatic impact on our understanding of trauma care: the historicity of trauma, trauma as a chronic state, blasts the Eurocentric concept of 'post-injury stress syndrome'; there is no 'pre' or 'post' for these families, but mines, war and poverty all the way. The psychiatrist Derek Summerfield conducted extensive studies of Western humanitarian psycho-trauma interventions in the war-torn South,[3] and sums up:

> Trauma programmes have not been asked for by survivor populations. The objectification of the understandable misery of war as a pathological entity apart ("trauma") – a technical problem to which short-term technical solutions like counselling apply – is a serious distortion and for the vast majority posttraumatic stress is a pseudo-condition. Millions of dollars from donors have flowed to programmes whose as yet unevaluated impact may include negative effects on survivors' meaning systems and traditional coping strategies at the very point when these are damaged or destabilised. No general case has yet been made for mental health to be seen as an appropriate realm for humanitarian operations for war-affected populations. The humanitarian field should go where the concerns of survivor groups direct them, towards their devastated communities and ways of life, and urgent questions about rights and justice. The core issue is the role of the social world, invariably targeted in today's "total" war and yet still embodying the capacity of survivors to manage their suffering, adapt and recover on a collective basis. (Summerfield, 1999)

Poverty as context, or poverty as machine?

RK, the 16-year-old boy who looks far older than his age, the boy who had to keep on herding in the same minefield where he first lost his leg (see above) – who is he? What is his habitus? There are two different approaches to the study of disability and poverty. We may look at the disability problem as one where disabled people try to optimise their function in a context signified by poverty, the unwanted condition – disability – taking place in a social setting where resources are scarce. However, if we regard poverty as an agency and not merely as a context, it becomes clear that the context approach falsely simplifies the problem. Poverty itself disables people: what is a 'father' but the person who takes

care of his children? As a minimum he should care for them in a way that their minimum basic requirements for life are met; the 'father' who cannot provide daily food and water for his children is a non-able 'father'. He may very well be able in the instrumental sense as a farmer or fisherman, having two legs, two arms and two eyes; having a donkey or a boat and the knowledge of farming/ fishing gained from his forefathers. But his instrumental resources cannot convert job hours to food for the children because somebody took the water and the land – be it the landmines, the Israeli army, United Fruit directors, river pollution and river dams, World Trade Organization (WTO) patent rights, environmental destruction…. Some external powerful agency has disabled the father as a 'father' and by definition made him a 'non-father'. He is disabled in his identity as 'father'.

Seen at a glance, by outsiders, poverty appears to be some sort of universal state rather than a specific process for a given time in a given place. We are conducting research in the matter of disability and poverty; they inform us, and we report: 'They are poor'. Period. As if the condition of poverty is a static and (more or less) universal one. However, the study matter presents itself differently if we see poverty as the denial of rights, as a condition constantly reproduced in a process of rights claimed and rights denied.

The poor 'father' (normally) does not passively accept the social framing inserted on him: for love of his children and responsibility in the role of 'father' every hour and every day he tries to make the best out of the worst, finding a little here and a little there, always on the alert for any resources to be allocated – like a hungry fox or a street boy in an urban slum. And not only is our poor 'father' vigorously active, but also his wife, his brothers, his neighbours and his entire community. At any time there is an army of powerless poor on the move inside confined, narrow spaces defined for them by some powerful external agency. Being on the move, life is unpredictable and constantly changing for 'the poor'; there are hopes as well as set-backs, small nuances of ugliness hardly observable for us, although of vital importance regarding the key question: 'do I have food and water for my children tomorrow?'.

Second, the privileged have to protect themselves. When the army of poor pushes on the frames and borders set for them, and even more when they try to break through, the all-mighty has to try to contain them, by military coercion (Mau-Mau in 1952 and Burma in 2007, for example), controlling production and trade (the WTO, for example), censorship (embedded journalism, the war on Gaza in 2009) or political manoeuvres (UN declarations, Millennium Development Goals etc). There is a well-trimmed and well-managed politico-social system in action, reproducing conditions of poverty that constantly disable our 'father'. We may rightly call this system 'the poverty machine'.

Third, the poverty machine is a man-made construct; as such it has a history where outstanding social engineers like Machiavelli, Clausewitch, Stalin and Margaret Thatcher – to name but a few – have made significant contributions. Unless we take this history into account we may come to under-estimate the efficacy of the poverty machine.

Fourth, the better we understand the poverty machine, the more we should admire our poor 'father' for his resistance, for his not giving in.

"War, poverty and death is normal"

We will now let some of the muted 'others' speak out. Some readers may ask why we find it necessary to present such ugly stories of maiming, torture and killings, maybe claiming that "these stories are extraordinary, in general the situation is not that bad". We object; the accounts of reality are worse; the stories told are not extraordinary, but ordinary. Euro-reason has for too long dominated readings of reality with sufficient power to establish its readings as universalistic.[1] 4 In traditional Euro-representations the massacres, firebombing of civilians and silent killings by mines represent the extraordinary, but for the victims those events are ordinary – death is normal. Before we start to define research questions of poverty and oppression and enter the field of research, reality should be set on foot; the ordinary should be re-established as ordinary. Only by redefining the 'extraordinary' as ordinary can we understand how much it takes for the army of poor to manifest themselves as 'normal' human beings.

"Have you ever been caught under the F16s?"

From 1969 to 1973 the US Air Force blanket-bombed rural Cambodia (Husum, 2003). Setting up the chain–of–survival system for mine victims in Cambodia we met with some older people who were able to tell us about previous wars. One of them, an old farmer in Sompouv Lun, a Khmer Rouge base area, told us about the aerial bombing (he was unable to say exactly which year):

> We had been in the forest for some days, hunting – my neighbours and I.
>> When we approached our village, we heard thunder in the sky.
>> Then a big noise.
>> Suddenly the ground was on fire.
>> Pieces of persons and animals were thrown in the air.
>> Houses and large trees as well.
>> But there were no enemy soldiers around, which surprised us.
>> You know, we had no knowledge of planes and bombs at that time.
>> Every night since then I have been awake
>> thinking of my wife and daughters.
>> There was nothing left of them. (quoted in Husum, 2003, p 52)

During the US invasion of Iraq in March 2003 we sat with Saya in her house in Arbat in northern Iraq. The village is not far from the Khurmal mountains, a stronghold for the Islamic resistance. While talking we could hear F16s and B52

bombers 'doing their job'. During incoming fire, Saya paused and listened. This is what she said:

> 'One Sunday morning in November last year, I went downstairs to get some water for the breakfast tea. I was living with my husband at that time, we were newly married. In the stairs I stumbled into a trip wire; then a sudden blast, and I was thrown to the roof. When I woke up I smelled burned flesh and saw that my leg was gone. You see, they had placed a mine inside our house during the night, to punish us because we had joined the Islamic resistance. The PUK peshmergas are clever in making booby traps.[5]
>
> 'My husband is a journalist. We joined the resistance both of us because we had no other options. Facing increasing corruption, mismanagement, public poverty and destruction of our society we had to do something. The political parties are all dead here in Kurdistan. The leaders are not even looking at us, they don't even see our children. Trying to rebuild a society where people could live a decent life – not man against man – that was our crime. For that they had to destroy my body.
>
> 'Now my husband is up there, in the mountains, under the American planes. I am proud of him. But every time I hear the planes, a tremendous pain runs from my amputation stump into my heart and all over my body. It is like electrical torture.
>
> 'Still I don't regret. What should I regret?
>
> 'Being in love with my husband?
>
> 'Wanting to live as a full human being?' (quoted in H. Husum, 2003, Notes from a field mission to Iraq)

Saya's husband was killed during a Cruise missile attack on a Khurmal village two months after the interview took place.

"Do you know the beginnings of chronic pain?"

The injured person starts dying at the time of injury. Of course the doctor asks how it happened and registers the injury mechanism and diagnosis. But everything and everybody is exterior to the person who got his body torn up. The written version, the doctor's story, is a socially produced story told by an outsider. A mountain farmer in northern Iraq tells another story – about the heart of the drama.

> I went down to the spring where the shepherds use to make tea.
> Suddenly I heard an explosion and was thrown to the ground.
> When I opened my eyes, I was inside a cloud of dust.

>The explosion had lit the grass on fire.
>I tried to move, but my legs were gone.
>I looked for my knife to kill myself, but couldn't find it.
>So I crawled to the spring and put my legs into the water.
>The water became red.
>I thought maybe somebody downstream will see the red water
>and come to help me.
>After the accident everything changed.
>I lost both my legs.
>Soon after coming home, my two wives died.
>So now we are poor.
>Everything is over. (quoted in Hedelin et al, 2006)

"Doctor, you're too late"

The stories citied are ugly, but still just snapshots, tiny fragments of a long history of lived hardship. The research problem – rehabilitation and coping – is one of action, of building something. It is a process from one position towards another. The nature of the problem thus makes historicity a necessary condition for access as well as understanding. In 2004 we studied poverty and coping in villages in North Iraq. During a tea break in the interviews with a mine medic – one of Hikmat's colleagues (see Hikmat's story above) – the father of the house entered, watched us sharply, and said:

>Your project is nice and we are grateful – but I am sorry, you're too late.
>   We fled the village during the Iran-Iraqi war.
>   When we came back we lost 35 neighbours to the mines in this small village.
>   They bled to death in our arms and we didn't know what to do.'
>(quoted in Edvardsen, 2006, p 88)

The landmine problem is but an extension of previous wars; the villagers rightly say they are still in battle with mines sold to Saddam in the 1980s by European countries, for example, the Italian Vallmara-69 jumping fragmentation mine which maimed Abdul in 1999 (see the photograph above). So, Saddam was a customer of the West when he bombed Halabja and other Kurd villages using chemical bombs. Then, in 1990, in an elegant turnabout, the United Nations (UN) imposed an embargo on 'The Evil' and his people. Within a year local people had to sell all their valuables to buy food; hunger and malnutrition became endemic. This also occurred in the Kurdish zone in northern Iraq. Based on Food and Agriculture Organization (FAO) surveys *The Lancet* reported in 1995:

>The moral, financial, and political standing of an international community intent on maintaining economic sanctions is challenged

by the estimate that since August 1990, 567,000 children in Iraq have died as a consequence. (Zaidi and Smith Fawzi, 1995, p 1485)

On 12 May 1996 Lesley Stahl's guest on the US television news programme '60 Minutes' was Madeleine Albright, at that time US ambassador to the UN:

Stahl: We have heard that a half a million children have died. I mean, that's more children than died in Hiroshima. Is the price worth it?

Albright: I think this is a very hard choice, but the price – we think the price is worth it. (quoted in Campaign Against Sanctions on Iraq, 1999)

We are writing in September 2009; the embargo on Iraq has been replaced by a 'war machine'. We recently studied the atrocities at close quarters in Baqubah Province, some miles east of Baghdad. While working routinely in a crowded emergency room at a local hospital something happened; there was a sudden silence; fear could be read in everyone's faces: a canvas bag was placed on one of the beds, inside were the heads of two local youngsters – nicely cut off just below the jaw. We all got the message: in this world we – somebody unidentified or the stealthy oppressor – can make anything happen to everybody, everywhere, at any time, for no other reason than simply being who you are.

What we want to say is simply that there are perpetrators and there are victims. Throughout history academics on research missions in the South have not always been on the right side of it – as seen by the victims. This fact poses problems of access and problems of understanding, the more so if the visitors disregard the impact of history's tracks of blood.

"The world is a very narrow place"

People don't hang their dirty linen out in public – they keep it 'hidden' in the backyard. Public stories, narratives told to outsiders at the main entrance, may not be false – which does not mean that they are true. We have to protect ourselves; it is normal not to share painful stories with anybody; we don't and neither do they. The hidden transcripts of oppression and pain are therefore hard to get hold of. Here, however, is one of them, Chit Chompa's story of her own death. This 13-year-old girl was one of four children caught in a landmine accident in January 2005 in Battambang, Cambodia. Three of the children died on the site; Chit died later in the hospital. The narrative is written by the local village medic who has spent his entire life inside the minefields, who was close to Chit and her family years before the accident happened – and all the way down.

'After the war many years ago, my family and other poor farmers came back to our old village. We were like newcomers with no homeland, no land to build a house, no rice field, no nothing. The village leader allowed us to get some new land, but this land is in

the war zone and full of land mines. We are young; we do not think about the dangers around us or the problems of our parents, so we just enjoy ourselves playing around near the family. Every early morning my father went out to clear the land for farming. Because we are poor we have to do this, we cannot escape from the danger zone.

'This Sunday we were off school. My mother was preparing food. Some of the big boys took the cows to the grassland. My father planned to clear land some way from our house. After lunch I joined six other children, and went over to Taqil village. There is a nice tree with fruit where we used to meet and play. It is a few hundred metres from my house. We were eating fruit there when Bun Chien called on Cham Sakon to come and see some strange item on the ground. Also my younger brother Chit Vanna, 12, came running from the house, a young girl running behind him playfully beating him with a stick. Bun Chien boldly told my brother to pull out the mine by the branch but Chit refused and said "I will take a report to the mine clearers about this mine because it is so close to our house." But Bun Chien challenged him: "If someone reports this, I will hit this mine and kill all together." We were frightened and my brother pulled on me to take the children home. He pulled so hard that I fell over. Then, suddenly, a big and very painful bang. Bun Chien had hit the mine with his knife. Bun Chien, Nea Sahon and Cham Sakon died immediately, they were just one metre from the explosion. The painful heart-bang hit many people around and they came running to the place of the explosion, the village first aid helper also. By hammocks and motorbike taxies he took all the injured to the health centre in Ampil Pramdam.

'Arriving at the health centre I am in deep pain. My breathing is fast and I am thirsty; I cannot see clearly, I just hear voices and feel hands touching me. Getting one bottle of fluid into my blood I can see better and recognise my mother, my relatives, my family and hear them talking. My mother sits at my side with my small baby sibling; I can hear her tell that this child is injured like this; the other child is injured like this. That made me very sad. I could hear somebody say that I have wound fractures on the thighs. Sometimes the fluid runs fast, sometimes it slows down. When the medic runs it fast, I can open my eyes and hear the other injured children shouting for their parents. I am worried that I cannot see my father; he is still out there clearing the land. Then I hear somebody say "Hurry up, hurry up, transfer her, transfer!" And I think, "What are they doing?" I don't know this place and don't know where to go.

'I wake up on my father's arm in a big, nice room in the hospital. Seeing father, my tears start running. In the hospital both Khmer and Barang doctors come to see me.[6] It is evening time now and darkness is falling. There are many other injured people around me, also my two brothers waiting for treatment. People are very busy. I hear them say my legs are not broken, there are large wounds only. I asked my father if they had to cut my legs off, but he said "No!" Then my feeling become hopeful again; my wounds will heal and I can walk as before. Even though treatment will take a long time, it is no problem when I can walk again. These are the words I hear them say. The doctors worked all evening and by midnight all injured children lay in beds next to each other, also my two brothers.

'But myself I am still in the emergency room. I had heard the doctor say "Your wounds are not severe" – but I am still in the emergency room. My strength and energy is going down and down. But still I can remember what I have seen before, the tree, the children playing. The time is passing. My mother had to leave; I know she left with a bad feeling. But the time cannot wait for anybody, it goes on. My breathing is getting weaker, my vision gets blurred again. My father tries to encourage me by nice words, "Don't worry, you are OK, no problem, you will get better." But I cannot hear voices clearly even if I try hard to catch the words.

'Early morning five o'clock things cannot wait for us any longer; my mind becomes confused and restless. I know the doctors helped us very much, and I am very thankful that they tried hard to save my life. But this is my destiny, my hopeless unlucky destiny.

'These are the last words to my father: I cannot live because the inside of my body is very wrong. Please father, don't make life hard for the rest of the brothers; don't beat them but care well for them.

'Then suddenly I am gone. Very young. My father and mother cared for me from newborn up to this time. Now there is no more left.

'The body is gone. The only thing left is the sadness behind. This sadness is carried by the father, mother, brothers and relatives.

'Everybody is crying for me: "Now she is gone." But they cannot speak to the dead body. Mother said: "I am sorry you have to live another place and you are now away from us. I am very sorry. You have to live alone without us in the new world."

   'Bye, bye family – all family.

     'Bye, bye relatives – you used to give hope and trust.
     'Bye, bye friends – all friends.
     'Bye, bye minefield – very dangerous.
     'Bye, bye world – a very narrow place.'[7]

Chit's story should make us reflect on representations: "How can a dead informant talk to us? This is far from reliable research data!" Narratives of murders and massacres are not presentations (immediate and unmediated) of the world, but re-presentations – or better, reconstructions – of lived experience set up in retrospect by the actual storyteller. Chit versus the landmine; the political prisoner versus the interrogator; Fallujah versus the US army; any photograph taken, any story told is a reconstruction defined by either of the two positions. Because both sides – for example, US marines and the citizens of Fallujah – tell a true story, ugly accounts of oppression challenge the researcher with a very basic and simple question: 'who are you, which story are you out for?'. There are dangerous military checkpoints,

mistrust and hatred so you are not normally able to get both stories; there is no room for neutrality here. As Western researchers we roam freely worldwide, this is our normal lifestyle. Victims of war and poverty, by contrast, live in containment. By his poetic representation of her death, Chit's friend, the medic in Battambang, makes a desperate attempt to make us globetrotting outsiders understand the containment of poverty, to help us re-establish a world vision (*Weltanschaung*) where what we thought of as extraordinary is seen as ordinary. Readers may, of course, find Chit's story irrelevant, but it is hard to claim that it is unreliable, that it is unscientific.

Over-defining 'disabled'

A mine amputee is not only defined as disabled by the damage to their body but also by the ever constant threats and damage inflicted on them by the 'poverty machine'. The agency approach to poverty – recognising the power of the 'poverty machine' – shifts the representation of disability from the individual and specific to the total: disability is everywhere. This raises an epistemological problem: as fish in the water are wet, poor people are disabled. The fact of wetness and disability are not meaningful characteristics – at best the terms are confusing – for fish and for poor people. We must scrutinise the meaning carried by seemingly meaningful concepts such as 'able/ability' and 'poverty'.

For the study object, for the Kurd father with one leg left, the implications of over-definition are far more dramatic. He cannot escape the fact of being legless – and the poverty machine keeps on redefining him as poor. Adjustment is impossible; there is no way out unless he refuses to accept the identity enforced on him – and rebels.

There is another problem here that also carries moral implications for the researcher. When people are oppressed for a long time, they tend to adopt the institutional definition of themselves as inferior – inferiority becomes internalised. There is a risk that studies where disability is seen as a marker event taking place in a non-actional and value-neutral context of poverty adds to the burden by confirming the father's self-image of being deemed a victim of the poverty machine.

Studies of poverty and tracks of blood – which, in the era of 'extreme sports', we could call 'extreme research' – pose methodological problems. Our aim is not to provide simple solutions here, but hopefully our own experiences from the war zones can at least help disclose some of the methodological and moral difficulties faced by researchers daring to study such ugly realities close up. We would like to conclude with a reminder from a philosopher of science, Theodor Adorno, the restless critic of mainstream and easy-going research:

> … to find out what is the truth – objectively – has always been hard. One of the most reliable criteria they use against you is that your statement is "too subjective"…. The concepts of objectivity

and subjectivity have been turned totally upside-down. For them, objectivity means the non-controversial side of the matter, the uncritical accept of superficial patterns, the frontage carefully composed of classed data – which is the subjective. And they say subjectivity is everything breaking through the frontage, that penetrating the specific experience of the matter, everything liberating us from the approved convention regarding the matter, placing our relation to the matter instead of the majority decision by those who don't look at the matter, and even less study it – which is the objective.... Those in power like powerless subjects, because they fear the objectivity that only those subjects carry. (Adorno, 2003, p 69)

Notes

[1] Trauma Care Foundation (TCF) is a Kurdish non-governmental organisation (NGO) running training programmes for trauma care providers in minefields and war zones.

[2] The full story was written by medic Hikmat in Kurdish and translated into English by Mudhafar Murad, TCF.

[3] 'The South' is a political term referring to poor and oppressed countries (see Mao Zedong's Three World Theory [http://reference.canadaspace.com/search/Three%20 Worlds%20Theory/]).

[4] Here we lean on Husserl's definition of Europe, not '… understood geographically as on a map, as if the group of people living together in this territory would define European humanity. In the spiritual sense the United States etc. clearly belong to Europe…. Here the title "Europe" refers to the unity of spiritual life, activity, creation, with all its ends, interests, and endeavours, with its products of purposeful institutions and organizations' (Husserl, 1970, p 273).

[5] At times the Kurd nationalistic freedom fighter has been called 'peshmerga'. The Patriotic Union of Kurdistan (PUK) is one of the state-bearing parties in north Iraq, now allied with the US regime.

[6] Barang is a common Khmer term for 'Westerner', originally used for the French colonialists. It means 'long nose'.

[7] The story was transcribed by Yang Van Heng, head of TCF, Battambang, Cambodia in January 2005. The English translation is by Merete Taksdal.

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Some concluding thoughts: the way ahead

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Disability and poverty and the relationship between the two are complex and dynamic phenomena and thus not easy to grasp in one theoretical model or within one scientific paradigm. As exemplified in the chapters in this book, explanations to the disability–poverty circle may be social, structural, political and cultural. A refreshing, and even provoking, perspective is brought forward in questioning the very distinction between the two (Hansen and Sait, Chapter Six). As both concepts have developed, they may at least be seen as overlapping. It is particularly interesting that this challenge to most literature on disability and poverty emerges through the voices of the poor and disabled themselves. This demonstrates the potential value of the particular methodological approach in this book and that disabled people and poor people have something to offer in the development of our understanding of the disability–poverty relationship.

It has not been the purpose of this book to develop or test a model of disability and poverty but rather to disentangle the complex relationship through a combination of perspectives, and in particular through the voices and experiences of individuals with disabilities themselves. We, as authors, believe that this is necessary in order to fully understand the working mechanisms behind the persistent situation of 'poverty within poverty' (Yeo and Moore, 2003) faced by a large number of individuals with disabilities, particularly in low-income countries. This is, however, not to say that other perspectives that are not included here are important and necessary in this endeavour, but without a systematic approach to the lived experiences of those who struggle within the 'vicious circle' (Yeo and Moore, 2003) we will only be able to scratch the surface of a huge global problem. Through the voices represented in the various contributions in this book, poverty emerges as the main problem for disabled people in poor contexts, and the dynamics of poverty strongly contributes to keep disabled people within the 'vicious circle'.

With the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), the World Health Organization (WHO) has evidently contributed to the discourse on the concept of disability. While the time period following the previous WHO model (International Classification of Impairments, Disabilities and Handicaps, ICIDH) (WHO, 1980) was marked by a pronounced contradiction between the medical and the social model of disability, ICF may be seen as an attempt at merging the two and bringing the development of a universal model a

few important steps forward (Shakespeare, 2006). Two of the chapters in this book (Eide and Loeb, Chapter Three and Braathen and Loeb, Chapter Four) are (partly) based on research that has aimed at utilising ICF by exploring new methods for survey-based measurement and analyses of disability (Eide and Loeb, 2006; Loeb and Eide, 2006). This type of research has the potential to contribute to the further development of a theoretically based conceptual framework for disability studies. In this endeavour different types of knowledge are needed, however, and there are certainly limits to the basically quantitative approach represented by ICF. Individuals' interpretation and understanding of their subjective experiences and situations are outside the scope of this book. This implies that an important perspective, that is, the perspective of the disabled people themselves, falls outside of the ambitions of ICF and that it is also necessary to look outside this framework to obtain a more complete understanding on how it is to live with a disability in different contexts, including the relationship with poverty. Without this perspective we run the danger of generating knowledge that may represent poor guidance for changes at policy level. A culture-sensitive approach to disability and poverty, in our view, quite simply requires an understanding of individuals' values, interpretations and understanding, as these are fundamental aspects to influence, utilise and/or incorporate for any sustainable change to take place.

Attitudes and even more so culture represent established patterns for understanding and reacting to a phenomenon. No doubt we can identify established and culturally rooted discriminatory practices that affect individuals with disabilities and their families, as for instance in the gender differences in Yemen (Ingstad, Baider and Grut, Chapter Seven). Cultural patterns are, however, not static, not even homogeneous in a society, and influenced by collective understanding and practices, and by structural and social factors (Ingstad and Whyte, 1995). While poverty is largely the result of structural and often international/global phenomena (see, for instance, Chapter Ten), a situation of permanent living in poverty will affect social relations as well as attitudes and, over time, cultural beliefs, and thus also how individuals with disabilities are treated. As described by Grut, Olenja and Ingstad (Chapter Eight), discrimination against disabled (children) may easily be seen as negative cultural practices, while another explanation may be that it is simply a forced reaction to poverty, largely a mechanism of survival or absence of options. Hansen and Sait (Chapter Six), on the other hand, describe a situation whereby collective efforts and solidarity contribute to change people's understanding and thus challenge the political and structural level in society.

The distinction between explaining discrimination and negligence of the needs of disabled people by culture versus poverty has direct bearings on how researchers, policy makers and other groups external to the situation perceive possibilities for breaking the poverty–disability circle. Emphasising culture may easily lead to inaction, as this is often regarded as stable phenomena or at least slowly changing over generations. Although influence, change and heterogeneity within nations and geographical areas are key aspects of culture, even in a globalised world,

patterns of meaning and practices will still be understood as relatively stable or slowly evolving, and sometimes even reinforced as social reactions to external influence (Friedman, 1994).

The structural level is one obvious level for explaining the persistent relationship between disability and poverty. As analysed by Sagli and Fjeld (Chapter Two), increased political interest for disability policy and development of health and rehabilitation services has not been able to provide necessary health services for the disabled rural population in China. A market economy, urban and gender bias combined with the particular political structures of a one-party state has produced a situation whereby services are provided for the most able-bodied of the male, urban disabled, while the poor, rural disabled are hit by increasing costs and inadequate health services in a situation of rapid economic growth. Likewise, the analysis of policies and instruments in Malawi and Uganda by Wazakili et al (Chapter One) reveals that a disability perspective is easily sidelined in poverty reduction efforts if not specifically incorporated in the process. The contradiction between the policy level and the reality of disabled people living in poverty is further demonstrated in the study by Hansen and Sait in South Africa (Chapter Six), where the introduction of a medically and individually based disability grant is countered by culturally based solidarity and understanding of disability.

Structural phenomena may be regarded as relatively stable. It is, however, evident that they can change quickly and be directly targeted for intervention. Several of the chapters in this book focus largely on structural and political phenomena for explaining the poverty–disability circle (Chapters Two, Nine, Ten and Eleven), that is, on phenomena that may be changed at a political level, either nationally or globally. Sagli and Fjeld (Chapter Two) demonstrate how shifts in economic and health policy and country-specific power relations have influenced the situation for disabled people in China, in practice creating more disability and strengthening the relationship between disability and poverty due to increasing health costs. In South Africa (Chapter Six) the introduction of a disability grant has contributed to social change and an emergence of a popular-based understanding of disability that counters the intentions of the policy.

Reflecting on the consequences for disabled people of political and structural changes, it may be argued that without putting the needs of individuals with disabilities in the forefront, there is a risk for maintaining the disability–poverty relationship even if this was not intentional and even in cases where the intention was to alleviate poverty. As seen in the example from Uganda and Malawi (Chapter One), the voices of the poorest of the poor are easily sidelined, even when they are crucial in combating poverty. Likewise, Muyinda and Whyte (Chapter Five) demonstrate that the exclusion and/or marginalisation of disabled people in essential service development in Uganda results in the needs of disabled people not being met, and consequently contributes to drive individuals and families further into permanent poverty. These and other examples illustrate very clearly that mechanisms are needed that ensure that the voices of disabled people are heard and acted on.

Husum and Edvardsen (Chapter Eleven), and in particular Chapter Six by Hansen and Sait, challenge the very distinction between poverty and disability; poverty *is* disability. Consequently, combating poverty equals the reduction of disability. This may be a very fruitful and not least politically powerful perspective in contexts where poverty is endemic and the consequences of poverty are particularly severe for individuals with impairments and their families. The view is further interesting in relation to the Millennium Development Goals (MDGs) (www.undp.org/mdg/) and the efforts of the international community to eradicate poverty. While the MDGs have been criticised for not including disability (Albert, 2006), it may thus be argued that it is all about disability in the sense that eradicating poverty will also imply preventing disability, alleviating consequences of disability, and eradicate disabling conditions. This may, however, be questioned simply by observing the situation globally. In many societies at different levels of welfare and economic state, there is a persistent pattern of disabled people being poorer and less engaged and participating in society, for instance through employment and education, than non-disabled people. Bringing people out of poverty will thus not in itself eradicate disability and disabling conditions, regardless of the level of understanding of disability. Many of the mechanisms that sideline individuals with disabilities in society are at work in developed welfare states as well as in poverty-stricken countries. This implies primarily that disability, discriminatory practice, cultural beliefs, environmental barriers, supply of equitable basic services, etc, all need to be integrated in poverty alleviation efforts in order to ensure that disabled people benefit in an equitable manner. Otherwise, the risk is that a segment of society, that is, individuals with disabilities and other vulnerable groups, will remain in poverty while a successful reduction on the poverty rate is celebrated. The examples from Uganda and Malawi (Chapter One) have shown how easily sidelined disability issues are in poverty reduction efforts.

Individualisation of disability as we can find in the Western/European-dominated discourse on disability has its evident limitations when the main problems are structural and political. It is in this perspective interesting that recent development of our conceptual understanding of disability, with the ICF as the current culmination of this development, has, in fact, incorporated social and political structures (environment). Phenomena at this level are thus accepted as being central parts of 'the disablement process'. While cultural, social, political and structural phenomena clearly can cause poverty and disability, we do not, however, understand these contributions as presenting arguments against the relevance of the individual level. Rather, in poverty-stricken contexts, political and structural changes will be cardinal to allow people to live their lives in dignity and to be able to fulfil their potential, contributing to their families and communities. The different levels of explanation are intertwined, and it would be a mistake to discard individuals' own efforts, as exemplified in several of the chapters in this book. Individuals with disabilities living in poverty do struggle to survive and to make the best out of their situation – and there are encouraging examples of individuals who have used their disability as a resource for themselves and

for others in their community. The distinction between the political/structural level and the individual level is a reality, however, and many individuals with disabilities are born into or brought into poverty by forces outside themselves and their families. Bearing in mind the dangers of victimisation and defeatism, it is nevertheless evident that structural and political changes are crucial for breaking the poverty–disability circle. It is particularly important to underline this as the understanding of disability often centres around the individual. Even ICF, with its attempt at incorporating environmental/social factors, basically represents an individual understanding, at least if this is not challenged and the environmental aspects are not further developed and strategically utilised.

The concepts of social suffering and structural violence are particularly useful in understanding the situation for disabled people living in poverty. Social suffering is the result of social, political and structural violence inflicted on people, creating the reaalities of poverty that constantly limits people's possibilities (Kleinman et al, 1996; Farmer, 2004). There is thus a clear link from the environmental barriers individuals with disabilities experience in their daily life, and the structural level. The link between structural violence and the suffering of disabled people directly due to political decisions, absence of political action and structural problems and barriers is thoroughly described and analysed by Muderedzi and Ingstad (Chapter Nine), and Husum and Edvardsen (Chapter Eleven).

As argued by Wazakili et al (Chapter One), inclusion of disabled people in poverty reduction processes is crucial for the effectiveness of such programmes, but obvious obstacles are identified. While inclusion of civil society in government decision-making processes may not always be understood as important due to lack of consciousness about the poverty–disability relationship, it is also often the case that organisations representing disabled people may be weak and/or inexperienced. Some of the very same mechanisms that drive disabled people into poverty will also cause political marginalisation and resource deprivation in the disability movement. The two contributions in this book focusing particularly on involvement of disabled people in the political process tell two very different stories. While Sagli and Fjeld (Chapter Two) describe a very well organised and powerful organisation in China, Hansen and Sait (Chapter Six) describe the emergence of organised resistance against the health authorities and the way of implementing the disability grant in South Africa. While the first is an example of how the movement is co-opted into power structures but still unable to avoid increasing poverty among disabled people due to increasing health costs, the example from South Africa may be seen as resulting from failure in engaging the disability movement. The point here is that these very different examples highlight the need for a disability perspective on social reforms that is not necessarily achieved without a thorough analyses of the context and the situation. Effective involvement of disabled people in poverty reduction strategies is bound to challenge established power structures, which may be why this seems to be complicated.

Both disability and poverty are dynamic phenomena in the sense that there are many interrelated, changing and contextually rooted mechanisms involved.

The contributions in this book confirm that poverty and disability are closely interconnected and that this relationship and its persistence are caused by social, cultural, political and structural phenomena. However, not all individuals with disabilities in low-income countries are poor, and there are some fascinating examples of individuals with disabilities who have been able to break the poverty–disability circle and even been able to utilise their disability status as basis for their (relative) success (for instance, Hansen and Sait, Chapter Six, and Grut, Olenja and Ingstad, Chapter Eight). At least such examples may invite a critical view on relying solely on structural phenomena when analysing disability and poverty.

Some major lessons may be drawn from the insights brought by the authors. First, the different levels of explanation, which is also where the keys for breaking the poverty–disability circle may be found, cannot be viewed separately from each other. Policy changes with the best of intentions may fail or even be counterproductive if people's cultural beliefs or structural barriers are not considered. Second, while there is clearly general knowledge and experiences that can contribute to understanding disability and poverty as a global phenomenon, contexts are different and require separate analyses and unique solutions. Third, a valuable challenge to established and largely Western-dominated thinking around disability and poverty is found in the distinction between individualised and political/structural explanations. Fourth, including disabled people and their representatives or advocates from the policy process is not only correct in a democratic and a justice perspective, it is also crucial for finding the right solutions. As for all social phenomena, among which this clearly is, studies need to be carried out in different contexts and cultures in order to develop context-specific as well as more general knowledge.

Finally, several of the chapters in this book provide an insight into the lives of people with disabilities living in poverty, and the vulnerability implied by living in poverty.

While disabled people in poor contexts are and have been deprived of basic services, including individuals with disabilities and their representatives will in many instances be a challenge due to lack of education, experience and not least due to weak organisations. As shown in some of the chapters, individuals with disabilities have struggled and survive under very difficult conditions, bringing evidence to the fact that they also represent a tremendous resource that can be used to improve the situation for the poorest of the poor. After all, individuals with disabilities are experts on living with disabilities. Without this expertise, and without challenging and breaking up established power structures, the fight against poverty will be jeopardised.

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