



REPORT FOR THE

**SOUTH AFRICA NETHERLANDS RESEARCH PROGRAMME ON
ALTERNATIVES IN DEVELOPMENT (SANPAD)**

**INCLUDING DISABILITY WITHIN THE
CONTEXT OF DEVELOPMENT:
OPPORTUNITIES, CHALLENGES,
CONSTRAINTS AND STRATEGIES**

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2008

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ABSTRACT

This study sets out to assess the extent to which disability has been included in development in South Africa and to explore the opportunities, constraints and potential strategies for mainstreaming disability in development. Towards this end, interviews were conducted with the representatives of 32 disability and development agencies currently operating in South Africa.

The survey showed that while there was some understanding by development agencies of the relevance of disability to development, it was clear on a number of levels that the majority of development agencies operating in South Africa did not place a high priority on disability. Development agencies repeatedly rated disability as a lower priority than what DPOs rated development.

However, there were also a number of positive signs in relation to the integration of disability in development. Half of the development agencies and 80% of the DPOs in this study had projects which included elements of both disability and development. Two-thirds of the development agencies interviewed had formal policies or position papers relating to disability and development. The study also indicated fairly extensive contact between the development and disability sectors. On the other hand, there were clear indications that in many cases policies and guidelines developed at the central level by international organizations had not filtered down to staff working at the country or regional levels. Furthermore, the majority of projects in the development sector specifically targeted people with disability rather than making provision for people with disability within more general development projects. Inclusive approaches to development were more apparent in the disability sector where a number of projects included both disabled and non-disabled people or aimed to encourage partnerships between the two.

In terms of orientation to disability and development, there were both indications of common ground and differences between the two sectors. For example, disability was most commonly characterized by both sectors as a human rights issue, with 75% of DPOs and 50% of development agencies seeing disability as a human rights issue. This overlap in the emphasis on human rights could play an important role in facilitating understanding between the two sectors, particularly as right-based approaches to development have gained considerable ground in recent years.

These and other findings of the survey are assessed against the background of evidence that poverty and disability are strongly related to one another in South Africa as in other parts of the world, and that the combination of disability with other social inequalities such as gender and race can create extreme vulnerability and exclusion.

In spite of areas of disagreement and in particular the challenge of the low priority assigned to disability by many development agencies, there would appear to be a basis for closer co-operation between the two sectors, although this would require a more systematic approach to mainstreaming disability in development.

ACRONYMS

ADPD	AFRICAN DECADE OF THE PERSONS WITH DISABILITIES
ASD	ASSOCIATION FOR THE SENSORY DISABLED
AUS-AID	AUSTRALIAN AGENCY FOR INTERNATIONAL DEVELOPMENT
AUTISM SA	AUTISM ASSOCIATION OF SOUTH AFRICA
CAAC	CENTRE FOR AUGMENTATIVE AND ALTERNATIVE COMMUNICATION
CASE	COMMUNITY AGENCY FOR SOCIAL ENQUIRY
CBM	CHRISTOFFEL-BLINDEN MISSION
CBO	COMMUNITY BASED ORGANISATION
CIDA	CULTURAL INDUSTRIES DEVELOPMENT AGENCIES
CSDS	CENTRE FOR THE STUDY OF DEVELOPING SOCIETIES
DANIDA	DANISH INTERNATIONAL DEVELOPMENT AGENCY
DEAFSA	ASSOCIATION OF DEAF SOCIETIES IN SOUTH AFRICA
DEAFBLIND SA	THE DEAF AND BLIND FEDERATION OF SOUTH AFRICA
DECT	DISABILITY EMPOWERMENT CONCERNS TRUST
DFID	DEPARTMENT FOR INTERNATIONAL DEVELOPMENT
DICAG	DISABLED CHILDRENS ACTION GROUP
DPI	DISABLED PEOPLE INTERNATIONAL
DPO	DISABLED PEOPLE'S ORGANISATION
DPSA	DISABLED PEOPLE SOUTH AFRICA
DSSA	DOWN SYNDROME SOUTH AFRICA
ENABLE	ENABLE EDUCATION TRAINING AND DEVELOPMENT INITIATIVE
ESCAP	ECONOMIC AND SOCIAL COMMISSION FOR ASIA AND THE PACIFIC
FHR	FOUNDATION FOR HUMAN RIGHTS
GDPS	GEOGRAPHICALLY DISPERSED PARALLEL SYSPLEX
GTZ	GERMAN TECHNICAL COOPERATION
ISRDS	INTEGRATED RURAL DEVELOPMENT STRATEGY
MODE	MEDUNSA ORGANISATION FOR DISABLED ENTREPRENEURS
NCCPDSA	NATIONAL COUNCIL FOR THE PERSONS WITH PHYSICAL DISABILITIES IN SOUTH AFRICA
NDA	NATIONAL DEVELOPMENT AGENCY
NDSISA	NATIONAL DEAF SERVICES INSTITUTE OF SOUTH AFRICA
NGO	NON GOVERNMENT ORGANISATION
NMCF	NELSON MANDELA CHILDREN'S FUND
NORAD	NORWEGEN AGENCY FOR INTERNATIONAL DEVELOPMENT
OHS	OCTOBER HOUSEHOLD SURVEY
OSDP	OFFICE ON THE STATUS OF PEOPLE WITH DISABILITIES
OXFAM	OXFAM GB IS A DEVELOPMENT, ADVOCACY AND RELIEF AGENCY WORKING TO PUT AN END TO POVERTY WORLD-WIDE.
QASA	QUADPARA ASSOCIATION OF SOUTH AFRICA
SAFCD	SOUTH AFRICAN FEDERAL COUNCIL ON DISABILITY
SAFMH	SOUTH AFRICAN FEDERATION FOR MENTAL HEALTH
SAFOD	SOUTH AFRICAN FEDERATION OF THE DISABLED
SANCB	SOUTH AFRICAN NATIONAL COUNCIL FOR THE BLIND
SANGOCO	THE SOUTH AFRICAN NATIONAL NGO COALITION
SANGONET	SOUTH AFRICAN NGO NETWORK
SAT	SOUTHERN AFRICA TRUST
SCF	SAVE THE CHILDREN FUND
SHIA	SWEDISH ORGANISATION OF PERSONS WITH DISABILITIES INTERNATIONAL AID ASSOCIATION
SIDA	SWEDISH INTERNATIONAL DEVELOPMENT COOPERATION AGENCY
UNDP	UNITED NATIONS DEVELOPMENT PROGRAMME
UNESCO	UNITED NATIONS EDUCATIONAL, SCIENTIFIC AND CULTURAL ORGANIZATION
UNICEF	UNITED NATIONS CHILDREN'S FUND
USAID	UNITED STATES AGENCY FOR INTERNATIONAL DEVELOPMENT
UYF	UMSOBOMVU YOUTH FUND
WHO	WORLD HEALTH ORGANISATION

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SECTION 1: EXPLORING THE INTERFACE BETWEEN DISABILITY AND DEVELOPMENT

1.1 Introduction

Over many years the disability community has struggled for the recognition and inclusion of individuals with disabilities in all aspects of society. The human rights in particular have played a significant role in creating awareness of the need to look beyond physical, emotional and cognitive abilities in recognising the rights of people with disability. The recent signing of the UN Convention on the Rights of People with Disabilities is a reflection of the success of these efforts throughout the world.

Poverty, however, remains, and the link between poverty and disability becomes better defined as the voices of those with disabilities themselves and their families become louder.

An inclusive society implies that government and company policies are cognisant of including a broad range of citizens in the development and implementation of these policies. Although important provisions have been made for the inclusion of people with disabilities within the framework government policies in South Africa since 1994, the implementation of these policies have not always been inclusive of people with disabilities.

This study sets out to explore the link between disability organisations and development agencies in an attempt to understand better the nature of the differences and similarities in their thinking surrounding disability issues within the broader context of socio-economic development in South Africa. Interviews were conducted with disability stakeholders as well as representatives from development agencies who are involved in disability in one way or another. These interviews were analysed and used as the main source of information for the study.

The study extended over two years, from 2005-2007 and was funded by South Africa Netherlands Research Programme on Alternatives in Development (SANPAD).

1.2 Background

Since the emergence of the disability rights movement in the 1960s and 1970s there have been significant advancements in human rights advocacy and international standard setting to promote equity for persons with disabilities. Starting with the United Nations' Declaration of the Rights of Mentally Retarded Persons in 1971 and the Declaration on the Rights of Disabled Persons in 1975, global commitment to equalising opportunities for people with disabilities has grown steadily, and culminated in the establishment of the Convention of the Rights of Persons with Disability in 2007 alongside the existing Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and the Convention on the Rights of the Child (CROC).

In spite of these human rights advances, disability strategies even in the industrialised countries have "tended to consist of disconnected combinations of modern inclusive approaches, and elements of the rehabilitation, special education and/or custodial care approaches of the past" (Metts, 2000: ix). While developing countries have also begun to commit themselves to the new inclusive approaches, disability services have remained limited, reaching only small numbers of the disabled populations. In both the industrialised and developing countries issues of disability have been addressed by distinct government structures and policies and academic and research endeavours relating to disability have retained distinctive disciplinary foci separate from mainstream societal concerns.

However, in recent years a number of developments have begun to point the way towards a more integrated approach to disability. In the past decade in particular, there has been renewed interest in the relationship between disability on the one hand and poverty, gender inequality, social exclusion and other forms of social disadvantage and marginalisation on the other. Most of the major international development agencies have placed disability on their development agendas (see, for example, United Nations, 1997; USAID, 1997; DFID, 2000; NORAD, 2002; Wolfensohn, 2002, 2004; European Commission, 2003).

In tandem with this development, the understanding of poverty has deepened over the last two decades with the development of multi-dimensional conceptions of poverty that explicitly or implicitly includes disability as a manifestation or even an integral component of poverty.

1.2.1 The multi-dimensionality of poverty¹

Since the 1970s thinking about poverty has evolved from a narrow focus on income to a broader focus that takes into account other dimensions of being poor. Our understanding of poverty has expanded with the introduction of notions such as social exclusion, human development, participatory approaches to poverty, and capabilities, and the definition of poverty has been expanded to include living standards such as longevity, literacy and health, vulnerability and risk, and powerlessness and lack of voice. This broadening of the definition of poverty has not only changed those whom we count as poor, but has also resulted in a deeper understanding of poverty and the poor.

The ways in which we define poverty have important implications for both the measurement of poverty and for the strategies we design to combat it. One of the earliest and most common conceptions of poverty is to see it as lack of money or income. Early conceptions of and attempts to measure poverty focused on income and expenditure (or consumption), that is, the amount of money or material goods (food, shelter, clothing, etc.) necessary to secure subsistence. These approaches focused attention on objective measures of poverty, such as poverty lines, which usually involve the calculation of a minimum amount of money needed to support a family or household. All households falling below this poverty line are then defined as poor.

To define poverty purely in terms of income deprivation may be convenient for operationalisation and measurement, but it is also arbitrary. This is because, while income undoubtedly plays a key role in determining the kinds of lives that people can lead, it is not the only influence on their lives. Nor can all the other manifestations of poverty be reduced to income deprivation. For example, one might think of unemployment as a social ill because it deprives the unemployed of an income. However, the lack of an income is not the only disadvantage associated with unemployment, as a broad range of individual and social costs can be attributed to it. These include psychological harm and ill-health (as a result of not having a job), skills loss, loss of output, loss of motivation, constraints on human interaction, weakening of social values, etc. Loss of income is therefore not the only deprivation that is suffered as a result of unemployment, and even when compensation is provided by way of unemployment benefits, for example, other deprivations resulting from being unemployed have to be taken into account (Sen, 1999:94-96; 2000:18-23).

It might still be argued that even if one takes the other ill effects of unemployment into account, one might still be dealing with essentially the same group of people; that focusing on the other dimensions of poverty may not fundamentally change those whom we regard (or count) as poor. Sen (1999) convincingly demonstrates that this is not the case in relation to mortality and income in different parts of the world. For example, while African Americans have considerably higher levels of income than many of the populations of developing countries, as a group they

¹ For a more detailed exposition of changes in our understanding of poverty, see Emmett, 2005, pp. 70-80

suffer considerably higher rates of mortality than do the populations of nations that have much lower levels of income, such as China, Sri Lanka, Jamaica, Costa Rica, and the Indian state of Kerala (Sen, 1999: 21-24).

These differences in the relationship between income and mortality may also be found within the developing countries. Sen (1999:46-48), for example, compares the GNP per capita and life expectancy at birth of seven developing countries and finds that in spite of their very low levels of income (\$500 and less), Sri Lanka, China and Kerala had significantly higher life expectancy rates than Gabon, South Africa, Brazil and Namibia. In spite of their considerably higher incomes (ranging between \$2000 and \$4000), these four countries had life expectancy rates ranging between 54 and 65 years, in contrast with the three Asian countries where life expectancies ranged between 70 and 73 years. As these figures were for 1994, they are unlikely to have been significantly influenced by deaths associated with the AIDS pandemic. Statistical comparisons of GNP per capita and the Human Development Index (HDI) also show significant deviations within countries when they are ranked by these two variables (UNDP, 1990:14-16).

While it is sometimes argued that income is a good proxy for all other features of development because money can be used to purchase food, healthcare, education, etc., this is only partly true. Income is a means and not an end. It may therefore be used for 'good' or 'bad' purposes, for example, to feed a family or finance a criminal syndicate, to buy medicines or narcotics. The well-being of society therefore depends more on the uses to which income is put rather than the level of income itself. Improvements in health and education, for example, are not only important in their own right as contributions to the quality of life, they may also be seen as an investment in human capital that can yield returns by increasing income as well as contributing to a better quality of life. For example, healthier children perform better at school, while more educated mothers are better able to care for the health of their children. Similarly, a healthy and well-nourished person can be more productive in the workplace than someone who is ill and under-nourished, and thus has the potential to earn more, ensuring both her continued nutrition and greater work capacity.

Further confirmation of the multidimensionality of poverty was provided by the ways in which poor people perceive poverty. Extensive consultations of the poor at the turn of the century showed that the poor do not define their quality of life purely in terms of material deprivation, but see it as having "multiple, interlocking dimensions", which combine to create and sustain powerlessness and to constrain freedom of choice and action. Although not all of these dimensions apply at the same time and may vary between different categories of the poor, they manifest a consistency over both time and place and constitute a trap from which the poor continuously struggle to extricate themselves. For example, Narayan, Chambers, Shah and Petesch (2000:2) identified ten interlocking dimensions of powerlessness and ill-being associated with the experiences of the poor including the precariousness of livelihoods, the isolation of the poor in unsafe, under serviced and stigmatised places, hunger, ill-health and exhaustion, gender inequality and conflict, social discrimination and isolation, insecurity and lack of peace of mind, disregard and abuse by the powerful, disempowering and excluding institutions, weak and disconnected organisations, and weak capabilities as a result of lack of information, education, skills and confidence.

Poverty assessments have shown that poor people themselves often associate disability with poverty. For example, assessments conducted by Chambers (1995) in Asia and sub-Saharan Africa showed that many poor people regarded disability (i.e. blindness, mental and physical impairment and chronic illness) as an indicator of the lack of well being associated with being poor. Other indicators included being widowed; lacking land, livestock and farming equipment, etc.; being unable to decently bury their dead; unable to send children to school, etc. Similarly, Narayan *et al.*, (2000:89-108; 140) identified ill health and bodily ill being as both a cause and a consequence of poverty.

In describing their experience of poverty, poor people also placed considerable emphasis on vulnerability. As Kanbur and Squire (1999:20) point out, poverty is not just “a state of having little, but also of being vulnerable to losing the little one has”, and therefore of being plunged even deeper into poverty. The poor are subjected to a range of vulnerabilities created by changes in their physical and social environments. Such changes cover a broad range of contingencies, including changes in the natural environment such as droughts and floods, market fluctuations such as increases in the price of food or a drop in the price of agricultural commodities produced by the poor, wars and civil strife, crime and violence, and even seasonal fluctuations that produce periods of financial and other stress.

The vulnerability of poverty is not only a product of the poor being economically marginalized, but also of their lack of social and political power. The social and political powerlessness of the poor finds strong expression in the ways in which the poor experience poverty. Participatory approaches to poverty consistently demonstrated that the poor experienced social relations as discriminating and isolating, that they perceived themselves as disregarded and abused by those with power, that social and political institutions were disempowering and excluding, and that their own organisations were weak and disconnected. The social and political vulnerability of the poor can be seen as having at least two aspects: an “external” aspect involving discrimination and exclusion by those who are not poor, and an “internal” aspect involving weaknesses in their own organisations and social relationships.

An alternative approach that has attempted to come to grips with the multidimensionality of poverty and deprivation has developed around the concept of social exclusion. This approach or more accurately *set of approaches*, first made its appearance in France in the 1970s, and has become an important policy focus within the European Union and within the United Kingdom’s Labour Government.

While there is considerable debate about what social exclusion means, definitions and accounts of social exclusion usually place emphasis on a number of specific characteristics. Firstly, social exclusion is multidimensional and involves more than a lack of resources or income. Secondly and closely related to its multidimensionality, is an emphasis on the interconnection of problems and deprivations that have a cumulative impact on the individuals, social groups and areas subjected to exclusion.

Thirdly, both an outcome and cause of these multiple deprivations is a process of social marginalisation involving a denial of opportunities for the excluded to participate in economic, social and civil life and consequent isolation from society. Fourthly, the concept of social exclusion places emphasis on the *relational* features of deprivation, bringing out the social aspects of derivation. (See also Peace, 2001; Silver, 1994; Watt, 2001; Sen, 2000.)

Trends in the development of multidimensional approaches to poverty and development may be seen as culminating in the work of the Nobel prize-winning economist Amartya Sen (1999). Rather than simply aggregating the various different dimensions of poverty, Sen (1999:3) has developed a conceptually coherent framework in which poverty is seen as *capability deprivation*, that is “the lack of freedom to do certain valuable things” (Sen, 2000:5). Development on the other hand is seen as expanding the freedoms that people have in order to lead the kinds of lives that they value. In terms of the capability perspective, the poor are subject to restrictions on their freedom that leave them with little choice or opportunity to exercise their will or agency to achieve the kinds of lives they have reason to value. The importance of freedom (as opposed to more ‘objective’ measures of deprivation) may be illustrated by Sen’s (1999:75) example of an affluent person who *chooses* to fast as against a destitute person who is *forced* to starve. While both of these people may consume the same amounts of food and both may suffer similar degrees of nutritional deprivation, the former still has the freedom to choose to eat well, while the latter does not.

The expansion of freedom to enjoy the kinds of lives that people have reason to value is understood as both the major *goal* and the principal *means* of development. From Sen’s (1999:xii) perspective therefore development “consists of the removal of the various types of

unfreedoms that leave people with little choice and little opportunity of exercising their reasoned agency” in countering deprivations. Because individual and collective freedom of agency (i.e. the ability of people to shape their own destiny and to help one another) is qualified and constrained by the economic, social and political opportunities that are available, Sen’s perspective on development and poverty is necessarily multidimensional.

While Sen acknowledges the importance of income to being able to pursue what one values and as a powerful determinant of many of the freedoms we value, its importance is ultimately instrumental (i.e. as a means towards achieving certain ends):

“Income may be the most prominent means for a good life without deprivation, but it is not the only influence on the lives we can lead. If our paramount interest is in the lives that people can lead – the unfreedom they have to lead minimally decent lives – then it cannot but be a mistake to concentrate exclusively only on one or other of the *means* to such freedom. We must look at impoverished lives, and not just at depleted wallets (Sen, 2000:3).”

One application of the capability approach that illustrates the importance of going beyond income in the measurement of poverty relates to poverty assessment among people with disability and their families. This approach argues that in terms of economic well-being, people with disability face two sets of disadvantages or handicaps (Sen, 2004; Kuklys, 2004). The first of these disadvantages (which Sen calls an ‘earning handicap’) relates to people with disability having access to less income because of their disabilities whether this is due to functional limitations, discrimination and exclusion, or a combination of the two. However, in addition to this ‘earning handicap’ people with disability often also face a ‘conversion handicap’ in which they frequently need more income just in order to do the things that non-disabled people can such as moving from one place to another. Such expenses include assistive devices such as wheelchairs, hearing aids and Braille books, modified home environments such as ramps, stair lifts and accessible bathrooms, and medical, rehabilitative and personal care, and are also incurred as a result of both functional limitations and environmental barriers. An example of the latter is when people with disability have to use more expensive forms of transport because public transport is inaccessible to them.

Using British data on disability, Kuklys (cited by Sen, 2004) showed that taking the ‘conversion handicap’ of families with disabled members into account made a considerable difference to the percentage of households that qualified as poor. Taking a poverty cut-off line at 60% of the national median income, Kuklys found that 17.9% of *all* individuals in the United Kingdom lived in families with incomes below the poverty line. When only *families with disabled members* were taken into account, 23.1% of these families had incomes below the poverty line. However, when the ‘conversion handicap’ of families with disabled members was taken into account, the percentage of families with incomes below the poverty line rose to 47.4%. These results demonstrate that when only income is taken into account (as poverty is traditionally measured), a very small part of the disadvantage suffered by people with disability and their families is made evident, in that there was only a five percent difference between the overall poverty rate and the poverty rate of households with disabled members. When the ‘conversion handicap’ is taken into account, this gap increased to nearly 30%. In terms of this example therefore, income on its own would account for less than 20% of the disadvantage suffered by people with disability and their families.

1.3 Disability, human rights and development

International commitment to establishing equal rights for people with disabilities culminated in the establishment of the Convention of the Rights of Persons with Disability in 2007. Article 32 of the Convention on International Cooperation highlights the measures to be undertaken by states to conduct and support inclusive development. The Article states that development programmes should be inclusive and accessible to persons with disabilities. The convention therefore defines disability as a mainstreaming issue to be considered in *all* development

programming rather than as a stand-alone issue (United Nations (Enable), 2007). In all instances, organizations of persons with disabilities should participate in formulating these development programmes. Provision is also made for the participation of international and regional organizations, such as the United Nations, the World Bank, the European Commission and the African Union.

Following ratification of the Convention, compliance will have to be reflected in the national development frameworks of participating countries. To ensure implementation and monitoring of the Convention, countries have to create a national mechanism to promote and monitor implementation. Provision is also made for a Committee composed of independent experts to receive periodic reports from participating states on their progress in implementing the Convention.

1.4 Poverty and Disability

Disability has been seen as both a cause and a consequence of poverty. This is because disability increases the risk of poverty, while poverty creates the conditions for increased risk of disability-related impairments. Poor people with disabilities may therefore be seen as caught in a vicious cycle of poverty and disability. For example, poverty increases vulnerability to disability through poor nutrition, lack of access to healthcare, greater exposure to violence and unintentional injuries, lack of knowledge of prevention, *etc.* Conversely, disability increases vulnerability to poverty because of the costs associated with disabilities, discrimination in the labour market, difficulties related to accessing education, *etc.* On this basis, it has been argued that eliminating world poverty is unlikely to be achieved unless the rights and needs of people with disabilities are taken into account (DFID, 2000:1; Elwan, 1999; Yeo, 2000, *etc.*).

While the linkages between poverty and disability have often been noted, they have not been systematically examined (Elwan, 1999:iii). This applies in particular to the developing countries where information and research are limited, and rely heavily on anecdotal evidence and case studies. Rough estimates based on census, survey and registration data do exist for some countries, but these tend to be very divergent, and there is little information about linkages with the correlates of poverty (Elwan, 1999:2). In 1981 the World Health Organization noted that it was impossible to estimate the number of disabled people more accurately than at 10% of the total population (Elwan, 1999:5).

1.4.1 From poverty to disability

The relationship between poverty and disability has been more clearly demonstrated for developed countries than for developing countries. Demographic studies in the United States, for example, have found a growing relationship between poverty and risk of disability/impairment (Park, Turnbull and Turnbull, 2002:152). For example, longitudinal estimates of Fujiura and Yamaki (2000) indicate “a significant increase in the rate of childhood disability over the past 14 years among constituencies defined by poverty and single-parent headed families.” On the basis of their review of recent findings, Park, Turnbull and Turnbull (2002:152) concluded that “poverty is not a secondary topic in the field of special education services and disability policy anymore”.

While knowledge of the prevalence, incidence or epidemiology of disabling diseases in developing countries is limited, it is clear that disability in impoverished contexts is strongly associated with *preventable* impairments arising from communicable, maternal and peri-natal disease and injury. Among the conditions that are frequently associated with disability in developing countries are malnutrition (including vitamin deficiencies), lack of basic sanitation, limited access to preventive health and maternity care, limited knowledge of health practices, diseases and disability, inadequate housing, dangerous work conditions, and injuries resulting from political and criminal violence, civil conflict and natural disasters (Elwan, 1999; DIFD, 2000).

The World Health Organisation has estimated that as many as 20 million women a year suffer impairment leading to disability as a result of pregnancy and childbirth (DFID, 2000:3). Malnutrition can either directly cause disability or increase susceptibility to debilitating diseases. Malnourished mothers are at risk of bearing low birth-weight babies, who in turn are at risk of contracting disabling diseases. Adverse environmental conditions, including inadequate shelter, the lack of clean water and poor or no sanitation facilities, compound the risk of infection. Failure to provide adequate and timely health care (whether due to lack of parental knowledge or poor or inaccessible health facilities) can intensify disease outcomes so that remedial impairments become permanent disabilities. According to one estimate only 2% of disabled people in developing countries have access to rehabilitation and appropriate basic services (Despouy, 1993 cited in DFID, 2000:2).

Among the major disabling communicable diseases are poliomyelitis, trachoma, onchocerciasis (river blindness), schistosomiasis, malaria, measles, German measles and leprosy. The WHO also estimates that up to 70% of blindness in children in developing countries is either preventable or treatable and that about 50% of disabling hearing impairments are preventable (DFID, 2000:3). It has been found that maternal education, access to information, dietary and food preparation practices, and the level and coverage of primary health care play a greater role in prevention than more specific interventions (Elwan, 1999). As much of the disability in developing countries stems from preventable impairments, a large part of this disability could therefore be eliminated through treatment or alleviated through rehabilitation (DFID: 1; Elwan: iv, 16, 21-23).

The complex interactions of risk factors in impoverished environments are vividly depicted in the following passage:

“The child in a poor family who is malnourished and living in an unheated apartment is more susceptible to ear infection; once the ear infection takes hold, inaccessible or inattentive health care may mean that it will not be properly treated; hearing loss in the midst of economic stress may go undetected at home, in day care, and by the health system; undetected hearing loss will do long-term damage to a child who needs all the help he can get to cope with a world more complicated than the world of most middle-class children. When this child enters school, his chances of being in an overcrowded classroom with an overwhelmed teacher further compromise his chances of successful learning. Thus, risk factors join to shorten the odds of favorable long-term outcomes.” (Schorr and Schorr, 1988, cited by Pokempner and Roberts, 2001)

Accidents and conflict are also an important cause of impairments resulting in disability, especially in developing countries, where levels of conflict are often high. In conflicts, both active combatants as well as civilians are at risk both during active conflict and after such conflicts due to unexploded ordnance and land mines. In particular, disabled persons are especially vulnerable to deteriorating health, (including psychological problems) under the conditions caused by war and political violence. Health care and social welfare systems are often disrupted or break down completely, and some conditions that might have been treatable under more normal circumstances, can become disabling.

Furthermore, psychological trauma resulting from war or violence often remains undiagnosed and unrecorded. While information on disabilities resulting from war is limited, existing data show that civilians are equally likely to be victims of land mines, and a study of Afghanistan, Bosnia, Cambodia, and Mozambique demonstrated that the economically active were most at risk. For example, Afghanistan had the highest proportion of child victims, where children often worked as herders (Elwan, 1999:19-21). Furthermore, poverty has been associated with demanding and risk-prone work environments, where disabilities can result from accidents or contamination by toxic substances.

In general disabled people and their families are poorer than the rest of the population. In many of the industrialised countries, the presence of a disability has been shown to be associated with lower levels of income and an increased likelihood of being in poverty. Employment rates for disabled persons are usually lower, and both employment and income appear to be negatively associated with the severity of the disability. Disabled people are also likely to have lower educational and literacy levels than the rest of the population, and, when disabled people are employed, they are likely to be under-employed relative to their levels of training. They are also less likely to have savings and other assets than the non-disabled population (Elwan, 1999: iv; 11-15).

These findings apply to both developing and developed countries. In the industrialised countries, the incomes of disabled persons do not match those of their non-disabled peers even when compensatory benefits are taken into account, and in spite of substantial transfer and employment programmes, the disabled continue to face higher risks of poverty. In some developing countries higher disability rates have been shown to be associated with higher illiteracy, poor nutritional status, lower inoculation and immunization coverage, lower birth weight, higher unemployment and underemployment rates, and lower occupational mobility (Elwan, 1999: iv).

The International Labour Office estimated in 1984 that the unemployment rate for disabled people in industrialized countries was two to three times that of non-disabled people. Surveys conducted in Australia, Canada, the United Kingdom and the United States showed similar trends. While there is little data on relative employment rates in the developing countries, data from Mauritius and Botswana suggest that similar trends exist in the developing countries. Existing data also suggest that disabled people work longer hours than non-disabled people, are paid at lower rates, are more likely to work in poor working environments, have poor promotion prospects, and are at greater risk of becoming unemployed (Elwan, 1999: 12-14).

Studies conducted in industrialised countries show that disabled people generally have lower incomes than non-disabled people. For example, surveys carried out in the United States between the 1950s and the 1970s showed substantial disparities between disabled and non-disabled incomes, with the average wage rates of disabled people about 60% of those of people without disabilities. A survey conducted in the US and Germany in 1987 found that on average disabled men earned half of what non-disabled men earned. Studies in the United Kingdom also showed that home ownership was lower among disabled than non-disabled people, and that disabled people had fewer substantial assets, and fewer rights to pensions and other welfare benefits. Furthermore, many of these disabled people had a need for higher incomes than those without disabilities. The lower incomes observed during their working years continued into old age and disabled people were less likely to have the kind of pension or the level of provision that would adequately protect them from poverty in old age (Elwan, 1999: 14-15).

On average, disabled people receive less education, and have lower literacy rates and educational qualifications than the non-disabled population. Recent studies suggest that about two percent of children with disabilities in developing countries receive an education. Boys with disabilities attend school more frequently than girls with disabilities, and disabled women, who suffer discrimination both on the basis of their impairments and their gender, generally have even lower literacy rates than disabled men. It has also been shown that women with disabilities are two to three times more likely to be victims of physical and sexual abuse than women without disabilities (Elwan, 1999:11-12; DFID, 2000:3).

Using longitudinal data from the British Household Panel Surveys in conjunction with other studies conducted in the United Kingdom and Germany, Burchardt (2003) systematically demonstrates the two-way relationship between disability and poverty/social exclusion. In Britain it was shown that those people in the lowest quintile of the income distribution were two and a half times more likely to become disabled than those in the highest quintile. Similarly, the risk of disablement was nearly four times higher for those people with no educational

qualifications as for those who held a degree. Burchardt (2003) was also able to show that this association between the risk of disablement and educational levels was not simply a product of the higher risk of disability associated with aging together with the generally lower levels of education of older generations in relation to younger generations. Rather she found that the risk of disablement was higher for young people without qualifications than for their older counterparts.

Secondly, in addition to higher rates of poverty among people with disabilities as a result of the risk factors discussed above, it was also found that the onset of disability was associated with an added risk of entering poverty, as well as “a decrease in the proportion of people leaving poverty” (Burchardt, 2003: 63). In other words, becoming disabled increased the risk of those who were not poor before the onset of disability becoming poor and diminished the odds of those who were already poor for escaping poverty. In spite of Britain’s highly evolved social security system, social security benefits were only able to compensate for the loss of income of a small minority of those who became disabled. As Burchardt (2003: 64) observes: “Contrary to the popular myth that the onset of disability is a random occurrence, it is strongly patterned by social and economic circumstances.”

Disability impacts not only on individuals, but also on households that have disabled members. This has meant that a larger proportion of the population is affected by disability than the percentage of individuals with disabilities. In the United States in 1990, for example, the proportion of families with a member with a disability was 29.2%, while the proportion of individuals with a disability was 13.7% (Elwan, 1998, 8-9). Very similar trends were found in Scotland where 13.7% of the population had a long-term health problem or disability, whereas 29% of households contained one or more persons with a long-termed illness (Scottish Poverty Information Unit, 1998). Analysis of Tanzanian survey data showed that households with disabled members had mean consumption levels of less than 60% of the average and headcounts twenty percent higher than the average. On the basis of these results the author concluded that disability was “a hidden face of African poverty” (DFID, 2000: 4).

In addition to their lower income and consumption rates, disabled persons and their families are often burdened by additional costs resulting from disability. Such costs include special medical care, rehabilitative and restorative equipment and services, providing for special education needs, and costs incurred for or by care providers, including opportunity costs of foregone income. In developing countries where income maintenance and other social security programmes are uncommon, disabled persons are usually the responsibility of their families, and even in the industrialised countries, families play an important role in providing care and financial support to the elderly. There are also various costs associated with marginalisation or exclusion of disabled persons from services and social and community activities. Such exclusion and marginalisation, which often reduce the opportunities that disabled people have to contribute to their households and communities, include negative attitudes to disabled persons, lack of adequate or appropriate transportation, physical inaccessibility, and lack of learning opportunities. Such barriers can affect access to education and employment, as well as reducing opportunities for social participation (Elwan, 1999: 5).

Lukemeyer, Meyers and Smeeding (2000) studied the impact of caring for children with disabilities and chronic illnesses on poor families in the United States, and found that both out-of-pocket expenses and foregone earnings represented a substantial burden for many of the families studied. Using a sample of low-income families in California, the study found that almost half of those families with special needs children had incurred some direct, out-of-pocket expenses in the preceding month, and about 20% incurred costs of more than \$100. Half of the mothers with disabled children indicated that care for the child made it difficult to work and 19% reported that special care responsibilities prevented them from working at all. Based on their data, the writers estimated an average loss of about \$80.52 per month in mothers’ foregone income for each household with a severely disabled child. They conclude that families with exceptional children are at “exceptional risk for economic hardship, due to heightened demands on family resources and to reduced availability for employment” (Lukemeyer, et al., 2000:412).

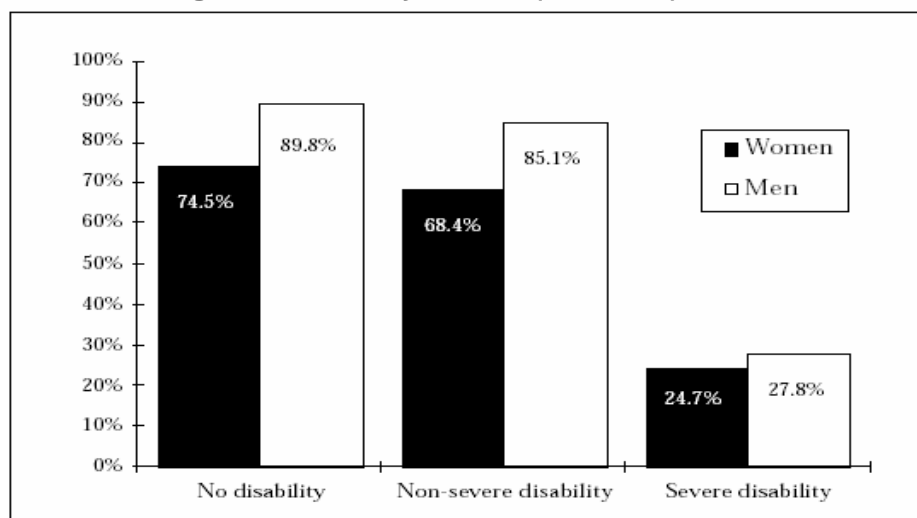
1.4.2 Disability and other disadvantages

In certain segments of the disabled population multiple disadvantages, including, gender, race, age and location, may combine to produce greater vulnerability to poverty. In this section of the report, attention is focused on the ways in which gender and race have compounded the disadvantages of poverty and disability.

1.4.2.1 Disability, gender and poverty²

In her review of poverty and disability (Elwan, 1999:28) presents data from the industrialized countries that show that women with disabilities are consistently disadvantaged in relation to men with disabilities in terms of income, education, employment and social assistance. More detailed information on disability and gender in the United States can be found in Jans and Stoddard's (1999) *Chartbook on Women and Disability in the United States*. They show, for example, that women with disabilities face a double disadvantage in the workplace based on both their gender and their disability status. Women with disabilities were not only less likely to be employed; they also earned less than men (Jans and Stoddard, 1999:17). The dual disadvantages of gender and disability are illustrated in Figure 1.1 below. The figure clearly shows that women had lower rates of participation in the labour market whether they had a disability or not. The presence of a disability has an impact on the employment of both women and men, with the severity of the disability having the greatest impact. It is also clear that, especially in relation to severe disabilities, the impacts of gender and disability are cumulative.

Figure 1.1: Percentage of employed US population by disability status and gender, 21 to 64 years old, (1994-1995)



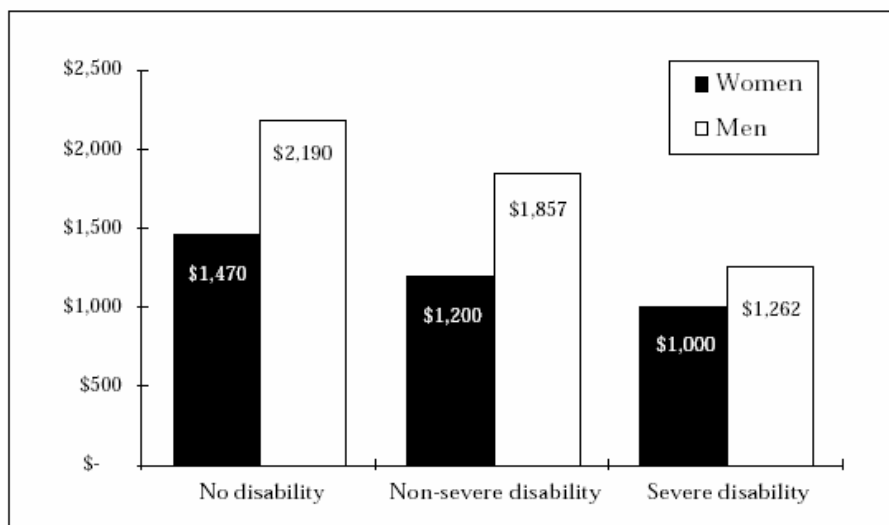
Source: Jans and Stoddard, 1999:18

Similar trends were apparent in relation to income as illustrated in Figure 1.2. Firstly, working women between the ages of 21 to 64 years earned less than working men, whether or not they had a disability. Disabled women also earn less than non-disabled women, as well as less than non-disabled men. In 1994-95, for example, non-disabled men earned 49% more than non-disabled women. The severity of impairments also played a role in determining the income gaps between men and women. Among people with a non-severe (or mild) disability, men earned 55% more than women. In the case of severe disability, the gender gap was smaller, with men earning 26% more than women, although for both men and women the gap between those with mild and severe disabilities was substantial. However, in spite of this large

² For a more detailed exposition on gender and disability, see Emmett & Alant, 2006. See also Emmett, 2006.

gap, it is interesting that the median earnings of men with severe disabilities were still slightly above those of women with mild disabilities.

Figure 1.2: Median monthly earnings, by disability status and gender, 21 to 64 years old, 1994-1995



Source: Jans and Stoddard, 1999:23

Gender inequalities were also evident in relation to education for children with disabilities. Although males and females were equally represented in the school-age population, boys made up about two-thirds of students in special education, with the greatest discrepancies occurring in learning disabilities (74% boys) and emotional disturbances (76% boys). On the other hand, girls in special education scored lower on IQ tests, and were reported to have disabilities at earlier ages. It is also of interest that girls in special education tended to do better academically than their male counterparts. However, upon completing their education, girls were (as we have seen) less likely to be employed, earned lower wages, and were also less likely to enrol for post-secondary education.

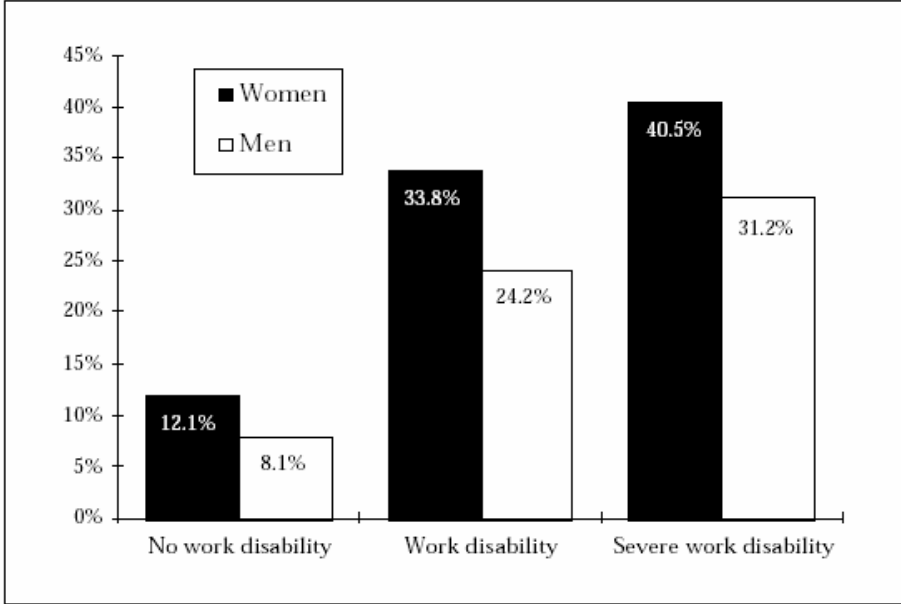
Inequalities were also evident in relation to social assistance in the United States. As the primary programme of federal benefits for children with disabilities and their families, Supplemental Security Income (SSI) is biased in favour of boys. In 1998, for example, 63.5% of children receiving SSI grants were boys, while only 36.5% were girls. Between 1988 and 1998, boys were consistently awarded more SSI grants than girls. Similar inequalities were also evident for adults. In 1997, for example, 59% of those receiving OASDI (Old Age, Survivors and Disability Insurance) benefits were men. At the same time, the average monthly benefit for men in 1997 was \$810, while for women it was only \$595. It was also shown that OASDI benefits were consistently higher for men over four decades and that the gap between average monthly grants to men and women had grown since the 1970s (Jans and Stoddard, 1999:16).

Data collected in the USA in 1987 and updated to 1993 showed that the medical expenditures on people with disabilities³ (activity limitations) was four times greater than expenditures of people with no disabilities. The study also showed that males with disabilities had higher per capita expenditures than females with disabilities in all age groups except children. These differences were particularly pronounced for the 45 to 64 age group, where per capita expenditure on men (\$6,100) was 40% higher than on women (\$4,365) (Jans and Stoddard, 1999).

³ In this case disability was defined as an *activity limitation* in a major life area such as work, school or housework, due to a chronic health condition or impairment.

In keeping with these trends, the data show that women were more likely to be living in poverty than men, and that people with a disability were more prone to be living below the poverty line than those with no disability. In 1992, it was estimated that for people with work disabilities⁴ in the 16 - 64 age group, 33.8% of women as against 24.2% of men were living in poverty. For those classified as having a severe work disability (a condition that prevented them from working), 40.5% of women compared to 31.2% of men were poor. Figure 1.3 clearly demonstrates the *cumulative* impact of disability and gender on poverty. The data not only show that having a work disability has a dramatic impact on poverty for both men and women, but also that gender inequality contributes to very high rates of poverty among women with work disabilities.

Figure 1.3: Percentage of people (16-64 years) living in poverty by work disability status and gender



Source: Jans and Stoddard, 1999:24

Similar trends have been shown to exist in Canada. For example, according to 1991 statistics provided by Barile (2002) the unemployment rate among women with disabilities in Canada was 16% compared to 13.2% for men with disabilities. Similarly, poverty among women with disabilities was 25.1% compared to 18% for men with disabilities and 21% for non-disabled women. It is of interest that the poverty rate of non-disabled women was higher than the poverty rate of men *with* disabilities. Barile also cites a 1999 study by Doe and Kimpson which showed that women who became disabled received fewer disability pensions than men, that part-time work for those on disability pensions was more limited for women than for men, and that in general women received fewer retirement pensions than men.

To sum up, the data from the US and Canada show that disability has had a consistent, and in some cases severe impact on the lives of both men and women in North America. However, the negative impact of disability is unevenly spread among the genders. While in some cases the differences between men and women might be relatively small, especially when considered against the background of the overall impact of disability, it is clear that women bear a heavier burden than men, and that these inequalities are systematic.

Pokempster and Roberts (2001) argue that the overlap of disability, poverty, and race in the USA is significantly affected by family structure and gender inequalities. Women are especially

⁴ Work disabilities were determined by survey questions that asked respondents whether they had a condition that limited the kind or amount of work they could do. In 1998, for example, 17.2 million people, or 9.9% of the working age U.S.A. population (16-64 years) had a work disability.

vulnerable not only because of their weak positions within labour markets, but also because most of the responsibility for parenting and care giving falls on them. This vulnerability is intensified when women have to care for one or more children with disabilities. As Sen (2004) and Kuklys (2004) have demonstrated, people with disability and their families are often burdened by additional costs resulting from disability, and these costs have a major impact on the poverty status of households with disabled members.

The problem of costs associated with disability is compounded by family structure, particularly among the more impoverished sections of the community where single parent families and women-headed households predominate. Since the 1960s the USA, in common with many other parts of world, has witnessed a dramatic increase in female-headed households. For example, between 1960 and 1990 the percentage of all children who were living in mother-only families grew from 8% to 20% (Corcoran and Chaudry, 1997: 42). This trend and the strong association between female-headed households and poverty (for example, between 1959 and 1988, the percentage of poor children living in mother-only families rose from 20% to 57%) have prompted social commentators to talk about the “feminisation of poverty” (Pokempster and Roberts, 2001; Corcoran and Chaudry, 1997: 43). Racial differences in family structure follow similar patterns. In the USA in 1992, for example, 59% of African-American children lived in female-headed families in contrast with only 17% of white children. In South Africa the 1999 October Household Survey showed that 42% of all African households (2.7 million) were female-headed (Aliber, 2003:480).

Very little hard data exists on disability trends in developing countries and the evidence that does exist is, for the most part, fragmented and often anecdotal. Existing information does, however, suggest that in general very similar trends to those in industrialized countries exist also in the developing countries, except that conditions in the developing countries are likely to be worse and considerably more prejudicial to people with disabilities and especially women with disabilities. This is likely to be the case for a variety of reasons including higher rates of poverty and unemployment, pervasive deficits in services and social security, environmental and social conditions that are not conducive to health, and political and cultural limitations relating to human (and especially, women’s) rights.

It has been argued, for example, that girls with disabilities receive less care and food, have less access to health care and rehabilitation services, and may have reduced access to education and employment opportunities. Women with disabilities sometimes also have fewer marriage prospects than disabled men, and can be at risk of being physically and sexually abused. Abuse from persons outside the family often goes unreported because of the shame that some families feel in having a daughter with a disability (DFID, 2000: 3, Elwan, 1999;). Shah (1992:20) also argues that especially in the rural areas of the East, a woman who loses her sight also loses her “status, privileges and rights both in society and in the family”.

While women have to bear the greater burden of caring for others, their own access to care and treatment appears to be limited in both industrial and developing countries. For example, higher rates of blindness among rural women in India has also been attributed to the limited access that women and girls have to transport to health facilities where they can receive the necessary medical care for eye diseases. As Harriss-White (2003) observes, the process of care for people with disabilities in India is “socially constructed and extremely male-biased”. In a study of disability in three villages in India, for example, it was found that the percentages of adult males receiving treatment ranged between 53% and 56%, while for adult females the corresponding percentages ranged between 11% and 39%. (See also Boylan, 1991:28-29).

1.4.2.2 Disability and race

There is far less information on disability and race than on disability and gender (see, for example, Sharma, 1991 and Stienstra, 2002). However, the limited information that does exist suggests that race and disability interact with one another in similar ways to gender and disability. For example, in the US the 1994–95 Survey of Income Participation showed that the proportion of persons with a severe disability between the ages of 22 to 44 years was 11.8% for African Americans, 5.6% for whites, and 6.7% for Hispanics. For individuals aged 45 to 54, the percentages were, 18.4%, 10.5%, and 15.7%, respectively. African American children, who are twice as likely as white children to be poor, also disproportionately experience illness and disability (Pokempner and Roberts, 2001:5).

Figures provided by Stienstra (2002:6-7) for the US in 1991/1992 show somewhat different trends, with disability rates being 21.9% for Native Americans, 20% for African Americans and 19.7% for white Americans. However, Hispanics and Asian Americans had lower rates of disability, at 15.3% and 9.9% respectively. Canadian data for 1991, also cited by Stienstra, showed an overall disability rate of 15.5% for the general population and 31% for the Aboriginal population.

Racial trends are also apparent in relation to HIV/AIDS in the USA. In 1991, for example, African Americans were 3.5 times more likely to contract AIDS than whites. The risk was even higher among African American women who were 13.8 times more likely to contract AIDS than white women. Infant mortality rates for African American children in the USA are also twice as high as those for white children. Between 1950 and 1991 the racial gap in the infant mortality rate actually increased from 1.6 to 2.2 (Pokempner and Roberts, 2001; American Medical Association, 2003).

In our discussion on gender and disability above, we drew attention to the association between female-headed households and poverty, and the steep rise in the percentage of poor children living in mother-only families in the latter half of the 20th century in the United States. Racial differences in family structure follow similar patterns. In the USA in 1992, for example, 59% of African-American children lived in female-headed families in contrast with only 17% of white children.

In part, the association between race on the one hand and ill-health or disability on the other can be attributed to the lower incomes of African Americans, but it has been shown that even when controlling for socio-economic status, at every level of income, African Americans experience shorter life expectancy and poorer health outcomes. “Blacks have a higher mortality rate than whites for eight out of ten leading causes of death, and the gap has been widening. A recent review of data and research indicates the persistence of racial disparities in the incidence of illness and disease, and the likelihood that disease will lead to death” (Pokempner and Roberts, 2001).

As pointed out earlier, African Americans suffer considerably higher rates of mortality than do the populations of nations that have much lower levels of income, such as China, Sri Lanka, Jamaica, Costa Rica, and the Indian state of Kerala. As Amartya Sen, (2000: 23-24) points out, “for example, Bangladeshi men have a better chance of living to ages beyond forty years than African American men from the Harlem district of the prosperous city of New York. All of this in spite of the fact that African Americans in the USA are very many times richer than the people of comparison groups in the third world.”

A somewhat different manifestation of the interaction between race and disability relates to the overrepresentation of African Americans and, in certain circumstances, other minority groups in the special education categories of mild mental disabilities and emotional behavioural disabilities in the United States. Extensive research has shown that African Americans, poor children, and under certain circumstances Latino and American Indian students “are represented in special education in numbers greater than their percentages in the general school population” (Meyer & Patton, 2001:2). For example, while African Americans represent 16% of school enrolments, they constitute 21% of enrolments in special education. The

corresponding percentages of Native American children are 11% and 16.8%. It has been estimated that poor African American children are 2.3 times more likely to be labelled as mentally retarded by their teachers than their white counterparts (Meyer & Patton, 2001:3).

As Meyer & Patton (2001:9) argue, overrepresentation of minorities in special education “is not just a problem of numbers. It is rather more about the fact that students are being *misdiagnosed as disabled as disabled and being placed in special education programs they do not need.* (Emphasis in original)

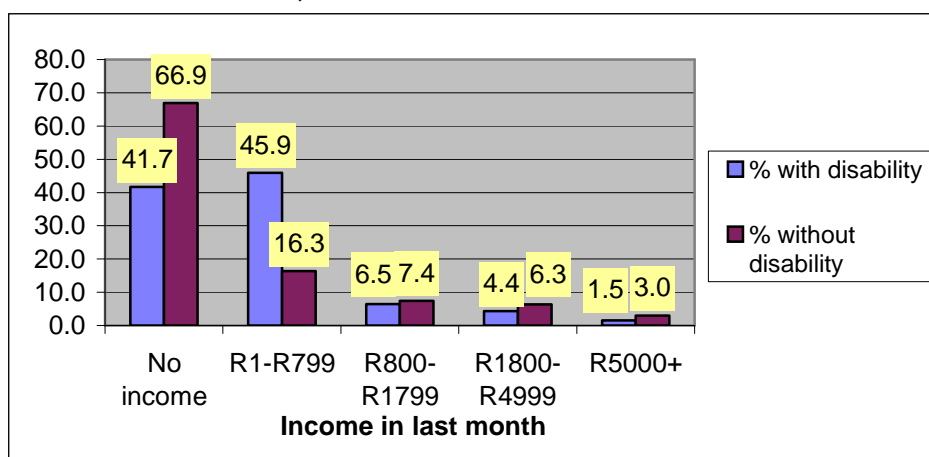
Using data on public schools in Arizona, Ladner (2003:4) found that even after controlling for school spending, student poverty, community poverty and other factors, a pattern emerged “of predominantly White public school districts placing minority students into special education at significantly higher rates.” Most telling was that in heavily minority districts disability rates for African Americans and whites were almost identical, while in predominantly white districts African American and Hispanic disability rates increased substantially and white rates declined. In an earlier study, Ladner and Hammons (cited in Ladner, 2003) found similar patterns in nine other American states.

1.5 Disability and poverty in South Africa⁵

While existing statistics on disability and poverty in South Africa are generally limited in both quantity and depth and their reliability have often been questioned especially by the disability sector, available data on the whole do provide support for trends relating to disability and poverty that have been observed in other countries.

In relation to income, for example, data from the 1999 October Household Survey (OHS) show, with one major discrepancy, that people with disability in South Africa were disadvantaged in relation to their non-disabled counterparts (see, for example, Woolard, 2002: 5). In Figure 1.4, the disadvantage is clear in terms of incomes of R800 and above, with 12.4% of people with disability earning incomes above R799 as against 16.7% of the non-disabled population. It is also clear in relation to people with incomes between R1-R799 most of whom can be considered to be poor. Proportionately, nearly three times as many people with disability fell into this income category than non-disabled people. The discrepancy alluded to above, however, occurs in relation to the category of people with no income, in that there were considerably fewer people with disabilities without income (41.7%) than non-disabled people (66.9%).

Figure 1.4: Percentages of people with and without disability by income categories, South Africa, 1999



Calculated from the 1999 October Household Survey, Statistics South Africa, 1999

⁵ An earlier discussion of disability and poverty in South Africa can be found in Emmett, 2006.

The obvious explanation for this finding, and the large percentage of people with disability in the R1-R799 category, is that people with disabilities are more likely to receive social security grants, especially disability grants, than non-disabled people. The most important⁶ sources of income from social security grants and other sources of income (excluding wage income and other earnings) as captured in the 1999 October Household Survey, are presented in Table 1.1. This shows that while about 15% of people with disabilities received disability grants, the percentage of people with disabilities receiving old age pensions was slightly higher at 16.5%. Proportionately, people with disabilities received more than four times as many pensions as non-disabled people. Three times as many people with disabilities also received retirement benefits than non-disabled people, as well as receiving proportionately more support from outside the household than non-disabled people.

Table 1.1: Percentages of persons with and without disabilities receiving major grants and other sources of income in 1999

Type of grant	Percentage of people with disability receiving grant	Percentage of non-disabled people receiving grant
Old age pensions	16.47	4.02
Disability grants	14.93	0.28
Retirement benefits	2.46	0.78
Support from outside household	5.03	3.09

Calculated from the 1999 October Household Survey, Statistics South Africa, 1999

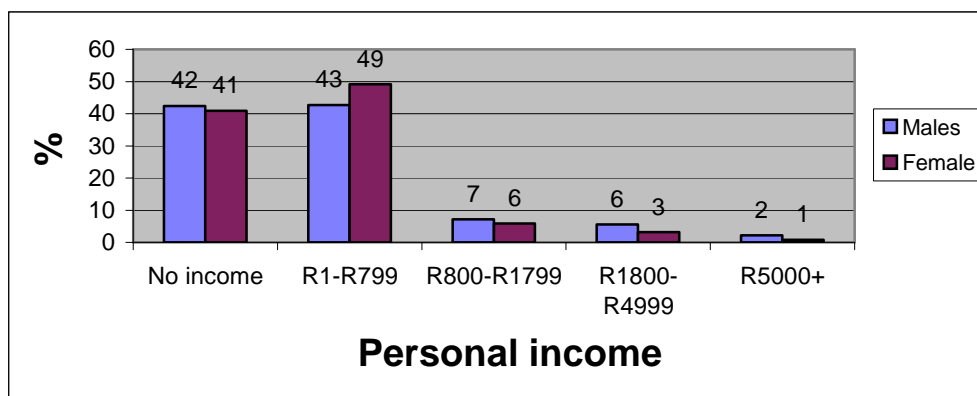
Taken together the data on income and social security highlight the vital role social security, and particularly disability grants and old age pensions, play in poverty-alleviation among people with disability. There is little doubt that without disability grants and pensions people with disability and their families would face the most dire poverty. On the other hand, even with the existing social security system, there are indications that in terms of income people with disability may be poorer than their non-disabled counterparts. In addition to proportionately fewer people with disability than non-disabled people having incomes of R800 and above, a slightly larger percentage of people with disabilities (87.6%) than non-disabled people (83.2%) had incomes of less than R800 when the two categories are combined.

Secondly, as social security grants are on public record, respondents are less likely to conceal information on this source of income than are respondents with other (particularly, illegal) sources of income. Thirdly, as personal income is involved, it is not possible to know what the income situation of either the household as a whole is, or how many persons are dependent on the income derived from pensions and grants. Studies of poverty in South Africa have shown that unemployed adults often attach themselves to pensioner households in order to tap into the resources of pensions and other social grants.

Finally, there is also the issue of the additional costs associated with disability (care-giving, assistive technology, transport, etc.) which means that low levels of income have to cover greater costs. Indeed, if we accept the argument of Kuklys and Sen discussed above, the income figures presented in Figure 1.4 above represent only a small fraction of the deprivation experienced by people with disability in South Africa. Factoring the 'conversion handicap' into the income data is therefore likely to yield far higher rates of poverty among South Africans with disability

⁶ Only those grants and sources of income in which proportionately one percent or more of either of the two categories of respondents received benefits were included in Table 1.1. It should also be noted that in 1999/2000 old-age pensions and disability grants accounted for R15.3 billion (or 86%) of the total state expenditure on grants in contrast with only R1.6 billion for all other grants (Taylor Committee, 2001: 373).

Figure 1.5: Percentages of personal income of people with disabilities by income and gender, South Africa, 1999



Calculated from the 1999 October Household Survey, Statistics South Africa, 1999

In Figure 1.5 the personal incomes of people with disabilities are disaggregated by gender. While the differences between males and females are relatively small, relatively clear disadvantages are apparent for women, particularly in relation to incomes of R800 and more. In particular, twice as many men as women earned incomes of R1800 and above. For those at the bottom of the income scale, the proportions of males and females without income are similar, but slightly more women (90%) had incomes under R800 than men (85%) when the two income categories are combined. Here again the number of dependents in households would have to be taken into account, especially within the context of female-headed households which have been shown to be considerably poorer than male-headed households.

Given the association between poverty and disability and the extreme racial inequalities in the distribution of income in South Africa, one would expect higher rates of disability in South Africa among Africans and coloureds than among whites and Indians. The available data provides some support for this, but not in all cases. In Table 1.2 below, the distribution of disability among the major population groups of four datasets, the 1996 and 2001 censuses, the 1999 October Household Survey and the CASE disability survey of 1998, are presented. Both the 1996 and 2001 census and the CASE survey indicate relatively higher rates of disability among Africans, with the 1996 Census data producing a prevalence rate for Africans that is more than twice as high as the rate for whites. For the October Household Survey of 1999, however, the highest prevalence rate was for coloureds (4.5%) followed by Africans (3.4%). In general the results of these surveys do suggest that the distribution of disability is racially biased and that Africans are likely to have higher prevalence rates. However, as we argue in the conclusion to this section of the report, the relationship between poverty and disability prevalence is complex. On the one hand poverty increases the risk of acquiring an impairment, while on the other it may also result in earlier mortality and reduced life spans of people with disability.

Table 1.2: Percentage distribution of disability among the major population groups in South Africa

	1996 Census	2001 Census	CASE survey, 1998	OHS, 1999
African	7.6	5.2	6.1	3.4
Coloured	3.7	4.2	4.5	4.5
Indian	4.2	3.7	4.8	2.2
White	3.5	4.5	5.3	3.2

Sources: Schneider et al., 1999; 1996 and 2001 Census and 1999 OHS calculated from the Statistics-South Africa datasets

Using data from the 1996 census, Aliber (2003:481) found only small differences in the unemployment rates of people with disabilities and those without disabilities. For example, for Africans with disabilities 45.3%, were unemployed (according to the broad definition), as against 42.5% of Africans without disabilities. Similarly, 26.7% of coloured people with

disabilities were unemployed as against an unemployment rate of 20.9% for all coloured people. Aliber (2003) attributes these small differences to the very high rates of unemployment in South Africa in general, but the ways in which unemployment is defined in the census may also have played a role.⁷

When employment (rather than unemployment) data are used, the differences in the employment rates of the disabled and non-disabled populations become clearer. Using data from the 2001 Census, Statistics South Africa (2005: 21) calculated employment statistics for age groups ranging between 15 and 65 years. As may be seen from Table 1.3, the employment rates of disabled persons were lower than those of non-disabled persons for all the age groups. The gap in the employment rates of the two groups was particularly pronounced for those age groups in which employment rates were higher. For example, for the 35-39 year age group, which had the highest rates of employment for both disabled and non-disabled, the rate of employment of people with disability was less than half the rate of the non-disabled population. For all age groups, disabled persons had an employment rate of 18.6% as against an employment rate of 34.6% for non-disabled persons.

Table 1.3: Percentage of disabled and non-disabled persons employed by age group, 2001 Census

Age group (years)	Disabled persons	Non-disabled persons	Total
15-19	2.5	3.9	3.9
20-24	12.5	22.0	21.7
25-29	21.0	39.6	38.9
30-34	25.2	49.0	47.9
35-39	25.9	52.2	50.8
40-44	25.7	53.5	51.7
45-49	24.8	51.7	49.5
50-54	21.2	46.8	44.3
55-59	16.6	37.9	35.5
60-65	8.7	19.3	18.0
Total	18.6	34.6	33.7

Source: Statistics South Africa, 2005: 21

Table 1.4, which presents the employment profile of the disabled and non-disabled populations by province and gender, shows that the percentage of disabled persons who were employed was relatively low in all provinces compared to that of non-disabled persons. The data also show that gender plays an important role in the employment statuses of both the disabled and the non-disabled populations. For both populations, female rates of employment are consistently lower than male rates of employment. Overall, these data suggest that gender and disability have cumulative impacts on employment rates.

While it is more difficult to generalize about the provincial data, it should be noted that those provinces with the lowest rates of employment of people with disability, particularly the Eastern Cape and Limpopo and to a lesser extent KwaZulu-Natal, are characterized as poor and underdeveloped provinces with large percentages of their population living in poverty, small GDPs per capita, large percentages of their populations living in rural areas, limited water supply and sanitation facilities, and with high percentages of their female populations having no schooling. In general the data therefore suggest that together with gender and disability, geographical location plays some role in determining outcomes in the labour market.

⁷ Statistics South Africa uses the following *official* definition of unemployment:

The *unemployed* are those people within the *economically active population* who:

- (a) did not work during the seven days prior to the interview,
- (b) want to work and are available to start work within a week of the interview, and
- (c) have taken active steps to look for work or to start some form of self-employment in the four weeks prior to the interview.

Table 1.4: Percentage of disabled and non-disabled persons aged 15-65 years employed by province and gender

Province	Disabled person		Non-disabled person		Total	
	Male	Female	Male	Female	Male	Female
Western Cape	28.4	22.7	57.2	42.4	55.8	41.6
Eastern Cape	9.6	8.0	25.3	18.0	24.1	17.4
Northern Cape	21.1	12.2	51.1	31.2	49.1	30.1
Free State	28.7	18.5	42.9	26.9	41.8	26.3
KwaZulu-Natal	17.6	12.9	35.1	23.1	34.1	22.6
North West	22.9	11.6	43.0	22.5	41.7	21.9
Gauteng	30.9	24.1	53.2	37.9	52.3	37.4
Mpumalanga	29.3	16.5	44.5	24.0	43.4	23.5
Limpopo	17.9	12.8	30.2	17.7	29.5	17.5
South Africa	22.0	15.2	42.5	27.0	41.3	26.8

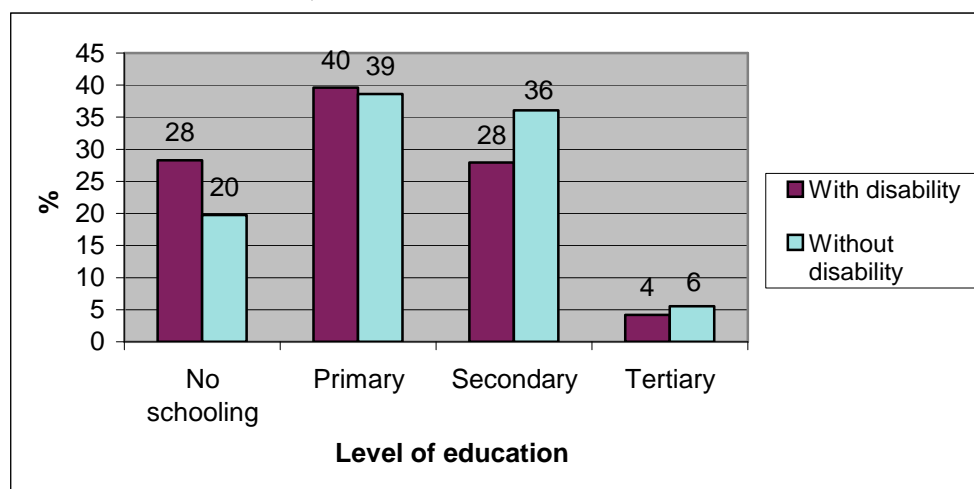
Source: Statistics South Africa, 2005: 22

The 1998 CASE survey of disability also found significant differences in employment rates relating to race, gender, the number of disabilities, and age of onset. The study found an overall employment rate of 12% for people with disabilities. This represented about a third of the employment rate for the general population at that time.

In terms of race, the CASE study found that whites were more likely to be employed, with 19 % of white people with disabilities employed in full-time positions compared to 6 % of Africans, 4 % of Coloureds and 9 % of Indians. Women with disabilities were also less likely to be employed, with 11 % of women with disabilities included in the sample indicating that they were employed as against 15 % for men with disabilities. This difference was statistically significant. The study also shows that age of onset played a role in the employment of people with disabilities in that only 7 % of those who had acquired impairments before two years of age were employed, as against 17 % of those with age of onset between 19 and 65 years.

One of the ways in which early onset of disability may impact on employment is through education. For example, data from the 1999 October Household Survey showed that nearly 30 per cent of school-age children with disabilities were not attending school or not attending full time, compared to 10 per cent of non-disabled children (Taylor Committee, 2001: 358). Inequalities in the levels of education attained by people with or without disabilities are also reflected in Figure 1.6, which shows that more people with disabilities had no schooling and fewer had secondary or tertiary education. In relation to primary school education, however, there was very little difference between those with or without disabilities.

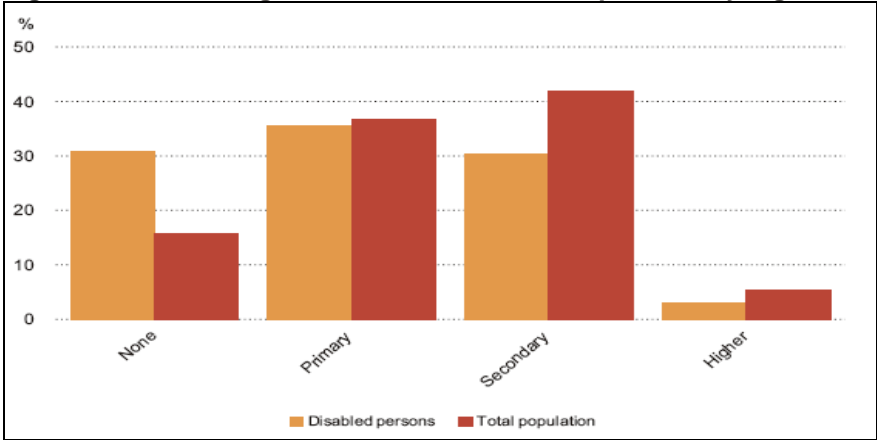
Figure 1.6: Percentages of people with and without disability by level of education, South Africa, 1999



Calculated from the 1999 October Household Survey, Statistics South Africa, 1999

Very similar trends were obtained from the 2001 Census (Statistics South Africa, 2005), with the percentage of disabled persons with no schooling being twice as large as that of the total population. Both datasets showed very small differences in primary school attendance of the two populations, but more significant differences in secondary and tertiary attendance.

Figure 1.7: Percentage distribution of disabled persons by highest level of education



Source: Statistics South Africa, 2005: 20

The CASE study also found that attendance of primary school by children with disabilities was relatively high with 79% of respondents attending mainstream primary schools and a further 12% at special schools. Only five percent of the qualifying respondents were not attending primary school. In contrast, 44% of respondents were attending mainstream high schools and a further 9% were attending special secondary schools. CASE attributes the relatively low attendance of secondary schools by children with disabilities to the lack of attention to their special education needs in primary schools, so that they were unable to reach high school.

The 2001 census data also show considerable disparities in terms of race and gender. Table 1.5 shows the percentages of people with disability aged 20 years and above who had never attended school by population group and gender. Clear differences that are consistent with the inequalities inherited from the apartheid era are apparent between the racial groups, with, for example, 38.8% of Africans having no schooling as against only 6.7% of whites. Differences based on gender are generally smaller than for race, but show that for all the population groups, women fared worse than their male counterparts. It is only in the case of Indians/Asians that the gender difference is substantial, with more than twice as many females having no schooling as males.

Table 1.5: Percentage of people with disability aged 20 years and above who had never attended school by population group and gender

Population group	Male	Female	Total
African	35.3	41.8	38.8
Coloured	19.1	21.5	20.3
Indian/Asian	10.0	22.5	16.0
White	6.3	7.0	6.7
South Africa	30.5	36.7	33.8

Source: Statistics South Africa, 2005: 20

Further evidence of how the educational disadvantages of people with disabilities are compounded by racial inequalities is provided by the CASE study of disability. The study found that at the secondary school level, 51% of African children with disabilities were out of school in contrast with only 11% of white children with disabilities. Furthermore, white children were more likely to be attending special schools than African children, with 32% of white children in special schools at the primary level and 33% at the secondary level. In contrast only 8% and 5% of African children attended special schools at the primary and secondary levels, respectively. Far more African children with disabilities (85%) were therefore in mainstream primary schools than their white counterparts (56%).

As Schneider et al. (1999:21) point out, these results need to be seen against the background that special schools “have traditionally captured most of the budget for special needs” (Schneider et al., 1999:24) and that only limited provision is made for catering for the special education needs of children with disabilities in mainstream schools. For example, the CASE data showed that children attending special schools were more likely to have access to and to be using assistive devices than those attending mainstream schools. (Schneider, et al., 1999:22) In general, Indians and whites with disabilities were more likely to be using assistive devices than Africans and coloureds with disabilities. Furthermore, the majority of assistive device users lived in urban areas.

The CASE study also demonstrated that access to assistive devices and personal assistance were shown to “have a highly significant impact on how respondents rated their disability or activity limitation” (Schneider, et al., 1999:20). Whereas 58% of those with no personal assistance or assistive devices rated their disabilities as severe, only 5% of those with access to an assistive device and 12% of those with personal assistance rated their disabilities as severe. Similar situations applied to diagnostic and assessment services, with more privileged and urbanized populations having access to specialised services (Schneider et al., 1999:24-5). Lack of access to effective identification and assessment of disabilities in turn were associated with “ad hoc placement within mainstream schools with no real consideration of the child's needs” (Schneider et al., 1999:25).

As in the case of assistive devices, the complex interrelationships between disability, poverty, gender and race in South Africa appears to be intertwined with issues of locality, and in particular location in rural and urban areas. This is particularly relevant to South Africa where under apartheid the former (largely rural) homeland areas were severely under-funded and deprived of social and economic services. As pointed out in the Integrated National Disability Strategy, the location of people in disadvantaged areas like the former homelands has “had a particularly severe impact on people with disabilities who found themselves in an inhospitable environment, facing poor living conditions and unable to access the help they needed”.

The Disabled Children Action Group (DICAG) estimates that 98% of mothers of children with disabilities living in rural areas are unemployed, semi-literate or functionally illiterate single women. Deserted by husbands and lovers, often socially ostracized by their communities, and banished into isolation by their extended families, they tend to withdraw into a world of their own (South Africa, 1997).

1.6 Conclusion

Overall, existing data on disability in South Africa suggest that disability, poverty, gender and race are intimately associated with another, and that the cumulative impact of disability, poverty and other social disadvantages such as gender, race, and physical location can therefore create extreme vulnerability and exclusion for those sections of the population who suffer multiple and overlapping disadvantages. Together with the more comprehensive data that are available on disability in the industrialised countries, a strong case is made for the relationship between disability and poverty in *both* industrialised and the developing countries.

The association between disability and poverty is likely to be even stronger if the multidimensionality of poverty is taken into account. In the analysis of disability and poverty in South Africa, for example, inequalities between disabled and non-disabled persons were clearer in relation to education than they were in relation to income. In addition to the complications created by social assistance, especially disability grants and pensions, in the income data, the available data on income in South Africa does not take into account the special needs and expenses associated with disability. As Kuklys (cited by Sen, 2004) was able to show using British data, the gap in income between disabled and non-disabled people represents only a small part of the monetary disadvantage suffered by people with disability. It is not surprising therefore that some attempts to demonstrate high rates of poverty among

people with disability in developing countries using income data have not always been successful. See, for example, the discussion of Massey and White's data on poverty and disability in five developing countries in Miles (2006).

Another aspect of the multi-dimensionality of poverty that complicates our understanding of the relationship between disability and poverty is mortality. There are strong indications that people with disabilities have higher rates of mortality, and it is claimed that "in some parts of the world, as many as 80 per cent of disabled children die before the age of 5, even in areas where the overall child mortality rate has been brought down to under 20 per cent" (World Bank, 2004; DFID, 2000: 5). Several studies in different parts of the world including developing countries, have shown higher mortality rates among children and adults with visual disabilities, and that mortality rises with the severity of impairment. (See, for example, Gooding (2006: 27-28) for a review of some of these studies). While life expectancy among people with spinal cord injuries has improved considerably in industrialized countries in recent years, life expectancy in many of the poorer countries can be one or two years.

Although higher mortality rates among disabled children and adults have been linked to the specific impairments and injuries themselves, inequalities in the treatment of especially children with disabilities may also have an impact on life expectancy. For example, impoverished households are often limited in the resources and time they can invest in disabled members, particularly children. As Yeo and Moore (2003: 573) point out, where "there are limited resources it may be seen as economically irresponsible to give an equal share to a disabled child who is perceived as unlikely to be able to provide for the family in the future". Lack of investment in disabled children is not merely a "reflection of ignorance", but may involve "a desperate but rational decision".

Thus, disabled children often get last access to food and other basic resources. When disabled children become ill they are often not given any treatment. In households or communities already living in poverty, this exclusion is frequently a life or death situation. Erb and Harriss-White found that in their focus villages in Tamil Nadu "disabled children were very rare," and suggest that this is because they are either not disabled or they do not survive. Early and preventable death is the most extreme symptom of poverty; thus, disability must be a central concern of those committed to poverty reduction.

In addition to the as yet unmeasured deprivation of preventable deaths, mortality among people with disability may also be related to the paradox of disability prevalence rates in the developing and industrialised countries. Given the strong association that has been established between disability and poverty in the industrialized countries, one would expect that disability rates would be higher in the developing countries where conditions of poverty and ill-health are more pervasive. Existing data do not support this assumption. Instead, estimates of the percentages of the population with impairments tend to range between 10 and 15 % in industrialized countries, while in developing countries the figures tend to be significantly lower, usually below 6 % of the total population.

While definitional and measurement issues are important in understanding these differences (for example, surveys in the industrialized countries have generally been more sophisticated and more comprehensive than in developing countries), other reasons, such as "the premature death of disabled people (mainly infants, female children and women), failure to record disabled people in censuses and surveys, and higher 'thresholds' for the identification of impairment and disability" (Albert, McBride and Seddon, 2002:4), have probably also played a role. In addition to differences in the quality of, and resources available for, research in low and high income countries, conditions in developing countries also present difficulties for research on disability, including poor infrastructure in the more remote areas, problems associated with reaching poor households, and difficulties associated with the identification and awareness of disabilities, particularly of children. The stigma that is often associated with disability may also play a role in that some people may conceal their disability status or that of members of their households. This is most likely to occur in those households and

communities that are poorer and located in rural and less accessible areas, that is, in contexts in which one would expect disability rates to be higher (Taylor Committee, 2001: 357).

Lower prevalence rates for disability in developing countries may therefore at least in part be a product of higher mortality rates among people with disabilities. If this is the case, then it is likely that those segments of the population that are most vulnerable to disability would also be most vulnerable to premature mortality. This in turn would have the effect of lowering disability rates among those parts of the population that one would expect to be most vulnerable to disability. In order to obtain a more comprehensive understanding of disability within developing contexts, it may therefore be necessary to locate disability trends within the context of mortality trends. As Hulme and Shepherd point out, how to deal with people who die preventable deaths is a key conceptual challenge for the study of poverty: 'These need to be incorporated in our analysis as they experience the most acute form of deprivation (i.e. deprivation of all capabilities) for all of the "lost" years of the life they would have had' (2003: 409).

In addition to lower overall disability prevalence rates in developing countries, available data also indicate that women in the developing countries may have lower disability rates than men, while women in the industrialised countries generally have higher rates of disability than their male counterparts. Lower female rates may indicate that severe impairments may be male-dominated or that females with disabilities may be under-reported or may receive less care and die sooner. For example, estimates from India and Pakistan indicate that male disability rates are higher than female rates. This 'could indicate that girls and women with disabilities receive less care and support, and die earlier. Another possibility is that the gender division of labour is such that disabled women contributing to household activity are not identified as disabled, whereas the visibility of disabled men is greater' (Elwan, 1999: 9). Studies conducted in Yemen and Egypt showed similar trends, with higher prevalence of disability among boys, which researchers attribute to higher mortality rates among girls with disabilities (Abu-Habib, 1997: 1–2). As Harriss-White (2003) observes, the process of care for people with disabilities in India is "socially constructed and extremely male-biased". In a study of disability in three villages in India, for example, it was found that the percentages of adult males receiving treatment ranged between 53% and 56%, while for adult females the corresponding percentages ranged between 11% and 39%.⁸

Disparities in the disability rates of males and females in developing countries suggest that for at least some developing countries inequalities associated with gender and disability are a matter of life and death. One indication of the links between gender, disability and mortality relates to orphans and abandoned children in China. According to official figures for 1999, of 100 000 to 160 000 orphans and abandoned children, 90% were girls and the majority of the remaining 10% were boys with impairments (Chronic Poverty Research Centre, 2004: 22).

The above analysis suggests that interactions observed earlier in relation to income poverty, employment and education between disability and other disadvantages such as gender and race, may also apply to mortality.

⁸ The suggestion that lower rates of disability among women in developing countries may be related to higher mortality rates for women and girls in these countries receives some support from the demographic phenomenon of the 'missing women' that emerges from Amartya Sen's work on poverty and inequality. Using a range of demographic analyses, Sen (1999) showed unusually higher age-specific mortality rates for women in some developing countries, particularly those in South and West Asia, North Africa and China. Comparisons with male:female ratios in Europe, North America and sub-Saharan Africa show more than 100 million women 'missing' in selected countries in Asia and North Africa. Sen attributes these gender specific mortality rates directly to extreme gender inequality in these countries, and more specifically to 'the comparative neglect of female health and nutrition, especially – but not exclusively – during childhood' (1999: 106).

SECTION 2: AIMS AND METHODS

This section of the report describes the aims and research design of the research study and the methods that were used in the survey of disability and development agencies on mainstreaming disability in development, including the respondent selection process, the data collection process, and data analysis procedures.

2.1 Aims and research questions of the study

The overall aim of the study was to assess the extent to which disability has been included within the current development policies, strategies and programmes of major development agencies in South Africa and to explore the opportunities, constraints and potential strategies for the incorporation of disability as an issue, and people with disabilities as participants, within development policies, programmes and projects.

This aim may be broken down into two main research questions, namely

1. What are the policies, practices and interactions between disability agencies and development agencies in relation to integrating disability into development?
2. What opportunities and constraints exist in relation to the integration of disability into development and how may the opportunities be realized and constraints addressed?

2.2 Research design and phases of the study

Although the research proposal of this project made provision for seven steps in the research process, these steps were consolidated into four major phases as presented below:

1. *Preparatory phase: Operationalisation and pilot interviews*
This phase included the initial planning of the project, a comprehensive literature review, and development of the measuring instrument or survey questionnaire. During this phase a web-based discussion was held with interested parties in order to explore their perspectives on issues relevant to disability and development and assist in the design of the questionnaire. Pilot interviews were also conducted with stakeholders in the two sectors in order to test the usability of the measuring instrument. Modifications were made after the pilot interviews and the questionnaire was finalised for use in the main study.
2. *Fieldwork and data-collection*
Data collection was done through interviews (telephonic and in some cases, face-to-face) with key personnel in development and donor agencies, disability agencies and state agencies involved in disability and/or development. A standardised questionnaire was used in order to ensure comparability of responses.
3. *Analysis and interpretation of data*
This phase began with the coding of the questionnaires, and then proceed to data capture, data checking, statistical and qualitative analyses, and finally interpretation of the survey results. Where possible, primary data was supplemented with textual analyses of documents e.g. policy documents.
4. *Finalisation of report and dissemination*
Following analysis of the data, a report was written and circulated to stakeholders and discussed during a workshop.

2.3 Preparatory phase of the study

As already mentioned, this phase included the literature review as well as the development and testing of the measuring instrument. Table 2.1 provides some details on the aims and findings of each activity of this phase.

Table 2.1: Description of the Preparatory Phase

Objectives	Methods	Results and Recommendations
1. Development of literature review and initial interaction with stakeholders	<ul style="list-style-type: none"> - Web-based and library searches - Development of a SANPAD project list serve to facilitate interaction between team members (Sanpad2005@kendy.up.ac.za) - Seminar with research partners (31 August 2005) - Seven-day asynchronous web-based discussion with stakeholders (27/2-3/3 2006) 	<p>Apart from researchers participating in seminar presentations and discussions on relevant literature, two students from the Hogeschool Leiden also conducted literature searches and wrote a paper in preparation of the study.</p> <p>For detailed account of the findings of the Web-based discussion and interpretation see; Alant, Emmett and Samuels, 2007 – Appendix 1)</p>
2. Development of measurement instrument	<ol style="list-style-type: none"> 1. Initial development of questionnaire 2. Distribution of the questionnaire to all research partners for comments and modifications 	<p>Initial development was undertaken by the South African team and circulated to the Dutch partners and other interested parties for comments. Various modifications resulted from these interactions</p>
3. Pilot testing of the questionnaire/interview schedule	<p>Conducting of 6 pilot interviews to</p> <ul style="list-style-type: none"> - test the relevance and ease of administration of the questionnaire and - Evaluate the usability of telephonic interviews for the purpose of the study 	<p>The South African team conducted the pilot interviews. Various changes were made to the initial questionnaire following the pilot interviews.</p> <p>The research team felt that telephonic interviews were sufficient for obtaining the relevant data, but that the team would be flexible and do face-to-face interviews, self-administered questionnaires as well as video conferencing where necessary, to ensure the inclusion of as many as respondents as were willing to participate. Generally interviews lasted between 45-60 minutes.</p>
4. Organisations consulted in addition to 32 organisations included in the survey	<p>World Bank, Washington, DC – via video conferencing</p> <p>Southern Africa Trust – by telephone and e-mail</p>	<p>The video-conference with World Bank personnel in Washington, DC. was organised after we requested an interview with locally-based personnel.</p> <p>The Southern Africa Trust was approached in order to supplement information from one of the other respondents.</p>

2.4 Respondents: Selection of Organisations

As an initial starting point in identifying disability and development organisations for potential inclusion in the project, a matrix was developed using the Prodder online directory of South African NGOs and development organisations as well as a number of existing lists of disability organisations in South Africa. Development organisations were initially selected on the basis of their professed involvement with disability as listed in the Prodder directory. Please see Table 2.2 for the initial outline used in the approach to the selection of organisations. Although a distinction was initially made between regional and local level organisations, these were collapsed into one category because of the difficulty of distinguishing between regional/provincial and local organizations, particularly in relation to non-governmental

programmes. Not all the categories listed were included in the sample. Please note that the organizations listed are examples and not a comprehensive list of organisations.

The 32 organisations that were included in the survey, together with the position of the person interviewed, the classification of the organization and the mode of the interview are presented in Table 2.3.

Table 2.2: Mapping of SA development agencies and disability organizations

Level of operation	Type of organisation	Development Agencies	Disability Organisation
International	Donor/development agencies	USAID, DFID, DANIDA, World Bank, CIDA, SIDA, UNICEF, UNESCO, etc.	<ul style="list-style-type: none"> • DPI • Pan African Federation of the Disabled • SAFOD • APDP
	NGOs	Care International, OXFAM, Save the Children Fund, Topsy Foundation, Treatment Action Campaign, SHIA, CBM	
National	Government agencies and parastatals Sectoral/Departments Multisectoral Programmes	Social Development, Health, Education, Labour, etc. NDA, DPSA, government clusters, etc.	<ul style="list-style-type: none"> • OSDP • QASA • NCCPDSA • DEAFSA • DEAF-BLIND SA • DSSA • AUTISM SA • SAFMH • EPILEPSY SA • DPSA • SANCB • NATIONAL ASSOCIATION FOR PERSONS WITH CEREBRAL PALSY • DICAG • NDSISA
	Donors, Foundations, Trusts	Kagiso Trust, Nelson Mandela Children's Fund, Nelson Mandela Foundation, Anglo American, UYF, etc. Foundation for Human Rights Thabo Mbeki Development Trust	
	NGOs Coalitions Individual	SANGOCO, SANGONET Soul City, Treatment Action Campaign	
Regional/local	Provincial and local government	Provincial administrations, municipalities and related institutions	PROVINCIAL DISABILITY DESKS <ul style="list-style-type: none"> • Mpumalanga • Limpopo • North-West • Eastern Cape • Western Cape • Northern Cape
	NGOs/CBO's	Rural Action Committee, Valley Trust Lamontville Community Resource Centre.	<ul style="list-style-type: none"> • ASD • MODE
Other	Private development consultants	TEBA Development, McIntosh, Xaba and Associates	<ul style="list-style-type: none"> • DEC • ENABLE • Disability Solutions
	Academic institutions	CSDS, CAAC, School of Public Management and Planning	
	Private sector social responsibility initiatives	Overlaps with national donor agencies, but also includes specific (usually local) development initiatives	

Table 2.3: Organisations with which interviews were conducted

INSTITUTION	DESIGNATION	TYPE OF ORGANISATION	INTERVIEW
Alexander Forbes Community Trust	Trustee	Development	Telephonically
Department for International Development (DFID)	Social Development Adviser	Development	Face-to-face
Department of Health	Director: Chronic Diseases, Disabilities and Geriatrics	Development	Telephonically
Department of Labour	Manager: Gender, Disability and Youth	Development	Self-administered
Department of Social Development	Director: Disability	Development	Face-to-face
Development Bank of Southern Africa	Employment Equity Analyst	Development	Face-to-face
Parliament	Member of Parliament	Development	Face-to-face
Sasol	Human Resource Manager	Development	Telephonically
Sweden Embassy/SIDA	First Secretary: Development and Co-operation	Development	Face-to-face
Thabo Mbeki Development Trust for Disabled People	Central Executive Officer	Development	Face-to-face
United National Development Programme	Assistant Resident Representative	Development	Face-to-face
Valley Trust	Organisational Development Facilitator	Development	Telephonically
Alexandra Disability Movement (ADM)	Development Officer	Disability	Telephonically
Autism South Africa	National Director	Disability	Face-to-face
Cheshire Homes	National Director	Disability	Telephonically
Disability Action Research Team	Human Resource Manager	Disability	Telephonically
Disability Solutions	Co-founder	Disability	Telephonically
Deafblind South Africa	National Director	Disability	Face-to-face
Disabled People South Africa, Eastern Cape	Provincial Development Organizer / Eastern Cape Secretary General	Disability	Telephonically
Disabled People South Africa (National)	Secretary General	Disability	Telephonically
Down Syndrome South Africa	National Chairperson/Director	Disability	Telephonically
Eco-Access	Founder and Honorary Life President	Disability	Telephonically
Enable Education Training and Development Initiative (ENABLE)	Principal	Disability	Telephonically
Epilepsy South Africa	National Director	Disability	Telephonically
Kamohelo Day Care Centre	Project Co-ordinator	Disability	Telephonically
National Council for Persons with Physical Disabilities South Africa	Manager of Advocacy and Development	Disability	Telephonically
Public Relations and Awareness Association for Persons with Disabilities, Free State	Deputy Director	Disability	Telephonically
QuadPara Association of South Africa	National Director	Disability	Telephonically
S A Federal Council on Disability	Chairperson	Disability	Telephonically
SA National Council for the Blind	Access Consultant	Disability	Telephonically
Secretariat of the African Decade Of Persons with Disability	CEO	Disability	Telephonically
Association for Persons with Disability, Northern Cape	Social worker	Disability	Telephonically

2.5 Description of the Survey Instrument

The survey instrument is described in Table 2.4.

Table 2.4: Description of the Survey Instrument

Section	Example of questions
1. Information on the Respondent	Organisation, classification of the organisation and respondent's position in the organisation
2. Attitudes and orientations to disability and development	Definition of disability, estimate and motivation of incidence of disability in South Africa, familiarity of the social model, whether disability is a significant factor in causing poverty, whether enough attention is given to the issue of disability and development, level of importance ascribed to development/disability by the organisation, assign priority value on issues in development and disability
3. Policies on disability and development/poverty alleviation	Existence of any written policies on disability and development, if yes, what are the documents and the goals within the organisation? Desirability of having policies on disability and development
4. Communication between disability and development sectors	Nature and frequency of contact in last 12 months, usefulness of this contact, knowledge of other organisations that might be useful to enter into dialogue with?
5. Implementation, projects and practices	Projects and programs that the organisation presently run that address both disability and poverty alleviation in terms of what is done, who is responsible, rating of success of project and limitations

From Table 2.4 the 5 areas included in the survey instrument are detailed to provide information on the specific content of each category. These questions were included in a questionnaire that was used as a basis for all the interviews conducted.

2.6 Material Fieldworkers/Interviewers

Altogether eight interviewers (staff and post-graduate students at the CAAC) participated in the study. All interviewers were professionals with experience in research. In compliance with the ethical requirements of the University of Pretoria, all fieldworkers signed a Declaration of Ethical Intent in which they undertook to protect and safeguard the rights and autonomy of all parties involved in the project and abided by the ethical guidelines of the University of Pretoria. Thereafter a training session was held to ensure that each interviewer was familiar with the process of data collection and the use and completion of the questionnaire. Most of the interviewers also participated in the pilot phase of the study.

2.7 Data collection strategy

2.7.1 General procedures: Setting up of interviews

- Personalised emails were sent out to targeted respondents in organisations after their names and contact details were obtained from the relevant organisations.
- After each respondent agreed to participate in the study, an interview time was scheduled with the respondent.
- The interview was confirmed by the person who conducted the interview shortly before the interview and if the respondent preferred, a copy of the questionnaire was emailed to him/her in preparation of the interview.
- Where possible interviews were tape recorded to facilitate analysis of data.
- Interviewers were encouraged to take notes during the interview and to complete the questionnaire immediately after the interview to ensure that all relevant information was captured. Interviewers were encouraged to contact respondents in

case they were uncertain or felt they needed to verify their responses to a particular question.

2.7.2 Specific interview procedures

- All respondents were informed of the purpose of the interviews prior to the interview. At the start of the interview, they were asked if they would mind if the interview was recorded for analytical purposes. If they consented, the interviews were recorded.
- Interviews were conducted using a speaker phone in the offices at the CAAC at the University of Pretoria. Face to face interviews (nine in total) were generally conducted on the premises of the respondent.
- Fieldworkers went through each of the questions of the questionnaires to facilitate obtaining all relevant information.
- In cases where the respondent had additional information of interest eg. policy documents of the organisation they represented, copies of these documents were requested.
- Fieldworkers were required to submit their completed questionnaires within three days of the interviews.
- Each of the questionnaires were checked by an independent researcher to ensure that all questions were completed and requirements met.
- Thereafter, questionnaires were sent to the senior researcher for data processing and analysis.

2.7.3 Data analysis

- The questionnaire included a large number of open questions for which coding lists had to be constructed. The coding lists were constructed by the senior researcher and reviewed by the entire research team.
- After the questionnaires had been coded and checked, they were delivered to the University of Pretoria's Department of Statistics for data capturing.
- The captured data were checked for errors before descriptive statistics were generated using Statistical Analysis Software (SAS).
- Those responses which could not be coded beforehand were analysed qualitatively according to themes and rated by two independent raters.

SECTION 3: FINDINGS OF THE SURVEY OF DISABILITY AND DEVELOPMENT AGENCIES

This section of the report sets out the results of the interviews conducted with stakeholders in the disability and development sectors. As pointed out in the methodology section above, the majority of interviews were conducted by telephone, with some interviews conducted face-to-face. Use was made of a formal questionnaire to allow for standardization of responses and quantification of the results. However, the questionnaire included a large number of open questions, many of which were also coded. Those open questions which could not be coded were analyzed qualitatively. In total 32 questionnaires were completed.

3.1 The sample

Although considerable effort was expended in attempting to ensure a balanced sample, substantial difficulties were experienced in obtaining interviews with development agencies. In spite of the research team's endeavors to ensure that the relevant agencies were fully informed of the purpose and relevance of the research project and repeated telephone calls and e-mails to personnel associated with the development agencies, most of the agencies contacted were reluctant to provide interviews. Calls were not returned and emails and faxes remained unanswered. In some cases where appointments were obtained, these were cancelled and attempts to obtain a new appointment failed. The research team was frequently asked to submit its request for an interview in writing after which no response was received. In a number of cases international organizations referred the researchers to personnel based at their head offices, even though it was made clear that the study was focused on South Africa. On a number of occasions researchers were referred to human resource managers because the employment of people with disability formed part of their portfolios. One international development agency responded to the request for an interview by stating that it "only work(ed) with fit people".

Responses like these provide an early indication of how the development sector in South Africa relates to the issue of disability in development. They suggest that at least some (if not a majority) of people working in the development sector are uncomfortable with disability as a development issue, have limited knowledge of the issues involved, regard disability as an issue for specialists, or attach little value to it as a development issue although they are probably reluctant to admit it.

The response from the disability sector stands in sharp contrast to that of the development sector. Representatives of disabled people's organizations (DPOs) readily agreed to be interviewed and expressed strong interest in the issues raised in the interviews.

The uneven response from the two sectors produced two important consequences for the study. Firstly, it led to an under representation of development agencies and an overrepresentation of DPOs in the sample. Of the 32 interviews conducted, 12 were with development agencies and 20 with DPOs. Secondly, because of the large number of refusals from the development sector, the realized sample of respondents from the development agencies may have been biased in favour of respondents who were more sympathetic to and knowledgeable of the issue of mainstreaming disability in development than the population from which they were drawn. Table 3.1 sets out the realized sample.

Table 3.1: Organizational affiliations of respondents included in the interviews

Type of organisation	Frequency	Percent	Cumulative Frequency	Cumulative Percentage
Development International - Foreign Government	3	9.38	3	9.38
Development National - Government	4	12.50	7	21.88
Development National - Donors, Foundations, Trusts	2	6.25	9	28.13
Development National - Private sector	1	3.13	10	31.25
Development National - NGOs	1	3.13	11	34.38
Development Regional - NGOs and CBOs	1	3.13	12	37.50
Disability International	1	3.13	13	40.63
Disability National - NGOs	12	37.50	25	78.13
Disability Regional - NGOs and CBOs	5	15.63	30	93.75
Disability other (Consultants)	1	3.13	31	96.88
Development for PWD	1	3.13	32	100.00

Because of the concentration of organizations in the major cities and in particular in the metropolitan complex of Gauteng, the majority of interviews (nearly 60%) were conducted with respondents in Gauteng, with an additional quarter of the interviews conducted with respondents in the Western Cape and KwaZulu-Natal. In spite of this bias, respondents were drawn from six of the nine provinces.

Table 3.2: Location of respondents that were interviewed

Location of respondent	Frequency	Percentage	Cumulative Frequency	Cumulative Percentage
Gauteng	19	59.38	19	59.38
Free State	2	6.25	21	65.63
Northern Cape	1	3.13	22	68.75
Western Cape	4	12.50	26	81.25
Eastern Cape	2	6.25	28	87.50
KwaZulu Natal	4	12.50	32	100.00

Just over half of the respondents were people with disabilities. This was largely due to the overrepresentation of Disabled People's Organisations (DPO), many of which are run by people with disability, but also because a number of people interviewed in the development agencies were PWDs.

Table 3.3: Disability status of respondents

	Frequency	Percentage	Cumulative Frequency	Cumulative Percentage
Person with a disability	17	53.1	17	53.1
Not a PWD	15	46.9	32	100.00

3.2 Definitions and orientations to disability

In order to establish the orientation of development and disability agencies to disability, respondents were asked how they defined disability. The definitions provided were then coded according to the three components of the International Classification of Functioning, Disability and Health (ICF) and various combinations of these components. Table 3.4 shows considerable variation in the ways in which respondents defined disability, although the most common responses related to environmental barriers on their own or in combination with functioning and impairment. It is of interest that none of the respondents attempted to define disability exclusively in terms of impairment.

Table 3.4: Definitions of disability provided by respondents

Definition of disability	Frequency	Percentage	Cumulative Frequency	Cumulative Percentage
Impairment	0	0	0	0
Activities/functioning	4	11.11	4	11.11
Environment	8	22.22	12	33.33
Impairment, functioning and environment	7	19.44	19	52.78
Environment and impairment	3	8.33	22	61.11
Functioning and environment	2	5.56	24	66.67
Impairment and functioning	7	19.44	31	86.11
Other	2	5.56	33	91.67
Hesitant to provide definition	3	8.33	36	100.00

The emphasis on the environment as a defining factor in disability can largely be attributed to respondents who represented DPOs. As Table 3.5 shows, a third of respondents representing DPOs defined disability in terms of the environment as against only 7% of respondents representing development organizations. This trend is consistent with the strong environmental emphasis of the social model of disability. For development agencies the major emphasis fell on impairment in combination with functioning or functioning and the environment.

Table 3.5: Definitions of disability by type of agency

Definition of disability	Development agency		Disability agency		Total
	Frequency	Percentage	Frequency	Percentage	
Activities/functioning	1	6.67	3	14.29	11.11
Environment	1	6.67	7	33.33	22.22
Impairment, functioning and environment	4	26.67	3	14.29	19.44
Environment and impairment	1	6.67	2	9.52	8.33
Functioning and environment	1	6.67	1	4.76	5.56
Impairment and functioning	4	26.67	3	14.29	19.44
Other	1	6.67	1	4.76	5.56
Hesitant to provide definition	2	13.33	1	4.76	8.33
Total	15	41.67	21	58.33	100.00

In order to supplement the information obtained on definitions of disability, respondents were also asked to categorize disability as an issue. Although respondents were encouraged to choose only one issue that *mainly* characterized disability, some respondents opted for two or more issues. The most common response was to characterize disability as a human rights issue. In addition to the 50% of the respondents who chose human rights as the main issue of disability, a further five respondents chose human rights in combination with other issues, accounting for 66% of the responses. It should also be noted that only one respondent categorized disability as primarily a development issue, although five other respondents chose development in combination with other issues.

Table 3.6: Characterisation of disability as an issue

Respondents' characterization of disability as an issue	Frequency	Percentage	Cumulative Frequency	Cumulative Percentage
A medical or health issue	3	9.38	3	9.38
A human rights issue	16	50.00	19	59.38
A social welfare issue	2	6.25	21	65.63
A development issue	1	3.13	22	68.75
An issue of social exclusion	4	12.50	26	81.25
Human rights and development	3	9.38	29	90.63
Medical and social welfare	1	3.13	30	93.75
Social exclusion, human rights and development	2	6.25	32	100.00

When the categorization of disability as an issue is differentiated by the types of agencies represented by respondents as in Table 3.7, clear differences are apparent between development and disability agencies. The clearest difference relates to disability as a human rights issue. Sixty percent of respondents representing disability agencies saw disability as primarily a human rights issue with an additional three respondents choosing human rights in combination with other issues, accounting for 75% of responses of the DPOs. In contrast, a third of respondents in development agencies saw disability as primarily a human rights issue with an additional two respondents choosing human rights in combination with other issues. It should be noted, however, that this makes up 50% of responses from the development agencies, indicating some common ground between development and disability agencies. As already stated above, only one respondent saw disability as primarily a development issue and that respondent belonged to a development agency. This means that none of the respondents associated with disability agencies saw disability as primarily a development issue.

Table 3.7: Characterisation of disability as an issue by type of agency

Respondents' characterization of disability as an issue	Development agency		Disability agency		Total	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percent
A medical or health issue	2	16.7	1	5.0	3	9.4
A human rights issue	4	33.3	12	60.0	16	50.0
A social welfare issue	0	0	2	10.0	2	6.3
A development issue	1	8.3	0	0	1	3.1
An issue of social exclusion	2	16.7	2	10.0	4	12.5
Human rights and development	1	8.3	2	10.0	3	9.4
Medical and social welfare	1	8.3	0	0	1	3.1
Social exclusion, human rights and development	1	8.3	1	5.0	2	6.3
Total	12	99.9	20	100	32	100.1

Respondents were asked what level of importance their organizations ascribed to disability and development. As might be expected, all of the disability agencies rated disability as very important, in contrast with only 42% of development agencies.

Table 3.8: Level of importance ascribed to disability by type of agency

Type of organisation	Level of importance ascribed to disability?			Total
	Very important	Important	Slightly important	
Development agency	41.67 (5)	33.33 (4)	25.00 (3)	37.50 (12)
DPO	100.00 (20)	0.00 (0)	0.00 (0)	62.50 (20)
Total	78.13 (25)	12.50 (4)	9.38 (3)	100.00 (32)

There was greater agreement between development and disability organizations on the importance of development as an issue, with more than 90% of development agencies and

85% of DPOs rating development as 'very important'. The one development agency that rated development as 'slightly important' was a government department (Dept of Health). This was a personal assessment of the respondent interviewed, who felt that development was less important to the department because its core business was health status.

Table 3.9: Level of importance ascribed to development by type of agency

Type of organisation	Very important	Important	Slightly important	Total
Development agency	91.67 (11)	0.00 (0)	8.33 (1)	37.50 (12)
DPO	85.00 (17)	15.00 (3)	0.00 (0)	62.50 (20)
Total	87.50 (28)	9.38 (3)	3.13 (1)	100.00 (32)

Respondents were also asked to rate a number of development issues in terms of their importance to their organization. As Table 3.10 below illustrates, Education and Training, Employment and Income Poverty were accorded the highest priority by respondents, with housing, HIV/AIDS and disability being given lower priority.

Table 3.10: Prioritization of development issues by development and disability agencies

Development issue	Priority						Total %
	High		Medium		Low		
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage	
Income poverty	25	78.1	7	21.9	0	0	100
Housing	12	37.5	11	34.4	9	28.1	100
HIV/AIDS	16	50.0	12	37.5	4	12.5	100
Disability	22	68.8	8	25.0	2	6.2	100
Employment/unemployment	25	78.1	6	18.8	1	3.1	100
Education and training	26	81.3	4	12.5	2	6.2	100

In terms of the rating of disability issues, the highest priorities were given to discrimination against people with disability and poverty alleviation and development for people with disability (71.9% rated as high priority), while the lowest priority was given to the prevention of disability/impairment (37.5% rated as high priority) and inclusive education (45.2% rated as high priority).

Table 3.11: Prioritization of disability issues by development and disability agencies

Disability issue	Priority						Total %
	High		Medium		Low		
	Frequency	Percent	Frequency	Percent	Frequency	Percent	
Accessibility to PWDs	20	62.5	7	21.9	5	15.6	100
Appropriate health services for PWDs	19	59.4	8	25.0	5	15.6	100
Prevention of disability/impairment	12	37.5	15	46.9	5	15.6	100
Discrimination against PWDs	23	71.9	7	21.9	2	6.2	100
Poverty alleviation and economic development for PWDs	23	71.9	6	18.7	3	9.4	100
Employment of PWDs	19	59.4	8	25.0	5	15.6	100
Inclusive education	14	45.2	12	38.7	5	16.1	100

When the data is disaggregated according to the types of organizations involved, some clear trends emerge. In relation to development issues, for example, there would appear to be a high degree of consensus between development and disability agencies on the priority of issues such as income poverty, housing, employment, and education and training. This is not the case in relation to the issues of disability and HIV/AIDS. While 90% of disability agencies rated disability as of high priority, only a third of development agencies did so. These data confirm a trend observed earlier where, for example, fewer than half of the development agencies rated disability as 'very important' in contrast with disability agencies all of which felt that disability was 'very important'. In relation to HIV/AIDS, however, a majority of development agencies (75%) rated this issue as of high priority, while only 35% of disability agencies assigned a high priority to the issue.

Table 3.12: Prioritization of development issues by type of agencies

Development issue	Priority					
	High		Medium		Low	
	Development agency	Disability agency	Development agency	Disability agency	Development agency	Disability agency
Income poverty	75	80	25	20	0	0
Housing	33.3	40	33.3	35	33.3	25
HIV/AIDS	75	35	25	45	0	20
Disability	33.3	90	50	10	16.7	0
Employment/unemployment	83.3	75	16.7	20	0	5
Education and training	75	85	25	5	0	10

There was less agreement between disability and development organizations on the prioritization of disability issues. In general, development agencies assigned a lower priority to all of the disability issues than disability agencies. This trend is consistent with development organizations' low prioritization of disability as an issue of development and provides further confirmation of this earlier trend. It was only in relation to accessibility and discrimination that half of the respondents representing development agencies assigned a high priority to these issues. This may be an indication that development agencies tend to think of disability as a human rights issue in the narrow sense, that is as a human rights issue *rather than* a development issue.

In contrast, all of the issues, with the exception of prevention of disability/impairment, were assigned high priority by a majority of the disability agencies. In particular, the high priority assigned by the disability sector to poverty alleviation (90%), discrimination (85%) and employment (80%) should also be noted. Prevention of disability/impairment therefore stands out as an issue that has limited importance within the disability sector. This is probably related to the focus of DPOs on the rights and needs of the current population of people with disability rather than the larger issue of disability and development, which includes the prevention of disability. The prevention of disability would appear to be a sensitive issue for the disability movement in general. This is made clear, for example, in an interview conducted with Judith Huemann in 2003 (Geagan, 2003) while she was Advisor on Disability and Development at the World Bank. In response to a question about why USA development aid has generously supported disability prevention campaigns but has been less generous in supporting disability development projects, Huemann replies: "I think the issues are the same: the USA government, like the Bank, like other donor agencies, still focus their attention more on prevention, and there's nothing wrong with focusing attention on prevention. ... We are not saying we want to do away with disabled people, because disabled people are here to stay. We're a part of life. People will always become disabled for various reasons, but we do want to remove the causes of disability." On the other hand, it is of interest that the development agencies also did not assign a high priority to disability prevention.

Table 3.13: Prioritization of disability issues by type of agencies

Disability issue	Priority					
	High		Medium		Low	
	Development agency	Disability agency	Development agency	Disability agency	Development agency	Disability agency
Accessibility to PWDs	50.0	70.0	33.3	15.0	16.7	15.0
Appropriate health services for PWDs	41.7	70.0	33.3	20.0	25.0	10.0
Prevention of disability/impairment	33.3	40.0	50.0	45.0	16.7	15.0
Discrimination against PWDs	50.0	85.0	41.7	10.0	8.3	5.0
Poverty alleviation and economic development for PWDs	41.7	90.0	33.3	10.0	25.0	0
Employment of PWDs	25.0	80.0	33.3	20.0	41.7	0
Inclusive education	18.2	60.0	63.6	25.0	18.2	15.0

In contrast to the relatively low priority assigned by development agencies to disability and disability issues, nearly all respondents from both the disability and development sectors agreed with the statement by former president of the World Bank, James Wolfensohn, that “it would be impossible to conceive of achieving the Millennium Development Goals (MDGs) of halving poverty by 2015 without the inclusion of disability in development.” Only one respondent, a person from a disability agency, chose to disagree with the statement. Although this respondent conceded that disability had an impact on poverty and therefore poverty alleviation, she maintained that it was unclear how significant this impact would be, suggesting that it was likely to be small.

Although unanimous agreement with Wolfensohn’s statement might seem contradictory to the relatively low priority assigned by development agencies to disability and disability issues, it should be noted that the statement is general enough to accommodate a broad range of views. For example, Wolfensohn’s statement does not specify the *extent* to which disability should be included in development, nor does it provide any indication of how much disability might impact on poverty and the MDGs. In other words, while the statement acknowledges the relevance of disability within development, it provides no indication of *how* relevant disability is and therefore of what priority should be assigned to it. Against a background in which the MDGs are silent on the issue of disability, Wolfensohn’s statement may well be compatible with assigning a low priority to disability as an issue of development.

In order to explore orientations to disability and development further, respondents were asked to elaborate on why they agreed or disagreed with Wolfensohn’s statement. Their responses, disaggregated by development and disability agencies, are presented in Table 3.14 below. The table shows that nearly 90% of all the responses could be coded into three major categories, namely: ‘Disability is an integral part of society’ (Category A), ‘Disability and poverty are connected’ (Category B), and issues relating to employment, skills and education (Category C). It is also clear that while the disability sector favored responses relating to disability as an integral part of society (Category A), the development sector was more likely to favour responses relating to the connection between disability and development as well as issues relating to employment, skills and education (Categories B and C). There is a subtle, but distinct difference between Category A responses and Categories B and C. While the latter posits a direct link between disability and poverty/development (e.g. disabled people are the poorest of the poor; disabled people make up a large part of the poor; there are many people with disability in developing countries; poverty is linked to disability through employment, skills and education; PWD are excluded from employment, etc.), Category A responses do not

make a direct link between disability and poverty. Instead these responses are based on a general claim for equal; access to development and other benefits (e.g. PWD have to be included in everything, including poverty alleviation; until PWD are fully participating members of society, we are not going to advance into development; PWD are part of the social fabric, etc.)

Table 3.14: Reasons provided by respondents for agreeing/disagreeing with Wolfensohn statement⁹

	Development agency		DPO		Total	
Disability is an integral part of society	3	21.43	10	45.45	13	36.11
Disability and poverty are connected	5	35.71	6	27.27	11	30.56
Employment, skills and education	5	35.71	3	13.64	8	22.22
PWD twice disadvantaged	0	0.00	1	4.55	1	2.78
Impact might be small	0	0.00	1	4.55	1	2.78
No answer or irrelevant	1	7.14	1	4.55	2	5.56
Total	14	100.00	22	100.00	36	100.00

3.3 Estimates of the South African population that is disabled

One reason why development agencies may place a lower priority on disability than other development issues relates to the size of the population of people with disability. For example the last census (2001) found that people with disability made up only 5% of the South African population (Statistics South Africa, 2005). As in many other developing countries, disability prevalence rates and their measurement are highly controversial. Many in the disability sector believe that existing statistics on disability are unreliable and grossly underestimate actual prevalence rates. As a result, estimates of the population with disability vary considerably. As Table 3.15 shows, the estimates of respondents in this study varied between 3% and 35%, with the largest concentration of estimates at 10%. While most of the respondents were aware of existing statistics, both local and international, more than a third (36%) of the sample mentioned the unreliability of existing data or said that available data underestimated the prevalence of disability. Where estimates diverged from the official statistics, these estimates were often based on local attempts to measure disability prevalence or extrapolated from international trends, as well as on local data on acquired and congenital disability. One respondent argued that as many people infected with HIV/AIDS become disabled, disability rates were likely to be high because of the South Africa's high rate of HIV/AIDS. Another respondent who provided a very low estimate based his estimate on the current target of employment equity for people with disability.

Table 3.15: Respondents' estimates of the percentage of the South African population that is disabled

What percentage of SA population do you think is disabled?				
	Frequency	Percent	Cumulative Frequency	Cumulative Percent
3	1	3.33	1	3.33
5	5	16.67	6	20.00
6	3	10.00	9	30.00
7	1	3.33	10	33.33
8	2	6.67	12	40.00
10	7	23.33	19	63.33
11	1	3.33	20	66.67
12	3	10.00	23	76.67
13	2	6.67	25	83.33
17	1	3.33	26	86.67
25	1	3.33	27	90.00
30	2	6.67	29	96.67
35	1	3.33	30	100.00

⁹ "It would be impossible to conceive of achieving the Millennium Development Goals (MDGs) of halving poverty by 2015 without the inclusion of disability in development."

As Table 3.16 shows, respondents from the disability sector generally provided higher estimates of disability prevalence than those from the development sector, although the responses of both sectors were widely dispersed. While the majority (50%) of estimates from development agencies fell into the under 10% category, the majority (also 50%) of estimates of disability agencies fell into the 10-15% category.

Table 3.16: Estimates of the percentage of the South African population that is disabled by type of organization

Type of organisation	Under 10%		10-15%		16%+		Total	
	n	%	n	%	n	%	n	%
Development agency	5	50	3	30	2	20	10	100
Disability agency	7	35	10	50	3	15	20	100

3.4 Disability and poverty

In addition to questions about the conceptualization and prioritization of disability, respondents were also asked whether they thought disability was a significant factor in causing poverty. While nearly 80% of the respondents said that disability was a significant factor in causing poverty, seven respondents, constituting 22% of the sample, disagreed. Of the respondents who felt that disability was not a significant factor in causing poverty, three (25%) were from development agencies and four (20%) were from disability agencies. Although one of the respondents argued that people with disability constitute too small a part of the population to be a significant cause of poverty, other responses in this category were more qualified. For example, two of the respondents argued that there was a need to distinguish between 'personal poverty' and 'poverty in country as a whole', suggesting that while disability contributes to 'personal poverty', it should not be seen as a cause of 'poverty in country as a whole'. Other respondents argued that disability was just one of many factors causing poverty; That if someone has a disability this does not necessarily mean they cannot provide for themselves; that with adequate services and access, people with disability would not fall into the trap of poverty; and that it was not so much disabled people who cause poverty, but as with everyone, the lack of skills and opportunities.

Table 3.17: Is disability a significant factor in causing poverty?

	Yes		No		Total	
	n	%	n	%	n	%
Development agency	9	75.0	3	25.0	12	100.0
DPO	16	80.0	4	20.0	20	100.0
Total	25	78.13	7	21.88	32	100.0

Table 3.18: Reasons for believing that disability was a significant factor in causing poverty

Disability as factor in causing poverty	Frequency	Percentage	Cumulative Frequency	Cumulative Percentage
Costs associated with disability	7	13.21	7	13.21
Employment and income	18	33.96	25	47.17
Poor at greater risk of being disabled	8	15.09	33	62.26
Barriers/social exclusion of PWD	10	18.87	43	81.13
Distinguish between personal and social poverty	2	3.77	45	84.91
Disagree that disability causes poverty	6	11.32	51	96.23
Difference between rural and urban	1	1.89	52	98.11
Other	1	1.89	53	100.00

In elaborating on their responses, respondents listed a broad range of factors that accounted for the association between disability and development. The most frequently mentioned of these factors (34% of responses) was the impact of disability on the employment and income of people with disability and their families. Children with disabilities were often not properly educated, jeopardising their opportunities in the labour market caring for PWD impacted on the employment and therefore the incomes of their families. Furthermore, dependence on social grants prevented people from becoming economically productive. A further 19% of responses focused on barriers and social exclusion that prevented PWD from getting into the mainstream, resulted in their isolation and exclusion, and nurtured the belief that PWD were not capable of being economically productive. Other linkages between disability and poverty such as the poor being at greater risk of being disabled constituted a further 15% of responses, while the costs associated with disability, such as medication, assistive devices and care made up a further 13%.

While the distributions of responses between the development agencies and disability agencies do not differ markedly from one another, one difference does stand out. Proportionately, more than twice as many respondents from the development sector as the disability sector mentioned social barriers and exclusion as a factor leading to impoverishment of people with disability. This is surprising; particularly against the background of the strong emphasis placed by disability agencies on social barriers, exclusion and discrimination in their definition of disability and the prioritization of disability issues (see Tables 3.4 and 3.13, for example). This finding suggests that, in spite of the importance ascribed by disability sector to redressing discrimination against and exclusion of people with disability, the development sector may have a better understanding of how discrimination and social exclusion contribute to poverty.

Table 3.19: Reasons for believing that disability was a significant factor in causing poverty by type of organization

	Development agency		DPO		Total	
	n	%	n	%	n	%
Costs associated with disability	2	10.00	5	15.15	7	13.21
Employment and income	6	30.00	12	36.36	18	33.96
Poor at greater risk of being disabled	2	10.00	6	18.18	8	15.09
Barriers/social exclusion of PWD	6	30.00	4	12.12	10	18.87
Distinguish between personal and social poverty	1	5.00	1	3.03	2	3.77
Disagree that disability causes poverty	3	15.00	3	9.09	6	11.32
Other	0	0.00	2	6.06	2	3.77
Total	20	100.00	33	100.00	53	100.00

All of the respondents representing DPOs and more than 80% of respondents representing the development sector felt that development agencies should give more attention to disability. The most frequently cited reason provided by both development agencies and DPOs was that development programmes needed to be more inclusive. Disability as an issue and people with disability should be integrated into development work, although, as one representative of a DPO pointed out, "this must be done in a normal way, as people with disability don't want special treatment because that makes them more dependent." In implementing the MDGs, there was a need to ensure that the full range of issues, including disability, was addressed. Development agencies need to take disability into account when they design their programmes. For example, housing needed to be accessible to people with disability, and feeding schemes should ensure that they were also reaching people with disability.

Table 3.20: Should development agencies give more attention to disability?

	Yes		No		Total	
	n	%	n	%	n	%
Development agency	10	83.3	2	16.7	12	100.0
DPO	20	100.0	0	0.0	20	100.0
Total	30	93.7	2	6.3	32	100.0

A relatively large number of people from the disability sector and one from the development sector argued that disability was not a priority for development agencies, that development agencies focused on other issues, and that disability had always been “an add-on” in development programmes. As one representative of the disability sector pointed out, when applying for funding from development agencies, DPOs had learned to include HIV/AIDS in their programmes because this stood them in better stead to obtain funding. A related issue raised by both DPOs and development agencies in relation to mainstreaming disability into development related to the lack of awareness or institutional knowledge of disability in the development sector. Development agencies, it was argued, needed to be educated about the capabilities of people with disability. People in the development sector, one respondent argued, were “afraid of people with disability because they don’t know what to do with them.”

An overwhelming majority (94%) of respondents also felt that disability agencies should give more attention to development. Here also considerable emphasis was placed on inclusion and the linkages between poverty and disability. DPOs should give greater attention to development and poverty alleviation because of the high rates of poverty in South Africa, especially among people with disability. As another respondent argued, people with disability were the “poorest of the poor”, especially those living in the rural areas. A number of respondents pointed out that DPOs were already focusing on poverty, and that although development might have been neglected in the past, the disability sector was now paying more attention to it.

Table 3.21: Should development agencies give more attention to disability?

	Yes		No		Qualified		Total	
	n	%	n	%	n	%	n	%
Development agency	11	91.7	0	0.0	1	8.3	12	100.0
DPO	19	95.0	1	5.0	0	0.0	20	100.0
Total	30	93.8	1	3.1	1	3.1	32	100.0

3.5 Knowledge of and attitudes to the Social Model

Over at least the past three decades the social model has become the dominant approach to disability within the disability sector and the major critique of disability activists against the more conventional medical, social welfare and philanthropic approaches to disability. Given the dominance of the social model within the disability movement, it is important to assess whether knowledge of the social model has filtered through to the development sector and whether it can serve as a basis for communication between the two sectors.

As Table 3.21 shows, only a quarter of all respondents in this study were not familiar with the social model. While respondents within the development sector were less familiar with the social model than those in the disability sector, it is of interest that a majority (58%) of respondents in the development agencies were familiar with the social model. It should also be noted that not everyone working within the disability sector was familiar with the social model and that 15% of respondents interviewed within this sector did not know of the social model.

Table 3.22: Are you familiar with the social model of disability?

	Familiar with social model		Not familiar with social model		Total	
	N	%	N	%	N	%
Development agency	7	58.3	5	41.7	12	100
Disability agency	17	85.0	3	15.0	20	100
Total	24	75.0	8	25.0	32	100

Among those who were familiar with the social model, definitions and understandings of the model varied, although more than half of these respondents emphasized the inclusion and integration of people with disability within society and the identification of barriers to inclusion as the central feature of the social model. Other common definitions offered included that the social model involved a move away from the dominance of medical and health definitions of disability to a social understanding of disability, and an emphasis on human rights.

Table 3.23: Definitions and understandings of the social model by those familiar with it

Understanding of social model	Frequency	Percentage	Cumulative Frequency	Cumulative Percentage
Disability not just a health problem	7	20.00	7	20.00
Inclusion/integration	19	54.29	26	74.29
Human rights approach	5	14.29	31	88.57
Focuses on person as a whole	2	5.71	33	94.29
Looks beyond disability to ability	2	5.71	35	100.00

An overwhelming majority of those who were familiar with the social model also felt that it provided a useful approach to thinking about and understanding disability. However, not everyone was uncritical of the social model. For example, one respondent argued that there was a huge shift away from the social model to human rights, and that while the model was good in theory, this was not the case in practice as without sufficient resources the model had had an adverse effect on people with disability. Other respondents also pointed out that many people were not familiar with the social model and that work had to be done to popularize it.

3.6 Policies on disability

About half (47%) of the organizations involved in the study had policies or formal position papers on disability and development. Such policies were more common among the development agencies than the DPOs, with two-thirds (66.7%) of the development agencies having policies as against a third (35%) of disability agencies. However, because of the overrepresentation of DPOs, overall less than a half (47%) of the 32 organisations included in the study had policies or formal position papers on disability and development. The qualified response relates to a respondent who was unsure whether his organization had a policy on disability and development because he had only been with the organization for a short time. Of those organizations that did have policies or formal position papers relating to disability and development, all but one claimed that they had developed concrete goals based on these policies.

Table 3.24: Percentage of organizations having policies on disability and development

Type of organisation	Have policies		Do not have policies		Qualified answer		Total	
Development agency	8	66.7	4	33.3	0	0.0	12	100.0
DPO	7	35.0	12	60.0	1	5.0	20	100.0
Total	15	46.9	16	50.0	1	3.1	32	100.0

Three-quarters of the organizations that did not have policies or formal position papers on disability and development said that they had informal, unwritten guidelines or orientations that related to disability and development. An overwhelming majority (88%) of these organizations

also felt that it was desirable for their organizations to develop policies on disability and development.

3.7 Contact between the development and disability sectors

The survey results are indicative of relatively extensive contact between the development and disability sectors, with 82% of development agencies reporting that they had had contact or dialogue with organizations representing people with disability over the preceding 12 month and 80% of DPOs reporting contact with development agencies over the same period.

Although respondents provided a broad range of reasons for contacts with the other sector, the most common reason for contact between the sectors related to obtaining or providing funding (35% of responses). Other more frequently cited reasons for contact included partnerships to secure the involvement of people with disability, for example, (19% of responses), employment and skills development (16% of responses), and issues relating to employment and skills development (11% of responses). When the reasons provided by development agencies and DPOs are compared with one another, certain trends become apparent. For example, DPOs placed greater emphasis on obtaining or providing funding (43.5%) than development agencies (21.4%). On the other hand, development agencies placed greater emphasis on partnership and liaison. Together partnership and liaison accounted for half of the responses of the development agencies as against only 13% of the DPOs' responses. These trends may be indicative of development agencies commitment to work more closely with disability agencies and to involve people with disability in their work.

Table 3.25: Purpose of contact with other sector

	Development agency		DPO		Total	
	n	%	n	%	n	%
Obtain or provide funding	3	21.4	10	43.5	13	35.1
Partnership	4	28.6	3	13.0	7	18.9
Liaison	3	21.4	0	0.0	3	8.1
Discussion, advice, consultation	1	7.1	3	13.0	4	10.8
Employment and skills development	2	14.3	4	17.4	6	16.2
Information and research on disability	0	0.0	2	8.7	2	5.4
Other	1	7.1	1	4.4	2	5.4
Total	14	100.0	23	100.0	37	100.0

For both the development agencies and the DPOs, a majority of respondents regarded their contacts with the other sector as positive, describing their interactions as successful, empowering, or useful in raising funds and sharing information. Some of the DPOs were impressed by the interest that development agencies had taken in their work, while some development agencies admired the commitment, motivation and hard work of the DPOs with which they were involved. Others were more critical. For example, some of the DPOs complained about the difficulties of maintaining contact with development agencies, the lack of generosity of funding, and poor service delivery by government. For both DPOs and development agencies, the lack of follow through and implementation following discussions were identified as a problem. Discussions were promising, but implementation remained a challenge. It was difficult to gain the trust and respect of DPOs, and working with DPOs took a lot of time and patience as there were often delays and failures to meet deadlines.

Table 3.26: Impression of contact with other sector

	Development agency		DPO		Total	
	n	%	n	%	n	%
Critical	4	36.3	7	38.9	13	44.8
Favourable	5	45.5	10	55.6	13	44.8
Other	2	18.2	1	5.5	3	10.4
Total	11	100.0	18	100.0	29	100.0

Those organizations that had not had contact with the other sector over the preceding 12 months felt that contact would be useful for sharing knowledge and skills, for engaging on a strategic level and in order to access resources and funding.

3.8 Current projects on disability and development

About two-thirds of the organizations involved in the study had or funded projects or programmes that addressed the issues of both disability and development. Projects on disability and development were broadly defined and included all projects implemented or funded by development agencies that addressed disability as well as all projects implemented or funded by DPOs that addressed poverty or development. In terms of these criteria, half of the development agencies 80% of the DPOs were currently funding or implementing projects that qualified.

Table 3.27: Percentage of organizations that have disability and development projects

	Have projects		Do not have projects		Total	
	n	%	n	%	n	%
Development agency	6	50.0	6	50.0	12	100.0
DPO	16	80.0	4	20.0	20	100.0
Total	22	68.7	10	31.3	32	100.0

Qualifying projects covered a broad range of issues. Although the sample of development agencies with projects that addressed disability and development was relatively small, the dominant trend, especially among the larger development agencies, appeared to be projects that focused exclusively on people with disability and were managed by DPOs. There was little sign of broader development projects that were inclusive of people with disability or made provision for addressing the issue of disability. The only exception to this rule was The Valley Trust, a longstanding socio-medical NGO based in the Valley of a Thousand Hills in KwaZulu-Natal. Its broad-based health and development programmes such as the Izingane Zethu Early Childhood Intervention and Integrated Schools Community Development programmes are inclusive of disability while retaining a broad community focus.

While the majority projects in the disability sector targeted people with disability, this sector appeared to be more aware of the need for inclusiveness and in spite of financial constraints had a number of projects that targeted non-disabled as well as disabled people. For example, Cheshire Homes had a day care centre for disabled and disadvantaged children which included poor, able-bodied children. Eco-Access' Twinning Programme was specifically designed to bring disabled and non-disabled children together to foster environmental awareness and break down barriers between disabled and non-disabled. The organisation's advocacy and information provision project aimed not only to increase the access of people with disability to nature, but also to provide information and advice to nature resorts on making facilities more accessible to people with disability. There are a number of other projects, such as the bookbinding and employment creation project of the DPSA in the Eastern Cape, that specifically aim to encourage the integration and partnership between disabled and non-disabled people. Other DPOs provide services, such as internet access, copying and printing, which serve the whole community. A number of projects also target the families of people with disability.

The most common problem or limitation mentioned by DPOs in relation to their projects was the difficulty of securing funding to keep projects going or to reach larger numbers of people. Problems relating to distance and access were also frequent especially for projects that targeted rural areas, and costs associated with the transportation of people with disability was common to both rural and urban areas. Many of the DPOs also reported that their projects were limited by the lack of skills, especially managerial and financial skills. Cultural and

attitudinal barriers and the need to change mindsets with regard to disability were also frequently mentioned by the DPOs.

3.9 Ideas and suggestions for mainstreaming disability in development

Respondents were asked whether they had any ideas or suggestions on what needed to be done in order to make disability a more prominent issue in development. A broad range of suggestions were made and these were organized into a number of categories as presented in Table 3.27 below.

Table 3.28: Ideas and suggestions for making disability a more prominent issue in development

Ideas and suggestions	Development agency		DPO		Total	
	n	%	n	%	n	%
Awareness-raising/dissemination	7	30.43	9	27.27	16	28.57
Contact and cooperation between sectors	5	21.74	8	24.24	13	23.21
Disability movement needs to be more united	1	4.35	4	12.12	5	8.93
Political or legislative activity	2	8.70	5	15.15	7	12.50
Conceptual	1	4.35	0	0.00	1	1.79
Different approach to disability in development	0	0.00	3	9.09	3	5.36
Other	7	30.43	4	12.12	11	19.64
Total	23	100.00	33	100.00	56	100.00

The most common suggestions related to awareness-raising and the dissemination of information among the general public and accounted for about 29% of the responses. Among the suggestions made was that the public should be made more aware of the capabilities of people with disability. There was a need to demonstrate that children with disabilities can succeed as well as any other child if given the opportunity of early childhood education. Awareness of the capabilities of people with disability could also be accomplished through role models. People with disability were still viewed as 'charity cases' and this needed to be changed. Disability needed to be de-stigmatized. There should also be awareness-raising and dissemination of information among people with disability. Action research was needed to create awareness and empowerment among people with disability. The social model needed to be properly understood and popularised. There was a need to go beyond employment equity and other policies by educating senior civil servants and enforcing accountability for implementation of policies. Government Departments needed to be made aware that disability was part and parcel of their programmes. Development agencies needed to be more realistic in their understanding of disability. For example, development agencies had provided entrepreneurial training for people with disability without taking their functional limitations into account.

A second category of suggestions accounting for a further quarter of responses related to facilitating contact and co-operation between the disability and development sectors. Suggestions included the creation of a database of development organisations for DPOs; more effective ways of communicating with development agencies and government, and increasing contact between disability and development organisations. Disability agencies should be less 'radical' in their dealings with the development sector as this made development agencies afraid to engage with them. DPOs should work collaboratively because there were fewer resources. There was also a need for the development sector to be exposed to 'ordinary' disabled people not only figureheads. Development agencies should create opportunities for the training of people with disability in development. Development agencies should also utilize experts in the disability field. DPOs should lobby the development sector.

Other responses dealt with the disability movement and with political or legislative activity. For example, it was argued that the disability movement needed to be more united in advocating for the needs and interests of people with disability. The disability sector was too fragmented, and needed to speak with one voice. There was a need for the transformation of DPOs,

especially those that had traditionally been run by white people. A national disability commission should be set up similar to the National Youth Commission. While disability policies looked good on paper, there was very little implementation. Implementation of policies dealing with disability should be monitored, and DPOs should work together with other NGOs in this regard. Government departments should be held accountable for the lack of implementation. South Africa should promulgate a disability act similar to the Americans with Disabilities Act. The Integrated National Disability Strategy should be promulgated as an Act and employment equity should be written into law. Legislation should be introduced to enforce the inclusion of disability in all government programmes. A certain percentage of all government programmes should be allocated to people with disability. Government should put more emphasis on mainstreaming disability in development. A certain percentage of government programmes should be devoted to people with disability to help bring them on board.

A further category of suggestions involved developing different approaches to disability in development: There should a greater focus on the potential of PWDs. More emphasis should be put on success stories rather than emphasizing emotions and pity. There was also a need to focus on people with mental disabilities, and not only physical disabilities. Finally there was also a need to create a better understanding of relationship between disability and development.

3.10 Conclusion

To sum up, while there was some understanding by development agencies of the relevance of disability to development, it is clear on a number of levels that the majority of development agencies operating in South Africa do not place a high priority on disability. This is not to say that development agencies regard disability as irrelevant, rather which within the context of other more pressing development challenges, and disability tends to take a back seat. Development agencies repeatedly rated disability and disability issues as lower priorities than DPOs rated development and the majority of development issues. Many of the respondents from the disability sector also perceived development agencies as having only limited interest in disability as an issue and some of the programmes and policies of the large international development organizations were seen as window dressing.

In addition to assigning lower priorities to disability and disability issues, development agencies showed a clear resistance to taking part in the study. Although heavy work schedules may have played some role in their reluctance to participate, there were also clear indications that at least some of the personnel working in the South African development sector were uncomfortable about the prospect of being interviewed on the issue of disability, regarded disability as an issue for specialists and had limited interest in disability as a development issue. There were also indications from responses during the interviews that development agencies tend to think of disability as a human rights issue in the narrow sense, that is that they thought of disability as a human rights issue *rather than* a development issue. There were also indications that disability and development organizations had different understandings of the relationship between disability and development. For example, the disability sector tended to emphasise its claim for inclusion of people with disability in every sphere of life, including development, rather than understanding the ways in which disability and poverty are connected. The data also suggest that respondents from the development sector had a clearer understanding of how social exclusion and discrimination against people with disability contributes to their poverty.

In spite of the limited priority development agencies ascribed to disability as an issue of development, there were also a number of positive signs in relation to the integration of disability in development. Half of the development agencies and 80% of the DPOs in this study had projects which included elements of both disability and development. Two-thirds of the development agencies interviewed had formal policies or position papers relating to disability and development. The results of the study also indicate fairly extensive contact between

development agencies and DPOs, with 80% of both types of organizations having had contact with one another over the preceding 12 months.

However, these hopeful developments need to be qualified. In relation to policies on disability and development, for example, there were clear indications that in many cases policies, position papers and guidelines developed at the central level of international organisations had not filtered down to staff working at the country or regional levels. Similarly, although more than two-thirds of the organizations included in the study had projects which included disability and development, there was little sign of the mainstreaming of disability in development. With only one exception, all the projects in the development sector specifically targeted people with disability rather than making provision for people with disability within more general development projects. Although a majority of the projects of the disability sector also catered only for people with disability, there were a significant number of projects that included both disabled and non-disabled people or which aimed to encourage partnerships between the two. This was particularly impressive given the limited resources of DPOs and the often specialized nature of the issues they were addressing. While many respondents were positive about interactions between the disability and development sectors, equally many were critical, particularly of the lack of follow through and implementation following discussions between the two sectors.

In terms of orientation to disability and development, there were both indications of common ground and differences between the two sectors. For example, although there were some differences in emphases in the ways in which respondents in the two sectors defined disability, these were not large and none of the respondents defined disability solely in terms of impairment. Disability was most commonly characterized by both sectors as a human rights issue, with 75% of DPOs and 50% of development agencies seeing disability as a human rights issue. This overlap in the emphasis on human rights could play an important role in facilitating understanding between the two sectors, particularly as right-based approaches to development gain favour.

There was also a high degree of consensus between disability and development agencies on the priorities they assigned to development issues, with the exception of HIV/AIDS which received a substantially lower rating from DPOs. On the other hand, development agencies consistently rated disability issues lower than disability agencies. The two sectors were also largely in agreement that disability was a significant factor in causing poverty.

In spite of areas of disagreement and in particular the challenge of the low priority assigned to disability by many development agencies, there would appear to be a basis for closer co-operation between the two sectors. Such co-operation would require the disability sector to adopt a more systematic approach to mainstreaming disability. This issue will be explored in greater detail in the next and final section of this report.

SECTION 4: CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

While existing information appears to make a strong case for a relationship between disability and poverty and for mainstreaming disability in development, comprehensive and systematic research on disability, poverty and development, especially in the developing countries, is still lacking. Much of the information that exists on the relationship between disability and poverty tends to be anecdotal, to lack firm scientific grounding, and to be formulated in broad, simplistic and sweeping statements that resemble slogans, as the quotation below testifies:

“When broad and contested terms like 'poverty' and 'disability' meet, simplistic slogans soon arise (e.g. "Disabled People are the Poorest of the Poor") to remove the need for careful thinking. Most people will agree that poverty and disability are often linked; yet most poor people do not think of themselves as disabled, and many disabled people are not poor.” (Miles, 2006)

While it is possible to contest some of Miles' assertions¹⁰, it is clear that the relationship between poverty and disability is complex and that there is a need for careful and systematic research on these issues. However, in addition to the slogans and unsubstantiated or poorly substantiated statements that have been made on the subject, rigorous and scientifically credible research, most of it carried out in the industrialized countries, has made a strong case for a relationship between disability and poverty. No clear reason has been provided by critics why the same relationships between disability and poverty should not hold in the developing countries as well. Indeed, conditions in the developing countries such as higher rates of poverty and inequality, poor services and in some cases poorer records of enforcing human rights, might lead one to believe that the relationship between poverty and disability is likely to be stronger in the developing countries than it is in industrialized countries.

New approaches to understanding and measuring poverty have also contributed to a better understanding of the complexities of disability and poverty. For example, attempts to measure poverty among people with disability by conventional income means have been shown to be inadequate because they do not factor in the costs that are associated with disabilities. Similarly, they have made us aware of the deprivation associated with mortality and how disability impacts on life expectancy. For example, the United Kingdom's Department for International Development (2000: 5) maintains that “mortality for children with disabilities may be as high as 80% in countries where under-five mortality as a whole has decreased below 20%.”¹¹

Although data on disability and poverty in South Africa are limited, available statistics from the Census and other large household surveys provide strong support for the association between disability and poverty in South Africa. The data presented in Section 1 of this report not only suggest that people with disability are clearly disadvantaged in terms of income, employment and education, but also that these disadvantages are compounded by both race and gender. When the impact of disability is considered in conjunction with other disadvantages such as race and gender, critically large inequalities are revealed. In relation to education, for example, data from the 2001 census showed that the percentage of people with disability with no schooling was twice as large as that of the total population (see Figure 1.7). However, when racial and gender inequalities are taken into account (as in Table 1.5), the inequalities become

¹⁰ For example, his assertion that “most poor people do not think of themselves as disabled” is contradicted by extensive participatory research on poverty which suggests that poor people do see disability as an aspect of poverty. See discussion on the multi-dimensionality of poverty in Section 1 of this report.

¹¹ Although these estimates have been widely cited, including by the United Nations and the World Bank, they need to be treated with some caution as DFID has not made clear how it arrived at these estimates.

even more stark. For example, while only 6.3% of disabled white males had no schooling, the equivalent percentage for disabled African females was 41.8%, i.e. 6.6 times greater than the percentage for disabled white males.

The interactions between disability and other social inequalities such as race and gender are important not only because they demonstrate the cumulative impact of different inequalities, but also because they highlight the role of externally imposed social injustice (as opposed to the functional limitations created by impairments). Comparison of the educational attainments of disabled white males with disabled African females clearly demonstrates that by far the greater part of the inequality in educational attainment between people with disability and people without disability can be attributed to externally-imposed social inequalities rather than to functional limitations associated with impairments.

Another issue highlighted by the interaction of different forms of disadvantage is identity. The example of educational attainment discussed above clearly demonstrates that in addition to their disability identity, people with disability also have other identities (in this case racial and gender identities) and that these identities play a key role in determining the extent to which disability impacts on the lives of people with disability. The issue of identity is important because the disability movement and disability politics have been built around the idea of disability as a distinct identity and people with disability as a distinct political minority. We shall return to the issue of identity later, but before doing so it is necessary to return to some of the constraints in mainstreaming disability in development that have been identified in this study.

4.2 Constraints on mainstreaming disability in development

Although international development agencies have begun establishing formal policies and position papers on mainstreaming disability in development, there are strong indications that inclusive approaches to disability have not successfully been established at the country level. This was apparent not only in the generally low priority that development agencies included in this study placed on disability as an issue of development, but also by the resistance of many of the agencies that were approached to participate in the study. There were various indications that development personnel that were approached by the research team were uncomfortable about being interviewed on the issue of disability. A number of international agencies that had developed policies or positions on disability referred the researchers to personnel located in their head offices. In one case where an interview was granted by an international agency with a good record of involvement in disability in South Africa, the researcher was referred to a person at head office in order to obtain a copy of the agency's policy document on disability. Incidents like these suggest that while many international development agencies have developed strong positions on the inclusion of disability into development, these positions and their supportive documents have had only limited impact on development practices in a country like South Africa.

National development agencies did not fare much better, even though they did not have the option of referring the research team to international headquarters. For example, the research team requested an interview with a member of staff of a prominent national development agency because this person had recently headed a large project dealing with disability. After considerable delays, the researcher was eventually referred to the organisation's employment equity analyst who was involved with human resource issues rather than development.

Although half of the development agencies included in the study were managing or financing projects that dealt with disability, with one exception, all of these projects specifically targeted people with disability rather than making provision for people with disability to be included within more general development projects. In contrast, disability agencies appeared to take a more inclusive approach and had a number of projects that included both disabled and non-disabled people or which aimed to encourage partnerships between disabled and non-disabled people.

In their various documents and position papers on disability and development, international development agencies place considerable emphasis on mainstreaming disability into their general projects. DFID (2000: 11), for example, proposes a twin-track approach to disability in

its development work which “entails the inclusion of an active consideration of disability issues in the mainstream of development co-operation work, and looking for opportunities to support more focused activities, including direct support to organisations of disabled people and to initiatives aimed specifically at enhancing the empowerment of people with disabilities.” Similarly, in its position paper on disability SIDA (2005: 14) states: “Persons with disabilities and their rights/situations shall be taken into account throughout the programme/project cycle, both in cases of special contributions and in those of contributions that do not directly target adults or children with disabilities. The rights and living conditions of persons with disabilities shall thus be integrated into preparation, implementation, monitoring and evaluation processes.”

Two recent publications of the World Bank (2006 and 2007) on the inclusion of disability in development also put the major emphasis on mainstreaming disability in general development projects. The first of these (World Bank, 2006) states upfront that the intention of the document is “not...to promote special, separate disability and development projects, but rather, to help Bank staff incorporate people with disabilities and a disability perspective in their ongoing development work, as well as adopt an integrated and inclusive approach to disability.”

Although the sample of development agencies included in this study was admittedly small, there was very little sign of the mainstream approach to disability being applied within the South African development sector. This should be seen against the background of the strong demand for inclusion from the disability sector. Indeed the reason most frequently cited by respondents from both sectors for believing that development sector should give more attention to disability was in order to make development more inclusive.

Article 32 of the Convention of the Rights of Persons with Disability also emphasizes the importance of mainstreaming, stating that *all* development programmes should be inclusive and accessible to persons with disabilities, rather than disability being treated as a stand-alone issue (United Nations, 2007). While there will always be a need for projects that specifically target people with disability, failure to mainstream disability in development has the potential to compound the social disadvantages and inequalities of people with disability. For example, the construction of schools, classrooms or toilets that are not accessible to people with disability is likely to add to the educational disadvantage associated with disability. Feeding schemes that do not make provision for people with disability are likely to exclude those with severe mobility problems, and in case of school feeding schemes to exclude disabled children who do not or are unable to attend school.

These are just two relatively straightforward examples, but there is a vast array of issues and problems, many of them specific to the different areas of development. Fortunately, there is also a rapidly growing literature on how to mainstream disability in development. In addition, for example, to the two World Bank publications mentioned above, a very comprehensive manual has been developed by Loughborough University for the design of water and sanitation systems accessible to people with disability and other vulnerable groups (Jones and Reed, 2005).

A great deal of ground will have to be covered before the ideal of inclusive development can be realised in South Africa. Mindsets will have to be changed in both the development and disability sectors, and new attitudes and orientations will have to be developed. The inclusion of disability in development has often been compared with the mainstreaming of gender in development. It should be borne in mind, however, that the acceptance of women as an important component of the development discourse was only achieved after decades of mobilisation and lobbying by the women’s movement.

4.3 Opportunities for the inclusion of disability in development

Having considered some of the constraints on mainstreaming disability in development, what opportunities exist for accomplishing this seemingly elusive goal? A number of hopeful developments have already been identified, including:

- The strong emphasis on inclusion in the disability sector and especially the growing trend in this sector to include the nondisabled in projects and seek partnerships with organisations outside the disability sector;
- The development of policies and position papers on disability and development by the major development agencies, even if these are not currently being effectively implemented at grassroots level;
- Developing dialogue between the disability and development sectors. The results of this study indicated fairly extensive contact between development agencies and DPOs, with 80% of both types of organizations having had contact with one another over the preceding 12 months.

However, perhaps the most hopeful development to emerge from this study was the growing consensus around disability and human rights, with 75% of DPOs and 50% of development agencies seeing disability as essentially a human rights issue. These results are indicative of common ground being established between the two sectors, but the matter goes further than that. Firstly, rights-based approaches to development are gaining increasing recognition in the development sector, and it was observed during the fieldwork for this project that development agencies that had adopted rights-based approaches to development were generally more accepting of disability as a legitimate issue for development.

Secondly, the focus on human rights may also hold the potential to broaden the orientation and vision of the disability sector, allowing for a more inclusive approach to development, and a potential revitalization of the disability movement in South Africa.

4.4 The South African disability movement

In order to consult with stakeholders in the disability sector and explore their attitudes to and perceptions of the issue of mainstreaming disability in development, an asynchronous online electronic forum (e-discussion) was created early in this research project to allow for the consultation of stakeholders in the disability sector. The outcome of the e-discussion was reported in some detail in Alant, Emmett and Samuels, 2007.

One of the more prominent themes to emerge from the e-discussion on disability and development related to the fragmentation of the disability sector and the negative impact this has had mainstreaming disability in development. While the South African disability movement had been a force to contend with prior to 1994, it has since then lost a great deal of its power and unity and has failed to adjust to post-1994 conditions. The sector was therefore seen as characterized by squabbling and infighting, competition for scarce resources and fragmentation into a number of small organizations that lacked a common purpose or vision. The lack of unity within the disability sector, it was argued, discouraged collaboration with the development sector. One of the discussants summed up the situation as follows:

“The New South Africa has evolved in many ways politically, socially and economically, but the disability sector has not. We are largely stuck in (a) pre-1994 approach to development. Ten years later, we have not made the transition from being a sector that demands, and rightly so, policy inclusion at every level of government to a sector responsible for knowledge production on disability, a sector that values its own intelligentsia”. (Alant, Emmett and Samuels, 2007: 37)

Reasons for the failure of the disability sector to meet the challenges of the current context of disability and development are analyzed in the paper by Alant, Emmett and Samuels, 2007, and include both exogenous and endogenous factors. In terms of the former, it was argued that civil society as a whole has had to face a number of new challenges in post-1994 South Africa. These included substantial losses in resources as donors began channeling their funding to the new democratic state rather than civil society, losses in leadership and capacity as people who had previously worked in the sector took up positions in the post-apartheid state, and a general loss of direction under the new conditions of post apartheid society:

“Prior to 1994 the focus of the NGOs was to organise and support resistance to the apartheid state. Many NGOs became rudderless when a democratic dispensation came into being. Instead of focusing on what the democratic government was unable or unwilling to do they attempted to continue with their old tasks, often duplicating the functions of, especially, the local state.” (Govender, 2001)

These external difficulties were compounded by the internal characteristics of the disability movement, especially in terms of what Shakespeare and Watson (2001:557) called the “complexities and contradictions of disability politics”. Traditionally, disability had been divided into specific groups of impairments, and organizational structures had tended to coalesce around these essentially medical diagnoses and groupings. A central thrust of the disability movement was to emphasize commonalities between the different impairment groupings and to encourage the development of umbrella or cross-impairment groupings to represent all people with disability. Central to this process of unification was the claim that people with disability constitute a distinct minority that should itself initiate and lead social change. According to Shakespeare and Watson (2001:547), this claim put identity politics at the centre of the new movement.

The fragmentation and decline of the South African disability movement since 1994 may therefore be seen as a reversal of the processes of unification based on identity politics and is represented not only by infighting within the movement, but by the weakening of cross-impairment organizations such as the South African Federal Council on Disability (SAFCD) and that currently the most robust disability organizations in South Africa appear to be those that have organised themselves around specific impairments.

This discussion, in conjunction with the analysis of Shakespeare and Watson (2001), raises a number of questions, the most pertinent of which are:

- Does the lack of unity in the disability sector not reflect a failure of identity politics, indicating a need for redefinition of the sector that will allow for a broader definition of identity?
- Do identity politics based largely on the oppression of people with disability not reinforce disabled people’s status as ‘different’ rather than opening up the possibilities for mainstreaming and inclusion?
- To what extent is the disability movement able to accommodate other social cleavages such as gender, race, ethnicity or sexual orientation?

4.5 Human rights and multiple identities

Against this background, the application of a human rights approach to mainstreaming disability in development has the potential to broaden the identities of people with disability and focus attention on the other identities that they have and share with other oppressed and marginalized groups in society.

The idea that people with disability can broaden their identities and find common cause with other oppressed social groupings is not new. Vic Finkelstein (1996 and 2001), one of the founders of the social model and a former South African, has argued that the next phase of

disability politics was for disabled and non-disabled people to work together in identifying and addressing the social barriers that “affect the quality of life of all citizens”:

“For me *repossessing* the social model of disability means searching for openings in the structures of society where we might effectively contribute with others in the restructuring of society so that it is neither competitive nor disabling for all people.”(Finkelstein, 2001: 5)

More recently Tregaskis (2004) explored in greater detail the potential for the disability sector to enter into strategic alliances with non-disabled people. Among the issues she raises is that of multiple identity as a means of engagement and of understanding “the intersections between the various expressions of identity politics as a means of developing future political strategy” (Tregaskis, 2004: 76). This finds resonance with the findings of this study that disability interacts with other social inequalities such as gender and race to produce cumulative inequalities and injustices.

Tregaskis (2004:68) makes it clear that alliances between disabled and non-disabled people “is only one thread in the development of disabled people’s struggles against oppression. There will be times when disabled people need to organize alone. When the primacy of the disabled identity is of paramount importance and cannot risk dilution of energy and effort.” This is precisely the point that Amartya Sen (2006) makes in his book on identity and violence, namely that in the context of the diversity of identities we have choice in exercising our different identities:

“...the main hope of harmony in our troubled world lies in the plurality of our identities, which cut across each other and work against sharp divisions around one single hardened line of vehement division that allegedly cannot be resisted. Our shared humanity gets savagely challenged when our differences are narrowed into one devised system of uniquely powerful categorization.

Perhaps the worst impairment comes from the neglect – and denial – of the role of reasoning and choice, which follows from the recognition of our plural identities.”

4.6 Towards a more systematic approach to mainstreaming disability in development

If, as suggested earlier, the time and effort it took for women and gender to be included in the development agenda is anything to go by, then it is likely that the successful inclusion of disability in development will be a slow and drawn out process. However, should the disability and development sectors wish to fast-track the mainstreaming of disability in development, then a more systematic approach would have to be adopted by both sectors? Some of the requirements of such an approach might include the following:

The development of a strategic plan by the disability sector: A sector-wide plan of action is necessary if the disability sector is to make an impact on the agendas of the development sector. Piecemeal approaches by different DPOs, each with its own agenda, are unlikely to have much impact, and if anything are likely to alienate the development agencies that are approached. The development of a common plan or approach to the mainstreaming of disability will of course be contingent on addressing the problems of fragmentation in the disability sector and on the development of stronger leadership within the sector as a whole.

Focus on common ground between the two sectors: In order to improve co-operation between the disability and development sectors, it is necessary to identify and focus on common interests, approaches and orientations between the two sectors and build on these commonalities. One area of commonality identified in this study was the orientation in both sectors to human rights. While militancy and confrontational tactics have their place in any political movement, a more conciliatory approach may

sometimes be required. As a respondent in this study pointed out, disability agencies needed to be less 'radical' in their dealings with the development sector as this made development agencies afraid to engage with them.

A steeper learning curve for both sectors: There were strong indications from both the interviews and the e-discussion that the two sectors could benefit from learning from one another. Awareness-raising and the dissemination of information among the general public and members from both the development and disability sectors was a prominent theme that emerged from the interviews. Although some of the larger development agencies had made concerted efforts to educate their staff about disability, a great deal of ignorance about disability appears to exist within the development sector, and respondents from both camps were quick to point this out. Similarly, it was also clear that while the disability sector was in agreement about the importance of development, members of the sector often had only a superficial knowledge of the issues and debates of development. In particular there is a need for people who have a good grasp of both disability and development to drive the process of mainstreaming.

Focusing on the development sectors: Many of the guidelines that have been developed for the mainstreaming of disability in development have been framed in broad principles that apply across the various development sectors. However, the needs of the various sectors often differ from one another as do the ways in which these sectors can accommodate or make provision for disability. It is not difficult to see, for example, that what may be necessary for mainstream disability within the agricultural sector is going to differ markedly from what is required in the water and sanitation sector, or the education sector. People responsible for designing and implementing development projects are often at a loss about what to do when confronted with the demand to include disability in their projects. What is needed therefore are more concrete and sector-specific guidelines for the accommodation of disability within specific projects. The earlier mentioned manual developed by Loughborough University for the design of water and sanitation systems accessible to people with disability is one such example.

Taking account of the linkages between different vulnerabilities to poverty: In developing strategies for the inclusion of disability in development, account must also be taken of the ways in which disability interacts with other inequalities such as gender, race and geographical location. The intersection of different inequalities would have important implications, for example, for the targeting of vulnerable social groups.

Exploring the creation of alliances between disabled and non-disabled people: Such alliances can take many forms depending on the requirements and overlapping interests of the organisations involved. One example of co-operation suggested by a respondent in our study was that DPOs should work together with other NGOs in monitoring the implementation of policies and holding government departments accountable for the lack of implementation.

Expanding knowledge of disability: An important limitation on the acceptance of disability as a legitimate issue in development relates to the paucity of scientifically credible research on the relationship between disability and poverty especially in the developing countries. While there are a broad range of issues requiring research, among the issues identified in this study are the following: More accurate and rigorous measurement of disability prevalence rates in developing countries; mortality rates of people with disability and how they impact on prevalence; the measurement of poverty among people with disability that takes the costs of disability in account; and understanding how disability interacts with other social inequalities.

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