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DISABILITY AND HIV & AIDS IN MOZAMBIQUE

A research report by Disability and Development Partners

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Abstract

We were motivated to undertake research into disability and HIV & AIDS to contribute to a body of knowledge that, despite very recently being a strong focus of attention, was the subject of longstanding neglect.

Our previous work with local partners in Mozambique made us aware that disabled people in general suffer social exclusion and we were therefore interested to find out whether this applies equally in HIV & AIDS policies and programmes.

The research began with a literature review. We selected two of Mozambique's eleven provinces where HIV prevalence is known to be high among the general population to conduct a survey with dual objectives: firstly, to establish the extent to which disabled people are vulnerable to HIV and their awareness of the pandemic and, secondly, to determine whether disabled people and their needs are included in current HIV & AIDS statutory policies and service programmes.

We found that the prevalence of HIV among disabled people is likely to be at least as high as among the general population. Our survey revealed very low levels of knowledge among disabled people of HIV & AIDS issues, that their needs are broadly not catered for in service provision and that policy makes no reference to disability.

We conclude that this situation reflects the trend of disabled people's marginalisation and that the link between poverty and disability is a key factor. The report's principal recommendation is the urgent need to combine a mainstreaming approach to service programme design and implementation to promote the inclusion of disabled people with advocacy to achieve recognition of disability as demanding attention and provision at the level of policy making.

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Abbreviations

ACAMO	Associação dos Cegos e Amblíopes de Moçambique (Association of the Blind and Partially Sighted of Mozambique)
ADEMO	Associação dos Deficientes de Moçambique (The Mozambican Association of Disabled People)
AIDS	Acquired Immune Deficiency Syndrome
ARVT	Anti Retroviral Therapy
ASUMO	Associação de Surdos de Moçambique (The Mozambican Association of Deaf People)
CNCS	Conselho Nacional de Combate ao HIV/SIDA (National AIDS Control Council)
COJ	Centro Ortopédico Jaipur (Jaipur Orthpaedic Centre)
CVM	Cruz Vermelha de Mozambique (Mozambique Red Cross Society)
DADP	Disability Awareness and Development Programme
DDP	Disability and Development Partners
DfID	Department for International Development
DOLASED	Disabled Organisation for Legal Affairs and Social Economic Development
DPO	Disabled People's Organisation
FAMOD	Fórum das Associações Moçambicanas dos Deficientes (Forum of Mozambican DPOs)
GTZ	Gesellschaft fur Technische Zusammenarbeit (German government Technical Cooperation Department)
HI	Handicap International
HIV	Human Immunodeficiency Virus
INEFP	Instituicao emprego e Formação Profissional (Institute for Employment and Professional Training)
INGO	International Non Governmental Organisation
JLC	Jaipur Limb Campaign (DDP's former name – until July 2005)
KEPA	Kehitysyhteistyon Palvelukeskus (Finnish Service Centre for Development Cooperation)
LARDEF	Liga de Apoio á Reintegracáo dos Deficientes (League for the (Re) Integration of Disabled People
MDGs	Millennium Development Goals
MiM	Miracles in Mozambique
MINTRAB	Ministério Trabalho (Ministry of Labour and Social Welfare)
MISAU	Ministério de Saúde (Ministry of Health)
MJD	Minstério da Juventude e Desporto (Minsitry of Youth and Sport)
MMAS	Ministério da Mulher e da Acção Social (Ministry of Women and Social Affairs)
MONASO	Mozambican Network of AIDS Service Organizations
NGO	Non Governmental Organisation
SMFR	Secção de Medicina Física e Reabilitação (Section of Physical Medicine and Rehabilitation
UN	United Nations
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

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Chapter 1

Introduction

This is a report on research into disability and HIV & AIDS in two provinces of Mozambique. The research, supported by the Big Lottery Fund, was undertaken between April 2007 and March 2008 by Disability and Development Partners (DDP) together with our Mozambican partner organisation, Associacao dos Deficientes Mocambicanos (the Mozambican Association of Disabled People - ADEMO) and a range of other stakeholders (see below in Chapter 5)

The stimulus for this study was the knowledge of the relatively high incidence of HIV among the general population of Mozambique and its relationship to disabled people in the country: specifically, we were interested to determine the extent to which disabled people are affected and whether mainstream mitigation and prevention work includes disabled people and their needs. Based on the low level of social inclusion of disabled people in the country and the low priority assigned to disability issues, our working hypothesis was that we would find that HIV & AIDS policies and programmes broadly took no account of disabled people and their needs, but we remained determinedly open minded about the scale of HIV & AIDS incidence among disabled people and other research objectives.

We soon found that the timing of our research was serendipitous. As we were beginning to plan the research, the African Decade of Persons with Disabilities launched its own campaign on disability and HIV & AIDS[1], sharing some of our objectives. This in turn helped to lead to increasing production and availability of resources, which made the desk study research component more straightforward.

We are now pleased to present our report and to disseminate it to as wide an audience as possible. It is our intention to contribute to the growing body of knowledge in this field and then to draw out the implications of our findings to inform future policy, programme design and methodology.

[1] www.africacampaign.info – now managed by Handicap International

Chapter 2

About Disability and Development Partners (DDP)

Until July 2005, DDP was called the Jaipur Limb Campaign (JLC). When we started out in 1992, this name brought together our inspiration - the Indian made, affordable Jaipur foot - with the campaigning fervour against landmines and for sustainable rehabilitation services for disabled people in the South where the un-met needs were great. JLC was co-founder of the UK Working Group on landmines, a campaigning coalition which brought together more than 50 UK agencies to join the international movement to ban landmines.

We worked with local partners to set up an orthopaedic centre for amputees in Gaza Province, Mozambique; a Research, Rehabilitation and Training Centre in Bangalore, India; and a Limb and Brace Centre in Dhaka, Bangladesh. Other projects under the JLC banner were community based rehabilitation projects such as Makkala Bhavishya (Children's Future) in the slums of Bangalore which supported disabled and other excluded children to go to school, and research and development on appropriate and low cost technology such as pre fabricated knee, ankle and foot orthosis calliper components for children with polio.

Through this work we learned that the provision of rehabilitation services is inextricably linked to other basic human needs and rights such as education, livelihoods and health care – so often denied to disabled people. This prompted us to begin the quest for a new name – one that would better express what we do, disability and development, and how we do it, with partners.

DDP's vision is a society where disabled people have equal social, economic, civil and political rights; our mission is to develop partnership with organisations *of* and *for* disabled people, international agencies and governments to reduce poverty among disabled people and their families, by setting up programmes in the areas of socio-economic empowerment, capacity building, advocacy and education, and promoting appropriate rehabilitation technology and South to South exchange of know-how.

DDP's current partnerships are in post conflict Angola and Mozambique, Ethiopia and India. Our partners are disabled people's organisations, national and grassroots rehabilitation organisations, national and international development agencies and others. DDP has recently re-launched our website (www.ddpweb.org) which contains full details of our work.

DDP in Mozambique

The Centro Ortopédico Jaipur (COJ) was DDP's first project in Africa. The long civil war which ended in 1992 and the use of landmines in Mozambique left many amputees and disabled people needing help. In 1995, two provinces still lacked a rehabilitation workshop and service, so, together with our local partner, *Cruz Vermelha de Mozambique* – CVM (Mozambique Red Cross Society) and in consultation with the Mozambican

ministry of health, we set up a rehabilitation service in a new centre in one of them - Gaza province.

DDP supported the building of the centre from scratch, acquiring and installing equipment and sourcing the materials needed to make such aids as prosthetic limbs and callipers; together with CVM, we recruited staff and organised training for technicians, which included training in India at different rehabilitation centres so that they were exposed to good practice.

Located in Manjacaze district, COJ brought essential rehabilitation services to communities which really needed them. It is the first centre set up in a rural area of Mozambique and the first to be fully managed by a local organisation. People from all over Gaza and neighbouring provinces have benefited from its prosthetic, orthotic and rehabilitation therapy services. As always, while providing these services is a worthwhile end in itself, DDP's philosophy is that they should not exist in isolation; disabled people's needs do not end with mobility aids - indeed, often, that is where they start. Therefore, the social support programme we initiated with CVM helped provide economic security for disabled people and their families, be it through providing the means for them to support themselves financially or building a new house.

The formal partnership through COJ has now ended but DDP's commitment to the centre and its clients continues. We have provided technical support through DDP's Partners' Training programme – sponsoring a technician to attend Mobility India's prosthetics courses in Bangalore - and we support COJ in working with partners in India and elsewhere so that the South to South dialogue started in 1996 continues to this day.

Disability Awareness and Development Programme (DADP)
Most recently, COJ and CVM were involved in the Disability Awareness and Development Programme (DADP), a tripartite initiative also including DDP's Mozambican DPO partner, Associação dos Deficientes Moçambicanos (ADEMO – the Mozambican Association of Disabled People). As per worldwide Red Cross policy, CVM makes no charges for COJ services provided as most disabled people simply could not afford to pay, but the centre's survival is dependent on finding funds to pay running costs – salaries, utilities and so on. For that reason DADP provided resources for COJ to construct a guesthouse very close to the centre to provide a continuing income stream – and to provide a much needed service in a fast growing town with only one other place to lodge. Right now, we are working with COJ continuing to develop the guesthouse and planning to add an internet café to the guesthouse, which will be the town's first.

At the same time, DADP continued our commitment to enable COJ's clients to earn an income by supporting CVM's programme distributing resources such as cattle and fishing kits that allow disabled people to be more self sufficient as well as to generate a surplus which they can sell.

To date, COJ has provided services for over 5,000 people. It is renowned as a centre of excellence where the quality of aids and appliances is matched by the warm, welcoming

and professional attitude of its staff. DDP will continue to respond to their suggestions – even today people are becoming disabled as there remain an unknown and unmapped number of landmines in some parts of Mozambique.

DDP's partnership with ADEMO began with the DADP programme with capacity building as the central element. DADP enabled ADEMO to re-energise as an organisation and put in place properly democratic governance structures – an added benefit was that these provided a model for other DPOs. . One of the programme's most significant components was the development and adoption of a new 3-year strategic plan to direct ADEMO's short and medium term activities and assist their growth as a professional organisation.

During the 2nd phase of DADP a particular focus was to revitalise ADEMO's branch in Gaza province. The programme therefore set up an office in Xai Xai (the provincial capital) and recruited new staff to oversee and manage DADP's income generation element. A group of ADEMO members received livelihood support to start enterprises or were provided with cattle or fishing equipment. Full training was given to beneficiaries and a system has been established to provide follow up and continuing support.

This aspect of the project helped to combat the stigma and discrimination that disabled people routinely face in Mozambique – as in many countries – by highlighting people's capabilities rather than their disabilities, with extra positive effects such as helping to provide economic security for disabled people's families and increasing self esteem and dignity.

Chapter 3

Disability in Mozambique

The domestic scenario

There are no exact or accurate figures for the number of disabled people in Mozambique[2]. Data from the 2007 census are not yet available; the 1997 census cites disabled people as comprising 2% of the population. We may assume, however, that the percentage is much greater, taking into account the World Health Organisation's estimate of 600 million disabled people worldwide[3], which equates roughly to 9% of the world's population, and their assertion that 80% of the world's disabled population live in low income countries[4]. In addition to this, there is a high number of people in Mozambique who have lost limbs as a result of landmines or other ordnance during or after the 25 years of war. Nevertheless the 1997 census report provides some characteristics of disability in Mozambique which remain valid:

- The most prevalent type of disability is mobility impairment (77 per cent reported with physical disabilities against 16 per cent with mental health problems and 7% who suffered from both mental and physical disabilities);

- 80% of disabled people lived 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, services being predominantly found in cities.

- Gender distribution of disabled people shows that that 54 per cent are male (who make up 48 per cent of the population) and 46 per cent female. This is mainly attributed to the fact that men were more actively involved in the war and thus suffered disproportionately from landmine incidents and other disabling effects of war.

In 1999, the first National Policy for disabled people was approved by policymakers and in 2002 by a variety of disability stakeholders including disabled people's organisations (DPOs), but it was not sent to Parliament for enactment. It deals with principles and strategies aimed at encouraging the active participation of disabled people in socio-economic development. The policy also responds to disabled people's concerns regarding access to public buildings and other government infrastructures. However, the content of the policy has never been fully implemented, which the government attributes to resource constraints. This has resulted in disabled people facing the following challenges (among others):

- Lack of access to public services;

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[2] A separate issue is that there is little consensus as to how disability is defined which leads to constraints in the analysis of comparative data due to differences in survey methodologies – but this is outside the scope of this report.
[3] http://www.who.int/disabilities/introduction/en/index.html
[4] http://www.who.int/disabilities/publications/dar_world_report_concept_note.pdf

- Inaccessible buildings, means of transport etc.;
- Widespread stereotyping, stigma and discrimination;
- Low levels of education and literacy due to lack of access to education;
- Exclusion from employment and livelihood opportunities.

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 right to "assistance" for disabled people is provided for in article 95 of Mozambique's Constitution[5] and article 8[6] provides specific rights for people disabled as a result of the National Liberation War, and for those who became disabled during the civil war that led to the 1992 Peace Accord, including their dependents. In rural areas, however, many disabled people are not aware of the limited rights that do exist: an example is the *Certificado Oficiosa da Pobreza* (poverty certificate), which can be obtained from local administrations, and which gives the right to free medical treatment. But, since many people have no knowledge of these, they opt not go to a hospital because they cannot afford to pay

The institutional context

The government of Mozambique has ratified a number of international conventions with reference to disability and, on March 30th, 2007, signed the new (adopted by the United Nations General Assembly on 13 December 2006 and opened for signature on 30 March 2007) UN Convention on the Rights of Persons with Disabilities (although not the Optional Protocol). It has also subscribed to the United Nations Decade (1982-1992) for people with disabilities, as well as to the African Decade (1999-2009) in which the intention is that Mozambique be an "implementing country".

Government interventions towards disabled people have so far mostly been in the areas of policy definition and strategy design. We describe below the main statutory actors undertaking work connected to disability:

Ministry for Women and Social Action (MMAS)

MMAS disability related activities are principally geared to coordinating other sectors' activities relating to the dissemination of already established policies and supervising their implementation. It is apparent, however, that several factors constrain MMAS' ability to do this effectively.

- While the government introduces the National Action Plan for Disabled People (2005-9 – see below) to different ministries, almost all practical problems are transferred to the Department for Social Action, although all sectors have to be informed about disabilities and to comply with their respective responsibilities. This results in an uncoordinated approach and the shifting of responsibilities between ministries.

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[5] http://www.mozambique.mz/pdf/constituicao.pdf

[6] idem

- At the national, provincial and local levels MMAS is responsible for implementing the national plan (identification, referral and transport services to centres), but it has almost no financial means to do so and is also very short of human resources.

- Much of the plan, as well as the stipulations of the African Decade, effectively exists only as policy: there is a wide gulf between theory and implementation.

- Despite the existence of the national plan, there is very little knowledge and consciousness of its provisions among the staffs of the different ministries concerned. A plan to establish a national council for disabilities has been the subject of discussion for some considerable time, together with the establishment of a monitoring and evaluation systems for the implementation of the national plan but these plans have not yet materialized for lack of financial means. This is equally true of the new UN Disability Convention, which requires dissemination to be made meaningful.

Ministry of Education and Culture (MEC)

MEC is responsible for monitoring policies and implementing strategies to ensure that disabled people have access to basic education and skills training. The Department for Special Education at the ministry oversees this activity. MEC has recently initiated an "inclusive" education programme the main aim of which is the promotion of a public education network wherein all citizens, particularly those with special needs, are educated. MEC's activities are therefore orientated towards strategy, methodology and the development of learning materials for disabled children so as to facilitate their access and encourage their retention in the system until the completion at least of primary education. Article 29 of Law 6/92 articulates the right of disabled children to education and defines the form as to how educational processes shall be conducted, usually in special classes of mainstream schools. The law reaffirms the right of children with multiple disabilities or severe mental disorders to benefit from education tailored to their capacities in a personalised manner. Clause 3 of this same article determines that vocational training shall be provided to disabled children in order to assist their integration into society and the labour market.

Ministry of Health (MISAU)

MISAU is responsible for the design and implementation of policies that enable disabled people to access health care, rehabilitation, aids and appliances. Rehabilitation services fall under the ambit of the *Seccao Medicina Fisica y Rehabilitacao* (SMFR - Physical Medicine and Rehabilitation department) which is responsible for the provincial network of rehabilitation centres. Each of Mozambique's eleven provinces apart from Manica has its own rehabilitation centre but in many cases these are inaccessible to the country's dispersed rural population, and, in any event, only 2 of the 10 even approach being fully functional. There could be a number of reasons for this paucity of services: deskilling as a result of non transfer of skills from international NGOs which had originally set up these centres to the SMFR personnel now running them (apart from COJ which is still in CVM hands), professionally trained people leaving jobs in the sector, lack of funds, lack

of materials many of which have to be imported, political will and interest in disabled people's needs or a combination of all the above factors.

Ministry of Labour (MINTRAB)
MINTRAB works through the Institute for Employment and Professional Training (INEFP) by providing them with the policies and strategies for disabled people's personal development, enhancing their employment opportunities either in both the public and private sectors. INEFP provide training and kits which enable disabled people to acquire specific skills and thus become self employed. Training courses include tailoring and shoe repairing, woodwork and chicken farming, the last two being run in the Chimoio Training Centre in Manica province. Employment legislation of 1999 also provides for a quota system for disabled people throughout the job market, although no evidence could be found that it is respected.

Ministry of Youth and Sports (MJD)
MJD provides an enabling environment for young people of both sexes to engage in sporting and recreational events, with specific provisions to promote the involvement and participation of disabled youngsters, especially girls, in sporting and recreational activities, and they have established the Sports Federation for People with Disability.

Ministry of Finance
This ministry is responsible for the design and implementation of budget allocation policies and the control of macro-economic programmes. This includes managing poverty reduction strategies (a macro level instrument) with their implications for and impact on Mozambique's disabled population.

Legislation and other disability related documents
Resolution nº 20/99, which approves the disability policy, is based upon non-discriminatory constitutional principles and outlines the following specific rights for disabled people:

- Right to an independent life
- Right to integration in the family and community
- Right to rehabilitation and access to compensation means
- Right to formal, special or vocational education
- Right to employment
- Right to social protection
- Right of access to social services and equipment, including public places, transport and designated places
- Right to individual representation or through specific organisations to decision making about disabled people's issues
- Right to recreation.

The Transportation Regulation approved in 1990 through Resolution 24/89 indicates three important rights:

- Exemption from any sort of payment on public transport anywhere in the country
- Reduction of rates in interurban public transport
- Designation in public transport of specific seats

National Action Plan for Disabled People
The Plan's goal is to support the social inclusion objectives of the African Decade within the framework of universal human rights. It was developed as a result of surveys directed at the Mozambican DPO forum, Fórum das Associações Moçambicanos dos Deficientes (FAMOD), with the aim of identifying constraints that would affect disabled people and from that defining appropriate solutions to eliminate such constraints and meet disabled people's basic needs. A number of government institutions, NGOs, civil society and international partners were consulted in order to raise funds aimed at improving disabled people's social integration.

The above sections delineate the rights and consequential material benefits that ought to be guaranteed for disabled people. They can also be taken to exhibit genuine political will to achieve equality and inclusion. But this research has served to re-iterate DDP's original rationale for working with local partners in Mozambique: we found and continue to find that disabled people are among the most marginalised and prone to poverty. Stigma and discrimination clearly play their parts (sometimes in the form of "traditional" beliefs) but the reciprocal relationship between poverty and disability has as one of its effects reduced prevalence of autonomy and dignity in the lives of disabled people.

NGOs & INGOs
ADEMO was the first DPO to be established in Mozambique (in 1989) and remains the country's only national DPO with representation in every province and some 80,000 members. In addition, different groups within the disabled population have formed their own DPOs: war veterans, university students, young people, girls and women etc., and similarly, while ADEMO is a cross-disability DPO, other organisations exist for specific disabilities such as *Associação de Surdos de Moçambique* (ASUMO) for deaf and hearing impaired people and *Associação de Cegos e Amblíopes de Moçambique* (ACAMO) for blind and sight impaired people. It would be mistaken to make sweeping generalizations about these DPOs as some are better resourced than others and capacity to represent their constituencies varies. It is, however, generally agreed that the disability movement as a whole in Mozambique can be characterized as weak, especially in respect of its organisational and institutional capacity and consequent ability to effect change.

As the country lying 172nd (of 177) in the UNDP's Human Development Index[7], Mozambique is understandably the focus of intensive bi- and multi-lateral development efforts. With specific reference to disability, aside from DDP, Handicap International have a major presence with over 140 staff involved in 5 main areas of activity: health, social welfare, education, support for local associations and mine clearance. POWER International are working with groups of disabled people to support them to have a say through local radio programmes and supporting the disability movement generally

[7] http://hdr.undp.org/en/statistics/

through working with FAMOD. Finally, the Finnish government's overseas development department, KEPA, work principally in the areas of equal opportunities and human rights.

Conclusion

As a very general rule, the quality of life enjoyed by disabled people varies in direct proportion to the prosperity and overall level of human development of the country in which they live. However, it is important to qualify this statement by emphasizing the reality that, because poverty tends to impact most upon those least able to protect themselves, both relative and absolute measures of quality of life find that inequalities are in fact magnified in the poorest countries. Mozambique exemplifies this dynamic, exhibiting in addition to abiding poverty among its disabled population characteristics of stigma and discrimination, some founded on unenlightened belief systems, which serve to compound that poverty and render escaping it even more difficult. Mozambique, however, is better placed and more enlightened than many other sub-Saharan countries in that it has many instruments that exist to protect and promote disabled people's rights: as so often is the case in developing countries, an agglomeration of poverty related factors such as insufficient resource allocation, a weak disability movement and DPOs, and limitations of infrastructure create and perpetuate the gulf between principle and practice, even where the argument for disability rights has been won.

Chapter 4

HIV & AIDS in Mozambique

Synopsis
The first case of AIDS was reported in Mozambique in 1986 and, according to UNAIDS, Mozambique now has "..the 10th highest HIV prevalence in the world"[8]. The most recent data (2004) show a country-wide adult (15-49 years) prevalence of 16.2%, which implies a total people number of people now living with HIV & AIDS approaching 2 million[9]. The following table gives a breakdown for the country's 11 provinces[10]:

Province	Prevalence %
Maputo city	20.7
Maputo province	20.7
Gaza	19.9
Zambesia	18.4
Sofala	26.5
Tete	16.6
Inhambane	11.7
Nampula	9.2
Cap Delgado	8.6
Niassa	11.1
Manica	19.7

Within these provincial figures, there are marked variations between districts with some local clusters in Sofala approaching a prevalence rate of 40%. These variations have identifiable causes: the city of Beira in Sofala province is the main Indian Ocean port for road haulage from Zimbabwe, Zambia, Malawi and Botswana and the trade corridors pass through Tete, Zambesia and Manica as well as Sofala itself. It is widely acknowledged that the sex trade proliferates along such corridors and is a major cause of HIV transmission. In February, 2008, Reuters report the President of the World Bank, Robert Zoellick, voicing concern that the development of new transport routes to meet growing economic activity has the potential to produce a real "tipping point" in Mozambique[11]. It is further believed that the higher prevalence rates in the central provinces (Sofala, Manica, Tete and Zambezia) is partly accounted for by war returnees who had been displaced to neighbouring Zimbabwe and Zambia, where prevalence rates have historically been high, and rising prevalence in southern provinces (Maputo, Gaza and Inhambane) by migrant Mozambican miners returning from South Africa[12].

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[8] http://www.unaidsrstesa.org/countries/mozambique/mozambique.html
[9] Figure extrapolated from estimated population data; the World Health Organization's "worst case scenario" is 2.2 million:
http://www.who.int/GlobalAtlas/predefinedReports/EFS2006/EFS_PDFs/EFS2006_MZ.pdf
[10] http://www.cncs.org.mz/RelatorioVigilanciaEpidemiologicaHIV2004.pdf
[11]http://www.reuters.com/article/healthNews/idUSL0446656520080204?feedType=RSS&feedName=healthNews&rpc=22&sp=true
[12] HIV & AIDS prevention and care in Mozambique, a socio-cultural approach, UNESCO, 2002

As UNAIDS says, "difficulties faced by Mozambique cannot be overstated: there is limited access to any kind of health care, with 70% of its citizens living in rural areas and food insecurity continues to affect the country[13]. Coverage of services continues to increase but is still incommensurate with the problem. There is unequal access to HIV prevention, treatment, care and support and weak institutional capacity"[14]. Within this catalogue of constraints, Mozambique is seeing an increasingly disproportionate impact on girls and women: in the 15-24 age bracket, prevalence among women is three times that of men[15], yet only 5% of sex workers are estimated to be reached by prevention programmes[16]. And the World Bank expects life expectancy in 2010 to be just 36 years[17].

Approximately 112,500 children under 15 years of age are living with HIV or AIDS and this has precipitated a growing crisis of orphan numbers. More than 20% of the 1.6 million orphans[18] in Mozambique have lost one or both parents through AIDS and UNICEF estimate that the total will rise to around 626,000 by 2010[19]. Of the approximately 30,000 babies born each year with HIV, over 50% die in their first year; babies are most vulnerable to mother-to-child transmission during birth, with a 30% probability of fatality unless antiretroviral therapy (ARVT) is provided for both mother and child before birth[20].

The provision of ARVT is a further problematic area, with coverage averaging roughly 4%[21]. The figure for paediatric treatment is approximately 2%, fewer young people than adults generally receive it, and even among HIV positive pregnant women, the figure (September 2005) is just 6.7%[22]. Allied to this problem is the scarcity of voluntary counselling and testing (VCT) services: it is estimated that only 20% of the target number of VCT centres has actually been built[23]. Therefore, with many parts of Mozambique characterized by dispersed rural populations, large numbers of people have no real access

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[13] Author's note: this is compounded by the devastation caused by rain and flooding that occur with dismal regularity – over 150,000 families were affected in Spring 2008.

[14] UNAIDS Country Situation Analysis: http://www.unaids.org/en/CountryResponses/Countries/mozambique.asp

[15] UNAIDS: http://www.unaidsrstesa.org/countries/mozambique/mozambique.html

[16] UNAIDS Country Situation Analysis, *op cit*

[17]http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/EXTAFRHEANUTPOP/EXTAFRREGTOPHIVAIDS/0,,contentMDK:20450357~pagePK:34004173~piPK:34003707~theSitePK:717148,00.html

[18] This may appear an extremely high figure for a country with a population just below 21 million. It has been verified by reference to a variety of sources, for example, UNICEF and SOS Children's Villages, "the world's largest orphan charity", and the word "orphan" means a child who has lost i=one or both parents.

[19] UNICEF: http://www.unicef.org/mozambique/hiv_aids_2045.html

[20] HIV & AIDS in Africa: a brief overview of the global context, Justin Alexander and Iona Joy, New Philanthropy Capital, February 2005.

[21] For comparison purposes, the figure for Malawi is a little over 9% (http://www.unaids.org/en/CountryResponses/Countries/malawi.asp), while South Africa claims 42% (http://data.unaids.org/pub/Report/2008/south_africa_2008_country_progress_report_en.pdf)

[22] International Planned Parenthood Federation (IPPF), Mozambique Report Card, www.ippf.org/NR/exeres/224CF6A2-2167-46DA-B4EE-96BECE2C88CE.htm - 17k

[23] Estimate of Shareef Malundah, consultant and Director of Miracles in Mozambique

to VCT services, especially if their journey entails transport costs and the loss of income. Where the services are available, it is found that staff are poorly trained and can be prone to discrimination, and, while ARV drugs are free, a charge is made for other prescription medicines.

The common thread running through these characteristics of HIV & AIDS in Mozambique is poverty. Mozambique is indeed a poor country – not only does the latest United Nations Human Development Report (2007-8) rank Mozambique 172nd of 177 countries, it also places the country 101st of 108 developing countries or areas in its Human Poverty Index[24]. The cycle of HIV & AIDS and poverty is widely acknowledged: for individuals, poverty makes HIV & AIDS more likely and living with HIV & AIDS is a cause of poverty; for nations, as people of productive age fall victim to HIV & AIDS, national income falls so that less money is available to prevent and mitigate the pandemic, leading in turn to higher prevalence. Poverty is also linked specifically to HIV & AIDS in the poor health and malnutrition that lead to transmission in the first place and ultimately to death. HIV transmission is by no means certain from an HIV positive person to one HIV negative, but the risk increases the more poor health is experienced. Similarly, the viral load (the number of viral particles found in a sample of blood plasma) is high for the first 3 months after contraction, and the higher the viral load, the greater the risk of transmission[25].

HIV & AIDS in Mozambique is spread almost exclusively through heterosexual sex. But there is no law to prohibit sex work and, often due to imbalances in socio-economic and gender power relations, sex workers have little negotiating power for condom use. It is also the case that Mozambican law does not recognize rape inside marriage, and it is believed to be widespread[26]. Poverty additionally impacts on HIV & AIDS through low levels of education and literacy such that prevention messages can fail to be comprehended or missed altogether. Although there is no room here for a detailed discussion, the spread of HIV & AIDS is assisted by socio-cultural factors ("traditional practices") such as male initiation rites; polygamy; ritual sex (to "cleanse" upon spousal death); widow inheritance (whereby a dead man's wife is transferred to his brother) and the substitution of a husband or wife upon death by a sibling. The propensity for spreading HIV by these means is compounded in some areas by the persisting taboo against parents discussing sex and reproductive health with their children. Nevertheless, it must be acknowledged that these factors are waning and that they occur only in certain rural parts of the country[27].

The *Conselho Nacional de Combate ao HIV/SIDA* (National AIDS Control Council – CNCS) has prevention as part of its remit to co-ordinate the multi-sectoral response to the pandemic in Mozambique. The CNCS, chaired by the prime minister, is working

[24] United Nations Development Programme: http://hdr.undp.org/en/media/hdr_20072008_en_complete.pdf
[25] http://www.aids.org/factSheets/125-Viral-Load-Tests.html
[26] Bureau of Democracy, Human Rights and Labor, US Department of State (2006), *Mozambique: Country Reports on Human Rights Practices*, quoted in IPPF, *op cit*
[27] UNESCO, *HIV/AIDS prevention and care in Mozambique, a socio-cultural approach, 2002*

according to its second strategic plan[28] and all of its activities that are not strictly related to health are financed from the Common Fund, a "basket" funding arrangement to which major institutional donors contribute (the World Bank, the British government's Department for International Development, the German government's *Gesellschaft fur Technische Zusammenarbeit* Technical Co-operation Department - GTZ, the Global Fund etc.). The plan identifies 7 priority areas: prevention, treatment, advocacy, stigma and discrimination, mitigation, research and national response co-ordination. Within the CNCS, NUCLEO (focal point) is the body responsible for disbursing funds to the provinces. This report will examine responses to HIV & AIDS in Mozambique in chapter 6.

[28] http://www.cncs.org.mz/PENII.pdf

Chapter 5

Research Objectives and Methodology

Our research set out to achieve the following:

1. **To discover what research has been done and what is the body of knowledge about HIV & AIDS and disability.**
In preparing our research proposal, we had carried out a summary document review of the subject worldwide, rather than limited to Mozambique or the developing world. This review, while far from comprehensive, unearthed very little data of substance or relevance and clearly indicated the need to undertake a far more rigorous investigation.

2. To make an assessment of the scale of the incidence of HIV in Mozambique among the disabled population in two selected provinces where HIV incidence among the general population is known to be high.
The little material our pre-research review found seemed to take for granted that the incidence of HIV among disabled people is not negligible and warrants action. We found these assertions to be unsupported by scientifically verifiable evidence. We were determinedly open-minded and therefore resolved to rectify what we perceived to be a hypothesis open to question by generating valid empirical data. However, as the research progressed, we learned of the very good reasons why it is difficult to the point of impossibility to produce such exact data, and why it is accepted that there is a major HIV & AIDS problem among disabled people. These will be discussed further in chapter 6.

3. To test current levels of awareness of HIV & AIDS among disabled people.
With HIV & AIDS, as in many other fields of human activity, information is power. We were therefore interested to determine the extent to which disabled people are empowered with knowledge. It was important to reach an accurate assessment, as the findings would have implications for other aspects of the research: low levels of awareness might offer a partial explanation for prevalence rates and provide lessons for the dissemination of awareness materials.

4. **To enquire into variations in the incidence of HIV and the different types and severity of vulnerability suffered by people with different disabilities.**

Rather than treat Mozambique's disabled population as a homogeneous entity, we sought to derive a refined analysis of differing HIV & AIDS aspects relevant to people with different types of disability. By defining separate aetiologies for HIV prevalence by disability type, we intended to begin to identify mitigation and prevention strategies. However, ultimately small samples and methodological complications forced us to be cautious about the accuracy of results and so enquiry into this question became confined to differentiating between the constraints relating to HIV & AIDS prevention and awareness materials as they pertain to people with different types of disability.

5. To examine what measures, if any, are being taken in Mozambique or elsewhere by statutory agencies, NGOs or others to include disabled people and their needs in

HIV & AIDS policies and programmes. In other words, are disability issues being mainstreamed at all in HIV & AIDS work or are disabled people being excluded? As an NGO that works in partnership with organisations of and for disabled people in the developing world, DDP often finds that disabled people are ignored in mainstream development initiatives (i.e. those directed towards the general population and not specifically towards disabled people). We believed it would be instructive to enquire into the attitudes of HIV & AIDS service organisations and policy makers regarding the relevance of their work to disabled people, the extent to which they actively considered disabled people's needs and whether or not disabled people participate in interventions. Our starting point would be to test agencies' opinions as to whether HIV & AIDS affects disabled people and, if so, in what ways. This would enable us better to understand not only the degree of disabled people's exclusion (if any) but also the precise mechanisms fomenting that exclusion.

These headline research objectives are manifestly not discrete: findings for each have repercussions for others in a dynamic interplay. A further crosscutting objective was to examine the relationship between poverty, socio-economic inequality, disability and vulnerability to HIV & AIDS. This approach inherently recognises disability as an issue pertaining to development rather than to medicine.

We anticipated finding some examples of disabled people's inclusion in policies and programmes, and aimed to undertake a critical analysis to distinguish facets of their methodology that lent themselves to replication in the context of Mozambican culture and society. We were at the same time keenly aware of the notion of "cultural appropriateness" wherein the socio-cultural features and dynamics that are responsible for the success of a model in one location do not obtain in another, which can render its wholesale importation either useless or harmful.

Methodology

Desk research – Our literature search in the UK was conducted exclusively on the internet. The following two reference archives were found to be of the greatest use:

- **Source** is "… an international information support centre designed to strengthen the management, use and impact of information on health and disability"[29]. Source is maintained and managed by three organisations working in collaboration: the Centre for International Health and Development at University College, London, Healthlink Worldwide and Handicap International. Source's website contains a microsite (or "key list") dedicated to the subject of HIV & AIDS and disability[30], which is essentially the repository for the dissemination of almost every known study in the field, both published and unpublished, in the forms of books, reports, articles in journals etc. It was quite noticeable, however, that the microsite contains little of substance post 2004; this is readily comprehensible in that definitive arguments and principles were formed at or before this time but, considering the momentum behind the subject starting in

[29] www.asksource.info
[30] http://asksource.ids.ac.uk/cf/keylists/keylist.cfm?topic=az&search=QL_hivdis_AS04

2007, we expected to find more documents, for example, reports on applied work and country specific case studies. That we found only few such documents may be for two reasons: firstly, that they do not exist; or, secondly, that their audiences have been restricted to those in the specific areas – in other words, they have not been disseminated widely. A third possibility is that, like the present report, studies and other documents have been in the process of preparation for some while, as comprehensive reviews can be time consuming.

- **The Africa Campaign on Disability and HIV & AIDS** was launched at a meeting in Cape Town in January 2007 under the aegis of the Secretariat of the African Decade of Persons with Disabilities (1999-2009). The campaign launch incorporated the creation of a website[31] containing much of the information to be found in the Source microsite, albeit in (arguably) a more user-friendly format. As Handicap International were central to the campaign's organisation, this parallel may be understood as an intention to engage with a wider audience, particularly in sub-Saharan Africa.

Disability and HIV & AIDS survey

One of the key resources revealed by the desk study was the survey format *Global Survey on HIV & AIDS and Disability*[32]. Following correspondence with the survey team leader, Professor Nora Groce of Yale University, we were given permission to adapt the format to suit the requirements of the present research. Our survey template (In English and Portuguese) forms Annex 1. As we began to plan our survey's implementation, we chose to design it so as to capture all of our desired data within a single questionnaire rather than construct separate documents for each audience. We opted for this approach for the sake of simplicity and so that the best use could be made of DDP time in Mozambique.

The survey therefore sought to satisfy objectives 2-5 above. The most straightforward element was eliciting responses to achieve objective 5 by conducting face-to-face interviews with representatives of the organizations listed below. The organizations were selected to represent not only those involved in HIV & AIDS policy and services but also those working with disabled people - DPOs and international NGOs. The participation of the latter group – enquiring into whether they had experience and examples of their members or beneficiaries being included in HIV & AIDS prevention or treatment initiatives – served as a cross-check for the information supplied by the former group. The interviews lasted between half an hour and two hours as some respondents welcomed the opportunity to explore the subject matter in greater depth as well as responding to the specific questions. In fact, some of the most useful qualitative data emerged from these less structured sessions.

Participating organisations

- Associação dos Cegos e Amblíopes de Moçambique (ACAMO – the Association of Blind and Visually Impaired People of Mozambique), Beira, Sofala province

[31] www.africacampaign.org subsequently changed to www.africacampaign.info

[32] Professor Nora Groce, Yale University School of Public Health, 28th April, 2003

- Associação dos Deficientes Moçambicanos (ADEMO – the Mozambican Association of Disabled People) – Maputo branch
- ADEMO – Sofala branch
- Associacao de Jovens Deficientes de Mocambique (AJODEMO – Mozambican Association of Disabled Youth), Maputo
- Centro Ortopédico Jaipur (COJ - Jaipur Orthpaedic Centre), Manjacaze, Gaza province
- Cruz Vermelha de Moçambique (CVM – Mozambique Red Cross), Maputo
- UK government Department for International Development (DfID), Maputo
- Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ – German Corporation for Technical Co-operation), Maputo and Beira
- Handicap International (HI), Maputo
- International HIV & AIDS Alliance, Maputo (telephone interview)
- Landmine Survivors Network (LSN), Maputo
- Miracles in Mozambique (MIM), Beira
- Ministério da Saúde (MISAU – Mozambique Ministry of Health)
- POWER International, Maputo
- World Health Organization (WHO), Maputo

Objectives 2-4 were more difficult to achieve. We became aware very early of the need to respect the rights of disabled people to unequivocal confidentiality and to refuse to answer certain questions. Rather than subject individual disabled people to questioning that could be misinterpreted as interrogation, we sought to obtain data through modified participatory rural appraisal and appreciative enquiry techniques, focusing on group animation and the stimulation of discussion among disabled people as opposed to direct enquiry, facilitated by their DPO peers. Through these means, our Mozambican partners, ADEMO, surveyed 220 disabled people. While ADEMO was established in 1989 to represent the interests of people with all types of disability, some members believed that they would be more effective forming single disability groups – for instance, ACAMO broke away and formed separately in 1995. Nevertheless, ADEMO's sample included people with all types of physical disability.

We did not consider the use of anonymous self-completed questionnaires as it is the case that the majority of our survey target population is illiterate. However, to complement and partially verify the findings of the group sessions, ADEMO's Sofala province branch gathered village level data through their community activist members. Although much of this data is anecdotal, it supports the overall scenario that was established.

Methodology – general notes
The decision to concentrate the research in the provinces of Maputo and Sofala was governed by the knowledge of the relatively high HIV prevalence rates among the general population there. Constraints of time and other resources led to the conclusion that it would not have been feasible to extend the scope of the research, and attempting to cover a wider geographical area may have led to the dilution of the accuracy of the data generated.

The way in which DDP perceives disability inevitably affected the research methodology and consequently the findings. One of DDP's guiding principles is that the perceived dichotomy between service provision and rights is in fact spurious. We find no contradiction in supporting disabled people and their organisations to protect and promote their rights while *simultaneously* supporting the rehabilitation services that many disabled people need in order practically to demand and enjoy those rights. DDP contends that this conceptualisation is a robust and practical means of treating disability as a development issue – providing that we accept that the goals of development are to improve the quality of life and fuel human fulfilment. Our methodology was therefore diametrically opposed to the charity model of development and the medical model of disability. This affected the research by influencing its focus on agencies and institutions in a deterministic manner (by setting parameters to potential findings) but the data analysis was conducted in full awareness of this.

An unanticipated dividend of the actual activity of conducting the research was that it served as an exercise in both advocacy and awareness raising in its own right. Our partners report that disabled people were stimulated to seek further HIV & AIDS information as a result of participating in group sessions, and organisations that were surveyed were in many cases exposed to the concept of disabled people's vulnerability to HIV for the first time. This will be discussed further below.

Finally, the desk research explored the issue of disability and HIV & AIDS in Uganda, which is frequently cited as a model of the social inclusion of disabled people. It is certainly true that, through organisations such as the National Union of Disabled Persons in Uganda, disabled people are genuinely included in HIV & AIDS policies and programmes, and that Uganda has reported consistent falls in HIV prevalence rates since the early 1990s[33] (although increases have been reported in recent years[34]). However, as regards the methodology of this research, the differences between Uganda and Mozambique were judged more significant than the similarities: the disability movement in Uganda is considerably stronger than in Mozambique, with the concomitant effect that disability issues are routinely mainstreamed, and the political will to recognise disabled people's rights is reinforced by resource inputs far in excess of those able to be mobilised in Mozambique.

[33]STD/HIV & AIDS Surveillance Report, 2003, Ministry of Health, Uganda: http://www.health.go.ug/docs/hiv0603.pdf
[34] UNAIDS, WHO, e.g. http://www.aidsportal.org/Article_Details.aspx?id=7091&nex=

Chapter 6

Findings

Research hypotheses

Our hypotheses were informed by some 13 years' experience of working with partner organisations in Mozambique. Aware of factors such as Mozambique's poverty, the link between poverty and disability, and the general weakness of DPOs in Mozambique, our supposition was that we would find the widespread exclusion of disabled people from HIV & AIDS information and services, policies and programmes. We were determined, however, to avoid pre-empting the research findings and so designed our questionnaire so that the questions were as neutral as possible. DDP's experience combined with empirical evidence concerning disabled people's access to education and other variables further led us to infer that we would find low levels of HIV & AIDS awareness among disabled people.

The summary literature review we undertook prior to embarking on the substantive research led us to believe that, among the wealth of writing about HIV & AIDS, we would find little pertaining specifically to disability or in which disability featured prominently. This review did, however, provide compelling grounds for the hypothesis that disabled people are at least equally as vulnerable to HIV & AIDS as the general population and therefore that their impact would be at least as great with regard to morbidity and fatality.

1. To discover what research has been done and what is the body of knowledge about HIV & AIDS and disability.

Our trawl of the internet found a quantitatively small but qualitatively exemplary literature. Foremost among these is the work of Professor Nora Groce of the Global Health Division of Yale School of Public Health. Her *Capturing Hidden Voices: the Yale University/World Bank Global Survey on HIV & AIDS and Disability*[35], with other publications, provides the first comprehensive contribution to understanding the subject and, we argue, should be considered a seminal work. This is evidenced by her findings, conclusions and recommendations forming the basis of much subsequent writing.

The first reference to disability and HIV & AIDS we found was from 1996[36] but this, as with other early sources, focussed squarely on the developed world and particularly North America. It would be readily agreed that analysis of disability and HIV & AIDS should be subject to economic, social and cultural contextualisation as there exist vast variations between different locations (and especially the developed world and the developing) in conceptualisations of disability and HIV & AIDS, attitudes towards them and myriad other aspects. The first published substantial (and ground breaking) investigations to be found specific to sub-Saharan Africa were reports on the proceedings

[35] Nora Groce, Ph.D, January 2004

[36] HIV & AIDS: building partnerships; AIDS and Disability Action Project, Vancouver, Location in Source Information Centre: HC4.441DIS AID

of conferences in South Africa and Uganda[37] and Namibia[38]. Subsequently, disability and HIV & AIDS reports have been published for South Africa, Rwanda, Uganda, Malawi, Kenya, Zimbabwe and Swaziland but we were unable to locate any information or data for Mozambique. It was nevertheless most instructive to compare the findings of this research with previously published data for the purposes of comparison and to establish broad principles.

However, during the final research visit to Mozambique's second city, Beira in Sofala province, a meeting - initially scheduled to gather data – led to the discovery of an unpublished report: *Baseline Survey on HIV & AIDS & Disability in Mozambique*[39]. This report was commissioned by Disabled Organisation for Legal Affairs and Social Economic Development (DOLASED), which is based in Tanzania and mainly composed of blind and sight impaired lawyers. DOLASED is further connected to the World Band and the above-mentioned Professor Groce. The report's author, Shareef Malundah, in conjunction with the development organisation of which he is Executive Director, Miracles in Mozambique, had further been contracted to develop a manual for the inclusion of disabled people in the programmes of HIV & AIDS service organisations. This report provided an ideal opportunity for use as secondary data to compare findings, especially as it concerned itself with the same two Mozambican provinces (for the same reasons as for the present research) but was conducted using a different methodology.

2. To make an assessment of the scale of the incidence of HIV in Mozambique among the disabled population in two selected provinces where HIV incidence among the general population is known to be high.

We conclude that there is a very high probability that the rate of HIV prevalence among disabled people is at least as high as among the general population. However, we choose not to classify this as a definitive judgement due to the impossibility of obtaining scientifically verifiable prevalence data among disabled people within the compass of this research. The principal reason for this is one of this report's main findings: that disabled people in Mozambique are subject to extreme levels of stigma and discrimination. Stigma (often defined as a "social process of devaluation"[40]) in Mozambique is closely connected to the belief system in which a disability is perceived as a manifestation of a formerly committed "sin" or is morally reprehensible as a variation from the norm. Stigma then can be perceived (by the stigmatiser) as justifying the discrimination that blights disabled people's life chances. Under these circumstances, it is not reasonable to encourage disabled people to expose themselves to the second stigma that attaches to HIV positive status.

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[37] HIV & AIDS and reproductive health in relation to women and children with disabilities, African Network of Women with Disabilities Kampala, National Union of Disabled Persons of Uganda (NUDIPU) 2002

[38] HIV and AIDS and disability, NARIB, Leitago D Windhoek, National Federation for People with Disabilities in Namibia (NFPDN) 2003

[39] Malundah S, Disabled Organisation for Legal Affairs and Social Economic Development (DOLASED) consultant, Maputo, 2006.

[40] Discussed, for example, in Williams, P., International Journal of Disability, Community and Rehabilitation, Vol 3, no. 1

It is also the case that our DPO partners report that a significant minority of disabled people would not avail themselves of voluntary HIV testing even if the service were widely and non-judgementally available (a finding corroborated by the DOLASED study). In order to achieve objective 2, we believe that significant resources would need to be devoted by DPOs in awareness raising and confidence building over a long period – the objective remains worthwhile but can be broached only with caution and with a full understanding of disabled people's socio-cultural position.

Nevertheless, analysis of the data gathered relating to the aetiology and pathology of HIV among disabled people substantiates our assertion as to its prevalence. The first question is the extent of disabled people's sexual activity. Regardless of whether assumptions about disabled people's sexual activity are founded on bigoted attitudes, the evidence suggests that risk factors associated with sexual transmission of HIV are higher among the disabled population. ADEMO's Sofala branch report that disabled women are frequently rejected for "mainstream" marriage, are cast out and are "…three times more likely to have several sexual partners in a series of unstable relationships[41]", becoming vulnerable to unsafe sex "…as they too need an outlet for love and physical desires…[42]. This gender dimension can scarcely be overstated: gender power relations (the utterly dominant position of men and subjugation of girls and women) mean that condom use is determined by the male while disability is a known risk factor for sexual violence and institutionalisation. At the same time, "most individuals with disability have little or no access to police, legal counsel and courts for protection[43]".

The other side of this coin is, given disabled people's heightened vulnerability to HIV, to what extent are prevention messages effective for them? This question is directly related to this research's third objective:

3. To test current levels of awareness of HIV & AIDS among disabled people.
One may reasonably assume a strong correlation between HIV awareness and the effectiveness of prevention messages. The survey has produced the following raw hard data among disabled respondents:

Question	Response %age		
	Yes	No	Do not know
1. Do you feel that you are at risk of HIV & AIDS?	57	17	26
2. Do you know what HIV and AIDS are?	16	84	-
3. Do you know how HIV is transmitted?	30	70	-
4. Do you think disabled people would like to find out about their HIV status?	59	21	20
5. Do you think that disabled people are at greater risk of HIV & AIDS than non-disabled people?	14	25	61

[41] Africa Campaign Strategy, 2006-10, p.4
[42] Interview with Mr Thomo, ADEMO Sofala Executive Secretary, October 5th, 2007
[43] Groce, N. *op cit,* p. 10

Notes

- Question 1: the sizeable combined percentage responding "no" and "do not know" may reflect the residual belief that disability confers immunity from HIV & AIDS; surveying also produced evidence suggesting that it is also conceivable that the low self esteem resulting from stigma and discrimination means that some disabled people do not consider themselves "worthy" of HIV & AIDS having internalised the anti-normative nature of their disability.
- Question 2: based on knowing the difference between HIV and AIDS and/or being able to describe the symptoms of AIDS.
- Question 3: based on being able to describe one of the means of transmission.
- Question 5 asked disabled people to compare the risk of HIV contraction between disabled and non disabled people in order to determine whether disabled people themselves were aware of disability-reacted factors involved in contraction and therefore prevalence.

The inherent contradictions in the above data serve only to reinforce the conclusion that HIV & AIDS awareness among disabled people is extremely low, and appreciably lower than among the general population. This confirms the findings of the DOLASED study[44] which finds that "Less than 10% of people with disability know the difference between HIV and AIDS while only 4% can describe symptoms of AIDS".

As well as lending support to the theory of HIV prevalence among disabled people above (in point 2), it is evident that HIV awareness and prevention campaigns have failed to reach disabled people. Here we discovered similarities and differences in constraints between people with different types of disability. "Only 1-2% of children with disabilities receive an education, therefore they automatically miss out on school based HIV and AIDS education programmes"[45] and "as a result, the global literacy rate for all individuals with disability may be as low as 3% and as low as 1% for disabled women"[46], which means that written materials such as leaflets, newspaper articles etc. will not be effective among disabled people generally and useless for blind and visually impaired people specifically, for whom posters and hoardings are equally inappropriate. Televised messages whether in documentary, informational or dramatic form do not reach the overwhelming majority of disabled people too poor to own a set or who live in areas without electricity, and broadcast radio and narrowcast community radio, a development staple in Mozambique, miss deaf and hearing impaired people. People with mobility impairments may be unable actually to get to open air community awareness meetings and find buildings inaccessible while people with learning disabilities and mental and neurological disorders can find that none of these media suit their needs.

The clear implication is that the people who design prevention and awareness materials and the organisations that disseminate them pay little or no heed to disabled people's needs. This is discussed in the findings for question 5 below. It is also true that

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[44] Malundah S, *op cit,* p. 10

[45] Africa Campaign Strategy, p. 2

[46] Menon, A., Pomerantz, S., Harowitz, S. et al. (1994). The high prevalence of unsafe sexual behaviors among acute psychiatric inpatients. Journal of Nerv. Mental Diseases.182:661-666.(quoted Groce N., ibid)

Mozambique's HIV & AIDS Voluntary Counselling and Testing Centres (VCTs) are not set up or equipped to deal with disabled people. For instance, people with mobility impairments have little or no access to Mozambique's VCT service. There are two reasons for this: firstly, the centres' physical infrastructure is inaccessible as they have neither ramps nor room and door design to allow entry. Even if people with mobility impairments were able to gain entry, VCT staff have had no training at all in the different needs of disabled people, and their attitudes tend to be characterised by bigotry which leads to discrimination against disabled people in service provision. This is equally true of people with all types of disability.

5. To examine what measures, if any, are being taken in Mozambique or elsewhere by statutory agencies, NGOs or others to include disabled people and their needs in HIV & AIDS policies and programmes. In other words, are disabilities issues being mainstreamed at all in HIV & AIDS work or are disabled people being excluded?
The findings under this heading are derived from the series of interviews with HIV & AIDS policy and service agencies and organisations. They reveal a clear and virtually uniform picture of the effective exclusion of disabled people by dint of a generalised lack of awareness about their vulnerability and needs.

Policy
As stated above in chapter 4**,** HIV & AIDS policies are formulated and articulated in strategic plans and directed and co-ordinated by CNCS. Although technically independent, CNCS operates within the broad framework of the ministry of health (CNCS' Vice President is Snr. Garrido, health minister). The current strategic plan (2005-9), however, does not refer to disability or to disabled people's needs at all. On the other hand, the 2007 UN Convention on the Rights of Persons with Disabilities contains specific provisions for disabled people with regard to HIV & AIDS and has been signed by the Mozambican government (although it should be stated that the Convention has not yet been ratified and that dissemination has barely begun). While it may be that this can be explained simply in terms of time lag, it is equally true that the Mozambican government signed the Convention on March 30th, 2007, and that there have been no subsequent initiatives towards disabled people's inclusion at the policy level; more likely it is the case that this situation represents an example (in which Mozambique is far from being alone) of the interstice between principle and practice, policy and implementation.

At the ministry of health, the prevailing attitude was that, as part of the population, disabled people are naturally covered by existing policies and programmes, and that provisions to cater for disabled people's special needs had not been part of the thinking. However, the Director of the rehabilitation section of the ministry[47] was the first person interviewed to point out the dual nature of the issue: not only are disabled people at increased risk *of* HIV & AIDS, people are also disabled *by* HIV & AIDS.

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[47] *Secção de Medicina Física e Reabilitação* (Section of Physical Medicine & Rehabilitation)

Through NUCLEO (see above in chapter 4*)*, GTZ support the CNCS by devolving their initiative to mainstream HIV & AIDS throughout development activities to the Districts (there are 128 in Mozambique). This programme seeks to empower grassroots organisations (principally although not exclusively those engaged in primary education and gender) to develop and implement programmes with GTZ support, although there is currently no focus on disability either in terms of mainstreaming or as a development category requiring dedicated HIV & AIDS interventions.

DfID, meanwhile, work to develop organisational and institutional capacity within CNCS especially in the fields of policy development, prioritisation and financial arrangements. It was said that CNCS has been found to be immature by comparison to their counterparts in other sub-Saharan African countries – this is in no sense a value judgement but a reflection of the relative newness of initiatives addressing HIV & AIDS in Mozambique and the general inexperience of government agencies in managing relationships with civil society organisations. DfID expects to participate in the development of the next HIV & AIDS strategic plan and additionally provides funding for the Mozambique Network of AIDS Service Organisations (MONASO), a group which co-ordinates and supports a network of organisations working on HIV & AIDS and sexually transmitted diseases. MONASO provides training, helps network members to communicate among themselves and has instigated a new approach to HIV & AIDS prevention and care, including counselling. Traditionally, DfID has provided backing for advocacy along the human rights model wherein people living with HIV & AIDS actively contribute to policy formation but seem in recent years to have consolidated their approach behind local institution building, possibly recognizing this as a pre-requisite for civil society enabling.

Programmes

Of all the participating organisations, only two, Miracles in Mozambique (MiM) and Handicap International (HI), actively work to provide HIV & AIDS services for disabled people, which is hardly surprising as disability is the *raison d'etre* of both. HI, as prime movers within the African Decade campaign, have assembled an implementation task force and have secured campaign funding from UNAIDS, UNICEF and UNDP. They are connectedly lobbying the Mozambican government to ratify the new UN Disability Convention and planning to campaign for the inclusion of disability as a discrete issue in the next HIV & AIDS strategic plan, already trying to sensitise CNCS to the issue.

At the same time, HI are beginning relatively small projects with grassroots partner organisations to mainstream disability into HIV & AIDS and mainstream HIV & AIDS into disability – what they term "double mainstreaming". HI seemed frustrated by resource constraints especially as they consider the political climate favourable to developing the disability movement generally. HI did sound a warning note, however, which should be born in mind when analysing future HIV & AIDS data: there is a *possibility* that HIV & AIDS could be used as a political tool in that statistics could be misrepresented in order to reflect well on the present government. This informal observation is particularly prescient due to the proximity of elections – in 2008 for parliament and municipalities and a Presidential election in 2009.

MiM, currently based in Beira (although with plans to re-locate to Maputo) are taking a path different from HI in their disability and HIV & AIDS work. There is much to be commended about MiM's approach - they have opted to prioritise immediate action: following their research, they identified the need for a manual to mainstream disability in HIV & AIDS services, have compiled one, and are at the field-testing stage. They are currently working principally with blind and vision impaired and mobility impaired people and their organisations but their strategy – albeit restrained by resource limitations – envisages the inclusion of people with all types of disability.

The responses from representatives of other, more generalised, organisations consistently constituted an epiphany: upon being invited to think about and discuss the reasons why disabled people may be vulnerable, their being disregarded in policy and the unsuitability for them of awareness and prevention media, the need for disabled people's inclusion became immediately apparent. One common factor among all service organisation respondents was that, while on the one hand the disabling effects of AIDS are the focus of attention, on the other, the effects of AIDS on people already disabled are all but ignored. Responses from two senior representatives of the World Health Organisation's (WHO) Mozambique office in many ways exemplified the overall profile. As a substantial organisation engaged in raising awareness about HIV & AIDS and safe sex and running HIV & AIDS service programmes, it was acknowledged that disabled people might be at greater risk of HIV & AIDS than non-disabled. However, WHO were not aware of any HIV & AIDS organisations that include disabled people, did not believe that HIV & AIDS information reached disabled people and had no knowledge of any HIV & AIDS materials presented in formats accessible to disabled people. They also believed that disabled people have little access to testing and counselling services and would have less access to treatment than their non-disabled counterparts. The reasons that were cited for this situation were that HIV & 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.*

Cruz Vermelha Mocambique (CVM – Mozambican Red Cross) run a range of HIV & AIDS programme in 9 of the country's 11 provinces. While they do not provide drug treatments (ARVT), believing that to be the responsibility of government, over 4,000 people receive home based medical care in which trained community members liaise between people living with HIV & AIDS and clinics or hospitals collecting and delivering other medicines, ensuring that they are taken and that refills are provided on time. With AIDS taking its toll of the adult population, orphans are increasingly the focus of CVM services with 2 centres (in Maputo and Beira) open during daylight hours, providing basic schooling, medical care and vocational training. CVM have built homes for orphaned families where the head of the household can be as young as 12. However, the main thrust of CVM's HIV & AIDS work is in the field of prevention where it is estimated that over 80,000 people have been reached. Undoubtedly CVM have thought long and hard about effective means using folk theatre and public speaking among other methods in local languages and dialects often written and presented by

people living with HIV & AIDS. The senior CVM representative who participated in the research argued that disabled people are fully integrated into programmes in the sense that *they are not discriminated against* in provision. CVM staff and volunteers are not, however, trained in disability matters and there are no particular accommodations for disabled people's needs

Among INGOs working in HIV & AIDS, the International HIV & AIDS Alliance (the Alliance) is perhaps the largest. Supporting some 50 civil society organisations to enhance their ability to deliver better services, the Alliance estimates that their programmes reach around 27,000 people. Their support takes the forms of organisational, financial and technical capacity development as well as prevention initiatives geared towards behavioural change. The Alliance's chief criterion for inclusion in their programmes is vulnerability to exposure to HIV and it was accepted that disabled people suffer heightened vulnerability due to poverty. However, while the Alliance is not of the opinion that disabled people are excluded from their programmes, they have not encountered disabled people in the course of their activities. This does not at all reflect badly on the Alliance's work – the conclusion that may be drawn is further evidence for disabled people's "invisibility" in the sphere of HIV & AIDS which, due to stigma, may to some extent be self imposed.

Chapter 7

Conclusion

Recent initiatives in disability and HIV & AIDS notwithstanding, it is reasonable to conclude that the general area has been subject to longstanding and continuing neglect. This research has identified two possible explanations for this. The customary *reaction* that HIV & AIDS does not affect disabled people or does so to a lesser degree may well derive from mistaken assumptions regarding disabled people as sexual beings stemming from a "moral consensus". This moral consensus, being commensurate with the general perception of disabled people's diminished status, deems disabled people's sexuality to be both quantitatively and qualitatively different from (and/or inferior to) that of people without disabilities. These attitudes may be recognised as signifiers of the medical model of disability, which, with its focus on an individual's impairment – their *handicap* – conceptualises disability as illness and then expects suitable sexual behaviour. This value-laden paradigm then denies or belittles disabled people's sexuality as inappropriate as, by being counter normative, it disrupts social stasis.

The second, structural, explanation for neglect is that it illustrates or symptomises the exclusion or marginalisation of disabled people from human development. If "disabled people account for 15 – 20% of the world's poorest[48]", then the truth of DfID's statement that "eliminating world poverty is unlikely to be achieved unless the rights and needs of people with disabilities are taken into account[49]" is made manifest. However, the report of a conference[50] examining the MDGs in the context of disability found conclusively that the MDGs were framed without reference to disabled people, that their indicators take no account of disability and that disabled people and their conditionalities are conspicuous by their absence in MDG monitoring mechanisms. The consequences of this are far-reaching: as the primary development tools, the omission of disability from the MDGs means that disability does not cascade down through national MDG plans (which inform poverty reduction strategies) and then, in turn, to interventions (projects, programmes etc.) designed to contribute to the achievement of the MDGs.

While it is not a particularly original observation, we draw the firm conclusion that the single most important factor in determining disabled people's access and inclusion with regard to HIV & AIDS is poverty. Poverty is increasingly explicitly recognised as the hydra[51] of development: tackling symptoms individually does not necessarily mitigate the overall condition. Solving the problem of poverty, however, is ever more cited as the panacea – as UNDP state "World leaders have pledged to achieve the Millennium Development Goals, including the overarching goal of cutting poverty in half by 2015[52]"

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[48] World Bank, Elwan 1999, quoted by Action on Disability and Development: http://www.add.org.uk/disability_facts.asp

[49] Disability, Poverty and Development, DfID, Feb 2000

[50] Report of the European Conference on Millennium Development Goals:Inclusion of People with Disabilities 14 – 15 May 2007, Bratislava - Senec, Slovakia

[51] The terrifying many headed monster of Greek myth

[52] http://www.undp.org/about/

and DfID, meanwhile, define international development as "…. efforts, by developed and developing countries, to bring people out of poverty[53]". Here, however, we insert an important caveat: across the broad spectrum, not only is the link between poverty and HIV & AIDS unproven, but there is also considerable evidence to rule out a straight line deterministic relationship between them. Elizabeth Pisani, the former UN HIV & AIDS supreme, presents a radical critique of the "conventional wisdom" attaching to the links between poverty and gender and HIV & AIDS[54], citing, for example, countries such as Bangladesh which have high levels of poverty and gender inequality but low rates of HIV. Our comments regarding poverty, therefore, refer to its unique interplay with disability and HIV & AIDS.

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 (with the exception of people with mental disorders who in some formulations are classified as disabled). In Mozambique, as one of the world's poorest countries, poverty impacts with extreme force on its disabled population: among the sample of disabled people in the DOLASED study, only 12% were found to attend secondary school and, of the 26% attending primary education, the majority was forced into provision through night schools[55]. The literacy rate among disabled people in Mozambique is not known but "…the global literacy rate for all individuals with disability may be as low as 3% and as low as 1% for disabled women[56]". The effects of lack of education and consequent illiteracy are many: aside from rendering useless written HIV & AIDS materials, being deprived of the information and the building of intellectual apparatus that education provide means that disabled people are more prone to superstition and therefore to the harmful "traditional practices" mentioned above in chapter 4.

Further, within Mozambique's disabled population, girls and women face multiple layers of inequality – what is frequently referred to as the "double discrimination" of their gender and their disability may be more accurately depicted as quadruple inequalities of gender, disability, poverty and HIV status. Factors which predispose Mozambique's female population generally and disabled girls and women particularly to HIV & AIDS include: sexual violence, fewer rights and inability to uphold rights, worse access to treatment and insufficient provision of information. At the same time, the burden of caring for family members made sick by AIDS tends to fall upon women and girls, reflecting and compounding gender roles. Once again, their inferior socio-economic status may be seen to underlie all of these inequalities.

The extent and nature of stigma, bigotry and discrimination are noteworthy: as mentioned above, 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 personally intolerable, it would also practically serve further to reduce quality of life.

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[53] http://www.dfid.gov.uk/aboutdfid/
[54] Pisani, E. *TheWisdom of Whores: Bureaucrats, Brothels and the Business of AIDS,* Granta, 2008
[55] Malundah S. *op cit*, p 9 – people outside school age find provision only outside working hours
[56] Groce N. *op cit,*P10

Stigma, a vast field of work exercising both DPOs and HIV & 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 & AIDS has reduced in direct proportion to the provision of information and education about both.

In concluding, we ask why it is that disabled people and their organisations in Mozambique have not thus far been able to influence HIV & AIDS policies or programmes. Armed with the mantra *nothing about us without us,* disability movements have successfully brought their needs and priorities into the mainstream in different parts of the world. Mozambique's DPOs, however, despite their commitment and resilience in the face of seemingly perpetual resource constraints, are weak relative to some of their counterparts in other sub-Saharan African nations. The new UN Disability Convention provides an ideal opportunity for DPOs' campaigning to be coherent and cohesive as opposed to the factionalism sometimes observed, as well as a platform to support capacity development and resource enhancement.

Chapter 8

Recommendations

1. **To recognise the urgent need to tackle the exclusion of disabled people from HIV & AIDS policies and programmes in Mozambique.**

   As has been shown above, all of the available evidence points to vulnerability to HIV among disabled people being at least as great as that among the general population. At the same time, recognition of this phenomenon is severely limited, which means that HIV & AIDS service agencies do not cater for a need they are not aware exists, and policy formation and implementation omits the dimension of disability.

   The most effective and efficient means of including disabled people and their needs will be **mainstreaming**, which is comprehensively defined as "… the process of assessing the implications for disabled people of any planned action, including legislation, policies and programmes, in all areas and at all levels. It is a strategy for making disabled people's concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres so that disabled people benefit equally and inequality is not perpetuated. The ultimate goal is to achieve disability equality[57]." Applying this broad statement to mainstreaming disability into HIV & AIDS, the optimum approach would be a twin track methodology. DPOs' capacity should be built through training so that they are equipped to create awareness among government agencies and civil society organisations of the need to mainstream disability in all HIV & AIDS programmes. This in turn will enable the participation of disabled people as key actors in HIV & AIDS policies and programmes, promoting social inclusion with disabled people taking the lead and themselves being resource people and trainers. The second track should be training for HIV & AIDS service agencies in effective communication methods, disability awareness and sensitisation and mainstreaming techniques. Adopting this approach will have the additional benefit of promoting disabled people's social inclusion in a more far-reaching way than being confined solely to HIV & AIDS initiatives.

2. **Concomitant to this approach is the immediate need for the development and widespread use of HIV information, awareness and prevention materials suitable for disability-specific requirements, explicitly acknowledging and tackling the access restrictions of different types of disability.**

   It is also recommended that an imaginative approach be taken to this task: pictorial leaflets (the norm) should be reinforced by ideas such as community theatre, public

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[57] Albert B., Dube AK., & Riis-Hansen TC, *Has Disability Been Mainstreamed into Development Cooperation?*, KaR DfID, 2004

gatherings and inspirational speakers, and whatever research suggests will be effective in the light of local social, economic and cultural circumstances.

3. **As noted above (in chapters 4 & 7), national HIV & AIDS policy is at least partly dependent on frameworks agreed with bi-and multi-lateral donors which are in turn often determined by supra-national goals (the MDGs, for example). This report therefore strongly recommends concerted international strategic advocacy (perhaps through the Africa Steering Group) to ensure that indicators that pertain to disability are incorporated into MDG monitoring systems as a first step.**

   As the trigger mechanisms for cascading, this should lead to routine consultation with disabled people and their organisations in designing and developing country specific MDG implementation strategies. Ultimately, it may be possible to integrate the provisions of the new UN Convention into the MDGs but any realistic assessment of the time that would be required to achieve that makes it imperative that disabled people's inclusion be tackled at the micro level (lobbying and campaigning in-country nationally and regionally) as well as the macro.

   With specific respect to Mozambique, the next National AIDS Strategic Plan is due to commence in 2010. The consultation process to prepare the next plan offers an ideal platform and opportunity for advocacy to demand disabled people's inclusion overtly and by unambiguous reference as a group with a distinctive relationship to the pandemic. As the document that will govern HIV & AIDS work in Mozambique between 2010 and 2014, there will be no better chance to influence policy. For this to be followed through, it would be a prerequisite to have DPO representation on the body monitoring the plan's implementation. As noted above in chapter 7, the new UN Disability Convention, with its HIV & AIDS provisions, offers a sound framework to inform and drive this crucial strategic endeavour, and widespread dissemination of the Convention would help to mobilize new DPO activists. The Convention, incidentally, recently received its 20th ratification, which clears the way for it to have the force of international law.

4. **Both access to services for disabled people and their right to inclusion in policy should be simultaneous foci.**

   Some development theory contends that these are mutually exclusive but we argue that this is a false dichotomy and that a more refined analysis shows a dynamic process between the two in which service provision can actively facilitate the fight for rights.

5. **Gender specific provisions should become incorporated into policy and services, given the social, economic and cultural circumstances that result in the HIV & AIDS burden being disproportionately borne by girls and women.**

It is rather beyond the scope of this report to propose means to realign gender power relations in Mozambique but gender inequalities in HIV & AIDS would be mitigated by the achievement of the social equality of women in communities, families and workplaces. In the shorter term, however, awareness can be raised for instance about the harm caused by "traditional practices", the means by which disabled girls and women can protect themselves against HIV & AIDS, and gender violence. We also believe that, if men are part of the problem, then they must be part of the solution. This is complicated, however, by the fact that the 1997 census shows around 60% of the population as belonging to religions opposed to condom use, although there may be some potential to extend circumcision among males as this has been proved to help prevent the spread of HIV[58].

6. **Dedicated and sustainable economic support and livelihood security programmes should be a development priority, featuring especially training and skills and resource construction.**

   While it is arguable that any significant reduction in poverty in Mozambique would beneficially affect HIV infection rates among the whole population (and accepting the status of poverty reduction as the first priority of development), it is considered almost certain to be true of the country's disabled population. However, the experience of Mozambique's fellow Lusophone (Portuguese speaking) country, Angola, and others demonstrates clearly that the advantages of development and poverty alleviation are rarely if ever spread equally. As disabled people individually and collectively have the lowest or close to lowest socio-economic status at present, the tendency will be for material gains either to peter out as they filter through or to miss disabled people altogether (as has happened in Angola[59]).

7. **Finally, the beacon of hope that is the considerable improvement in HIV rates in Uganda no doubt offers salutary lessons for Mozambique. Although near geographically (separated by only Tanzania), a comparative analysis of responses to HIV & AIDS, let alone their relationship to disability and disabled people, would find little in common. For the purposes of this report, the recommendation that stems from the Ugandan experience is that DPOs must be strengthened institutionally and organisationally, with appropriate resource inputs.**

   This would enable the process in Mozambique then to unfold: strong DPOs with a sound tactical sense of lobbying and campaigning targets and tactics would be better able to represent their constituency in policy fora; at the same time, DPO representatives, that is, individual disabled people, would be able to participate and take the lead in designing and implementing HIV & AIDS services, working in partnership with mainstream agencies.

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[58] For example,. Szabo R. & Short, R, *How Does Male Circumcision Prevent Against HIV Infection?* British Medical Journal, *BMJ* 2000;320:1592-1594 (10 June)
[59] Evaluation of a programme called *Twendi*, Inge Remmert-Fontes, DDP, 2007

A major part of these activities should involve **combating stigma and discrimination** connected to both disability and HIV status. For as long as disability remains a cause of stigma, disabled people will remain reluctant to volunteer for HIV testing so as to avoid the possibility of finding themselves subjected to a second stigma. This stigmatization of people living with HIV & AIDS, disabled and non disabled people alike, means that they are liable to be rejected by their families and their communities, becoming socially marginalized and excluded.

There are key roles here for both FAMOD and ADEMO, the former as the DPO umbrella organisation should have the strength of speaking with a collective DPO mandate, and the latter as it has (at least nominally) national structures for dissemination and mobilization. Within all of these recommendations, there should be liaison with the African Decade Campaign on Disability and HIV & AIDS which would be able to provide practical assistance towards some of the objectives. At the same time, such liaison would prevent duplication of work and wasting ever more valuable resources.

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Williams, P., International Journal of Disability, Community and Rehabilitation, Vol 3, no. 1
Menon, A., Pomerantz, S., Harowitz, S. et al. (1994), The high prevalence of unsafe sexual behaviors among acute psychiatric inpatients, Journal of Nervous Mental Diseases.182
DfID, Feb 2000Disability, Poverty and Development

Albert B., Dube AK., & Riis-Hansen TC (2004), Has Disability Been Mainstreamed into Development Cooperation? KaR DfID

Useful websites

HIV & AIDS
www.africacampaign.info
www.aids.org
www.aidsportal.org
www.ippf.org
www.unaids.org
www.unaidsrstesa.org
www.undp.org/mdg/goal6.shtml
www.unicef.org
www.who.int
www.worldbank.org/eca/aids

Disability
www.add.org.uk
www.asksource.info
www.who.int/disabilities

ANNEXE 1: the questionnaire

Survey on HIV/AIDS and Disability

Disability and Development Partners está a fazer uma investiação sobre HIV-CIDA e deficiência nas provincias da cidade de Maputo e Sofala em Moçambique em cooperação com outras agências locais.
Disability and Development Partners (DDP) is conducting research into HIV/AIDS and disability in the Mozambican provinces of Maputo city and Sofala together with local agencies.

Por enquanto sabe-se muito pouco sobre a incidência de HIV-CIDA entre as pessoas portadoras de deficiência. O interesse nesta area de investigação está a aumentar, especialmente com a campanha da Decada Africana de Pessoas Portadoras de Deficiência (2000-2009).
At the present time, very little is known about HIV/AIDS among disabled people. There is, however, momentum building up behind this area of enquiry, especially with the Campaign headed by the African Decade of Persons with Disabilities (2000-2009).

Nós queremos descobrir:
We wish to discover:
1/ Os níveis actuais de consciencialização e conhecimentos sobre HIV/CIDA entre as pessoas portadoras de deficiência.
2/ Variações entre a incidência de HIV e os diferentes tipos e a severidade da vulnerabilidade das pessoas com diferentes tipos de deficiência.
3/Que medidas estão a ser tomadas em Moçambique ou noutros lugares pelas agências do Estado, ONGs e outros para incluir pessoas portadoras de deficiência e as suas necessidades na política e programas de HIV/SIDA.
1/ Current levels of awareness and knowledge of HIV/AIDS among disabled people.
2/ Variations in the incidence of HIV, and the different types and severity of vulnerability of people with different disabilities.
3/ What measures, if any, are being taken in Mozambique or elsewhere by statutory agencies, NGOs and others to include disabled people and their needs in HIV/AIDS policies and programmes.

Nós estamos interessados em pessoas portadoras de deficiência de todas as idades, que vivem com as suas famílias, ou em instituições. Estamos a procura de informação sobre programas que dão informação sobre HIV e CIDA, intervenções e serviços para pessoas portadoras de deficiência e comunidades.
We are interested in disabled people of all ages, and disabled people living with their families, on their own, or in institutions. We are looking for information

about programmes that provide HIV/AIDS education, interventions and services to disabled people and communities.

Nós enviamos este questionário com o pedido de o preencher em nome da organização ou grupo com quem trabalha. (Se achar que alguém mais na sua organização está mais informada sobre este assunto, por favor peça-lhes que preencham este questionário.) Nós etamos interessados em ter informação de organizações que estão a trabalhar neste assunto e em organizações de e para pessoas portadoras de deficiência. Por favor preencha só a parte do questionário que acha que é apropriada para a sua organização.
We send this survey with the request that you fill it out on behalf of the organization or group you work with. (If you think someone else in your organization would know more about these questions, please give it to them to fill out). We are interested in hearing both from organizations that are working on HIV/AIDS issues and from organizations *of* and *for* disabled people. Please complete only the sections that you feel are appropriate to your organization.

Por favor note que não há respostas certas ou erradas para este questionário. Também pode deixar em branco qualquer pergunta para aqual talvez não tenha a resposta ou com a qual não se sinta avontade em responder: nós não estamos a perguntar (e não queremos) informação pessoal ou nomes de individuais que talvez tenham HIV/CIDA – nós achamos que é muito importantre não invadir a privacidade de ninguém**.** No entanto, como há tão pouca informação disponível sobre este assunto, nós estamos interessados nas ideias das pessoas , impressões, conhecimentos, costumes ou hábitos e atitudes.
Please note that there are no ‘right’ or ‘wrong’ answers to any of these questions. Also, feel free to leave blank any questions for which you may not know the answer or which you may not feel comfortable answering: we are not asking (and do not want) personal information or names of individuals who might have HIV/AIDS – *we feel it is very important that we do not invade anyone’s privacy*. However, as there is so little information available on this subject, we are interested in people’s ideas, impressions, knowledge, practices and attitudes.

Se souber de algum programa ou projecto sobre o qual você achar que nós devemos ter mais informação, por favor informe-nos. Finalmente , se você souber de alguma outra fonte de informação sobre HIV-CIDA e deficiência, nós ficariamos gratos se pudesse enviar-lhes este formulário.
If you know of a programme or project that you think we should learn more about, please let us know. Finally, if you know of other sources of information about HIV/AIDS and disability, we would appreciate it if you would forward this announcement to them.

Lingua : Se para si for mais fácil escrever noutra lingua que não seja Inglês, por favor preencha o formulário na lingua que achar mais fácil.
Language: If it is easier for you to write in a language other than English, please fill out the form in whichever language is easiest for you.

Com os meus sinceros agradecimentos,
Sincerest thanks,

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Email: simon@ddpweb.org

1.1 Background Information

Nome da pessoa que preencheu este formulário
Name of person filling out form:
Nome da Organização
Name of Organization:
Endereço
Address:
E-mail:
Número de telephone
Telephone number:
Tipo de Organição

Type of Organization:
______ Government Organization Organização do Governo
______ National Nacional
______ State Estado
______ Municipal/City Municipal/Cidade
______Other Outro

______ Non-Governmental Organization Organização Não Governamental
______ International Internacional
______ National Nacional
______ Local Local
______ Other Outra

Are you a disability-run organization? A sua organização é de pessoas portadoras de dificência?
______ Yes Sim
______ No Não

Type of services provided: Qual é o tipo de sereviço que providenciam

______ Advocacy/Policy Advocacia/Política
______ Education Educação
______ Medical Serviços médicos
______ Rehabilitation Services Serviços de reabilitação
______ Development/ Economic Desenvolvimento/Economico

_____ Other (please specify) Outro (por favor especifique)

Type of Disability Served: Tipo de deficiência aque dão assistência

______ Physical Física
______ Sight Vista
______ Hearing/speech Ouvido e fala
______ Intellectual Intelectual
______ Mental Mental
______ Multiple disabilities Dificiências multiplas
______ All disability groups Todos os grupos de deficiêntes
______ Other (please specify) Outro (por favor especifique)
______None Nenhum

Number of disabled people/ families served Número de deficientes/famílias aquem prestam serviço.

______ 1-100
______ 100-500
______ 500- 1000
______ 1,000- 10,000
______ Above 10,000 Mais de 10,000

PARTE 1: SENSIBILIZAÇÃO SOBRE HIV/CIDA

2 PART I: HIV/AIDS AWARENESS

1. **ALL** Do you think that disabled people might be at risk of HIV/AIDS?
1. **TODOS** Acha que as pessoas portadoras de deficiência corrrem o risco de HIV/CIDA?

______ Do not know Não sei
______ No Não
If no, why not? Se acha que não, porque não?
______ Yes Sim
If yes, why? Se sim, porquê?

2. ALL Do you think that disabled people are at greater risk of HIV/AIDS than non-disabled people?
2. TODOS Acha que as pessoas portadpras de deficiência correm um risco maior de HIV/CIDA doque as pessoas sem dificiência?

______ Do not know Não sei
______ No Não
If no, why? Se não, porquê?
______ Yes Sim
If yes, why? Se sim, porquê?

3. INDIVIDUALS If you are disabled, do you feel that you are at risk?
3. INDIVIDUAIS Se você é portador de deficiência, acha que corre o risco de HIV/CIDA?

______ Do not know Não sei
______ No Não
If no, why not? Se não, porquê?

______ Yes Sim
If yes, why? Se sim, porquê?
______ Sexually active/multiple sexual partners
Sexualmente activo/multiplos parceiros sexuais
______ Rape/Sexual abuse
Estupro/Abuso sexual

______Suspicion that partner is taking risks with others
Suspeita que o parceiro está-se a arriscar com outros
_____ Drugs/substances
Drogas/substâncias
_____ Medical procedures
Procedimentos médicos
_____ Lack of information concerning HIV/AIDS
Falta de informação sobre HIV/CIDA
______Information is not accessible
Informação não é acessível
_____ Don't have access to prevention programmes
Não tem acesso a programas preventivos
_____ Families will not let them participate in programmes
As famílias não os deixam participar em programas
_____ They live in an institution
Eles vivem numa instituição
_____ Prevention programmes are not in a language that can be understood Os programas de prevenção não são numa linguagem fácil de compreender
_____ Other (Please explain) Outro (por favor explique)

4. **INDIVIDUALS** A) Do you know what HIV and AIDS are
4. INDIVIDUAIS A) Você sabe oque HIV e CIDA são?
_____Yes Sim
If yes, please explain Se sim, por favor explique
______No Não
Do you know how HIV is transmitted?
B) Você sabe como HIV é transmitido?
_____ No Não
_____ Yes Sim
If yes, please explain Se sim, por favor explique

5. ALL Do you have any information on how many disabled people in your area:
5. TODOS Você tem alguma informação sobre quantas pessoas portadoras de deficiência na sua area
A). have died from AIDS? A) morreram com CIDA?
_____ No Não
_____ Yes Sim
If yes, please describe:
Se sabe, por favor descreva

B). are living with HIV or AIDS? B) Que estão a viver com HIV ou CIDA?
_____ No Não
_____ Yes Sim
If yes, please describe:
Se sabe, por favor descreva

6. INDIVIDUALS/NGOs If there are disabled people in the community who have died from, or are infected with HIV/AIDS, how have others in the community responded?
6. INDIVIDUAIS /ONGs Se há pessoas portadoras de deficiência na sua cominidade que morreram, ou estão infetadas com HIV/CIDA, como é que a comunidade reagiu?
_____ HIV/AIDS is not discussed
HIV/CIDA não são discutidas

_____ It is said that they died from something else
Diz-se que elas morreram de qualquer outra coisa
_____ Stigma/prejudice against those who are infected
Existe estigma e preconceito contra os que estão infectados
______With sympathy
Com compaixão
_____ Other (Please explain) Outro (Por favor explique)

PARTE 2 : HIV/CIDA & ORGANIZAÇÕES DE PESSOAS PORTADORAS DE DEFICIÊNCIA

PART II HIV/AIDS & DISABILITY ORGANIZATIONS

7. AGENCIES A). Is your organization involved in raising awareness or providing services about:
7 AGÊNCIAS A) A sua organização está envolvida na sensibilização ou em providenciar serviços para
_____ HIV/AIDS? HIV/CIDA?
_____ Safe sex? Sexo com proteção?
_____ Sexually transmitted infections? Infecções transmitidas sexualmente?
_____ Drug usage? Uso de drogas?
_____ Other topics relevant to HIV/AIDS? (Please describe) Outros tópicos relevantes para HIV?CIDA? (Por favor descreva).

B). If your organization is involved in these activities, please describe the programme in more detail here:
B) Se a sua organização está envolvida nestas actividades, por favor descreva o programa mais detalhadamente aqui:

C) If your organization is involved in these activities, are disabled people included?
C) Se a sua organização está envolvidad nestas actividades, pessoas portadoras de deficiência estão incluidas?
______No Não
______Yes Sim
If yes, in what ways? Se sim, deque forma estão incluidas?

DPOs D). If your organization has not set up an HIV/AIDS programme, what are the reasons (please tick all that apply):
OPDs D) Se a sua organização não organisou um programa para HIV/CIDA explique porque motivo (por favor marque todos que sejam relevantes)
_____ It is not the type of thing your organization does
Não é o tipo de coisa que a sua organização faz
_____ Other organizations are better able to handle it
If so, which organizations?
Outras organizações estão mais bem preparadas para o fazer
Sim assim for, quais são essas organizações?
_____ You do not think it is a significant problem for the populations you serve
Você não acha que seja um problema significativo para as populações que vocês servem
_____ You worry about making disabled people even more stigmatized
Você preocupa-se com o facto disso estigmatizar as pessoas portadoras de deficência ainda mais
_____ Lack of resources
Falta de recursos

_____ Other (Please explain) Outro (Por favor explique)

8. AGENCIES A) Are there any other disability organizations that you know about reaching out to or trying to reach people with HIV/AIDS prevention information? Please describe:
8. AGÊNCIAS A) Sabe de outras OPDs que estejam a tentar atingir ou fazer chegar às populações informação sobre prevenção de HIV/CIDA ? Por favor descreva:

B) Are there any other HIV/AIDS organizations that you know about reaching out to or trying to reach disabled people? Please describe:
B) Sabe da existência de quaisquer outras organizações de HIV/CIDA que estejam a tentar atingir ou estejam a informar pessoas portadoras de deficiência? Por favor descreva

9. DPOs A). Have you ever seen any of the disabled people you serve reached by HIV prevention messages meant for the general population?
9. OPDs A) Conhece algum caso de alguma pessoa portadora de deficiência ter sido alvo de alguma mensagem sobre prevenção de HIV para a população em geral?

_____ No Não
_____ Yes Sim

If yes, how many of the people in your community do you think were reached? Se a resposta foi positiva, quantas pessoas portadoras de deficiência acha que receberam essa informação ?

_____ Few Poucas
_____ Some Algumas
_____ Most A maioria
_____ All Todas

If yes, what types of information were received? Se a resposta foi sim, que tipo de informação foi dada?

10 ALL B). Do you think the amount of information concerning HIV/AIDS that is reaching disabled people is:
10 TODOS B) Você acha que a quantidade de informação sobre HIV-CIDA que chega às pessoas portadoras de deficiência é

_____ Less than that reaching the general population?
É menor doque a que chega à população em geral?
_____ Equal to that reaching the general population?
Igual áquela que chega à população em geral?
_____ More than that reaching the general population?
Mais doque aquela que chega à população em geral?

11. ALL C). Do you think that the information concerning HIV/AIDS that is reaching disabled people is:
11. TODOS C) Você acha que a informação sobre HIV-CIDA que chega às pessoas portadoras de deficiência é

_____ Less accurate than that reaching the general population?
Menos correcta doque a que chega à população em geral?
_____ Equal to that reaching the general population?
Igual áquela que chega à população em geral?
_____ More accurate than that reaching the general population?
Mais correcta doque aque chega à população em geral?

12. ALL Do you know of any particular constraints preventing information concerning HIV/AIDS reaching disabled people?

12. TODOS Você sabe de algum constrangimento que impeça a informação sobre HIV.CIDA de chegar ás pessoas portadoras de deficiência?

_______ No Não

_______ Yes Sim

If yes, please explain Se for sim, por favor explique

13. HIV/AIDS AGENCIES Have large HIV/AIDS campaigns (by non-disability organizations) been inaccessible to the people you serve because they were:

13. Agências de HIV/CIDA Campanhas de informação sobre HIV e CIDA (feitas por organizações de pessoas sem deficiências) eram acessíveis ás pessoas para as quais vocês prestam serviço?

_____ Radio programmes
Programas de rádio

_____ Television programmes
Programas de televisão

_____ Billboards
Cartazes

_____ Other written materials
Outros materias por escrito

____ Complex materials not appropriate for intellectually disabled people
Materiais complexos não adequados para pessoas com deficiências intelectuais ou mentais

______School based
Com base em escolas

_____ Training/education sessions in locations not accessible by wheelchair
Sessões de treino e educação em locais não acessíveis para cadeiras de rodas

_____ Training/education sessions in which no sign language or captioning was available for those who are deaf
Sessões de treino e educação nas quais não havia lingua de sinais ou legendas para os surdos

_____ Other ways (please explain) Outras maneiras (por favor explique)

14. DPOs Has there been any attempt by non-disability organizations to put HIV/AIDS prevention messages into a format that would be more accessible to your group?

14. OPDs Houve alguma tentativa da parte de organizações de pessoas sem deficiências, de porem mensagens preventivas sobre HIV/CIDA num formato que seja acessível para o seu grupo?

_____ Do not know Não sei

_____ No Não

_____ Yes Sim

If yes, what kinds of formats? Se sim, em que formatos?

If yes, how well do you think it has worked? Se a resposta for sim, você acha que foi eficaz?

PART III HELP AND SUPPORT FOR DISABLED PEOPLE WHO ARE LIVING WITH HIV/AIDS

PARTE 3 AJUDA E APOIO PARA PESSOAS PORTADORAS DE DEFICIÊNCIA QUE VIVEM COM HIV/CIDA

15.INDIVIDUALS A) Do you think disabled people would like to find out about their HIV status?

15. INDIVIDUAIS A) Acha que as pessoas portadoras de deficiência vão gostar de saber qual é o status de HIV deles?

______Yes Sim

______No Não

If no, why not? Se a resposta for não, porque não?

B) **INDIVIDUALS** Have disabled people you know been able to find out about their HIV status (been able to get tested for HIV)?

B) **INDIVIDUAIS** Pessoas portadoras de deficiência que você conhece, conseguiram saber sobre o status de HIV deles (conseguiram fazer uma análise de HIV?)

_____ Do not know Não sei

_____ No Não

_____ Yes Sim

ALL Do you know any disabled people who were not able to be tested for HIV, or had trouble getting tested, due to:

13. **TODOS** Conhece pessoas portadoras de deficiência que não conseguiram fazer análise de HIV, ou que tiveram problemas em conseguir fazer uma análise, porque

_____ Inaccessible clinics
A clínica era inacessível

_____ No one willing to treat at them
Ninguém os queria tratar

_____ No Sign Language translation
Não havia ninguém para traduzir com lingua de sinais

_____ Other difficulties (Please explain) Outras dificuldades (por favor explique)

ALL Do you think that disabled people have the same access to HIV/AIDS treatment programmes as non-disabled people?

14. **TODOS** Acha que as pessoas portadoras de deficiência vão gostar de saber qual é o status de HIV deles?

_____ No Não

_____ Yes Sim

If no, please explain. Se a resposta for não, porque não?

PART IV ALL ADDITIONAL COMMENTS OR OBSERVATIONS

Please feel free to write anything on this subject you choose.

PARTE 4 TODOS OS COMENTÁRIOS E OBSERVAÇÕES ADICIONAIS

Por favor sinta-se à vontade para escrever qualquer coisa mais sobre este assunto se desejar.