Status of Disability Rights in Southern Africa

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In 2010 the Open Society Initiative for Southern Africa (OSISA) – in partnership with Open Society Foundations’ Disability Rights Initiative and the Open Society Foundation for South Africa – undertook a research project into disability rights in nine countries in southern Africa. This was a new area of work for OSISA and, while we had quite a bit of anecdotal evidence about the state of disability in the countries where we work, we felt that we needed a more comprehensive understanding of the state of disability in the region. The research was undertaken over a period of eight months and the findings make for depressing reading.

OSISA's main objective was to have a comprehensive overview of the disability rights movement in southern Africa and to obtain detailed country specific research to enable us to assess where best we could provide on-going support. Therefore, two reports were commissioned – this general overview and a compilation of the detailed country reports. OSISA was also very interested in the provision of disability rights courses to law students in the region so the reports contain information that is specific to the work that universities were doing on disability rights. Unsurprisingly, the findings show that there was very little such work taking place.

People living with disabilities (PWD) are the most marginalised people in a region where life is already difficult for the majority of the population due to severe poverty, lack of development and high unemployment. In all countries, the rights of PWD are not given any priority by their governments. Usually, any ministry dealing with disability also has to address other marginalised groups such as women and children, so disability rights and the protection of PWD receive minimal state funding and focus. Most of the organisations and individuals interviewed during the research had to conduct their activities and advocacy work on an extremely tight budget – in most cases with little or no state support. In depth country interviews showed that the continued survival of disability rights organisations was one of their greatest challenges. Yet despite all the hardships...
faced by the disability community, remarkable work was taking place. These findings are highlighted in the separate publication containing the country-specific reports.

Both reports include a variety of recommendations that would advance disability rights work in the specific countries and the region as a whole. OSISA regards this research as the first point of departure for on-going work in this field. Before embarking upon specific initiatives we needed to ensure that a situational scan provided us with sufficient information to enable us to appropriately identify areas for support and advocacy.

Indeed, OSISA has already responded to the findings in the research related to the work done on disability rights in universities in the region. This may seem like an anomaly to the reader but the organisations commissioning the research were particularly interested in offering a programme to law students on disability rights as part of their law degrees. Currently, and as a result of the research, a specialised disability rights law course is being offered in three universities in the region, Midlands State University in Zimbabwe, Eduardo Mondlane University in Mozambique and Chancellor College in Malawi.

The premise upon which we commenced this study is the knowledge that many PWD suffer some of the most profound human rights violations as a result of the denial of legal capacity, institutionalisation, and inadequate provision of community-based services and support. Only by ensuring their rights to (i) equal recognition before the law and legal capacity, (ii) equal access to the justice system, and (iii) live independently and be included in the community can these violations be addressed. While in some countries the disability movement is already taking on these issues - building on a developed rights discourse and a history of using legal tools and high-level advocacy to achieve results in this area - the challenge remains to ensure that these core priorities are relevant across the region, especially in places where the disability movement is not as developed and these rights have not been prioritised.

A first step towards this goal requires understanding that the patterns of exclusion may take other forms than the ones we recognise from working in other parts of the world. Identifying their manifestation in the African context is critical to devising an appropriate strategy for working there. For example, even where the legal system includes a formal institution of guardianship (which is not the case in all the countries in the region), our initial examination reveals that the most common form of denial of legal capacity occurs informally, unregulated by legal proceedings - for example by family members stepping in de facto for their family member with a disability.

Another example is how segregation within the community plays out. Institutions for PWD, and even psychiatric institutions, are much less common in Africa than in other regions where we work. However, against a backdrop of profound stigma and a dearth of social services in general, segregation takes the form of isolation within communities: non-attendance at school, lack of care and treatment, and absence from social and political life. In its extreme - but not uncommon - form, isolation may include being kept inside the house and even physical chaining. Institutions for ‘care’ of PWD may be few, but laws enabling imprisonment on the sole basis of not taking care of oneself turn prisons into a receptacle for people in need of support in their everyday lives.

Beyond the types of marginalising practices that take place in societies around the world and universally affect certain groups, it is important to identify context-specific practices and affected groups. In Africa, these may include women with disabilities, who are more acutely affected by impunity associated with sexual violence, and refugees and displaced people.

This study provides valuable information that OSISA and its OSF partners will utilise to support the protection and promotion of the rights of PWD in southern Africa.
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ACNIDAH Intersectoral Commission for Demining and Assistance to Victims (Angola)
ADD Action on Development and Disability
ANCA Angola National Association for the Nearsighted and the Blind
BCD Botswana Council for the Disabled
CRPD Convention for the Rights of Persons with Disabilities
DDP Disability and Development Partners
DFID Department for International Development (United Kingdom)
DHAT Disability & HIV and AIDS Trust
DOLASED Disabled Organisation for Legal Affairs and Socio-Economic Development
DPO Disabled People's Organisation
FAMOD Forum of Mozambican DPOs
FAPED Angolan Federation of the Associations of People with Disabilities
FEDOMA Federation of Disability Organisations in Malawi
FODSWA Federation of Organisations of Disabled Persons in Swaziland
HI Handicap International
ILO International Labour Organisation
INGOs International non-governmental organisations
ISTEG Higher Institute of Economics and Management (Mozambique)
LARDEF League for the (Re)integration of Disabled People (Angola)

LNFOD Lesotho National Federation of Organisations of the Disabled
MANAD Malawi National Association of the Deaf
MMAS Ministry of Women and Social Action, Mozambique
MINARS Ministry of Social Assistance and Reintegration, Angola
NACD Namibian Association of Children with Disabilities
NFPDN National Federation of People with Disabilities in Namibia
NASCOH National Association of Societies for the Care of the Handicapped (Zimbabwe)
NGO Non-governmental organisation
PEPDEL Project on the Employability of Persons with Disabilities (ILO)
PWDs People with disabilities
SAFOD Southern African Federation of the Disabled
SAP Structural Adjustment Programme
SINTEF Stiftelson for Industriell og Tegnisk Forskning (independent Norwegian research company)
UNDP United Nations Development Programme
USAID United States Agency for International Development
ZAFOD Zambia Federation of Disability Organisations
ZAPD Zambia Agency for Persons with Disabilities
ZAWD Zambia Association for Women with Disabilities
ZPHCA Zimbabwe Parents of Handicapped Children Association
WHO World Health Organisation
The research recorded in this document was undertaken to compile a comprehensive overview of existing disability policies and legislation in nine southern African countries – Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, Swaziland, Zambia and Zimbabwe. It was also intended to gauge the progress made in each of these countries towards ratifying and implementing the Convention for the Rights of Persons with Disabilities (CRPD), and to determine whether any strategic litigation concerning disability rights has taken place (or is in process). In addition, the research aimed to provide an overview of the most well-known disabled people’s organisations (DPOs) operating in the different countries, in particular those that focus on disability rights work, and to ascertain the sources and extent of their funding. The final research objective was to establish the extent to which teaching and scholarship in the field of disability rights is occurring at universities in the region.

The investigation started with a review of literature on disability issues and rights in southern Africa. The aim was to establish a broad socio-economic context for the study, and to obtain a sense of the trends and discourses concerning disability rights prevailing in the region. The review (described in Chapter 1) revealed an extremely bleak scenario across the region. The lives of the majority of people with disabilities (PWDs) are characterised by severe poverty and deprivation; lack of access to most essential services; low levels of education (and therefore high levels of illiteracy); limited access to formal employment and other income-generating opportunities; social marginalisation; and, a high level of vulnerability to HIV infection. This made it clear to the researchers that any examination of the legal and human rights discourses concerning disability rights in southern Africa should recognise the extreme hardship that characterises the daily lives of the disabled. As long as PWDs in southern Africa continue to live in such deprivation and die unnecessarily
(and unnoticed) of AIDS and other preventable diseases, analysts cannot focus only on disability rights and the ratification and implementation of the CRPD. That would court the danger of promoting disability rights in principle and on paper only. At present, there is an enormous gap between discourse and the lived experience of PWDs, who are mostly unaware that such a discourse exists, let alone that agencies are involved in the fight for their rights.

It follows that campaigns and university courses on disability rights should include a strong emphasis on the socio-economic rights and entitlements of PWDs, and the need to exert constant pressure on governments to provide essential services and opportunities to the disabled among their populations. These essentials should include not only physical care but provision for mental and social development, in particular education and literacy programmes. Unless governments provide such support, disabled rights activists will continue to find it extremely difficult to reach and involve PWDs in fighting for their rights and improving their chances of earning livelihoods.

In order to test the findings elicited from the literature review, the researchers drew up a questionnaire to be administered mainly to the staff and members of DPOs. This started with a very basic question about the general state and status of disabled people in each country. A large number of responses were received from the nine countries in the research sample, all of which mirrored the general trends and conditions described in the literature review almost exactly. The findings resulting from these answers (described in Chapter 2) made it clear that, in southern Africa, poverty is the frame within which the entire discussion of disability and disability rights must be set, because the majority of disabled people fall into the category of the poorest of the poor. Disability is clearly a central and cross-cutting development issue.

Better and broader access to education was widely regarded by the respondents as the only way out of poverty for the millions of PWDs in the region. It is also a fundamental requirement for the advancement of disability rights, because if the majority of PWDs continue to be ignorant of the existence of rights-based discourses and campaigns, they can neither contribute to, nor profit from, them. In some southern African countries in the sample, campaigns to broaden access to inclusive education are already under way. However, sufficient financial and human resources to achieve this objective are not always available. A great deal of attention with regards to practical and technical matters and measures is required if such campaigns are to succeed.

Chapter 3 concerns the general status accorded to DPOs by the governments of the countries in the research sample, and the situation in which DPOs find themselves. The overall assessment was that the majority of DPOs in southern Africa
are struggling both to survive and to exercise significant influence on the disability policies, legislation and provision of services of their respective governments. With very little donor funding to the disability sector still available, DPOs tend to encounter a range of difficulties in maintaining offices, attracting and keeping staff and volunteers, carrying out projects and supporting networks. Also, because most of their staff and members have limited education, most DPOs face many organisational constraints, for example in managing general and financial arrangements, drawing up funding proposals and donor reports, and designing and monitoring projects. Another significant shortcoming is that many are ill-informed about contemporary advocacy and lobbying approaches, and the potential uses of strategic litigation to advance disability rights and improve public recognition of these issues. Most DPOs have no, or very little, research capacity.

The findings obtained from the questionnaire also made it clear that in many cases, the staff of smaller, sectoral DPOs had little in-depth knowledge of the Convention, its various provisions and its potential as the ultimate advocacy tool. They were largely uninformed as to the Convention’s requirement that DPOs participate in the implementation and monitoring of adherence to its provisions. This indicated an urgent need for DPOs to develop a range of thoroughly-considered capacity-building and training initiatives, based on thorough consultation with PWDs and DPO staff members, in all the areas identified above (and many others).

There are, of course, many notable exceptions to the rule. These have been identified and are discussed in Chapter 3. It is also important to realise that, like PWDs themselves, DPOs represent a great diversity of interests, sectors and perspectives. The historical, political, socio-economic and cultural contexts of each country lend specificity and slightly different angles to their institutions and organisational priorities. In general, though, there are clear trends and tendencies to be found in DPOs throughout the region. These are discussed in detail in the chapter.

Chapter 4 contains an analysis of the responses of governments in southern Africa to the issues of disability and disability rights and the Convention, in terms of the introduction of relevant policies and legislation, and the allocation of responsibility for their implementation to various institutions or government departments. Although there are huge variations between the nine countries in terms of the disability policies and legislation that have been established and the various institutional ‘homes’ to which disability issues have been allocated by their governments, there is a common lament from DPOs across the region that these laws and policies are not put into practice. Although it is too early to judge compliance with the Convention’s provisions, among those interviewed in the four countries that have ratified the Convention questions are already being asked about whether any progress has been made.

The biggest challenge for DPOs appears to be persuading governments to take the crucial steps from discussion and consultation to policy-making and legislating, and then to actually ensuring that the promised services take concrete form.

Another pressing need identified by the interviewees was that governments and other concerned parties should develop detailed responses to the many difficulties faced by PWDs and institute practical measures to address them. These responses would have to be drawn up in close consultation with people who have a variety of disabilities, so that the specific needs of all can be accommodated. In most of the countries covered by the review, it is unlikely that such planning will occur in the foreseeable future, as the public and political profile of PWDs and disability issues remains low. Apart from a handful of countries in which Disability Units have recently been established in high-level political offices, the governments of the others follow a general trend of allocating disability as a sector to a government department that serves other vulnerable groups, for example social welfare, women and the elderly (or all of these...
together). The situation with regard to legislation and policies dealing with disability varies greatly between countries, ranging from very up-to-date and progressive approaches to fragmented efforts based on antiquated concepts of disability, or even a failure to provide for the disabled at all. Examples of each are discussed in this chapter, and greater detail is given in the separate Country Profile report.

Chapter 5 examines whether disability rights are taught at universities in southern Africa, particularly in law schools. The research findings indicated that, apart from a few law schools where disability rights were included in some of the standard law courses and curricula, no stand-alone courses in this subject were offered. Where courses on disability were taught in the humanities and health sciences, these tended to concentrate on issues such as rehabilitation and counselling, and were not rights-orientated. The legal academics in the nine countries examined proved to have very little awareness of disability issues and rights or knowledge of the Convention. However, once they had been introduced to the idea, most of them showed a guarded interest in pursuing the topic and introducing a course on disability rights.

Although few universities appeared to have formal policies concerning PWDs, most had some form of disability unit on their campuses and made what appeared to be ad hoc arrangements to make the buildings and facilities accessible to mobility-impaired students and staff, and to offer them accommodation reasonably suited to their needs. However, most of the universities visited during the course of the research appear unprepared at present to consider the more complex theoretical, practical and political issues connected with disability.

Each chapter ends with a conclusion in which some of the main issues raised in that chapter are summarised. The last chapter contains the final conclusions arrived at in this research project.
Research objectives

The aim of the researchers was to:

• conduct a comprehensive overview of policies and legislation regarding disability in each of nine countries, which includes mention of any strategic litigation related to disability that has taken place, or is in process, in any of these countries;

• perform a situational scan to identify which organisations are undertaking disability rights work in each country, and to provide details of their overall budgets and sources of funding;

• investigate whether any disability rights education is taking place at universities in the countries concerned;

• find out whether any law school in the nine countries is using innovative, participatory methods of teaching law students, and if so to discover what these methods are and assess their effects; and,

• discover whether universities in the nine countries have university disability policies (for disabled students, staff and employees) and, if so, to analyse how far-reaching these policies are.

Research methodology

The methodology used comprised:

• a desktop review of the general situation of PDWs and the degree to which disability rights are acknowledged in nine countries in southern Africa;

• an overview of disability legislation and policies in nine southern African countries (conducted by in-country research facilitators);

• a summary of progress made in ratifying the Convention on the Rights of Persons with Disabilities (CRPD) in the nine countries (involving both desktop and in-country research); and

• in-depth interviews with members of DPOs and academic staff at law schools, and a small number of government officials in the nine countries.
Introduction

In December 2006, the United Nations adopted a new international human rights treaty, the Convention for the Rights of Persons with Disabilities (CRPD), which in essence affirms that people with disabilities have the same human rights as all other people. The Harvard Law School’s Project on Disability describes it as ‘a revolution in the international conception of disability’, and points out the huge paradigm shift involved: ‘Instead of approaching people as ‘handicapped’ and naturally excluded from mainstream culture, they are viewed as equal and capable of claiming their human rights’.

It is important to emphasise that the Convention does not create any new or special human rights for PWDs, but rather asserts that all existing human rights apply equally to the disabled. Apart from the standard human rights and anti-discrimination clauses, the Convention also covers a range of socio-economic rights, including the rights of access to education, employment, health, housing, independent living arrangements, adequate living standards and social protection. All of these are of paramount importance to disabled people living in southern Africa. The Convention enjoins an integrated approach and is ‘intended as a human rights instrument with an explicit social development dimension’.

The concept of disability is increasingly described as ‘evolving’, and is referred to as such in the preamble to the Convention. This usage is an advance on the many terms and definitions (many derogatory and demeaning) attached to the notion of disability and PWDs through the centuries, and reflects the changing attitudes, perceptions and models that have replaced them over the last few decades. It also

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Literature review: Key issues around disability and disability rights in southern Africa
serves to remind people belonging to the ‘abled’ world of the diversity and variable degrees of disability, which no blanket term will cover. To replace the types of social labelling used in the past, human rights professionals have agreed on ‘people with disabilities’ as the preferred designation. As Victor Jere points out, this is an important and positive development, as it is a term that PWDs would ascribe to themselves, in so doing reclaiming the human dignity denied them by most of the earlier definitions.4

Like other marginalised groups that have experienced discrimination and exclusion from mainstream society, disabled people everywhere have had to organise themselves to fight for their basic human rights, which involves inclusion in, and access to, the political, socio-economic and cultural life of the societies to which they belong. On a practical level, this entails their benefiting from the full range of social services available to other members of society, such as the provision of education, health care, social security, housing and so on. Another of these rights is their entitlement to intellectual independence, to make their own choices, and to be consulted on matters that concern them.

According to most published accounts about attempts by PWDs to assert their rights, the earliest public manifestations occurred in industrialised countries during the 1970s and gradually spread to developing countries. Zimbabwe was a pioneer of this struggle in southern Africa, becoming the home of a strong disability movement. The momentum of the global disability rights campaign has continued to grow over the last four decades and it now boasts a wide range of impressive accomplishments – the most important being the adoption of the CRPD.

One of the most crucial issues contested by PWDs in developed countries was the attitude of their medical and social welfare establishments, which tended to think of disability in purely medical terms. This led to the assumption that disability was to be treated through various kinds of rehabilitation, institutionalisation and services offered by charitable agencies. In the literature, this is referred to as the medical/charity model, which places the locus of disability in the individual and regards the disability as a discernible personal trait. The most common criticism of this model is that it construes the disabled person as inferior, dependent, and in need of medical assistance and charity.

Although remnants of the medical/charity model remain apparent in the laws, policies and practices relating to disability and PWDs in most southern African countries, it has now been replaced officially by the social and human rights models. In these the focus has shifted from ‘individual impairment’ to a more holistic view, which locates disability in the more general context of the society and the environment in which the PWD lives. In the social model, the emphasis is placed on the ways in which a society creates and perpetuates limitations and obstacles for PWDs. The preamble of the CRPD refers to the social model when it says ‘recognising that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full participation in society on an equal basis with others...’15

In principle, this more integrated and progressive understanding of disability now informs disability discourses and policies in most international human rights and development bodies. It also provides guidelines for the development of better policies and best practice. The social model, on which the CRPD is based, has been adopted by the World Health Organisation (WHO) and the World Bank. It has also started to influence the work of major donor and development entities, including non-governmental organisations (NGOs) involved in the fields of disability and social development, and DPOs. However, more needs to be done by organisations in the disability movement to engage in active lobbying and constant awareness-raising campaigns. These will ensure that disability issues are placed, and remain, on international development and aid agendas, and are routinely given priority.

Given that PWDs constitute, on average, about 10 percent of any country’s population and are widely reported as belonging to the poorest section of the populace in most developing countries, there are many reasons to consider
disability as a cross-cutting development issue. As such, it can no longer be omitted from international discourses and programmes on social upliftment and poverty reduction. Foreign development aid and donor agencies can play a powerful role in establishing and standardising best practice in developing countries by setting the precedent of making disability a special focus in all their institutions and programmes. They could also insert a ‘disability clause’ into each of their agreements with recipients of donor funds and/or technical assistance. This would make an immeasurable contribution to the treatment of PWDs worldwide. The same applies to international NGOs (INGOs). However, at present, the general impression among disabled rights experts is that most of these progressive discourses and policies have not as yet trickled down to the level of influencing actual programmes and practices.

All in all, the international disability movement has come a long way and achieved a great deal. However, much remains to be done, especially at the grassroots level in developing countries, as the research findings from southern Africa attest. The greatest challenge facing agencies working in disability rights is the combination of high levels of illiteracy, extreme poverty and unemployment experienced by the majority of PWDs living in the nine countries examined. The governments of these countries face the daunting task of translating the many progressive provisions of the CRPD from agreement on paper to implementable practice when there are countless other demands on their limited resources. At present, the day-to-day lives of PWDs across southern Africa remain very far removed from those envisaged in the ideals and guiding principles set out in the Convention. As Marcus Power notes, ‘What partly defines disability in southern Africa…is the ‘voicelessness’ and institutional neglect of disabled people, who are often forced to take positions on the outermost margins of their societies.’

Implementing the CRPD in southern Africa involves not only substantial financial commitment but major changes to legislation and government institutions. Furthermore, such changes can come about only if all government officials are prepared to approach disability issues and PWDs in the manner required by the Convention, which makes disability issues a priority in all governmental activities. In most southern African countries, it seems likely that limited resources will be put forward as the reason for tardy implementation, whether this is indeed the case or merely a reflection of a general reluctance to accord disability-related issues greater attention.

On the other hand, once countries have ratified the Convention, they are bound by international law to implement its provisions. Monitoring compliance with the terms of the Convention will be the responsibility of civil society organisations, most crucially DPOs. Indeed, the Convention enjoins governments to consult DPOs and engage them as fully as possible in both implementation and monitoring. This provides DPOs with a very powerful advocacy tool in principle, but, as will be evident in the research findings, the ability of DPO staff to practise advocacy and lobbying differs widely from country to country. Chalklen, Swartz and Watermeyer make the following observation regarding the implementation of the objectives of the African Decade for Disability:

In some countries, the disability sector is highly energised and very active in advocacy work. In others, the lack of motivation and sense of despondency is palpable and distressing. Faced with demanding and complex problems, and severely under-resourced, many workers in these countries are filled with despair. This apparent despair is often linked with broader social challenges and not just with disability specifically.

Complex factors informing the discourse on disability in southern Africa

Disability, poverty and (under)development

The poverty levels which persons with disabilities face are far higher relative to the rest of society. The opportunities for livelihood available to a disabled person are less obvious since disability undermines the actual or perceived ability of a person to interact in educational, economic, social or indeed political arenas. Poverty itself breeds disability and disability is a harbinger for more poverty.
If anything can be said to provide a framework for the discussion of disability in southern Africa, it is the extreme levels of poverty and deprivation experienced by the majority of PWDs living in the region. Although poverty and unemployment affect large sections of the general population in most of the nine countries examined in this report, the material published on disability in southern Africa makes it clear through sheer repetition that PWDs almost always constitute the most extremely deprived, the very poorest of the poor. This in turn has wide-ranging implications for the realisation of disability rights and the implementation of the CRPD, as became evident in the research findings.

It is crucial to recognise the links between poverty and disability. Poverty is frequently a consequence of disability, as indicated in the quotation above. A recently-released Stiftelson for Industriell og Tegnisk Forskning (SINTEF) report on the living conditions of PWDs in Mozambique found that families with a disabled family member are, in most cases, poorer than families without. Although the causes and effects applicable to this situation are difficult to untangle, one of the reasons for this greater propensity to poverty is the extra costs involved in the care of a disabled person, which entail the expenses incurred by health care and assistive devices, and income foregone when a family member has to stay at home to assist that person.

On the other hand, impoverishment and under-development often contribute to disability, a phenomenon referred to in the literature as preventable impairment. In most of the published work on disability in developing countries, including southern Africa, there is a consensus that many forms of disability are caused by a range of political, social, economic and environmental factors that can be addressed. However, the conditions for prevention are very onerous, because they entail, among others:

- the political will in government to address the needs of the populace;
- a country at peace;
- the existence and implementation of sound development policies that pay attention to the needs of the poor (including PWDs);
- sufficient funds to carry out the country’s development agenda;
- government policies that allow equal access to education and employment opportunities for PWDs;
- the provision of essential services such as clean water and adequate sanitation to all; and,
- a reasonable standard of basic/preventative health care.

Very few of these basic conditions and service requirements are met in most developing countries. Where they are provided, their quality is nowhere near the level needed to make the required difference in the lives of PWDs. For example, the SINTEF study in Mozambique found that families with a disabled family member are, in most cases, poorer than families without.
found that although 23.7 percent of the PWDs interviewed reported that they had been born with their impairments, 52 percent of disabled respondents attributed the cause of their impairment very generally to ‘sickness’. The latter information led the SINTEF researchers to conclude that ‘other than telling us that the people of Mozambique live in difficult conditions, this is a strong indication of severe problems with health services in the country’. In most cases, the financial resources required by governments to provide public assistance over a wide range of socio-economic needs are either insufficient or allocated elsewhere.

This situation is often, in turn, a result of controversial economic policy choices that were adopted by, or imposed upon, governments in the past, and which hinder the proper prioritisation and funding of basic social services. For example, many developing countries were forced to make drastic cuts in their social expenditure during the 1980s and 1990s when the International Monetary Fund (IMF) and the World Bank gave them assistance conditional on their adopting Structural Adjustment Programmes (SAPs). The most notable cut-backs occurred in the very areas most crucial to the protection and survival of PWDs – health, education, social welfare and gender equality programmes. In most of the countries concerned, the implementation of SAPs generally led to widespread reversals in earlier development gains, resulting in increased poverty, unemployment and inequality.

It is doubtful whether any research has been undertaken to assess the effects of these policies on the disabled populations of the countries affected. One can only speculate that in many cases they would have made the difference between survival and death. PWDs, particularly children with disabilities, are even more vulnerable than the rest of the population to the effects of such deprivations as malnutrition, inadequate housing, contaminated water, and the collapse of essential health and welfare services. Chalklen, Swartz and Watermeyer, in writing about the challenges encountered when establishing the secretariat for the African Decade of Persons with Disabilities, raise the issue of this acute vulnerability and how it affects the life expectancy of people with disabilities in southern Africa:

The situation in Africa differs radically from that in the US or Europe for a number of reasons. Most fundamental is the issue of poverty. Severe poverty disempowers people and severely limits the extent to which people can organise themselves into successful DPOs. More pressing still than the disempowerment of poverty is the difficulty of survival. For example, though a person with a spinal cord injury in a wealthier country, or even in South Africa, has a long life expectancy, some have estimated the life expectancy for a person with a spinal cord injury in a poorer African country at between four months and two years ... Similar challenges face people with other impairments, rendering an overall scenario of substantial barriers to the meaningful organisation and self representation of disabled people.

Poverty is not the only hardship PWDs have to endure. Because there is a stigma attached to PWDs in many societies, they suffer neglect and discriminatory attitudes and practices, and frequently find themselves on the very lowest rung of the societal ladder. To illustrate this point, those children born with disabilities who survive the first five to six years are often unable to attend school, or prevented from doing so. The same applies to their access to post-school facilities. Yet basic education, followed by vocational, technical and academic training, is invaluable to disabled people because it offers them the opportunity to escape from poverty, achieve economic self-sufficiency and follow a reasonably independent lifestyle.

Apart from the limited amount of societal and public support available to children with disabilities, impoverished parents are forced to make cruel choices about which of their children to send to school. Although such choices are always strongly influenced by the socio-cultural norms of the community and the country in which that family lives, they are essentially made on a cost-benefit basis. They have to identify which child will be best able to provide for them in their old age – that is, the one most likely to offer the best return on their cash investment. In most cases, their first choice is a boy. Girls tend to be relegated to more traditional roles that do not require education. In this kind of scenario, where families lack government, donor, NGO or private assistance, disabled children, especially
girls, will be at the very end of the queue for receiving an education. In consequence, most of them are denied the range of opportunities that schooling may open up. The prospects for disabled girls do not improve as they grow up. Women with disabilities are generally poorer, more disadvantaged and more vulnerable than their male counterparts. This in turn makes them targets of physical and sexual abuse and rape, which exposes them to HIV infection. They are also less likely to marry than disabled men. This double discrimination against girls and women with disabilities is an area of concern that is routinely raised in the literature on disability and the academic field of disability studies. The latter is a multi-disciplinary academic subject that focuses on the many interrelated issues connected with disability.

Facilities offering special education are few and far between in most southern African countries, and staff members in mainstream schools usually lack any training in teaching disabled children. Those children with disabilities that enter school are frequently discouraged by discriminatory attitudes displayed by teachers, who have not received any training pertinent to teaching disabled pupils, and their own peers. In extreme cases, the disabled children drop out of the school system. However, there are also many advantages for disabled children in mixing with a wide range of other pupils of varying abilities – not least the opportunity for social integration. This explains why, in some countries in southern Africa, including Botswana, Namibia and Mozambique, there are now campaigns afoot to make their education systems inclusive.

Therefore, it is unsurprising that global literacy rates for PWDs are extremely poor (3 percent for all PWDs and as low as 1 percent for women). The consequences of such widespread illiteracy include limited access to employment, economic dependency on relations (or the state in countries where social welfare services are available), long-term poverty, lack of social integration, and difficulty in exercising their choices and realising their rights. It also means that PWDs are unlikely to be reached by, or receptive to, the awareness-raising and advocacy campaigns or programmes of international and national governments, NGOs and DPOs.

The right of PWDs to equal access to employment, with the additional requirement that jobs also accommodate their special needs, is a key element of the new rights-based discourse concerning disability. It is also given a central position in the Convention, because employment is crucial to the self-respect of PWDs. Among its many concrete benefits, earning a living generates economic self-sufficiency and assists social integration. However, this essential human right is extraordinarily difficult to satisfy. Many developing countries have very high unemployment levels, a situation that was greatly aggravated by the SAPs in a number of African countries, including those examined in this study. Like poverty, unemployment is a widespread phenomenon that affects all of southern Africa, and it has no simple solution.

The situation of PWDs in each country is therefore closely interwoven with its level of development, which is why disability is increasingly regarded as a development issue that forms part of the rights-based approach to development and human rights. Most of the major international development and finance bodies have started to prioritise PWDs in poverty reduction and other development programmes (although disability does not feature in the Millennium Development Goals). According to a United Nations Development Programme (UNDP) statement in 2000, it is important that planners and policymakers ‘remain sensitive to the disability dimension early on and throughout the development process’. In the same year, the British Department for International Development (DFID) stressed that ‘elimination of world poverty is unlikely to be achieved unless the rights and needs of people with disabilities are taken into account’.

This international focus on making disability a central theme in, and across, all development and governance programmes is obligatory on all states that have ratified the Convention. However, there are many reasons why these new policy directives will not immediately make a direct difference to the lives of PWDs in developing countries.
Disability, political violence and war

In countries that have experienced prolonged periods of internal factional violence, political upheavals and wars, the human toll is always heavy. The price paid involves loss of life but also severe trauma, whether physical or psychological. Both of these lead to disability. During the civil wars in Mozambique and Angola, which lasted for decades, landmines were used by all the warring parties. As a result, both countries contain large numbers of people who have lost limbs, primarily in landmine explosions - swelling the ranks of the disabled. Years after these wars have ended, people continue to be maimed by exploding mines, even though both governments, assisted by various international charities, have spent years attempting to clear the minefields. The cost of war-related injuries in terms of psychological scarring is obviously incalculable, although it too is a disabling factor. And one cannot even begin to imagine the long-term physical and psychological damage done to women and children by the lawlessness and displacement that usually accompany wars, and the regular resort to rape, either as by-product or a conscious strategy of intimidation (as seen most recently in the Democratic Republic of Congo). The effects would be even more severe when the women and children in question were disabled.

Political instability and violence can also trigger disability indirectly, through the collapse of essential services and economic stability, and directly through physical brutality directed at political opponents and civilians. The political violence in Zimbabwe before the elections in 2008, which included beatings, torture and reports of amputation of hands and arms, added to the number of PWDs. Meanwhile, the economic decline and bitter political rivalry of the last decade have had an extremely serious effect on Zimbabwe's disabled population. Although the country was a frontrunner in the development of a disability movement in the 1970s and notched up a good record for providing progressive social services during the 1980s, many of the gains for the poor, and PWDs in particular, have been lost in subsequent decades.

Apart from the deterioration in the economy and most essential social services (including halting social grants) that has taken place over the last 30 years, the Zimbabwean government's campaign to remove the urban poor from informal settlements in Harare has reportedly affected PWDs very badly. Disabled people who can make some kind of living in an urban environment often find themselves with very few means of economic survival in the peri-urban and rural areas to which they have been forcibly removed. (This is an illustration of the maxim that in times of conflict the most vulnerable members of society are bound to be the worst affected.) And among the inhabitants of these relocated settlements, many succumb to disability owing to the other deprivations visited upon them by an uncertain political environment.

“The price paid involves loss of life but also severe trauma, whether physical or psychological. Both of these lead to disability.”
Disability and HIV and AIDS

The family members are the first to discriminate. As a result you enter into self-denial. Instead of dying [of AIDS] next year, you die this year because you can’t share.

(Rule et al., 2008)\textsuperscript{22}

Another area of grave concern that has emerged relatively recently is the increasing incidence of HIV infection and AIDS in disabled people, and the effects on them. This phenomenon went unnoticed by researchers until PWDs started to die from the disease. The most difficult aspect of this newly-recognised problem is that there is a conspiracy of silence in the families of those affected, because social attitudes towards HIV and AIDS are generally governed by shame and a wish to avoid the stigma associated with the disease. Another constraint, mentioned in a seminal report on HIV and AIDS and disability in Mozambique published in 2008, is that the average ‘abled’ person subscribes to a ‘moral consensus’\textsuperscript{23} that PWDs are not interested in sex, or sexually active. This general societal ignorance of sexuality in the disabled and the accompanying risks of exposure to infection extends not only into the domain of governments but, surprisingly, into those of national and international HIV and AIDS organisations, which are usually more progressive in their approaches. Stephen Lewis, a former Special Envoy for UNAIDS in Africa, showed his lack of awareness of AIDS in PWDs in the comment, “I have been approached by a disabled person here and there, but it never occurred to me that this is a large group of people.”\textsuperscript{24}

Researchers began to pay attention to this difficult and rather opaque topic in the early 2000s. A body of literature on the subject has since accumulated. Although important studies in this field have been carried out in South Africa,\textsuperscript{25} Namibia,\textsuperscript{26} Zimbabwe,\textsuperscript{27} Mozambique\textsuperscript{28} and Swaziland,\textsuperscript{29} the pioneering research work was done by Professor Nora Groce, who led the HIV & AIDS and Disability Global Survey – a collaboration between Yale University and the World Bank (2004).\textsuperscript{30} The overall conclusion of the Global Survey is that ‘HIV and AIDS present a significant threat to disabled populations around the globe, at rates at least comparable to – and quite possibly significantly higher than – rates found in the general public.’\textsuperscript{31}

The authors add that ‘individuals with disability have equal or greater exposure to all known risk factors for HIV infection’.\textsuperscript{32} Most of these factors are attributable to the many forms of insecurity that PWDs routinely suffer from, as described by Swartz et al.: ‘Every aspect of life which makes people with disabilities more vulnerable than others in general, may make people with disabilities more vulnerable to the epidemic.’\textsuperscript{33} The primary risk factor is the vicious cycle of disability and poverty already referred to, which has severely limiting effects on the lives of PWDs. These constraints apply to sexual behaviour and choices, as well as other aspects of their lives, and are particularly problematic in the case of girls and women with disabilities, who tend to be economically dependent on parents and/or partners, and are therefore seldom in a position to insist on the use of precautions like condoms to prevent infection during sex. They are frequently more vulnerable to sexual exploitation and violence, and consequently to infection by the HIV virus than disabled men. The situation of the former is described as ‘the quadruple inequalities of gender, disability, poverty and HIV status’ by the authors of the Disability and Development Partners (DDP) report referred to above.\textsuperscript{34}

However, it is not only women with disabilities who are affected. The Global Survey on HIV & AIDS and Disability found that ‘individuals with disability are up to three times more likely to be victims of physical abuse, sexual abuse and rape’.\textsuperscript{35} The survey, along with some of the other studies in this field, reports that PWDs who have been victimised in these ways tend to have little recourse to the police, legal counsel and the courts. They are also unlikely to receive medical attention, prophylactic treatment and counselling.

A contributory factor is that the lack of education and low levels of literacy that tend to characterise PWDs in general cut them off from claiming the kinds of assistance (for example, legal and medical services) that are normally offered to citizens. It also makes them inaccessible to social
projects like HIV and AIDS prevention campaigns, as is confirmed by the findings of researchers who found that PWDs have very low levels of awareness of HIV and AIDS.\textsuperscript{36} In order to bridge this gap between need and practical assistance, DPOs and governments will have to develop more appropriate means of communication that cater directly to the varying needs of PWD, for example verbal presentations for blind people and sign language interpreters for deaf people.

For the subject of HIV and AIDS to be brought into the open so that appropriate prevention and treatment strategies can be developed, the stigma attached to the disease must be addressed. PWDs and people living with HIV and AIDS tend to ‘share common characteristics of stigmatisation’,\textsuperscript{37} although the exact forms and focus of acts of social repugnance differ. When PWDs develop HIV and AIDS, they are prone to a ‘double burden’, as a study in Rwanda and Uganda\textsuperscript{38} terms it. The DDP research in Mozambique also led to the conclusion that ‘stigma undergone by people by dint of disability acts as a powerful disincentive to HIV testing, as exposure to a secondary stigma would not just be felt as personally intolerable, it would also practically serve to further reduce quality of life’.\textsuperscript{39} The writers also make a crucial point about the link between what is perceived as social disgrace and lack of information: \textsuperscript{40}

\textit{Stigma, a vast field of work, exercising both DPOs and HIV and AIDS organisations, can be thought of as a barometer of knowledge – in the developed world, stigma against both disabled people and people living with HIV and AIDS has reduced in direct proportion to the provision of information and education about both.}

Even when PWDs manage to overcome all these obstacles and taboos (and the travails of public transport) sufficiently to approach health facilities in search of information about HIV and AIDS, condoms, voluntary testing and counselling and treatment, they face a further multitude of barriers.\textsuperscript{41} These range from practical physical difficulties like coping with public transport and entering health facilities, to concerns about confidentiality (for example, when someone has to interpret in public for a deaf person), to the ignorance of health personnel concerning the needs and sexuality of PWDs with different kinds and degrees of disability. There are widespread reports that PWDs have been turned away from clinics and even refused HIV testing, on the false reasoning that they are not sexually active and therefore not in need of such services. Both the Global Survey and the DDP study in Mozambique also report that PWDs who are HIV positive are often relegated to the very back of the queue for anti-retroviral (ARV) treatment, as the drugs are expensive and in short supply. The Mozambique office of the World Health Organisation (WHO) reports some of the reasons given for this exclusion:\textsuperscript{42}

\textit{The reasons that were cited for this situation were that HIV and AIDS are generally not conceptualised...}
as problems that affect disabled people and that they mirror the social status and discrimination of disabled people generally, and it could be equally true that it is also symptomatic of the routine omission of disabled people from development initiatives – disabled people’s invisibility.

Apart from PWDs being more vulnerable to HIV infection, they tend to be more severely affected by the virus, because it causes different forms of disability. In addition, some of these can be attributed to the side-effects of ARV treatment. There are also collateral consequences. Increasingly, the reports make reference to disabled children who have been orphaned by the deaths of both parents from AIDS. Some of these children are taken care of by their older siblings in ‘child-headed households’. Others are taken in by relatives, who are generally unable to provide the extra care and pay the costs involved in looking after disabled children. This in turn means that there is a strong likelihood that these children will be neglected, abused or abandoned.

HIV and AIDS and disability are therefore clearly linked in a multitude of ways, which are being investigated by a number of analysts. However, despite the growing number of publications on the subject worldwide, and the alarming but consistent research findings, little has changed in the perceptions and attitudes of the public. Even members of the public sector and those involved in NGO HIV and AIDS programmes appear to be ignorant of the connection. When in the course of the DDP research in Mozambique, the matter of PWDs and AIDS was raised with organisations involved in AIDS programmes, people were asked to consider the reasons why disabled people were vulnerable to HIV infection. Only then did ‘the need for disabled people’s inclusion became immediately apparent’.

Unless recognition of a link between being disabled and being especially vulnerable to HIV infection becomes sufficiently well established to justify the foregrounding of PWDs in HIV and AIDS programmes across the entire spectrum from prevention to treatment as standard practice, the neglect of the past will continue. If HIV and AIDS programmes were to be developed for PWDs, an obvious starting-point would be to offer the information and materials on the subject in a variety of media, and in formats accessible and appropriate to PWDs. In this way the specific barriers to communication experienced by people with different forms of disability could be surmounted. What is ultimately needed to remedy the present situation is a reciprocal prioritisation of disability into HIV and AIDS programmes and vice versa. All government departments, programmes and budgets should recognise the importance of doing so. However, it seems unlikely to happen in the foreseeable future.

Conclusion

The authors of the DDP report on Disability and HIV and AIDS in Mozambique refer to poverty as the ‘hydra’ of development, referring to the many forms of deprivation that poverty inflicts on those who suffer it. However, they warn that ‘tackling symptoms individually does not necessarily mitigate the overall condition’. The interlinked manifestations of poverty need to be constantly borne in mind by those initiating legal, academic and advocacy programmes concerning disability rights in southern Africa. It is only when these initiatives have led to the widespread recognition of disability rights in the region that the provisions of the Convention can begin to make a difference to the lives of PWDs.
4. General research findings:
The lives of people with disabilities in southern Africa

Poverty and disability

Within the totality of people in developing countries suffering poverty, there are of course gradations of susceptibility to poverty, and disabled people are arguably the most vulnerable of all.

(DDP report, Mozambique)⁴⁶

Overall, the responses garnered during interviews with leaders and staff of DPOs in southern Africa concurred with the analyses of socio-economic issues as they affect PWDs found in the published literature. During the interviews, the widespread and extreme poverty experienced by PWDs was the most frequently-cited cause for concern. Another aspect of the lives of PWDs that was repeatedly raised was their marginalisation in the family, the community, and society at large.

All the interlinking issues that were outlined in the previous chapter were reported as pertinent to the day-to-day lives of PWDs. The following is a brief list of the obstacles they encounter in obtaining: education or vocational training; formal or informal employment; health services (which would include the provision of assistive devices like wheelchairs and hearing aids and involvement in HIV and AIDS programmes); and, social welfare. They also encounter physical barriers when it comes to entering public buildings and using public transport.

These topics are discussed under broad thematic headings, starting with the effects of poverty on the disabled, moving on to the different forms of marginalisation to which they are subjected, and then to the marked differences between urban and rural areas in terms of the conditions under which...
PWDs live. After that the different barriers to the enjoyment of basic human rights by disabled people are described. Throughout the chapter the emphasis is on actual examples illustrative of typical aspects of life as a PWD, as reported by the interviewees.

**The effects of poverty**

The recently-published SINTEF study on the living conditions of PWDs in Mozambique found that the absence of, or the lack of access to, a range of social services – especially those relating to health, education and vocational training – were consistently rated the most acute problem experienced by PWDs in the ‘hierarchy of severity’.47 The compilers of the report also found that PWDs are frequently ignorant of the essential services that actually are provided, whether by the government or NGOs.48 This lack of awareness (which was also reported in some of the other countries) was generally attributed to the isolation within which many PWDs tend to live, which is compounded by their lack of education.

A point continually raised during the interviews was that women with disabilities are the most badly affected by poverty. As Josephine Chanda, Acting Director of the Zambia Association for Women with Disabilities, put it, “The situation is poor, with women at the tail end.”49 The SINTEF study in Mozambique found that women with disabilities generally have poorer records of school attendance, lower literacy rates and experience higher levels of unemployment and (therefore) poverty.50 As indicated in the literature review, this double discrimination appears to be prevalent across the region.

Although the situation obviously varies between countries, an income survey conducted by the National Association of Societies for the Care of the Handicapped (NASCOH) in Zimbabwe gives details of the worst-case scenario that has unfolded for PWDs there. According to Innocent Magweva, the organisation’s Disability Technical Advisor, the survey shows that ‘close to 42%’ of PWDs in Zimbabwe have no income at all, with ‘close to 39%’ earning between US$1 and US$99 per month and ‘about 15%’ earning between US$100 and US$199 per month.51 While the prolonged political impasse, the massive economic meltdown that resulted from it (which in turn raised the unemployment figure to 80–90 percent),52 and the complete collapse of most essential services and social protection mechanisms are particular to Zimbabwe, the survey suggests that the economic conditions PWDs have to endure in many parts of southern Africa are not much better.

Mozambique and Angola are both countries recovering from decades of war in which thousands of people, both soldiers and civilians, became disabled. In both of these countries, PWDs were reported as living in conditions of extreme poverty, deprivation and marginalisation. In Mozambique, one of the poorest countries in the world, the SINTEF study notes that ‘households with disabled members have a lower material standard, as compared to the control (non-disabled) households’.53 In Angola, the website of the League for the Support of the Integration of Disabled People (LARDEF), summarises the general situation as follows: 54

Seventy percent of the population still lives in poverty despite the post conflict reconstruction and development programmes. Among them an estimated 1.2 million people with disabilities are probably the most disadvantaged, as they are still marginalised and excluded from social, livelihood and development opportunities and denied equality.

Teresa Makwara, who heads the Zimbabwe Parents of Handicapped Children Association (ZPHCA), related the terrible effects of the political and economic situation in her country on children with disabilities and their parents. These include an alarming increase in child abuse and child rape. She concluded sadly that “poverty causes abuse.”55

In sum, although the connection between poverty and disability appears to have more extreme effects in some countries – most notably those that have been badly affected by years of war, political instability and violence – it is evident in all nine southern African countries that were studied during this research.
Stigma and discrimination

DPOs in every country surveyed told the researchers that an astonishing degree of stigmatisation continued to be attached to most forms of disability by most people. This is especially the case in rural areas, where disability is variously seen as a sickness, a shame, a contaminating presence, a stain on the family, a punishment for the ‘sins’ or other perceived wrong-doings of the parents or extended family of disabled children, or a result of witchcraft. According to interviewees throughout the region, PWDs are often regarded as stupid, sick, abnormal, useless, helpless, unable to make a useful contribution to society, and incapable of making choices and decisions for themselves.

Gerson Mutendere, acting secretary general of the National Federation of People with Disabilities in Namibia (NFPDN), explained that in some rural villages in Namibia, PWDs are made into objects of superstitious fear, with parents warning their children that a disabled person will come and get them if they do not behave well.56 This is just one example of how the impulse to shun PWDs is instilled in children from an early age, so that a deeply rooted aversion is implanted by the time they have become adults. It also puts PWDs squarely in the category of ‘the other’, ‘them’, or simply ‘the abnormal’, which creates a moral distance that enables ‘abled’ people to abdicate responsibility for, withhold compassion from, and discriminate against PWDs.

In many rural areas, some of this stigma is attributed to traditional or cultural norms. Angelo Dube, the in-country researcher in Swaziland, explains that excluding PWDs is sanctioned at the highest level in his country: 57

Citizen-to-citizen discrimination on the basis of one’s disability is common. Some discrimination is perpetuated by customary law norms, which prevent PWDs from participating in certain national or cultural events. The strongly held customary view is that a disabled person making contact or coming close to royalty will actually bring bad luck to either the king or the queen mother. As a result, PWDs are prohibited from attending national or cultural events such as the reed dance, etc.

The interviewee reported that he had personally experienced this form of discrimination when he was removed from a cultural event on grounds of his disability.

Although each form of disability is accompanied by unique challenges, the reported plight of deaf people in rural areas is particularly disconcerting. According to Juliana Mwase and Bison Khimenya of the Malawi National Association of the Deaf (MANAD), deaf people in remote rural areas are at a particularly grave disadvantage because deafness is not well understood in their communities. Like some of the interviewees from the other countries in the research group, Mwase and Khimenya reported horrific stories of deaf children being locked away in rooms, seldom

“PWDs are often regarded as stupid, sick, abnormal, useless, helpless, unable to make a useful contribution to society, and incapable of making choices and decisions for themselves.”

let out and not given any kind of education. In one particularly bad case, an orphan who had been confined and neglected was eventually discovered, emaciated and covered with his own faeces and urine, by visitors to the house. As sign language is the only means of communication for deaf people, being denied the opportunity to learn how to use and understand this language dooms deaf children to a life of almost complete isolation and marginalisation. Being illiterate and unable to communicate leaves them with very few prospects, which is why MANAD, like other organisations for the deaf, lobbies unremittingly for a more motivated national focus on sign language, and the allocation of more resources to its use to allow the deaf greater access to information. An example would be giving advanced training to sign language interpreters.58
In the course of interviewing DPO leaders in the nine different countries, the author was told many personal stories of how these individuals’ parents had abandoned, physically abused or hidden them from public view, or refused to allow them to attend school. Those who did manage the go to class related the hardships of being taunted by other children and the impatience of teachers who had no training in teaching children with disabilities. Many of these interviewees recounted the difficulties they had faced, and the dogged determination they needed to survive the rigours of school and make useful lives for themselves as adults.

In most cases, poverty and severe hardship were the common background to these stories. In one example, a boy, whose parents were farm workers in Zimbabwe in the 1960s, was abandoned at 10 years old. They moved away to another town while their child was in hospital having lost both legs when he was hit by a car while playing in the road. As an adult he managed to find his mother again, and became reconciled with her. He now holds a prominent position in the disability movement in southern Africa.

Another interviewee recounted the suffering he had experienced while growing up disabled in a rural village in Botswana. Because his father was away working in the mines in South Africa, his mother was head of a household containing eight children. By his account, his disability caused his mother great shame and frustration, which she regularly took out on him with vicious beatings.

It was only through his own determination that, step-by-step, he acquired a secondary and tertiary education and, eventually, after a great deal of discrimination and rejection in the workplace, employment. He is now in a senior position in the Botswana government.

In the literature review, the author found that in the opinion of analysts stigma usually derives from ignorance. What also became abundantly clear in the course of the interviews was that much of the stigma, discrimination and simply shoddy treatment of PWDs derives from a syndrome of simply not engaging with PWDs on the part of many ‘abled’ people. This leads to inconsiderate, dismissive and rude behaviour towards them. Charles Khaula, Director of the Association of the Physically Disabled in Malawi, described an occasion when he sat in his wheelchair in the street outside a bank in Blantyre for more than 40 minutes because someone had parked in front of the wheelchair ramp. When the driver eventually returned to his car, he could not understand that he had given Khaula cause for complaint, and accused him of being impatient and difficult. This may be a minor incident in itself, but it illustrates the general thoughtlessness and lack of empathy for PWDs shown by the general public.

Living on the extreme margins: disability in rural areas

Another theme that emerged in many of the interviews was the common perception that most PWDs live in rural areas. Although no statistical evidence was put forward, the sheer repetition of this observation by the respondents suggests that it is conventional wisdom within the disability movement in southern Africa. The authors of the DDP report on Disability and HIV and AIDS in Mozambique based their confirmation of this assumption on that country’s 1997 census report.

Eighty percent of disabled people live in rural areas where there is scant medical care, and are constrained in their ability to move far from home to seek care, due to being unable to pay for transport costs, [with] services being predominantly found in cities.

The report did not discuss the reasons for the concentration of PWDs in the country. It seems likely that they are the victims of a kind of natural selection, in terms of which only the most able and ambitious of the rural poor succeed in migrating to the towns and cities, which offer better services and an improved chance of employment. Given all the constraints PWDs face, this ‘escape’ to the cities is very difficult to accomplish. Another reason is a tendency in the parents of disabled children to send them to live with relatives in rural areas (to keep them out of view). This trend was reported by a number of interviewees, and although it describes a reverse migration from the towns to the country regions, the common factors are that the urbanised centres are more prosperous and the rural
hinterland much less so; and that DWPs appear to be concentrated in the latter.

As discussed in Chapter 1, poverty and under-development are also the cause of preventable impairment. Some PWDs are born with a disability that is a direct result of the economic, health and environmental conditions prevailing in poor and remote rural areas. Others develop a disability during their childhood, or even their adulthood, as a consequence of a preventable condition that has not been treated, or an accident. Apart from all the possible causes tendered in the literature review, there are obviously a multitude of conditions that arise owing to the remoteness of the areas in which they live. The DDP report notes: 62

Many disabilities in Mozambique could be prevented by better health care conditions, including greater access to primary health care. A simple example of this is that a number of people needlessly become disabled in Mozambique through snake bites, which can be readily treated if the victim can reach a health post and be given an antidote quickly enough.

The conditions in which PWDs live in underdeveloped areas are seriously deprived. They suffer from immediate hardships like malnutrition and exposure to diseases like malaria and HIV infection, partly because of lack of adequate shelter, clean water and sanitation. They are also cut off from any means of improving their lives by attending school or finding jobs, which traps them in dependency on other people.

Therefore, it is hardly surprising that many PWDs cannot imagine a better life, and are ignorant both of their entitlement to whatever dispensation their governments have made to acknowledge disability rights, and to the range of basic services their governments and NGOs actually provide.

The DPOs that attempt to address the many needs of PWDs find their main constituency in the rural areas, which poses enormous problems for them, since most of these organisations are based in the cities, and have very limited financial and human resources (see chapter 3). For example, they have few (or no) vehicles at their disposal, and most of them are unsuitable for travel on rough terrain. As a result, the work that they do manage to perform in rural areas – hampered as they are by logistical difficulties and the wide geographical spread of the rural areas that they are attempting to cover – often amounts to no more than a drop in the ocean. Only those DPOs that cultivate strong links with broader networks, such as NGO and government initiatives, or lobby these role players to undertake programmes that address disability issues, can be truly effective.

The situation of the National Association of Societies for the Care of the Handicapped (NASCOH), a well-resourced umbrella body that was established in Zimbabwe in 1969, illustrates some of the points raised above. Innocent Magweva of NASCOH described the increasing difficulties the organisation’s members experience when attempting to reach PWDs in the rural areas. The political and economic situation in that country has affected the infrastructure. The dilapidated state of the rural access roads poses a serious problem for their outreach programmes on several fronts. For example, their vehicles constantly break down, and repairing them adds considerable extra cost to their operations. The difficulties NASCOH experiences in maintaining contact with its organisational structures in rural areas were exacerbated by the deterioration of a previously good telecommunication system, but this problem is slowly easing as cell phones start to replace landlines.

Magweva reported that NASCOH staff also experience an increase in political and bureaucratic gatekeeping at village level, with more and more forms of ‘clearance’ required by the police, local politicians, chiefs and district councils. He also indicated that corruption has become so endemic in Zimbabwe that ‘clearance’ is usually synonymous with money changing hands. He added that, as a matter of principle, NASCOH has not stooped to the level of paying for admission. 63

In a country where everything has become so highly politicised (and policed), all outsiders are obviously regarded as suspicious and a threat to the status quo in the rural hinterland. In Zimbabwe, it would now appear that this category also includes organisations for the disabled.

In some cases, adversity has actually led DPOs to adopt ingenious methods of finding ways to...
ride on the back of other initiatives for the rural areas sponsored by government, bigger NGOs or donors. Charles Khuala of the Association of the Physically Disabled in Malawi, an organisation without any funding whatsoever, but representing 43 percent of PWDs in Malawi, reported that members of the Association often organise lifts on government vehicles going to the rural areas, and have been reasonably successful in ensuring that as many district-level decision-making structures as possible appoint a disabled person. These include District Executive Committees and the equivalent substructures of the National AIDS Committee. He also reported that he and his colleagues enjoyed a successful collaboration with the National Initiative of Civic Education (NICE), which has many programmes in rural areas. These include education on human rights, which has made it relatively easy for them to insert a component on disability rights.

The most impressive part of Khuala’s story is that he and a few collaborators (all of them volunteers) have succeeded in persuading district-level governance structures to make disability a mainstream issue. In the process, they have shifted responsibility for addressing the needs and rights of PWDs away from DPOs and towards government and society at large – where it belongs. Although the scale of these efforts could not be ascertained during the interview, the principle is excellent, as it takes disability out of its position of obscurity in a dark corner and starts to ‘normalise’ it, making it part of every day political and governance business (and budgets). This sets an admirable precedent.

Most of the DPO umbrella bodies in southern Africa try to set up their own structures and/or outreach programmes in rural areas. In practice it is nearly impossible to maintain these structures at anywhere near sustainable and effective levels because so little donor or government funding is available. In Namibia, for example, the National Federation of People with Disabilities in Namibia (NFPDN) set up structures in four regions on the strength of a five-year European Union funding agreement. However, as no plans were made for maintaining these structures, at the end of the funding cycle they were unable to sustain their operations, which have now all but collapsed.

The positive exception to the trend described above is the existence of a few well-funded DPOs, like NACOH in Zimbabwe and the Council for the Disabled in Botswana.

Barriers to the enjoyment of basic rights by PWDs

The right to education

Education is, of course, the ultimate portal to better opportunities for PWDs. An adequate education improves the chances of acquiring gainful employment for a disabled person, which in turn opens up a range of possibilities, the most important of which is the chance to escape from poverty and dependency. There are multiple indirect benefits, including improved self-esteem, fuller integration into society, participation in political processes, and better access to information. The latter exposes them to human rights and disability rights organisations and discourses.

In reality, the reverse is a better reflection of the lot of most PWDs in southern Africa. The widespread illiteracy among disabled people that results from lack of access to education has many harmful consequences, not only for the people affected but also for the DPOs and the disability movement in the region. Ultimately, it puts the attainment of equal human and socio-economic rights even further out of reach. In almost every DPO interview in Zambia, the respondents repeatedly emphasised that education is the single most important issue to be addressed if the disability rights dispensation is to improve.

The consequences of a widespread lack of a basic education, whether for PWDs or other people throughout the country, are manifold. For example, the leaders of DPOs frequently mentioned the generally low levels of education of their members and staff, and attributed most of the institutional weaknesses of their organisations to the lack of necessary skills in their employees. This will be a key consideration in the discussion and development of a more active and coherent disability rights movement, and of remedial initiatives in southern Africa in the following chapter.
Education for children with disabilities remains severely constrained across the region, especially in the rural areas, where the path to a basic education is strewn with all kinds of obstacles. Their parents may not be able to afford to send them to school or may believe that disabled children cannot be educated; there are few special needs programmes available with appropriate technology for blind and deaf learners; children in mainstream schools may ostracise them; and, teachers who have not been trained in accommodating the special needs of disabled children may punish or ignore them. There are more difficulties ahead for disabled children who finish school, because very little vocational training is provided for PWDs in southern Africa, and only a small number of PWDs reach the tertiary education level.

Deaf children tend to face even more severe challenges in entering (and remaining in) school, as their communication abilities are very limited and very few teachers are able to teach through the medium of sign language, or to instruct these children in using and understanding it. In most countries in southern Africa, there are simply no educational options beyond the secondary school level for deaf learners. It follows that deaf people have very little access to information, especially in the rural areas where most people rely on the radio for news and entertainment. When deaf people have access to television, the programmes they watch are seldom accompanied by sign language interpretation.68

Although statistics on the numbers of children with disabilities attending, or not attending, school are not readily available in southern African countries, the Mozambique Education Report for the African Decade of Persons with Disabilities69 estimates that about 80 percent of Mozambican children with disabilities do not go to school, even though the country offers free universal education. Angelo Dube, the in-country researcher in Swaziland, made a similar report. He said that because there are so few educational facilities for disabled children and adults, unemployment and poverty rates among adult PWDs remain high. The new constitution of Swaziland, which was adopted in 2006, makes provision for free primary education, but the latter was launched only in 2009, after the government had been forced by a court ruling to do so. In practice, Dube pointed out, many teachers remain untrained on how to relate to and teach children with disabilities. The result is that most disabled children in Swaziland are not benefiting from the free education dispensation.

The many personal accounts recorded in the course of the field research make it clear that it takes great perseverance and commitment from both disabled children and their parents for the former to get into school and stay on to complete their studies. Charles Khuala, Director of the Association of the Physically Disabled in Malawi, is wheelchair-bound as a result of his having contracted polio when he was a baby. His father, who was a schoolteacher in a small mission

“Staying at home to look after a disabled child often means that the mother cannot earn a living.”
village in Malawi, carried him to school in his arms every morning throughout the period he spent at primary school. It was only when he became a boarder at a secondary school and obtained a wheelchair that his father was ‘relieved of this duty’. The wheelchair gave Khuala his first real opportunity to socialise on equal and easy terms with his peers at school. Had it not been for his father’s dedication and commitment, he said, he was sure he would never have been educated.70

Pamela Somses, the National Co-ordinator of the Namibian Association of Children with Disabilities (NACD), related her experience of trying to get her son admitted to schools in Windhoek. The child is physically disabled and wheelchair-bound, and his mother was sent from pillar to post for years.71 Starting at a special school for disabled children, he was later transferred to a mainstream school, which wanted to put him in a special class for slow learners, although his mental abilities are normal. This school later recommended that he change to a special school for ‘backward’ learners. At the latter he passed an assessment test with distinction, which proved that he is not mentally challenged. He was sent back to the mainstream school, which, in the most recent development (at the time of the interview) wanted to send him to a school for the visually impaired.

According to Somses, the problem of providing a disabled child with aids to mental development starts early. There are few day care and pre-school facilities for children with disabilities, which means that these children are denied the benefit of early learning and socialising with other children. This forces the mothers to stay at home to take care of their children. This enforced childminding was a problem also raised by Teresa Makwara of the Zimbabwe Parents of Handicapped Children Association (ZPHCA),72 who said that the majority of the Association’s members are single mothers, some of them illiterate. Staying at home to look after a disabled child often means that the mother cannot earn a living. This is why NACD includes educational and income-generating programmes for parents of disabled children in its parent support services.

Namibia is a country generally well known for its progressive social policies. However, Somses’s bizarre tale of the general ineptitude of the country’s educational authorities in dealing with disabled children illustrates just how difficult it can be for them to acquire an education. The disability movement in Namibia is currently lobbying aggressively for inclusive education for children with disabilities,73 but this example gives one little hope that such a policy could be implemented successfully in the Namibian school system at present. Following the international trend favouring inclusive education systems, other countries in southern Africa, including Swaziland, Mozambique and Zambia, are also discussing or campaigning for this change.

Apart from the practical problems encountered by children with disabilities in existing mainstream schools, there are other major challenges to be met before education systems can become truly accessible to, and inclusive of, PWDs. Inclusion is possible only if there is greater general acceptance of children and adults with disabilities and a better understanding of their equal status in society, as guaranteed by the constitutions of most southern African countries. This would involve awareness-raising and anti-discrimination campaigns aimed at society at large, with the ultimate target a realisation that PWDs are simply part of the diversity of humanity found in every society and country. However, when one looks at the general picture that emerged from the research, one must conclude that fulfilling this ideal will take a gargantuan, dedicated and multi-faceted effort over many years in most southern African countries.

The ratification of the CRPD provides an ideal opportunity (and tool) for governments to initiate such campaigns, which are usually most successful when endorsed by senior politicians, preferably the president or prime minister, as in the case of HIV and AIDS awareness programmes. In some countries, like Namibia and Botswana, Disability Units already exist in the president’s or prime minister’s offices. However, these units were established very recently and contain only one or two staff. These units are similar to HIV and AIDS Units in presidential or mayoral offices (at local government level). Both types of unit are well positioned to create awareness of HIV and AIDS and to add impetus
to the process of mainstreaming. However, they normally consist of a single staff member, who generally lacks the seniority and political clout to set these complicated processes in motion.

The same seems to apply in the Disability Units. The senior politicians in whose offices these units are housed are often too busy to provide the necessary support to the units, so that making disability a mainstream concern across all government departments seems very far from being realised. Few officials understand or know how to implement disability rights. However, claims were made in both Botswana and Namibia that their disability movements had ‘the direct ear of the President’, so perhaps good decisions and practices will flow from these new Disability Units and their interaction with senior politicians and government officials. In Namibia, all government departments have been allocated budgets for those components of their work that address disability, but these budgets are reportedly never spent. In response to pressure from the disability movement in Zambia, focal people representing the interests of the disabled have been appointed in all government departments. However, they were widely reported by the DPOs to have little understanding of disability issues, and were therefore not deemed to be very effective as yet.

A number of fundamental and specific changes are required in the education sectors of countries that propose to adopt inclusive education systems. These changes need to start with practical and structural measures, like improving the physical means of access to school buildings and facilities in order to accommodate the needs of children with varying kinds of mobility impairment. There is also an acute need, according to interviewees in a number of southern African countries, for teachers to receive specialised training in instructing and assisting children with different disabilities and (therefore) different educational needs.

Apart from the addition of new courses on special needs education to teacher training curricula, it is also clearly necessary to upgrade the skills (and general awareness) of teachers already working in mainstream schools as regards disabled children, whether through special courses and/or regular in-service training. Courses in sign language were also identified as absolutely crucial by DPOs representing deaf people (including MANAD in Malawi and Deaf Vision in Zambia), if deaf children are ever to be given meaningful access to education. In addition, changing the attitudes of teachers towards disabled children will go a long way towards making schools more accommodating of their needs.

A theme constantly raised in interviews with many DPO leaders and disability activists was the need to move from generalities to specifics, if the various causes of PWDs are to be truly advanced. According to Willem Bekker, a blind person who is a veteran of disability issues and disability-related politics in Namibia, ‘everybody is very big on the big issues’, but what is really needed is more substance in the form of greater attention to detail, specific solutions for particular challenges and, most crucially, the use of specialist and technical skills, interventions and devices. He spoke at length (and in great technical detail) about the importance to disabled children and adults of access to computers and the latest software (dependent on the specific needs related to different disabilities). He extolled the enormous difference the acquisition of computer skills can make to the lives of PWDs, as they open up endless new possibilities and opportunities. Most importantly, they provide a gateway to knowledge and information – the very commodities that DPOs have reported as seriously lacking in much of the disabled community in southern Africa. Therefore, computers can help enormously in counter-acting the effects of marginalisation on PWDs and opening up better prospects for them.

The preceding paragraphs show that there is a pressing need for the authorities in each country to move away from very generalised talk about education and the rights of the disabled to much more concrete, specific and innovative solutions to the problems PDWs face. But these can only work if they also ensure that sufficient funding is made available to give these programmes material form. Devising projects that are appropriate will also require much more consultation with people and children living with different kinds and degrees of disability and with their organisations, to gain a deeper insight into their needs and
aspirations. The SINTEF report on Mozambique suggests more generally that, ‘disabled people who are qualified can help with the development of new ideas’.77

The right to employment

*Here in Zambia, professional jobs for blind people are only begging and teaching. If you don’t go to school, you will go straight to the streets.*

(Rule et al., 2008)78

As discussed at length in the previous section, access to formal employment is largely dependent on the level of education attained by an individual. Although this question was not raised in the questionnaire, the respondents made it clear while discussing other issues that obtaining formal employment remains extremely difficult, or even impossible, for PWDs. The reasons are not only their generally poor levels of education but also the high unemployment rates in most southern African countries. In an adverse economic climate, employers can choose new staff from a large labour pool. Unless they are forced to give preference to PWDs by affirmative action policies and/or quotas, or receive tax rebates or other economic incentives to do so, employers have little desire to employ PWDs. Most are likely to be deterred by the idea of spending more on appropriate accommodation and health care for a disabled employee than they would on one who is not.

Solving this problem entails returning to the question of the lack of educational qualifications common to most PWDs. According to Gerson Mutendere of NFPDN, the DPO umbrella body in Namibia, even in that country, where there are affirmative action policies to help advance the interests of PWDs, most of the Federation’s members cannot meet the educational requirements set out in job advertisements. This means that although companies that are anxious to fulfil their affirmative action commitments often send the NFPDN advertisements and ask for assistance in identifying suitable candidates, his organisation is usually unable to do so.

The lack of job opportunities for PWDs in Mozambique was stressed in almost every interview held with DPO representatives in that country. Macario Dubalelane of the Ministry of Women and Social Action reported that ‘even if PWDs are well educated, the employers are still not prepared to accept them.’79 This situation reflects the prevalence of discrimination against PWDs, a topic that was raised in most of the interviews held in Mozambique. The well-known result of the inability of PWDs to find jobs is a perpetuation of poverty. In the words of Josephine Chanda of the Zambia Association of Women with Disabilities: “Economically we are poor because of the lack of, or poor, education. We live at the mercy of people and the poverty trickles down to our children.”80

The right to health care

Earlier in this chapter, mention was made of the ignorance of many PWDs concerning services and campaigns that could be helpful to them. Lits’ipiso Mathlosa, the in-country researcher in Lesotho, found that limited information about, and access to, health services was a serious problem for PWDs in her country. She added that these problems existed at various levels of the health system.81

The responses from the DPOs reveal a lack of serious and concerted efforts to raise awareness on health issues among PWDs. The majority of them do not have basic information about health issues, including HIV and AIDS. There are limited attempts by the government and the communities to include them during the dissemination of this important information. As a result, PWDs do not know about various services that are available for them to address their health needs. In addition, PWDs do not have access to appropriate health treatment and care. Health centres do not have suitable infrastructure, necessary expertise and equipment to cater for the health needs of various disabilities. For instance, many health centres in the country are inaccessible to people who are physically disabled.

Similar problems were reported in most of the other countries in the research sample.

As was discussed at length in Chapter 1, the general public in the nine countries, together with
government officials and the staff of mainstream NGOs working in the field of HIV and AIDS in southern Africa, are almost completely ignorant of the acute vulnerability of PWDs to HIV infection. The DPO interviewees, on the other hand, were well acquainted with the phenomenon. Some of the veteran disability activists of southern Africa, including Alexander Phiri of SAFOD, Charles Khuala of the Association of the Physically Disabled in Malawi and Phillimon Simwaba of the Disability & HIV and AIDS Trust (DHAT), said that HIV and AIDS have been affecting PWDs since the mid-1980s. It would appear that the prevalence of HIV and AIDS among the disabled has been recognised as a cause for concern in the disability movement of southern Africa for more than two decades – in stark contrast to the ‘discovery’ of the connection, much more recently, by researchers. The only country in which this issue seems not have been considered very widely by DPOs is Angola, where most of the respondents (with the exception of LARDEF and some of the donor organisations) denied that AIDS was a problem for PWDs.

Although most respondents did not dwell on the complicated causal linkages between disability, poverty, and HIV and AIDS, many mentioned the high incidence of physical and sexual abuse and rape of children and adults with disabilities, especially girls and women. References were made repeatedly by respondents in each of the countries to a widespread myth that sex with a disabled person will cure AIDS. This is presumably an even more twisted version of the so-called ‘virgin cure’, which is based on the common misconception that PWDs are not sexually active, and must therefore be virgins. The interviewees also suggested that PWDs are, in many ways, easy targets for rapists, because a mobility-impaired person cannot run away, a person who is deaf and dumb cannot scream, a blind person cannot identify the rapist, and so on. For all of these and many other reasons (like the shame felt by the victim and the obstacles to obtaining medical assistance) rapes are seldom reported, so it is extremely difficult for DPOs and lawyers to take cases concerning the rape of a disabled woman or girl to court.

Only one case of litigation on behalf of a disabled person was reported during the research interviews. This concerned a charge of discrimination laid against a health worker in one of the country’s provinces brought by the Zambia Federation of Disability Organisations (ZAFOD), an umbrella body. The worker in question had verbally abused a disabled person and refused to provide treatment for HIV and AIDS. As a result of ZAFOD’s action, the health worker was subsequently dismissed. The case was discovered during an audit of health institutions undertaken by ZAFOD during 2008, with the intention of focusing mainly on the accessibility of these institutions. In the course of the audit, those involved also discovered how seriously the HIV and AIDS situation has begun to affect PWDs.

As indicated in the literature review, the complex and disastrous interaction of disability and HIV and AIDS is an area that requires urgent intervention from all the role players concerned with the promotion of disability issues and rights. These cover PWDs, donors and those members of DPOs, governments, and mainstream NGOs that are active in the HIV and AIDS field in southern Africa. During the fieldwork, the researcher found that the only organisation that currently focuses on this complicated field is the Disability, HIV and AIDS Trust (DHAT), which is based in Botswana and works in all of the nine southern African countries that form part of this study. This organisation would be able to provide
valuable insights and guidelines to inform any new advocacy campaigns seeking to prioritise the particular risk of HIV infection faced by PWDs.

The right to physical access and mobility

Another theme that was frequently raised by interviewees was the difficulties faced by PWDs – especially those with mobility impairment – in entering and moving around buildings. These include the whole array of public buildings that everybody has to visit in the course of day-to-day life: basic health care facilities, schools, government buildings, universities, banks, shops, hotels and many more. The many impediments to the mobility of PWDs caused by the lack of public transport that makes provision for their needs were also frequently mentioned. Interviewees from DPOs in Mozambique stressed these difficulties when they claimed that it was impossible for a person in a wheelchair to board a public transport bus or a mini-bus taxi, and that no alternatives were available.

Especially in Mozambique, Angola and Zimbabwe, many respondents described the difficulty and expense involved in obtaining assistive devices and technical aids – a situation that seriously impedes the mobility, personal autonomy and human dignity of PWDs. The lack of such aids places enormous extra burdens on the family members who help to take care of PWDs. Teresa Makwara, of the Zimbabwe Parents of Handicapped Children (ZPHCA), described the many deleterious effects of the political and economic situation in that country on children with disabilities and their parents. She also told the story of her 23-year-old son (a sufferer from cerebral palsy), who currently has no wheelchair and therefore has to crawl around the house. His old wheelchair has fallen apart, and a new one costs US$300, which her family cannot afford. (The average monthly salary in Zimbabwe is about US$200.)

This is just one more example of how crucial it is for governments to start following up their grand promises with deeds. What are needed are dedicated resources and practical measures to provide essential services that are relevant to the specific needs of people with different kinds of disability. The SINTEF study in Mozambique points to the difference that improved accessibility to public buildings and transport, and the right assistive devices can make: 87

Accessibility is thus an important issue for individuals with disabilities in Mozambique and represents an important obstacle for active participation at home or outside the home for many individuals. Accessibility problems either exclude individuals from participating or make them dependent on assistance from others. Availability of technical devices is also highly important for reducing activity limitations and restrictions in social participation – such equipment thus has a huge potential in breaking the disability – poverty cycle.

Conclusion and discussion

Although this chapter may seem to be overloaded with detail, it presents a series of glimpses into the lives of PWDs in southern Africa, especially those living in remote rural areas. These are intended to convey to the reader a more immediate sense of the day-to-day struggle most of them endure, because the brutal realities they face cannot be captured by reading reports and conducting interviews with legal academics and DPO leaders.

The key areas of concern that are used as the themes of this chapter are based on information elicited from respondents in the nine countries. Much of this information appears to show a remarkably consistent scenario across southern Africa, even though there are obviously differences in the political and socio-economic scenarios of these countries, and in the various levels of political will, implementation capability and preparedness to allocate public resources to the promotion of disability rights and issues shown by their governments. At present, there is one overriding similarity: the general living conditions and quality of life of PWDs appear to be dismal throughout the region.

The research findings underscore the claim that disability is a cross-cutting development issue, and as such should be made a central theme in all proposed plans, policy recommendations, programmes and (in terms of this particular report) academic curricula relating to disability.
rights. Human rights lawyers, legal academics and students entering the relatively new field of disability law and disability rights for the first time will need to acquire an understanding of the severe socio-economic and socio-cultural constraints faced by PWDs, and the obstructions these represent to the realisation of their rights.

In some countries in southern Africa constitutional reviews are under way. Many others have relatively new and progressive constitutions (in the wake of the ‘wave of democratisation’ in the region during the 1990s), but not all of them include socio-economic rights. And where they do exist, they are not always legally enforceable. This is another area meriting inclusion in the course on disability rights and law proposed by OSISA.

As the next chapters will illustrate, even the best-written policy documents and most progressive laws will gather dust if the groups that are intended to benefit – in this case the disabled – do not agitate constantly to ensure their implementation. Throughout history the actualisation of rights and entitlements has seldom followed hard upon the heels of the decision to grant them. Instead, they have to be claimed and fought for. However, the destructive effects of the conditions under which most PWDs live make it almost impossible for them to act on their own behalf, and the DPOs that represent them are currently unable to find the capacity, funds and energy needed to keep lobbying on behalf of their rights. The constraints that DPOs experience in most southern African countries will be the subject of the next chapter.

Because PWDs are among the most vulnerable members of any society, they are in need of certain forms of legal and social protection that assist them to take up their rightful and equal place in society. While recognising the merit of self-representation and the efforts of DPOs to advance the claims of PWDs, one must conclude that the responsibility for providing and formalising these protective measures rests on society at large. In support of this idea, Nsimba Paxe, a member of a government body in Angola, made a very valuable observation concerning the general practice of regarding disability issues and DPOs as a ‘separate sector’, and expecting PWDs and their organisations to be doing all the work of advocacy and awareness-raising on their own:

With respect to difficulties or not of people with disabilities to organise themselves in Angola, I do not like these procedures and strategies that create islands. The idea appears to me to be that we create islands as though we were a village of people with disabilities. This should not be so.

In some countries in southern Africa, legal and social protection mechanisms for PWDs are almost non-existent; in others (like Zimbabwe), they were established, but have been eroded by wars or political and economic mismanagement. In many cases, the long-term effects of structural adjustment programmes and the corresponding neo-liberal economic and governance policies prescribed by the international financial institutions have pruned back social spending and the funding of protection mechanisms. As noted in Chapter 1, poverty, inequality and unemployment have increased in almost every country in the developing world in which these policies were implemented. If PWDs are indeed the poorest and most vulnerable members of society, as is evident throughout southern Africa, they will have been worst affected by the SAPs. Therefore, one could argue that a large part of the blame for the dire socio-economic circumstances in which the majority of PWDs find themselves can be laid at the door of policy choices and budget priorities imposed on their governments over the last two or three decades. In most of the countries that adopted these policies, the recipient governments were allowed little room to manoeuvre independently, especially in terms of fulfilling their social-economic obligations towards their citizens.

Governments all over the world are tied into an ever-growing number of international financial and trade agreements, which generally set very clear parameters in terms of economic policy and budget priorities. Many governments in southern Africa are also bound by increasingly complicated bilateral and multilateral donor agreements, which tend to be programme- or sector-specific and are often very technical in nature, which reduces the scope of their political
“DPOs in southern Africa should work to improve their regional and international networking skills, so that they can be informed of all impending international developments and agreements related to their areas of concern.”

This leads to the question – what does the ‘down’ side of globalisation mean for the situation of PWDs in southern Africa? It appears that the demands made on African governments by international and regional treaties add to the difficulties experienced by the various disability movements, which include a widespread move by donors away from disability issues. The high levels of despondency reported in the ranks of DPOs almost everywhere in the region are justified by the fact that despite decades of effort on their part, the lives of PWDs have generally not improved much, but have, to the contrary, often stagnated or deteriorated. Therefore, DPOs might have their own internal problems, as we shall see in the next chapter, but their struggles also reflect what is happening on the world stage.

Faced with the exigencies of globalisation and geopolitics, DPOs might regard the present awareness of the CRPD as offering an opportunity to shift at least some of their focus and political energy towards advocacy and lobbying on the international front. This would require a two-pronged approach. Firstly, DPOs would need to redouble their efforts to lobby their own governments to ensure the inclusion and mainstreaming of disability issues in all international and donor agreements, national development plans and service delivery programmes. These would include poverty reduction and job creation initiatives. Secondly, DPOs in southern Africa should work to improve their regional and international networking skills, so that they can be informed of all impending international developments and agreements related to their areas of concern. In this way, they would be able to act in concert with international DPOs where international solidarity is likely to make a difference to the outcome.

Once awareness of the necessity to insert disability issues into all standard international development discourses, agreements and undertakings (for example the Millennium Development Goals) has been sufficiently raised at the international level, good practice will follow. Eventually it will begin to trickle down to national governments and finally to reach disabled people on the ground. In order to accomplish this, the first objective of DPOs should be to alter the mindset of decision-makers so that they stop perceiving disability as a separate (and marginal) matter and start recognising it a central and cross-cutting development and human rights issue. Doing so in the present climate would require not only a dramatic shift in the focus of the DPOs themselves, but a great deal of support to strengthen the power of these organisations to influence decision-makers in government.

Unfortunately, as we shall see in the next chapter, the general capacity of most DPOs in southern Africa to engage in advocacy and lobbying campaigns of this nature is currently severely constrained.
Disabled people’s organisations in southern Africa: A state of disrepair?

“The disability movement in southern Africa was variously described as weak, lukewarm, old, tired, stagnating, in a poor state, insular, unaccountable and ineffective.”

Introduction

The findings discussed in this chapter are grounded in the responses to the questionnaire of the leaders and staff of DPOs in the nine countries in which the research was conducted, supplemented by analyses obtained from international DPOs active in the region. The information gained from interviews was also compared with that contained in a number of seminal research reports on disability in southern Africa. The overriding impression was that the present state of DPOs leaves much to be desired. During the interviews, the disability movement in southern Africa, both at country and regional level, was variously described as weak, lukewarm, old, tired, stagnating, in a poor state, insular, unaccountable and ineffective. Some of these adjectives were also applied to the individual leaders of DPOs and the disability movements. Many references were made to the prevalence of a ‘founder syndrome’ – when the leaders of certain DPOs are no longer democratically elected but stay in office indefinitely. Some leaders were accused of seeking self-enrichment, following poor governance practices, and tending to refuse to delegate power to other office bearers and members. Perhaps the most disturbing item of information was that in general the public profile of disability issues and organisations in most countries in the region remains very low.

The interviews made it clear that most DPOs experience an array of serious capacity and financial constraints and internal problems. All of these hamper their effectiveness in securing donor funding, influencing government decisions and processes, managing their own projects and programmes, and bringing about positive changes in the public perception of PWDs. In other words, whatever the causes of these weaknesses, they undermine the paramount aim of DPOs, which is to help PWDS to enjoy the full spectrum of human and socio-economic rights, as envisaged in the CRPD.
Donor funding: ebbing away?

Donors are not looking at us. We survive by begging.

(Teresa Makwara, ZPHCA, Zimbabwe) 92

Most of the representatives of DPOs who were interviewed reported that their organisations had no, or very little, donor funding, and that they lacked alternative financial support from their own governments. Only in Botswana93 does the administration grant some funding to the DPO umbrella body, the Botswana Council for the Disabled (BCD). The disability sector in southern Africa appears to have all but lost its support from international donors. In the few cases where organisations are still receiving funding, it is usually on a very short-term and insecure basis, and tends to be allocated to specific projects or even components of projects, with no allowance made for operational costs. In certain interviews, the respondents hinted that some of the donors had withdrawn from the DPO concerned because of instances or perceptions of general managerial ineptitude, financial mismanagement and project failures. Bheki Jele of the Federation of Organisations of Disabled Persons in Swaziland (FODSWA), the DPO umbrella body in Swaziland, offered the following explanation: “There is no support from donor agencies, as most believe DPOs have no experience to manage finances and implement programmes.”94

Case study: Zimbabwe

The generally negative attitude of donors is particularly worrying in Zimbabwe, which has lost most of its international aid subvention during its years of political turmoil. Farai Makuta, Executive Director of the National Association of Societies for the Handicapped (NASCOH) in Zimbabwe, which is fortunate enough to be well funded and to employ highly skilled staff, reported that the majority of DPOs throughout the country are chronically short of funding. Most are either ‘unfunded or grossly under-funded’.95 The loss of funding from donors outside the country has added an enormous extra burden to a DPO sector already reeling under the many deprivations the political and economic situation has brought upon it. However, many of these organisations simply carry on, as there is no one else to look after their members, even if this means ‘surviving by begging’.

PWDs have been very badly affected by the political and economic meltdown in Zimbabwe because it has caused the loss of all forms of social protection (including welfare grants), social services that are essential to their survival (especially health facilities), and special educational programmes. Their few means of making a living have largely disappeared, as many were removed from their settlements in the cities and dumped in remote rural areas during the government’s contentious ‘slum clearing’ programme (Operation Murambatsvina). The drastic drop in income96 combined with food shortages and high food prices have caused extreme suffering for PWDs. Also, the collapse of essential services like water, electricity and sanitation services, although affecting the whole population, is reported to be having an even greater impact on PWDs who cannot, for example, go out and look for water and wood, and tend to be more vulnerable to the infections and diseases that are caused by a lack of clean water and adequate sanitation.

Essential assistive devices and technical aids - some as basic as crutches and wheelchairs - are generally no longer available, which denies physically disabled people mobility and, by extension, a measure of independence. This situation obviously increases the already heavy burden on caregivers and the families of PWDs. The lack, or prohibitive cost, of life-sustaining medication needed by some PWDs (such as people with spinal cord injuries) was also reported to be causing unnecessary suffering and preventable deaths.97 According to most of the DPO leaders interviewed in Zimbabwe, many PWDs, including children with disabilities and their caregivers, are starving, and mortality rates among PWDs have increased significantly.
A prominent disability activist described the cumulative effects of the situation in Zimbabwe on PWDs as ‘amounting to human rights abuse’. There were also widespread reports that the political violence accompanying the elections of 2008 swelled the number of disabled people in Zimbabwe, because some of the vicious beatings had led to permanent disabilment. Even more alarmingly, there are reports of militias having cut off of the hands and arms of voters whom they suspected of having voted for the ‘wrong’ political party.

Although there are a handful of DPOs across southern Africa that continue to command relatively large amounts of funding from major donors like the UK’s Department for International Development (DFID) and the United States Agency for International Development (USAID), the majority seem to largely rely on a handful of smaller aid organisations that remain involved in the disability sector in southern Africa. These are mostly DPOs from northern countries that tend to work within specific sectors, for example Scottish and Finnish associations for the deaf. In many cases, DPOs in southern Africa tend to rely on a single smaller donor, which makes them extremely vulnerable to changes in the donor’s goals, criteria and financial circumstances. Their dependency levels are therefore high, and there is generally little evidence of sustainability planning. In many cases (but not all), this situation is caused by weaknesses in a number of areas, as indicated by Audrey Relandeau of Handicap International in Mozambique: “DPOs are still too dependent on some partners. They have to improve their partnership and fundraising strategies, but for that they first need to improve their organisational, technical and political capacities.”

This is easier said than done, as the general education and skills levels of most of the people working in DPOs tend to be low, and these deficiencies cannot be remedied in the short term. Although donor funding to DPOs in southern Africa deserves closer scrutiny, it appears that where financial support is still available to DPOs it is conditional on the demonstration that the organisation concerned meets certain basic levels of competence. At a minimum, this would include the ability to undertake the management of projects and the costs involved, and to provide the donor with the necessary audited reports. DPOs also need to possess up-to-date knowledge of how proposals and reports should be written, and employees or volunteers who have the skills to produce such documents. The problem is that this capacity simply does not exist in many DPOs – a situation summed up in the brutally honest comment of Josephine Chanda of the Zambia Association of Women with Disabilities (ZAWD): “We have no knowledge of how to write business proposals nor the ability to pay others to write them for us.”

However, this is not always the case, as the situations and organisational capacities of DPOs vary widely. For example, the DPO umbrella body in Zambia, ZAFOD (of which ZAWD is an affiliate), reported that they have an expert fundraising committee that writes their proposals, and are supported by an adequate number and variety of donors as a result. The difference in situation between ZAWD and ZAFOD, both Zambian bodies, illustrates the wide discrepancy in capacity and funding levels between umbrella bodies and their affiliates. During many other interviews with DPOs in southern Africa, respondents reported the enormous effort and hours spent by DPO managers and staff in writing funding proposals, often in extremely difficult circumstances, only to find that they led nowhere. Many interviewees also complained that the funders to whom they had sent their proposals seldom even sent them a letter of acknowledgement.

During an interview with MANAD in Malawi, the executive director, Bison Khimenya, said that his organisation had submitted between 10–20 proposals during the previous year, to no avail. Despite the shortage of sustainable funding, MANAD had undertaken an extensive review of its strategic planning and budgeting, and become involved in a range of important projects and activities. These included the development of a standardised curriculum for sign language training, and baseline surveys of the living conditions, needs and problems of the deaf people resident in eight of the country’s districts. MANAD also manages other projects in the
general areas of empowerment, capacity-building and training for deaf people in Malawi, which teach such subjects as leadership, advocacy and lobbying skills. Therefore, the organisation is clearly not lacking in abilities and good ideas, but nevertheless has failed to attract the funding it requires. This raises the broad question: Are disability issues and rights a priority in the international donor environment? This issue needs to be investigated further.

In practice, most DPOs have arrived at what amounts to a Catch-22 situation: without the necessary skills and organisational competence, they cannot obtain donor funding; and without any funding whatsoever, it is very difficult for them to build up the required expertise in staff members, and, having done so, to hold onto them. For example, it is almost impossible to keep staff if you cannot pay their salaries. Another obvious result when an organisation has no funds is that it cannot maintain an office, use computers and telephones or afford any of the other means of creating and maintaining a visible and contactable presence. It cannot hold meetings, write proposals and reports, network and so forth. No funding also means no money for transport. During the fieldwork, the researchers frequently encountered evidence of all of these. The smaller, sectoral DPOs were mostly to be found in one or two dilapidated rooms in a house or somebody else’s offices. Many of them also reported that they constantly had to move from one such room to another. Bison Khimenya of MANAD said, “It’s like living in a tent.”

In some cases well-funded umbrella bodies do some sub-granting to the smaller DPOs, but there is widespread dissatisfaction in the ranks of the latter over the concentration of funding at the higher level. When asked about their relationship with their umbrella bodies, the standard answer of respondents from the sectoral DPOs was almost always, ‘It is very positive, except when there are resources involved’.

**Glaring gaps and great distances**

The noticeable differentiations in the fortunes of umbrella bodies and those of their affiliates are replicated further down the line by the huge gaps in communication that exist between the DPO sector and PWDs on the ground. Respondents contended that very little DPO activity and even less of the funding reached ordinary PWDs. These claims have been borne out by the SINTEF report on the living conditions of PWDs in Mozambique, which found that only about a quarter (26%) of PWDs were actually aware of the existence of DPOs. Of this small group, less than half (44%) indicated that they were members of a DPO.

According to Phillimon Simwaba and Robert Sinyisa of DHAT, these wide discrepancies are also evident between national and regional discourses about disability and the lived experience of PWDs, so that policy-makers are usually uninformed about the situation at grassroots level. This is another reminder of the need to question the prevailing tendency for the authorities to engage in too much generalised talk about ‘the big issues’, policies and structures, whilst overlooking or being unaware of the core issues. Simwaba and Sinyisa also stressed the need for ‘a voice on the ground’ to remind governments of the situation of the most needy, and to work towards a synthesis between discourse and deeds.
It appears that DPOs, in their current state of general weakness and under-funding, cannot carry out this task on their own, which raises the question: Who else should or could? This should be discussed amongst the key role-players in the disability sector in southern Africa. Apart from the obvious suggestion, which is that DPOs should be provided with increased financial support, training to improve their skills and managerial competencies, and help to overcome internal fragmentation, there is another option. More research should be undertaken of the kind conducted by SINTEF in Namibia and Zimbabwe (both during 2001–2002), Malawi (2003–2004), Zambia (2005–2006) and more recently Mozambique (2009). According to Bheki Jele of FODSWA in Swaziland, the latest SINTEF study is under way in that country.

These studies are based on national household surveys. The aim of the researchers is to ‘establish the first generation of data on the situation of people with disabilities in low-income contexts’ in the region. SINTEF is a reputable and independent Norwegian research company, and the findings it publishes and the general trends it identifies are well supported statistically and therefore difficult to dispute. When a country-specific report like that appears on the desks of senior politicians and government officials, they find it much more difficult to deny their responsibility to act on the information it contains. When it comes into the hands of DPOs, especially their co-ordinating bodies, it provides a very powerful basis for advocacy, not only for disability rights per se, but for addressing the dire socio-economic conditions experienced by the majority of PWDs in southern Africa. As indicated in the previous chapter, it became abundantly clear during the course of this research that there is little chance that, given the deprivation of their daily lives, PWDs will act on their own to claim their rights.

**Low levels of education, skills and capacity**

Academic education of PWDs is the way forward if their rights are to be adequately taken into account and to enable them to participate in these processes. Education is important as one of the steps to be taken in order for PWDs themselves to become true defenders of their rights and to do so effectively. They have to propose to the State what they need.

(Filipe Faria, Angola National Association for the Nearsighted and the Blind)

It is important to recognise that the widely-reported structural weaknesses and generally low levels of capacity of most DPOs are an institutional manifestation of the poor socio-economic conditions and marginalisation experienced by PWDs in the region. Many of the DPOs draw their staff and members almost exclusively from PWDs. The explanation most commonly offered for the many shortcomings of most DPOs was the generally low levels of education of their staff and members. The many barriers to obtaining even a basic education faced by children with disabilities have already been described at length. It is small wonder, then, that the multiple consequences of this situation will spill over into the organisations for PWDs and affect every aspect of their work. This problem was particularly strongly emphasised during interviews in Zambia. Mr Wamundila, Programme Manager of ZAFOD, described the situation as follows:

*Most of our organisations and members have low education levels and therefore have little or no knowledge or skills of management, budgeting, and other capacities. Our main challenges have (therefore) been funding and developing our affiliates in terms of management skills.*

Apart from mentioning managerial and fundraising shortcomings, some interviewees also commented on the limited capacity of most DPOs, including some of the umbrella bodies in the region, to undertake really effective advocacy and lobbying campaigns. In addition, with the exception of a handful of better-resourced organisations, the DPOs consulted reported that they had no one in their organisations who was qualified to undertake research. The difficulties DPOs face have already been described, but there are also some self-created drawbacks that hamper their attempts at advocacy. Some independent observers noted that DPOs tend to cling to well-worn strategies that are unrealistic and out-of-step with contemporary political,
policy and media thinking. They also claimed that the strategies used were incoherent and inflexible.

With one or two exceptions, the researcher also found that awareness of the potential use of strategic litigation as an advocacy and awareness-raising tool was almost non-existent amongst DPOs in the region, and that they had little knowledge of legal matters in general. The exceptions apply to cases in which some of the umbrella bodies (most notably ZAFOD in Zambia) have achieved major victories. DPOs in most of the nine countries appeared to have a limited practical grasp of mainstreaming, and of the skills and strategies required to put pressure on their governments to bring this about. Two countries, Angola and Zambia, are special cases in that their bigger DPOs demonstrated a solid understanding of mainstreaming and appear to be involved in a constant discourse with their governments regarding the responsibilities of the latter towards their disabled citizens. In some of the other countries, certain DPOs (like NFPDN in Namibia) claimed to have a direct link with the president or (in the case of FAMOD in Mozambique) asserted that they were working closely with the relevant government department.

Turning from the weaknesses of the DPOs to a closer consideration of the people who work for them, the researcher must acknowledge that it is a relatively small number of PWDs who manage to overcome the obstacles to obtaining a primary, a secondary and, in very few instances, a tertiary education. It follows that there is a very limited supply of reasonably qualified PWDs in most countries in the region, and it is from these that DPOs normally draw their leaders, managers, staff members and volunteers. DPOs also have to compete with other prospective employers in the public and private sectors because employment or voluntary involvement in DPOs is not always the first choice of job for the average disabled person. It often appears to be the case that the reasons that a PWD works in a DPO (usually one connected with his or her specific type of disability) are either that the PWD feels very strongly about the advancement of a certain set of issues and rights, or that no other form of employment is available.

The majority of people working in DPOs are disabled themselves or have some direct relationship with disability in their families. Women who run organisations for children with disabilities are usually mothers of disabled children themselves. These organisations, which are usually set up with very little in the way of resources and operate largely on a volunteer basis, are notable for their high level of commitment and perseverance against all odds. In cases where abled and disabled people work together in DPOs, the staff members frequently hinted in the interviews at some degree of tension between them. However, respondents from the more prosperous organisations, including NASCOH in Zimbabwe and DHAT (based in Botswana), commented that a degree of

“DPOs tend to cling to well-worn strategies that are unrealistic and out-of-step with contemporary political, policy and media thinking.”
friction was manageable if their organisations profited from both a diversity of talents and the contribution these made to the general performance of staff.

As has been noted, DPOs find it difficult to retain skilled personnel, as volunteers and employees tend to leave if they are offered better-paid (or simply paid) employment elsewhere. This trend was seen as pervasive at every level, from the small sectoral DPOs to the regional co-ordinating bodies like SAFOD. Because so few of those working in the DPO sector have highly-developed competencies, any new and more prominent position (for example in the new Disability Units being established in presidential or prime ministerial offices) is likely to attract them. Although these roles are potentially very useful in raising the visibility and profile of PWDs and DPOs, they also represent a constant drain on the supply of well-qualified people available to the latter.

This situation inevitably leads to some conflict of interest between the staff of DPOs and the new government disability structures or positions, and between those working for different organisations. This would seem to arise from a kind of familial rivalry in a small group of people devoted to the same cause. They all know each other very well, serve on the same boards and bodies (including each others’), go to the same meetings and conferences, and compete for the same funding sources, which make them to all intents and purposes – both players and referees. Audrey Relandeau, of Handicap International in Mozambique referred to it as ‘the problem of associactivism’. This undercurrent of competition tends to divide the staff of DPOs and prevents them from speaking with a united voice.

There are other divisions created by the different fields in which DPOs work, because it is routine practice for each to focus on a specific disability and sector. In almost every country, one finds a standard set of organisations that serve the visually impaired, hearing impaired, physically disabled, and (to a lesser degree) mentally disabled. There are also organisations for women with disabilities, young people with disabilities, and parents of children with disabilities. In Angola and Mozambique, one finds organisations for ex-combatants who became disabled during the prolonged wars in those countries. Despite the potential for conflict and competition for funding inherent in this kind of arrangement, the very different needs and kinds of help required by PWDs according to their specific disability have made this kind of fragmentation necessary. Some of the interviewees reported that intersectoral splits occasionally occurred because of disagreements (usually about resources), resulting in as many as three or four DPOs in the same sector. Another of the negative consequences is that resources (including personnel) become very thinly spread. As Henry Chanda and Justin Bakali of the Zambian office of the international DPO Action on Development and Disability (ADD) reported, this also ‘makes it difficult to gauge the impact of activities undertaken’.

As a result of all the factors described above, DPOs often seem to have a limited understanding of the bigger picture, as far as the relationship between disability, development, gender and HIV and AIDS is concerned. They also lack knowledge of the content and importance of the CRPD as the ultimate advocacy tool for DPOs. This is probably the reason for the relatively low
profile that disability issues and organisations have in most countries in the region. Public awareness of the work of DPOs is said to be low, and media coverage of events organised by them tended to depend on whether important politicians attended. Many interviewees reported that disability issues were seldom mentioned in political speeches and election campaigns. The explanation offered by respondents was that DPOs do not participate as fully as they should in national debates, fora, co-ordinating bodies and committees in most countries in the sample.

In Zambia, for example, the board of the Zambia Agency for Persons with Disabilities (ZAPD), a statutory body, consists of eight representatives from DPOs and eight from government, but according to the programme manager of ZAFOD, “the presence of the DPOs is not so effective, owing to the low levels of education of persons in the affiliate bodies.” The situation was perceived to be even worse with regards to women with disabilities. Josephine Chanda of the Zambia Association of Women with Disabilities (ZAWD) confirmed this perception: “Enlightenment among women with disabilities is low as a result of low education, thereby making participation in national issues very poor.”

### Strategic litigation

Most of the DPOs consulted during the course of the research appeared to have little awareness of the effectiveness of strategic litigation as a tool for advancing and enforcing disability rights. This situation is attributable partly to the dearth of skilled people in DPOs, partly a reflection of limited legal knowledge in most DPOs, and partly to the relatively recent emergence of disability rights law. A representative of ZAFOD in Zambia described the measures the organisation had to take when they embarked on several cases of strategic litigation:

> We have engaged a private law firm which is working with us on this. However, lawyers are not very conversant with disability rights law and the courts have also not dealt with these kinds of cases yet. Our approach has therefore been to bring in a disability lawyer from Disability Law Management Associates and we are also working with Blue Law in America.

Staff of FODSWA, the DPO umbrella body in Swaziland, reported that they were attempting to sensitise lawyers to the concept of disability rights and to make them aware of the provisions of the Convention. However, according to Angelo Dube, the in-country researcher for Swaziland and a law lecturer, these attempts are “likely to suffer from a lack of buy-in by the intended partners, who largely view themselves as income-generating entities and are highly likely to shy away from pro bono work or work that they regard as not that profitable.” He also mentioned another compelling reason for lawyers to keep their distance from disability issues: “In a political and legal climate like Swaziland’s, where fundamental rights have been demonised by the state, many lawyers prefer to remain politically neutral, and advocating for disability rights might affect their neutrality.”

This motivation is likely to apply in some of the other countries in the region as well.

ZAFOD is unique in the region, as it has used strategic litigation very successfully as part of its Advancing Disability Equality Project (ADEPT). The cases it has brought include:

- After conducting an accessibility audit of various buildings around the country, ZAFOD instituted...
action against five city councils and other
respondents, including farmers, banks and, most
ironically, the statutory disability body – the
Zambia Agency for Persons with Disabilities
(ZAPD). The charge against the councils is for
approving buildings with inadequate physical
accessibility, while against the others it is for
constructing such buildings;
• ZAFOD has instituted an action concerning
the provision of new housing for people,
including PWDs, which is already falling
apart, and irrigation systems that are failing.
In this case they are suing ZAPD (which has
agreed to be sued to advance the action),
which in turn will name the government as the
party responsible;
• ZAFOD has sued one of the teacher training
colleges for failing to ensure adequate physical
accessibility for one of its students; and,
• ZAFOD instituted proceedings against the
national university on similar grounds (lack of
access to buildings). The matter was settled out
of court and an agreement reached that all new
buildings will make provision for accessibility
and appropriate adjustments would be made to
the existing ones.

There is little evidence of any other strategic
litigation in any of the countries in the sample,
including Zambia. Some of ZAFOD’s affiliate
organisations, which were interviewed, proved
to be ignorant of ZAFOD’s pioneering work in
this field.

However, a case heard in Zimbabwe in
January 2010 sets a promising precedent. An
organisation representing the visually impaired
won a constitutional challenge against the
Zimbabwe Electoral Commission. The Supreme
Court chief justice nullified sections of the
Electoral Act, which mandated assisted voting
for the visually impaired. When applied in the
2008 elections, this provision had allowed
representatives of the political parties contesting
the elections, presiding officers at polling
stations, police officers and employees of the
electoral commission to provide assistance to
blind voters. The organisation bringing the action
argued that this practice violated their voting
rights, especially as regards privacy.119

Knowledge of the Convention and its
implementation

Throughout the region, most of the DPO staff
interviewed admitted that they had not seen
a copy of the CRDP, and knew little about the
DPO participation required by the Convention
at various levels of the implementation pro-
cess. (The latter involves legislative reviews,
the establishment of monitoring and evaluation
mechanisms, and the mainstreaming of dis-
ability issues into all government departments,
budgets, programmes and development plans.)
Therefore, it is hardly surprising that ordi-
nary PWDs know even less, as pointed out by Lits’ipiso Mathlosa in the case of Lesotho: 120

The majority of PWDs have little or no understanding of the CRPD and what it means to PWDs. This has forced the Lesotho National Federation of Organisations of the Disabled (LNFOD) and its member organisations to undertake a variety of advocacy activities on disability rights and campaigns to raise awareness about the CRPD among PWDs and members of the public.

However, Mathlosa emphasised that the Lesotho government had ratified the Convention in response to intensive lobbying by the country’s DPOs: 121

After it was opened for signature in 2007, DPOs in Lesotho employed different strategies to put pressure on the government to ratify the Convention. One such strategy was the ‘Joint Open Letter on the Convention on the Rights of Persons with Disabilities’ which, together with stakeholders from non-governmental organisations, service providers, international agencies, religious groups and trade unions, wrote to the Prime Minister. This letter outlined the benefits that PWDs would gain if the Convention was ratified. For instance, the stakeholders maintained that the Convention would offer guidance to the government on protecting the rights of the PWDs. Lesotho finally ratified the Convention on the Rights of People with Disabilities on the 2 December, 2008.

ZAFOD: Best Practice

The best exemplar of consistent and productive lobbying and advocacy campaigns appears to be ZAFOD, the DPO umbrella body in Zambia, which counts among its successes that it has caused the Zambian government to (a) ratify the Convention, (b) include a disabilities chapter in the country’s fifth national development plan, and (c) appoint disability focal point people in all line ministries. (The last of these has had disappointing results, as most of these appointees have no knowledge of disability issues.)

ZAFOD is also proactive in terms of taking advantage of opportunities offered by legislative changes. On hearing that the country’s Town and Country Planning, Housing and Education Acts were being revised, the body ‘jumped on and made proposals for inclusion or attention to disability issues’. 122 Working closely with the Zambia Law Development Commission, its staff members are considering reforms to the country’s criminal justice legislation. They have also, on their own initiative, carried out a review of current mental health legislation, and are lobbying for a repeal of the mental health law. This action was instituted after a prison audit, conducted in concert with the Human Rights Commission, found that a number of people held ‘at the President’s pleasure’ were being housed in prisons rather than in mental hospitals.

Much needs to be done to acquaint the DPO community with the CRPD and make workers in the field of disability rights cognisant of the many ways in which the Convention can serve their cause. This ‘know-your-CRPD’ campaign should probably start with the development and wide distribution of simplified versions of the Convention document, in formats accessible to people with different kinds of disabilities. There is also an urgent need to include the technical, legal, governance, mainstreaming, monitoring and evaluation aspects involved in the implementation of the Convention in all training programmes for DPO staff.

Currently, the preparedness and capability of southern African DPOs to undertake the duties envisaged in the Convention are severely constrained. The involvement of international DPOs active in southern Africa (including ADD, DDP, Power and Handicap International), donors with long experience in the sector, regional and international experts in the disability field, and academics from universities could supply a vast amount of expertise and support that would benefit government departments as well as DPOs.

Long-established DPO bodies – such as NAS-COH in Zimbabwe, the Botswana Council for the Disabled (BCD), and ZAFOD in Zambia – as well as the newer regional research and capacity building organisation, DHAT, based in Botswana, would also be in a position to make valuable contributions to new programmes. Financial and specialist technical support is also needed if the various processes involved in setting the implementation of the
Convention in motion in southern African countries are to get off the ground. As will be seen in the next chapter, implementation is already lagging behind in most southern African countries where the Convention has been ratified. In some instances, questions have been raised about whether some of its provisions can be implemented in the socio-economic and legal contexts of these countries.

Responses of DPOs concerning the proposed disability rights course to be offered in law schools

The reaction of DPOs in the region to the idea of a course on disability rights, which OSISA has proposed for the law schools in four of the nine countries, was that it was ‘a long overdue development’. Most of the respondents insisted that the course should be multi-disciplinary in nature, in order to provide students with the best possible understanding of disability as a cross-cutting issue. Some of them also suggested that shorter disability rights courses or modules should be included in foundation courses in universities. This would instil an awareness of disability issues and rights across the entire student body, which would ultimately percolate from these individuals to society in general. ZAFOD has already been active in this area. Staff members reported that they have been advocating for disability issues to be included in the curricula of law schools and within humanities courses, and they were in the process of preparing a position paper on how disability issues can be integrated into all relevant courses. This has already been done with regard to gender.\(^{23}\)

Conclusion

Although the general trends and tendencies described in this chapter apply across the region, the DPO community in southern Africa encompasses a great many diverse groups, different levels of organisational strength and capacity, and a variety of disparate interests and specific needs. The inherent diversity of the disabled community (that is among DPOs and PWDs themselves) was one of the most important findings of the research. It is one that should be heeded by governments and other role-players entering this field, because it suggests the importance of close observation before specific solutions can be planned. Signing the Convention and introducing laws and policies that centre on disability are important steps towards better living conditions and the enjoyment of the full spectrum of rights by PWDs, but these processes also have to be informed by knowledge of the actual conditions. Unless the specific needs of people with different kinds and degrees of disability are taken into account, the next step – actual implementation – should not be taken.

Many of those interviewed stressed that it is the point at which policies and conventions have to be implemented and detailed information, practical measures, technical strategies and dedicated funds are required, that the yawning abyss between noble undertakings and hands-on performance is revealed. Although almost all PWDs have similar burdens to bear in terms of socio-economic disadvantage and social discrimination, they also require interventions specific to the nature of their disabilities. For example, access to cutting-edge computer technology specifically designed for blind people could transform the prospects of the visually impaired, and the provision of wheelchairs and other assistive devices could do the same for those with limited mobility. Practical measures such as these can make enormous differences to the lives and competencies of PWDs, not least by enabling them to earn a livelihood. This point was emphasised by many interviewees.

Therefore, governments should devote much more attention to planning how ‘the big issues’ can be better combined with the ‘nuts and bolts’, as many of the interviewees put it. The latter approach would require all government departments to institute practical measures, use technical expertise, and allocate realistic amounts of funding to disability issues if mainstreaming guidelines are to be taken seriously. It is unlikely that this will happen unless DPOs, in concert with disability experts, lawyers, academics and others, lobby their governments relentlessly.

The nuts and bolts approach requires realistic needs assessments instead of generalised blueprints. Detailed information can be obtained from major national and regional research projects like the SINTEF studies, but the most cogent
source should be the country’s PWDs, their caregivers and their organisations. Consultations with these people would be far more informative and allow far better identification of the most pressing needs than vague blueprints and grand designs. In addition, needs assessments that focus on specific areas to allow for different disabilities would enable governments to ascertain exactly what needs to be done for PWDs. The use of participatory research methodology would also be desirable because it would raise the self-esteem of the participants, provide them with a temporary income, and allow them to improve their skills. This approach has been successfully applied by SINTEF in various country studies undertaken in the region.

Once again, it would be of great value if governments and all those involved in disability issues made some determination of the locus of responsibility for the protection of PWDs and the realisation of their rights before allocating responsibility for planning and practice. What is clear is that much more needs to be done if the dire situation of PWDs (who constitute about 10 percent of the total population of the nine countries)124 is to be improved. During the 1980s and 1990s DPOs had to take up the slack when large-scale cuts in social spending undermined the provision of basic services, but they cannot be expected – no matter how active their lobbying efforts – to carry the burden of obligations that belong to governments. Hope Ndlovu-Chanda, the in-country researcher in Zambia, commented, “The responsibility for supporting people with disabilities has always fallen on the family. Government intervention, where it has existed, has often been channelled through welfare policies with minimal commitment to addressing disability.”125 This is an indictment of every society and government that allows such a situation to continue.

At present, it is mainly the DPOs that use their scant funding to initiate sign language training programmes, provide rehabilitation treatment, supply life-saving medication and food for children with physical disabilities, and obtain wheelchairs through foreign donors. These are just a few examples of the ways in which DPOs have had to step in to take care of their members and other PWDs, because the most vulnerable people in society have largely been left to look after themselves by their governments. And since DPOs have had to focus on bread-and-butter issues (and survival as institutions) they have good reason for appearing insular and uninformed about disability theory in its current form.

The two quotations that follow suggest the balance required between different loci of responsibility for the disabled. The first, taken from the SINTEF report on Mozambique, emphasises self-reliance:126

While the situation for individuals with disability in low-income contexts like Mozambique calls for resources and involvement from government as well as the private sector, it is nevertheless the case that self-organisation of individuals with disabilities is necessary to achieve substantial progress.

The second is taken from an interview with staff members of ADD in Zambia:127

Advocacy and influence is making government accountable to meet its responsibilities. It includes monitoring of policy development, tracking of budgets and national development plans and (for DPOs) to sensitise government on local and international instruments.
Between political discourse and practice, there is a big difference.

(Ricardo Moresse, FAMOD, Mozambique)

This chapter looks at the general trends in the way governments in southern Africa address disability issues and rights. More detailed country-specific information is given in the separate Country Profiles Report, which lists disability policies and legislation, identifies those countries that have ratified the Convention, and charts the progress made in each towards its implementation.

The composite picture that has emerged from the research clearly shows that governments in the region have a long way to go before they can claim that disability issues and rights are adequately addressed in their countries. Although many of these countries have major national development plans, standardised poverty reduction programmes and nationwide HIV and AIDS projects, disability issues do not feature in most of them, even though PWDs are acknowledged as the most vulnerable group in the region.

Disability appears to be a blind spot in the consciousness of almost all southern Africans, including government policy-makers. Although there is growing pressure on governments from international bodies (most tellingly embodied in the Convention, and the moral force and binding legal obligations that it entails), and from internal advocacy, there seems to be a barrier between policy-making and concrete action. Much of this is psychological. The following list of reasons (all related to attitude) is not exhaustive, but suggests some of the impediments to implementation by governments:
• a lack of, or questionable, political will;
• the possibility that many politicians and bureaucrats do not take disability issues seriously, and therefore do not regard disability issues as a priority in governance programmes and budgets;
• a lack of information about the dismal socio-economic conditions experienced by the majority of PWDs;
• a failure to understand the notion that disability is a development issue that cuts across the normal departmental boundaries and needs to be considered and addressed in all government plans, programmes and budgets; and,
• ignorance of the concept of mainstreaming disability into all government departments.

Naturally governments are also hampered by practical barriers. The most obvious example would be whether the country concerned is able to commit sufficient financial resources to carrying out its development programmes.

Although the reasons listed above give reasons for governmental inaction on incorporating disability rights into domestic laws and policies, the DPO leaders who were interviewed complained that existing disability legislation and policies were not acted upon. Many shared the view of Alexander Phiri of SAFOD that “governments tend to think that once a law, convention or policy is there, that’s the end of it.”130 A DPO respondent in Zimbabwe also stressed that their biggest concern was not the country’s disability policies or legislation (which she described as “just a piece of paper, that most PWDs do not even know exists, as they live in rural areas, have no education and constitute the poorest of the poor”),131 but the failure of the government to put them into concrete form.

Even in countries with comparatively good disability policies and practices and higher levels of political will, the assessment remained the same: that there is a giant hiatus between policy and implementation, and between political rhetoric and actual deeds. In some cases, this scepticism on the part of DPOs extended to the implementation of the Convention.

Ratification and implementation of the Convention

At the time of writing, the CRPD had been ratified by four countries in the region: Lesotho, Malawi, Namibia and Zambia. Mozambique signed the Convention in 2007, but has not yet ratified it. In most cases these countries appear to have made no or little progress on complying with its provisions. None of them had instituted legislative reviews or taken any steps to introduce disability as a mainstream issue in all tiers of government, to the knowledge of the DPOs we consulted. Very few of these respondents were aware that the Convention requires the establishment of monitoring, evaluation and reporting mechanisms to keep track of implementation.

Dr. Ngosa Simbyakula, Dean of the School of Law at the Zambia Open University, described some of the difficulties inherent in ‘domesticating’ the undertakings the country has made, and expressed doubt that the government would carry them out:132

*In our current system, domestication has to be by way of enactment – it is an executive action not a legislative one. The challenges the CRPD faces are that civil society has agitated for it and government, in ratifying, is not committed but merely plays to the gallery – the necessary political will is not there and no proper analysis is conducted on the capacity and understanding of the implications of ratification.*

In some cases, the respondents questioned not the will of the governments concerned so much as the ‘implementability’ of aspects of the Convention, implying that in ratifying the CRPD some governments might have bitten off more than they could chew. The aspects of the Convention that they identified as impossible to put into practice included some of the legal provisions of the Convention (like the right to life, which is in direct conflict with the law of any country that endorses capital punishment) and the sheer number of practical obstacles that stand between having laudable intentions and realising the socio-economic rights of PWDs in practice.

However, most of the southern African countries that have ratified the Convention have done so within the last two years, so it is probably...
inappropriate to judge progress at this point. Willem Bekker, a PWD living in Namibia, said it was important to get a sense of the ‘lay of the land’ before forming an opinion. This would include “finding out what is going on in government departments regarding disability, talking to and engaging people, both to inform and obtain information and, above all, to try to concretise things.”

If DPOs are to play their part in implementation, there is clearly an enormous amount of work to be done. They will be required to act as partners, adversarial watchdogs, and monitors and advocates – to offer support to, or put pressure on, governments as required. Both governments and DPOs will also need expert help to master the technical, legal, financial and other requirements of the Convention. These experts will give guidance on ways to translate disability rights on paper into disability rights that make a material difference to the lives of PWDs. If this does not happen within the next few years, the Convention will be in danger of becoming yet another dusty document, and the scepticism of many interviewees will have been justified.

Mainstreaming disability

Apart from a few initial attempts at mainstreaming disability in countries such as Zambia and Namibia, the concept appears to be little understood by government officials across the region. The most common institutional arrangement for allocating responsibility for disability issues at present is to append them to one or other government department, where it generally has to compete for attention with those relating to other vulnerable groups, usually women or the elderly. In practice, these departments are almost always under-resourced in terms of staff and funding, so they can do little to supply the needs of PWDs or support disability programmes. They also tend to lack sufficient political influence to introduce the mainstreaming of disability across all government departments. Some DPOs reported that occasionally such departments guarded their disability components jealously, and refused to allow other departments to become involved in the area. These kinds of ‘departmentalism’ and bureaucratic boundary-setting make mainstreaming all but impossible to accomplish.

Among the efforts made by governments to give disability issues a higher priority and more central status are the new Disability Units in the presidential and the prime ministerial offices in Namibia and Botswana respectively, both run by PWDs who were recruited from the DPOs. Although Swaziland does not have a formal disability policy, its government is reported to have established a Disability Unit in the office of the deputy prime minister. The researcher who reported this innovation expressed some doubts about the effectiveness of the unit on the grounds that its approach is based on an out-dated model:

This office seems to be looking at disability from the medical model and its whole approach to disability is a mixture of this model and the charity model. DPOs were not involved in the appointment of a focal person within this unit and, as a result of internal lobbying, someone from within government eventually occupied this position in the Disability Unit.
Although the purpose of these units is to ensure the mainstreaming of disability issues and rights in government, they have insufficient influence to make much difference. The same applies to the disability focal points that ZAFOD has persuaded the Zambian government to appoint in each government department, although in this case the appointees have little understanding of disability issues. In Namibia, every government department already has a budget allocated to disability issues, but because the officials concerned are ignorant of what could and should be done by their departments to advance the rights of PWDs, the money is seldom used. The Namibian government has also instituted a Disability Accessibility Award as an incentive for those ministries at the forefront of promoting the interests of the disabled, especially around questions of planning to ensure infrastructural accessibility and adaptations to public transport to cater for disabled passengers.

Although these measures to make disability a matter that is recognised and incorporated into the thinking and planning of the governments concerned represent a promising start and set good examples, they are not sufficient to create a strong culture of mainstreaming disability. Alexander Phiri of SAFOD provided some practical advice: “My understanding of mainstreaming is that you must have a checklist in every department and that, whatever you do, you must ask yourself 'where is disability in my programme?'”

Conclusion

For the present, disability issues tend to remain separate and relegated to a lowly position on the agendas of governments across southern Africa. But the DPO interviews conveyed a feeling that the situation is slowly starting to alter, as governments become more responsive to pressure from above (the international and continental community) and below (the domestic community) to raise their awareness of disability issues. Many of the DPO respondents ended interviews with the standard phrase that ‘things are slowly but surely improving’. Most of them pinned their hopes on the ways in which gender and HIV and AIDS have been made mainstream concerns in government planning, and the assumption that disability will follow. None of them mentioned the inter-connectedness of these three areas or seemed to have any concept of the idea of triple mainstreaming.

The Convention is gradually being ratified by more countries in the region, which is a hopeful sign because it sets clear standards of good practice and binds governments to follow them. It has also strengthened the hands of DPOs, which can use the various provisions and standards set out in the Convention as benchmarks for what is required in their countries. Another source of hope is that the continental project, the African Decade of Persons with Disabilities, has been extended for another 10 years. Both instruments should cause governments to pay serious attention to disability issues and rights, and the consequences are bound to lead to improvements in the lot of PWDs.
General findings

The researcher’s investigations established that there are very low levels of awareness of disability issues and rights among the majority of legal academics in southern Africa. No courses dedicated to disability rights or laws relating to them are offered in the law schools of the universities in the region, and the situation is little better in the faculties of humanities and health sciences. Those courses that were available at tertiary level tended to concentrate on issues of rehabilitation and counselling rather than the rights perspective. The university teachers who were interviewed were largely ignorant of both the CRPD and the implementation processes it would involve for countries that ratify it, and had no knowledge of any instances of strategic litigation concerning disability rights.

Disability rights courses or modules in law schools

While there are no ‘stand-alone’ courses on disability rights, there are a handful of law schools in which disability rights are taught as part of standard law courses:

- At the law school of the University of Swaziland, disability rights are a component of courses on international and human rights law;\(^{138}\)
- At the law school of the Higher Institute of Economics and Management (ISTEG) in Mozambique, disability rights are incorporated into courses on political science and constitutional law, but are ‘very lightly touched’\(^{139}\) on; and,
- At the Universidade Zambeze in Mozambique, disability rights fell under the remit of International Public Law, ‘but [were not dealt with] ... very carefully’.\(^{140}\)
On the other hand, the law school at the University of Zambia offers an interesting precedent that shows how universities and law schools can help to pioneer new initiatives in the field of disability rights. According to the Dean, Dr Margaret Munalula, and her two deputy deans, Mr Ngambi and Mr Mudenda, the school had never before offered a dedicated course on disability rights. Furthermore, the standard courses they offered, including a Human Rights Law course, did not touch on that subject. However, the law school entered into a Memorandum of Understanding, which covers the conduct of research and the training of students and staff, with the ILO Project on the Employability of Persons with Disabilities (PEPDEL) for one year (2010). As a result, a component of disability rights has now been included in the compulsory Human Rights and Labour Law courses offered by the school.

When they were asked their opinion of the viability of a one-year course on disability rights, as proposed by the OSISA Law Programme, most of the respondents from law schools felt that it would be difficult to justify it as a stand-alone course. They advised that such a course would be more effective if it were to be incorporated into an existing course, especially if it dealt with ‘legal as opposed to social issues’. The respondents from the University of Zambia were more positive in their view, and said that offering such a course in their law school would make an important contribution.141

General perceptions of the proposed course

The majority of legal academics interviewed greeted the idea of a proposed one-year course in disability rights with cautious approval. Most of them thought it would find a ‘natural home’ in their Human Rights Law courses. However, many expressed doubts concerning the allocation of a whole year to the course, and suggested that instead it should be a short module or form part of a foundation course. Some advocated that it should be included in the undergraduate curriculum, while others favoured a course at postgraduate level, preferably for Masters students. There was a great deal of discussion concerning the merits of a multi-disciplinary course, which is the option that the DPO community would prefer, but the general impression gained by the researchers was that lecturers in law feel more at ease with disability rights seen from the perspective of their own discipline. The designers of the course will have to decide which of these preferences to act upon.

All of those interviewed warned that the establishment of such a course will require considerable extra resources. The minimum requirements would include appointing staff who are appropriately qualified in the field of disability rights law, providing training in this discipline to existing lecturers, allocating funding for visits by guest lecturers (for instance, disability experts and DPO leaders), assisting with the development of course materials, and drawing up reading lists. They also cautioned that the procedure for getting new courses accepted in universities is extremely slow, and usually lasts between six months and a year (in some cases, between two and three years). The wait for approval is not as long in some of the private universities and the newer state institutions, like the Midlands State University in Zimbabwe.

In the universities the researchers visited, teaching methods tended to lean quite heavily on a conventional balance between lectures and tutorials. However, in some cases the Socratic method, which emphasises rational argument, problem-based learning, mock trials and so forth, has been introduced quite recently. But it was difficult to extract information from respondents, who seemed to regard questioning on this matter as implying criticism. If further information on the approaches used by university teachers is deemed important by the designers of the proposed disability rights course, another investigation may be required.

University disability policies and units

Although many of the academic institutions in the region have Disability Units, the majority appeared not to have drawn up formal disability policies. Alternatively, if they did have them, they were generally not made available to the researchers. The sole exception was a hard copy of the final draft of the disability policy of the University of Zimbabwe obtained by the
lead researcher from the Disability Unit at that university. For the rest, the only documentation that could be found consisted of pamphlets issued by some of the Disability Units.

It appears that most of the universities are making some practical arrangements to accommodate the needs of mobility-impaired students by improving accessibility on campus. Many also provide a range of support services and technological aids to meet the assorted learning needs of disabled students, for example Braille computers with additional features. Where available, these services are usually clustered in the Disability Unit. Litse’piso Mathlosa, the researcher in Lesotho, provided a description of the kinds of assistance the university in that country offers staff and students with disabilities:142

At the University, members of staff are employed regardless of their disability. The admission of students also does not discriminate on the basis of their disability. In an attempt to accommodate students with disabilities the application form for the admission into the University requires all applicants to indicate whether or not they have any physical disability. If they do, they are expected to indicate precisely the nature of the disability and the special facilities they need.

To date, the University has admitted students who are physically impaired and those who are visually impaired. An attempt has been made to build ramps to most of all the buildings on campus to make them accessible to the learners who are physically impaired. In the same manner, Braille is made available for students who are visually impaired. An assistant has been employed to ensure that their Braille needs are taken care of. The library has also made books accessible to these learners through Braille.

Broader issues of access and accessibility

Given the low levels of education common to most PWDs, and the tiny proportion that manage to reach tertiary institutions, one might argue that the practical measures employed to open higher education to certain PWDs have to be seen in another context: How are these universities intending to cater for the broader needs of disabled people to whom entry to even secondary education is closed? Dr Mathlosa, who is a specialist in this field, raises some critical questions: 143

Despite the good intentions of making higher education accessible to students with disabilities, at least two remarks could be made regarding the section which mentions disability in the application form. First, is the assumption that disability is only physical. And second, that the students with other types of disability have never applied for admission into the University. The fact that students with other types of disability do not go beyond high school education is mainly due to lack of qualified teachers adequately trained to cater for their needs. The noticeable absence of students with other types of disabilities justified the establishment of the Special Education Department in the Faculty of Education in 2009. The Department aims to equip secondary and high school teachers with skills which would enable them to effectively teach learners with diverse needs. Prior to now, the government had placed emphasis [only] on the training of primary school teachers.

The need for greatly improved access to every level of education (starting at pre-school level) for children with disabilities is clearly a prerequisite if more students with a greater variety of disabilities
are to qualify for entry into universities. The situation of deaf children is particularly worthy of consideration, as the education systems prevailing in most southern African countries fail to supply the means for them to proceed beyond a fixed point in secondary school. Even if they surmount that obstacle, the lecturers in the region’s universities are seldom able to teach or communicate with them in sign language. Mathlosa describes some of the typical difficulties and dilemmas experienced by university teachers untrained in dealing with blind students:

Although efforts are being made to accommodate learners with diverse disabilities into the university, to date lecturers are not being trained to equip them with necessary skills to handle these learners. In a study conducted by Mathlosa and Matobo (2007), lecturers expressed the dilemma they found themselves in when dealing with learners who are visually impaired. They noted their frustration at not being informed about such learners in the first place. They admitted that they felt helpless when they did not know how best to handle them. These lecturers explained that sometimes they found themselves being accused of being insensitive to the needs of the visually impaired learners. Yet, when they try to be more lenient towards the same learners, they are accused of not treating them as equal to other learners. The frustration that lecturers experience due to lack of the necessary skills and training has resulted in some of them having negative attitudes towards the inclusion of visually impaired learners into the University.

Conclusion

Although they have instituted some measures to provide standard technological support and physical accessibility to disabled students and staff, which include appropriately-modified accommodation, the universities in the nine southern African countries have not addressed disability issues and rights in any depth. This is depressing, particularly when one compares their performance with the conventional assumption that universities are places where discussions and debates concerning important societal issues take place at an advanced level, and where cutting-edge research into these matters is taken up. Overall, the researchers found little evidence of either on the general subject of disability. It appears that the academics working in these institutions share the same blind spot as government officials.

In some ways, the relative invisibility of disability issues and rights in the eyes of law lecturers is understandable, in that they are not really exposed to the brutal realities of existence for most PWDs. The number of disabled students they encounter is very small, for the reasons already given, and although universities are changing fast and becoming ever more competitive, they tend to stay within the comfort zones of traditional subject choices.

The introduction of disability rights courses and discourses into law schools and universities in southern Africa would do much to extend the boundaries of research and thought in these institutions. Not only would these courses introduce an entirely new set of ideas and skills into law schools and impart them to those who will become lawyers and advocates, even judges in time, but they might bring about a higher awareness of disability issues and rights in the university as a whole.
As each chapter was followed by a conclusion and some discussion, the researcher’s sole aim in these concluding remarks is to draw together some of the major insights gained from the research and identify some areas that need urgent attention, support, guidance and intervention.

One of the key lessons derived from the research was that the promotion of disability rights in southern Africa has to be contextualised within the broader political and socio-economic dynamics of each individual country, the region and the global political and economic directives that shape government policies. The global standardisation of economic policies and procedures, and the conditions on loans and aid imposed by international financial institutions and donors tend to restrict the power of individual governments to make policy choices.

Over the past two or three decades, the neo-liberal economic policies forced on countries receiving loans have had destructive social and economic effects, which have swelled the ranks of the poor and vulnerable. Crucial social services, including basic education, primary health care, welfare services and essential infrastructure such as public transport and the provision of affordable electricity and potable water deteriorated, and many development gains that these countries had achieved earlier were reversed.

Currently, the people in most of the countries in the region face high levels of poverty and unemployment. The most badly affected are PWDs, who have the highest rates of poverty, deprivation, malnutrition, ill-health and child mortality. As indicated in Chapters 1 and 2, these conditions and a lack of essential services also cause disability amongst poor people, especially those living in the rural areas. Most
of the human development indicators show that PWDs have been worst affected by the deteriorating conditions in almost all southern African countries.

Although these macro-political and economic considerations were not included in the research brief, and the representatives from DPOs and other respondents did not engage with them during the interviews, they provide a broad context that helps to explain why the general situation of PWDs in southern Africa is so desperate. The bottom line is that, given the strong pressures on governments to conform and compete in the global economy and achieve specific economic and governance outcomes and targets, the plight of the disabled people in their countries – however intricately it is tied up with their broader development and service delivery agendas – is not a key priority. This is why disability issues are accorded so little attention and granted such scant budget allocations by most governments in the region, and why those laws and policies on disability that exist are not put into practice.

However, analysis and discussion of disability issues and rights from the global perspective could be used to underpin the kind of well-researched and high-profile advocacy that is clearly needed if governments in southern Africa are to be persuaded or pressurised into addressing their responsibilities towards the disabled members of their populations.

Learning the basic reasoning (and some of the technicalities and difficult trade-offs) involved in present-day national and international governance and finance would help to strengthen the hands of DPOs and their leaders, and allow them to enter into discussions and negotiations with government officials on the basis of equality. It would also provide a good counterbalance for the negative, dismissive and welfarist attitudes with which many government officials are reported to approach PWDs and their organisations.

The most important and persuasive insight that DPOs need to communicate to their governments is that disability is a cross-cutting development priority and not a separate side-issue. The first step, in many cases, would be for DPOs to refuse to be side-lined. They can do this most convincingly by acquainting themselves with the wider perspective on disability issues, and relating it to their traditional approaches. Making this change would involve a great deal of discussion and information-sharing within their own ranks before these ideas are conveyed to the government at the highest level. Another means of instilling the desired perspective would be to hold straightforward discussion forums or workshops, for example to illustrate how poverty and a lack of basic services can cause or perpetuate different forms of disability, which in turn leads to increased poverty and deprivation. Other examples that might prove instructive are tracing the many long-term consequences of being denied access to education and employment; the extra burdens carried by women with disability; and, the inter-linkages between disability, poverty, gender, vulnerability, sexual abuse, violence, and HIV and AIDS. The common lesson to be elicited from all these topics is that they interact to reinforce poverty and powerlessness, a situation that most DPO members will recognise from their personal experience.

Once this perspective becomes entrenched, it would provide a basis for discussions with government departments about service delivery and mainstreaming, and the participation of DPOs in monitoring government implementation of the Convention. In both of these areas, a great deal of preparation will be required before the discussions can take place. The preparation should include holding workshops on the content and purpose of the Convention and its potential as an advocacy tool. Both governments and DPOs will need support in working through the technical, legal, financial and other practical details and requirements of implementing the Convention, as well as the true meaning and the mechanics of mainstreaming.

Most DPOs also need up-to-date training in advocacy and lobbying methods, and the range of strategies that should be employed at different times and under various circumstances. Assistance is also urgently needed to improve regional and international networks and the networking skills of DPO staff, so that each organisation can learn from others in
DPOs, human rights bodies and development organisations, and identify benchmarks that can be applied in their own practice.

As emphasised repeatedly in the report, improvement in the general educational levels of PWDs is perhaps the most important issue that the disability movement in southern Africa needs to pursue. Whether their efforts are directed toward inclusive education and/or specialised education programmes for disabled children, DPOs and governments in the region need the financial support of donors and the expertise of different kinds of education and disability specialists to meet the technical, teacher training and other requirements of schools that offer PWDs the facilities they need. This is a huge and specialised area that merits a separate investigation. The researchers concerned would probably need to start by consulting PWDs, DPOs and key specialists in the disability movement.

The education of PWDs is particularly pertinent to OSISA’s proposed university-level course in disability rights and law, in that the research findings explain why very few PWDs progress as far as tertiary-level education.

Another issue raised by the research was the recent decrease in capacity and motivation of many DPOs and their leaders. This is a source of concern on several fronts. Perhaps the most important of these is the question: Who, in these circumstances, will be the torch-bearers for the realisation of disability rights? If DPOs are to continue to make a contribution, their organisations and the disability movement itself must be rejuvenated.

Finally, there is a need to consider ways of bringing about major changes in the mindsets of non-disabled people in southern African societies. In all nine countries, there were shocking reports of pervasive negative stereotyping, stigma and discrimination visited upon PWDs. The worst of these occurred in the rural areas. If the rights of PWDs are ever to be taken seriously, programmes that involve the whole of society will have to be undertaken (possibly with the help of television and radio) to counteract these false stereotypes. These campaigns could follow in the footsteps of others used to break down prejudice and misinformation, like racial and gender discrimination and the stigma related to HIV and AIDS. The support of high-profile politicians would also add credibility to public awareness campaigns on disability.

Although such campaigns and their central message should be given exposure at all levels and sectors of society, they could also be put to more specialised uses. For example, pilot courses could be offered in selected schools to try out the viability of inclusive education. Such courses would entail, at a minimum, teachers who are well-trained in the special needs of children with disabilities, the provision of specialised equipment (such as computers and relevant software), and the application of appropriately modified versions of the methods of breaking down stereotypes used for the public campaigns.

Whether sufficient political will and public resources can be found to accomplish these purposes is questionable, but the cause of the disability movement must continue to be advocated for until some ground is gained. People with disabilities and disability issues are severely neglected in most countries in southern Africa, and most of the DPOs appear to be ineffective. Therefore, it is time for disability activists to look for new ideas and fresh inspiration, which should, at the very least, include innovative ways to persuade governments and donors to try out new approaches and pilot projects.
Chapter 1

4. Ibid., section 2.2: ‘Disability Defined’ and pp. 9–14 for a much more detailed and nuanced discussion.
11. See, for example, Tony Emmett’s chapter on Disability, poverty, gender and race. In Watermeyer et al., op. cit. pp. 207-231.
12. SINTEF report, Mozambique. (2009) Living Conditions amongst People with Disabilities in Mozambique – A National Representative Study. Similar studies have been conducted in Malawi, Namibia, Zimbabwe and Zambia.
13. Various websites and articles, listed at the end of the document.
15. Chalklen et al. in Watermeyer et al. (Eds.), op. cit. p.96.
17. See, for example, Chapter 14 of Watermeyer et al. (Eds.) op. cit.
18. Ibid., p.10.
19. See the definition in Victor Jere’s dissertation, op. cit., p.4.
20. Quoted by Emmett, op. cit., p. 207.
21. Ibid.

Knowledge, personal risk and experiences of HIV & AIDS amongst people with disabilities in Swaziland. globalsurvey.med.yale/edu/ (click on Findings from Global Survey)
31. Ibid., p.15.
32. Disability and HIV/AIDS, at a glance (short briefing document on the Global Survey), www.globalsurvey.med.yale
34. DDP report, Mozambique, op. cit., p.29.
36. See for example the DDP report, Mozambique, op. cit., in which poverty, disability, illiteracy and HIV and AIDS are shown to intersect.
37. Swartz et al., op. cit., p.110.
40. Ibid., p.30
41. See pp.11-12 of the Global Survey report, op. cit., for more detail on these multiple barriers to the access of PWDs to health and HIV and AIDS services
43. See earlier references to the Global Survey.
45. Ibid., p.28.

Chapter 2

46. Ibid., p.29.
48. Ibid., p.91.
49. Josephine Chunda, ZAWD, interview conducted by Hope Ndhlovu-Chanda, in-country researcher in Zambia, June 2010.
50. SINTEF report, Mozambique, op. cit.
52. Unemployment figures provided by Revai Makanye, in-country researcher, Zimbabwe.
53. SINTEF Report, Mozambique, op. cit., p.87.
54. www.ddpuk.org/lardef.html
57. Angelo Dube, reporting on an interview with Mr. Bheki Jele, the coordinator of FODSWA, the national umbrella body for DPOs in Swaziland.
58. Interview with Malawi National Association of the Deaf (MANAD) board member (Ms Juliana Mwase), director (Mr. Bison Khimenya) and staff members, conducted by the author via a sign language interpreter, Blantyre, 12 May 2010.
59. Identity protected.
60. Identity protected.
61. DDP report, Mozambique, op. cit., p. 5.
62. Ibid., p.6.
63. Magweva, NASCOH interview, cit.
64. Interview with Charles Khaula, Director of the Association of the Physically Disabled in Malawi, interviewed. Khaula quoted the SINTEF study conducted in Malawi, which found that 15-20% of Malawians are disabled and that physically disabled persons constitute 43% of the total population of PWDs in Malawi.
65. Ibid.
66. Interviews with Gerson Mutendere of NFPDN, cit., and Natanael Areseb of the Namibia Association of Local Authority Officers, who had previously conducted programme reviews of NFPDN for donors of the organisation, conducted by the author, Windhoek, 13 May 2010.
68. Khimenya, MANAD interview, cit. This point was also emphasised in a number of interviews in Mozambique.
71. Pamela Somses, NACD, interviewed by the author in Windhoek, 14 May 2010.
73. Mutendere, NFPDN interview, cit.
74. These views on mainstreaming are based on the findings of a huge research project, The Impact of HIV and AIDS on Local Government in South Africa, that the author undertook for IDASA and the Development Bank of Southern Africa during 2007/08.
75. Similar references were made in most of the DPO interviews in Zambia.
76. Willem Bekker is the vice-chairperson of the Disability Council, a new statutory body in Namibia, but stressed that he was speaking in his private capacity. Interviewed by the author, Windhoek, 13 May 2010.
77. SINTEF report, Mozambique, op. cit., p.10.
78. Rule et al., op. cit.
80. Chanda, ZAWD interview, cit.
81. Lesotho country report, see Country Profile Reports.
82. See the section on Disability and HIV & AIDS in the literature review.
83. See the Angola country profile report.
84. Mr. Wamundila, Programme Manager of ZAFOD, interviewed by Hope Ndhlovu-Chanda, Lusaka, July 2010.
85. Phillimon Simwaba, Executive Director, and Robert Sinyisa, Monitoring, Evaluation and Research Manager, interviewed by the author in Gaborone, 18 May 2010. For more information email: dhat@info.bw
86. Makwara, ZPHCA interview, cit.
87. SINTEF report, Mozambique, op. cit.
88. For more details, see country profile reports.
90. DHAT interview, op cit.

Chapter 3

91. See bibliography.
92. Makwara, ZPHCA interview, cit.
93. The BCD is the main coordinating body for all DPOs in Botswana. It receives its operational budget from the government and—uniquely in the study—also receives funding from within the corporate sector in that country. BCD disburses a considerable number of grants to member organisations. Interview with Ms Sekgabo Ramsay, Executive Secretary of BCD, conducted by the author, 19 May 2010.
94. Bheki Jele, FODSWA, interviewed by Angelo Dube, in-country researcher in Swaziland, 21 May 2010.
96. See the reference made to the income survey conducted by NASCOH in chapter 2 of this report.
97. This was reported by several interviewees, but most compellingly by Ms Rejoice Timire of the Disabled Women’s Support Organisation (DWSO), herself paralysed as a result of a spinal cord injury caused by a serious car accident.
98. Identity protected.
99. This detail was far too widely reported to be dismissed. Identities of respondents protected.
101. Chanda, ZAWD interview, cit.
102. Khimenya, MANAD interview, cit.
103. Ibid.
104. SINTEF report, Mozambique, op. cit., p. 90.
105. Jele, FODSWA interview, cit.
106. SINTEF report, p. 81.
108. Interviews with Pamela Somses of NACD in Namibia, cit.; Tereza Makwaru of ZPHCA in Zimbabwe, cit.; and Mirriam Namanja of POPCAM in Malawi. POPCAM is considerably better funded than the first two organisations.
109. This information came from many different interviewees, including Alexander Phiri, the head of SAFOD, interviewed by the author, Johannesburg, 15 May 2010.
110. Key interview with Nathaniel Areseb, Executive Director of the Namibia Association of Local Authority Officers, who acted as a consultant for an EU programme review of the NFPDN, the DPO umbrella body of Namibia. Interview conducted by the author, Windhoek, 14 May 2010.
111. Relandeau, Handicap International interview, cit.
112. Magwevu, NASCHO Interview, cit.
113. Henry Chanda and Justin Bakali of the Zambian office of the international DPO Action on Development and Disability (ADD), interviewed by Hope Ndhlovu-Chanda, Lusaka, June 2010.
114. Wamundila, ZAFOD interview, cit.
115. Chanda, ZAWD interview, cit.
116. Wamundila, ZAFOD interview, cit.
117. Dube, Swaziland country profile report.
118. Wamundila, ZAFOD interview, cit.
119. Reported by Reval Makaney, in-country researcher, Zimbabwe. See the Zimbabwe country profile report.
120. Dr Litse’piso Mathlosa, Lesotho in-country report, Country Profile Reports.
121. Ibid.
122. Wamundila, ZAFOD interview, cit.
123. Wamundila, ZAFOD interview, cit.
124. World Health Organisation (WHO) estimate.
125. Hope Ndhlovu-Chanda, Zambia country profile report.
126. SINTEF report, Mozambique, op. cit.
127. Henry Chanda, ADD interview, cit.

Chapter 4

129. For example those prescribed by the World Bank and often sponsored by the EU.
130. Phiri, SAFOD interview, cit.
131. Identity protected.
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133. Bekker interview, cit.
134. Angelo Dube, in-country researcher, Swaziland, op cit.
135. ZAFOD and ADD interviews, Zambia, op cit.
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137. Phiri, SAFOD interview, cit.

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The Open Society Foundation for South Africa’s strategy is to support and engage in activities that focus on the delivery of a needed service. In doing so it has decided it will act in a limited number of priority areas and with projects which will initiate change and produce demonstrable results within two years; seek major ventures or fresh ideas that would not see the light of day without the resources and assistance of the Foundation; and, seek to act in co-ordination and co-operation with other organisations and funding agencies to ensure that resources are optimally used. The Foundation will seek to ensure that in its work all projects should have an ongoing institution-building impact; an emphasis on sustainability; and, a mutually reinforcing impact wherever possible.

The Open Society Foundations Disability Rights Initiative seeks to address discrimination against people with disabilities and promote their inclusion in society by supporting a rights-based approach to disability. Building on the momentum and opportunity created by the UN Convention on the Rights of Persons with Disabilities (CRPD), the initiative supports civil society to build networks and mobilize campaigns that advance disability rights through advocacy for ratification and for implementation of this new human rights instrument. The program provides funding for national and global advocacy efforts that galvanize constituencies and engage new partners to develop rights-based strategies to implement the CRPD. The initiative gives priority to efforts that envision collaboration across movements and sectors, combine monitoring and documentation with advocacy and litigation, and seek to strengthen rights protections and remedies.

The Open Society Initiative for Southern Africa (OSISA) is a growing African institution committed to deepening democracy, protecting human rights and enhancing good governance in southern Africa. OSISA’s vision is to promote and sustain the ideals, values, institutions and practice of open society, with the aim of establishing a vibrant southern African society in which people, free from material and other deprivation, understand their rights and responsibilities and participate democratically in all spheres of life.
Status of Disability Rights in Southern Africa

In 2010 the Open Society Initiative for Southern Africa (OSISA) - in partnership with Open Society Foundations’ Disability Rights Initiative and the Open Society Foundation for South Africa - undertook a research project into disability rights in nine countries in southern Africa. This was a new area of work for OSISA and, while we had quite a bit of anecdotal evidence about the state of disability in the countries where we work, we felt that we needed a more comprehensive understanding of the state of disability in the region. The research was undertaken over a period of eight months and the findings make for depressing reading.

OSISA’s main objective was to have a comprehensive overview of the disability rights movement in southern Africa and to obtain detailed country specific research to enable us to assess where best we could provide on-going support. Therefore, two reports were commissioned - this general overview and a compilation of the detailed country reports. OSISA was also very interested in the provision of disability rights courses to law students in the region so the reports contain information that is specific to the work that universities were doing on disability rights. Unsurprisingly, the findings show that there was very little such work taking place.

People living with disabilities (PWD) are the most marginalised people in a region where life is already difficult for the majority of the population due to severe poverty, lack of development and high unemployment. In all countries, the rights of PWD are not given any priority by their governments. Usually, any ministry dealing with disability also has to address other marginalised groups such as women and children, so disability rights and the protection of PWD receive minimal state funding and focus. Most of the organisations and individuals interviewed during the research had to conduct their activities and advocacy work on an extremely tight budget - in most cases with little or no state support. In depth country interviews showed that the continued survival of disability rights organisations was one of their greatest challenges. Yet despite all the hardships faced by the disability community, remarkable work was taking place. These findings are highlighted in the separate publication containing the country-specific reports.

The premise upon which we commenced this study is the knowledge that many PWD suffer some of the most profound human rights violations as a result of the denial of legal capacity, institutionalisation, and inadequate provision of community-based services and support. Only by ensuring their rights to (i) equal recognition before the law and legal capacity, (ii) equal access to the justice system, and (iii) live independently and be included in the community can these violations be addressed. While in some countries the disability movement is already taking on these issues - building on a developed rights discourse and a history of using legal tools and high-level advocacy to achieve results in this area - the challenge remains to ensure that these core priorities are relevant across the region, especially in places where the disability movement is not as developed and these rights have not been prioritised.

This study provides critical insights into the difficulties faced by PWD across the region as well as valuable information that OSISA and its OSF partners will utilise to support the protection and promotion of the rights of PWD in southern Africa.