DISABILITY AND HIV & AIDS IN LESOTHO

A research report by Lesotho National Federation of Organisations of the Disabled

October 2008

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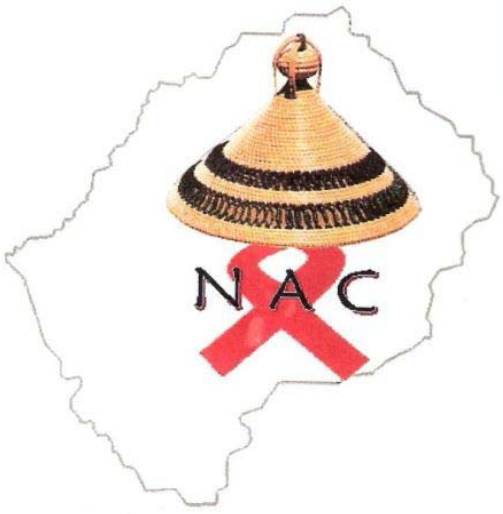

LNFOD

Abstract:

This is a report on research into the capacity needs of disabled people's organisations (DPOs) in management of disability and HIV & AIDS national response activities in the four districts of Lesotho. The research, supported by the National AIDS Commission Fund, was undertaken between August and October 2008 by Lesotho National Federation of Organisations of Disabled (LNFOD).

The stimulus for this study was the knowledge of the effective participation of DPOs and people with disabilities in the national response to HIV and AIDS activities and their capacity in mainstreaming HIV and AIDS activities in their organisational program activities. In particular, the research was focused on determining the extent to which DPOs take role in implementation of the national response within the key areas of management and advocacy as well as data and policy. Premised on little or no capacity of the DPOs on HIV and AIDS national response programmes in the country and the lack of social inclusion of such organisations and individuals with disabilities in the mainstream prevention, care treatment and support and impact mitigation activities, our working hypothesis was that we would find that the national AIDS strategy implementation is largely exclusive of people with disabilities and that DPOs lack capacity in identification and implementation of their roles in the HIV and AIDS strategy. 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, DPO capacity development program design and methodology.

The research began with a literature review and four of the ten districts of Lesotho were selected where HIV prevalence is known to be high among the general population, where broad national response strategic activities are effectively carried out and where Disabled People's Organisations are existent.

The survey objectives are: to identify capacity needs of DPOs in effective management and advocacy in the area of HIV and AIDS and: to establish the extent to which people with disabilities share in the national response to HIV and AIDS activities in prevention, care, support and treatment and impact mitigation.

We found that the DPOs greatly lack capacity in disability and HIV and AIDS management and advocacy. Our survey revealed very low levels of knowledge on DPOs role in HIV and AIDS national strategy that people with disabilities are often excluded from the community and national response programmes. The conclusion then drawn is that the situation reflects inefficiency and terribly low capacity of DPOs and the existing trend of disabled people's marginalisation to participating in the mainstream development projects.

The report's principal recommendation is the urgent need to design a capacity development program for DPOs and the advocacy network program to promote mainstreaming and recognition of disability as demanding attention and provision at all levels.

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Abbreviations:

AIDS
Acquired Immune Deficiency Syndrome

ARVT
Anti Retroviral Therapy

CPRC
Chronic Poverty Research Centre

CBOs
Community Based Organisations

CBR
Community-Based Rehabilitation

DPO
Disabled People's Organisation
(DPOs)

HIV
Human Immunodeficiency Virus

LCN
Lesotho council of non-governmental organisations

LENEPWHA
Lesotho network of persons living with HIV & AIDS

LNAD

Lesotho National Association of the Disabled

LNAPD
Lesotho National Association of the Physically Disabled

LNFOD
Lesotho National Federation of Organisations of the Disabled

LNLVIP
Lesotho National League of the Visually Impaired Persons

LSMHP
Lesotho Society of the Mentally Handicapped Persons

M&E
Monitoring and evaluation

MDGs
Millennium Development Goals

NAC
National AIDS Commission

NADL
National Association of the Deaf Lesotho

NGO
Non Governmental Organisation

NGOC
Non governmental coalition on the rights of a child

SHG
Self-Help Group
(SHGs)

UN
United Nations

UN CRPD
United Nations on the convention of rights of persons with disability

UNDP
United Nations Development Program

UNICEF
United Nations Children’s Fund

PWDs
People with disabilities

VCT
Voluntary Counseling and Testing

STI
Sexually transmitted infections

WHO
World Health Organisation

UN CRPD

Acknowledgements:

We first wish to register our deepest thanks to NAC for the remarkable support they handed over to disability movement to the carrying out of this research. We also thank and acknowledge the help and support given by our partner organisations in Lesotho, the LNAPD, LNLVIP and LSMHP particularly their representatives in the Executive Board of LNFOD, (Ms. Pascalina Letsau, Mr. Steven Thoahlane, Mr. Ts`eliso Leisa, Ms. Mamokete Sebatana, Mr. Hlalefang Konka) – for their collaborative approach in the entire research project.

This research would not have been possible without the cooperation and freely given time of participants. With apologies to anyone who has been accidentally omitted, and in no particular order, the following people gave their help and we thank them:

Moeletsi Rabasotho (LNAPD); Matumelo Liau (LNAPD); Regina Lephoi (NADL); Tholang Raliete (NADL); Masenate Tau (LSMHP)

CHAPTER 1

1.0 INTRODUCTION:

This is a report on research into the capacity needs of disabled people's organisations (DPOs) in management of disability and HIV & AIDS national response activities in the four districts of Lesotho. The research, supported by the National AIDS Commission Fund, was undertaken between August and October 2008 by Lesotho National Federation of Organisations of Disabled (LNFOD).

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The report's principal recommendation is the urgent need to design a capacity development program for DPOs and SHGs and the advocacy network program to promote mainstreaming and recognition of disability as demanding attention and provision at all levels.

CHAPTER 2

2.0 ABOUT LNFOD:

"We truly need to stand for our rights and freedoms; we need a true unity amongst all people with disabilities irrespective of the type or extent of the disability in the country!" Strongly voiced out the disabled throughout the country in 1984 calling upon formation of disabled people's organisations. It was in that year that the Lesotho National Association of the Disabled (LNAD) was formed by people with different disabilities to advocate for the human rights of people with disabilities and to strengthen unity amongst the disabled. With the inception of the then international theories and perceptions on the DPO, a number of specific disability based DPOs started to form in the late 1980s and early 1990s. This resulted in the splitting of LNAD to the DPOs as we know and have them today in Lesotho. However, it was still important and of course valuable to the people with disabilities (PWDs) to keep the unity between people irrespective of their disability and this was reaffirmed in 1991 when a federation of DPOs (Lesotho National Federation of Organisations of the Disabled/LNFOD) was officially established. The fundamental objectives were to keep unity in disability sector and to influence policy and law practices towards better protection and promotion of the rights of PWDs. However, today the LNFOD objectives have extended towards advocating for an inclusive society and inclusive development and certainly, building capacity of her member organisations.

What are we today?
LNFOD - 'Together as one'

LNFOD is a federation of DPOs which represents and advocates for all people with disabilities in Lesotho. LNFOD was established in 1991 to unify disability rights groups fighting for social change. Working with partners, it carries out various activities to strengthen its members and improve the lives of people with disabilities in Lesotho.

Our approach:

LNFOD believes disability is more than a medical problem. We see the social and physical barriers in society as the ultimate factors which define disability. Barriers to receiving an education, to gaining employment and to accessing quality health services, buildings and transport violate the human rights of people with disabilities and lead to exclusion and poverty. We strive to break these barriers, allowing people with disabilities to have equal opportunities and achieve their potential. This approach to disability underlies all of LNFOD's work.

Our activities:

1. Advocacy: LNFOD advocates for the rights of people with disabilities, lobbying at the national and district level for inclusive policies and better services.

2. Sensitization: Negative attitudes and stereotypes towards people with disabilities remain a major problem. LNFOD undertakes awareness-raising activities and uses the media to challenge these views.

3. Capacity-building: LNFOD builds the capacity of DPOs and their members through training and organisational development.

4. Women and human rights: Women and girls with disabilities face double discrimination, based on gender and disability. LNFOD educates these women about their human rights and options for legal protection.

5. Disability and HIV and AIDS: People with disabilities are particularly vulnerable to the impact of HIV & AIDS. LNFOD raises awareness of the causes and consequences of HIV & AIDS and helps people with disabilities to cope with its effects.

Our partners:

LNFOD works with a variety of national and international partners to achieve greater impact in our work. Our partners include:

- NAD
- DPI
- SAFOD
- Skillshare International Lesotho
- Rehabilitation Unit, Ministry of Health and Social Welfare
- NGOC
- CEF
- LCN
- NAC
- Embassy of the United States of America
- Red Cross Lesotho

Our mission...

To support disabled people's organisations and empower their members with life-skills, financial and material resources and to represent their needs to the government, development partners and wider society.

Our vision...

A country in which people with disabilities can enjoy their fundamental human rights and have equal opportunities without prejudice or discrimination.

Our membership...

LNFOD’s members are four disabled people’s organisations, which represent the major disability groups in Lesotho:

- LSMHP
- LNAPD
- LNLVIP
- NADL

CHAPTER 3

3.0 DISABILITY IN LESOTHO:

3.1 The Domestic Scenario

There are no exact or accurate figures for the number of disabled people in Lesotho. The preliminary data from the 2006 census give no indication to the numbers of people with disabilities in Lesotho[1]; although the national statistics set the disability rate at 4.2%. The CPRC survey found a much higher rate of about 10% which is hard to explain given that the Lesotho Demographic Survey found lower rates of disability in the rural areas than the urban areas[2]. Both surveys relied on subjective self-reported assessments. 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, which equates roughly to 9% of the world's population[3], and their assertion that 80% of the world's disabled population live in low income countries[4]. Nevertheless the two survey reports provide some characteristics of disability in Lesotho:

• Men are more likely to be disabled than women particularly in the rural areas which may be explained by the fact that cause of disability most often given was mining accident (31%).

- For women the leading cause was illness.
- Disability increases with age.
- Amputations, blindness, severe deafness and mental problems are the most common.
- 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 Inaccessible buildings, means of transport etc.

[1] 2006 Lesotho census population and housing preliminary results report.
[2] CPRC Working paper no. 40, 1993 – 2002.
[3] http://www.who.int/disabilities/introduction/en/index
[4] http://www.who.int/disabilities/introduction/en/index.html

- Widespread stereotyping, stigma and discrimination.
- Low levels of education and literacy due to lack of access to education.
- Exclusion from employment and livelihood opportunities.

Much impairment in Lesotho 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 mainly become blind in Lesotho through glochauma which can be treated. The specific measures essential towards realization of the rights of the disabled are not spelt out in any legal instrument in Lesotho. But, the Constitution of Lesotho provides for rehabilitation services and employment opportunities to people with disabilities only as a state policy not justifiable before any Court of Law[5].

3.2 The Institutional Context:

Although the government of Lesotho has ratified a number of international conventions with reference to disability, it has not as yet signed and/or acceded to a newly born UN Convention on the Rights of Persons with Disabilities and its Optional Protocol despite. It has also subscribed to the African Decade (1999-2009) in which the intention is that Lesotho be an "implementing country".

Government interventions towards disabled people have so far mostly been in the areas of program and strategy design. There is relatively little work done on the policy and legislation by the government with respect to disability. Very few statutes embody provisions on disabilities though they lack clarity and specificity. We describe below the main statutory actors undertaking work connected to disability:

Rehabilitation Unit Ministry of Health and Social Welfare

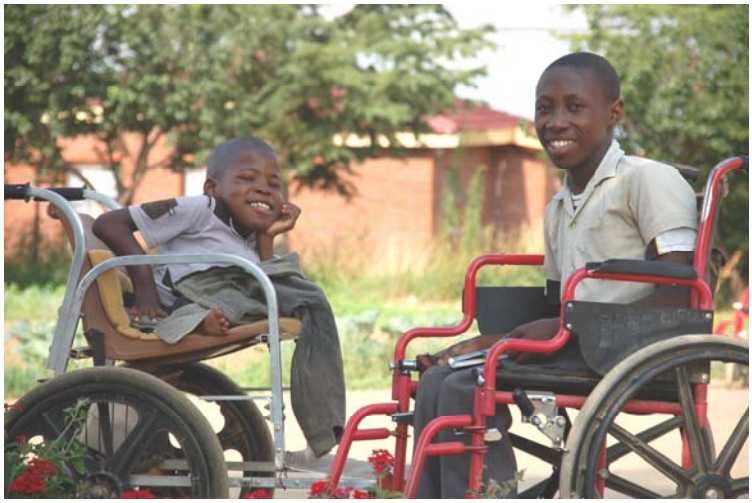
- Rehabilitation Unit disability related activities are principally geared to coordinating other sectors' activities of the CBR Program. The Unit further provides rehabilitation services to people with disabilities through referrals, medical assessment and assistive devices. There are however some challenges hindering effective performance of the Unit: Lack of resources both human and

[5] Lesotho Constitution, Commencement Order, 1992, Sec. 33.

financial rendering the Unit with very few staff members and with some districts having no rehabilitation officer at all, the CBR Program depends heavily on the donor fund with very little contribution from the government. The negative attitude of the Unit towards PWDs; viewing them in a medical model. Poor decentralization rendering district rehabilitation Units dependent on the national budgets; Lack of mainstreaming of the CBR in different government ministries, resulting in the perception that disability issues should get budget from the Ministry of Health and Social Welfare only.

-

- Special Education Unit Ministry of Education and Training: disability related main activities include coordination of all inclusive education activities; provide special education through giving out of special learning facility and building capacity of schools and teachers in including learners with disabilities. Apparently there is a number of challenges hindering the Unit's effective performance: Lack of resources both human and financial, rendering the Unit over-loaded and failing to reach other areas in the country and the Unit financially depends heavily on the Ministry of Health and Social Welfare through the CBR Program; The position of the Unit within the sector renders it unrecognizable, small and of less importance.



There is a national CBR Program although implemented only in the two districts of the country. The LNFOD Disability and HIV and AIDS is implemented throughout the country although it is only in its inception stage and also faced with a challenge of poor capacity of DPOs. Despite the existence of the national CBR plan, there is very little commitment on the part of government representatives in implementing the strategy. A

plan to establish a national Disability coordination structure has been the subject of discussion for some considerable time, together with the adoption of the National Disability Policy. These plans have not materialized primarily because of lack of commitment. The government has promised to accede to UN CRPD by December this year and a lot of dissemination about the Convention is necessary as well as concurrences from relevant government ministries to the government joining the Convention.

Legal and other disability documents

Constitutional principles and outlines the following specific rights for disabled people:

Buildings Control Act:

Education Act:

Children's Protection and Welfare Bill:

Sexual Offences Act:

HIV and AIDS Act:

Local Government Act:

As the country ranking 138th (of 177) in the UNDP's Human Development Index[6], Lesotho is understandably not so much of a focus of intensive bi- and multi-lateral development efforts at least with specific reference to disability. However, Skillshare International has just commenced a Disability Project through a remarkable presence with 5 development workers involved in 4 main areas of activity: health, advocacy, education and livelihoods.

[6] Human Development Report Country Fact Sheets Lesotho, 2007/2008.

Disability Day 2007 as one of LNFOD Advocacy Strategy Events in BEREA

Learnard Cheshire also has some work through Kananelo Centre of the Disabled. NAD also has a very intensive CBR Program they support in the country through their direct links with the government and the DPOs. The Programmes has focus in the 5 areas of health, education, livelihoods, empowerment of DPOs and social inclusion.

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. Lesotho 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. The situation of the disabled in Lesotho became relatively better through the start-up of the CBR Program and the completion of the draft National Disability Policy that both contributed a lot of enlightenment on different stakeholders in issues affecting people with disabilities. But the usual characteristics in developing countries experienced through an agglomeration of poverty related factors such as insufficient resource allocation, a weak disability

movement and DPOs, and limitations of infrastructure creating and perpetuating the gulf between principle and practice still continue.

CHAPTER 4

4.0 HIV & AIDS in Lesotho:

4.1 Synopsis

Lesotho's first AIDS case was reported in 1986[7]. The HIV and AIDS epidemic in Lesotho today is of a mature pattern, with a high case-fatality ratio, large numbers of orphans and vulnerable children, increasing mother-to-child transmission, decreasing life expectancy, declining productivity, affecting the national economy and very high demands on the health care system[8]. The prevalence of HIV in Lesotho is estimated at 23.2% of adult Basotho aged 15 to 49 years by 2005, translating to approximately 266, 000 adult men and women living with HIV infection. The prevalence is particularly high in urban areas at levels of 28.8% compared to 21.8% in the rural areas with a considerable variation in prevalence rates by district[9]. The HIV prevalence is highest among the 15 to 49 years age-bracket and skewed towards women with 55% of diagnosed cases of HIV, and more among young women than young men of similar age with a ratio percentage of more than 60% to less than about 30% for young males[10]. The followin table gives a breakdown for the country's 10 districts:

District Prevalence %
Butha-Buthe district 20.2
Leribe district 29.7
Berea district 24
Maseru city 25.5
Mafeteng 21.6
Mohale's Hoek 20.7
Quthing 23.2
Qacha's Nek 20.6

[7] http://www.avert.org
[8] www.safaids.net/?q=node/287 - 24k -
[9] www.safaids.net/?q=node/287 - 24k -
[10] www.safaids.net/?q=node/287 - 24k -

Mokhotlong 17.7

Thaba-Tseka 18.2[11]

The principal mode of transmission of HIV is through heterosexual contact. Although the probability of transmitting HIV in a single act of intercourse may be low, a number of factors increase the risk. These factors include the viral load of the infected partner, and the presence in either partner of STIs, such as syphilis, chancroid, or herpes, which cause genital ulcers or trauma during sexual contact. A significant number of adults in Lesotho suffer from STIs and some have multiple sexual partners, which increases their vulnerability and exposure to HIV. Consequently, most new HIV infections are because of heterosexual contact.

This is followed in importance by prenatal transmission, whereby the mother passes the HIV virus to the child during pregnancy, at the time of birth, or through breastfeeding.

Those born to HIV infected mothers who do not acquire the virus are at risk of becoming orphans when one or both of their parents die from AIDS-related diseases.

Programs designed to slow the spread of HIV need to focus on reducing transmission through sexual contact. Transmission risk also exists among men who have sex with other men, through blood transfusions, and use of unsterilised needles and skin piercing instruments.

The future direction of this pandemic depends on the level of knowledge of how the virus is spread and changes in sexual behaviour. The information obtained from the 2004 LDHS provides a unique opportunity to assess the level of knowledge and practices

[11] Lesotho Demographic Survey Report, 2004.

regarding transmission of the AIDS virus and other STIs although it greatly falls short of coverage of knowledge on the part of people with disabilities who are mostly at the risk of contracting the disease.

CHAPTER 5

5.0 RESEARCH OBJECTIVES AND METHODOLOGY:

5.1 Objectives

Our research set out to achieve the following:

1. To discover the extent of DPOs' capacity in formulating clearly stated long-term organisational HIV and AIDS purpose, and plans for the medium and short term.

In preparing our research proposal, we had carried out a summary document review of the subject worldwide, rather than limited to Lesotho or the developing world. The review indicated very little data of substance or relevance and resulted in an emphasis on the need to undertake a far more rigorous investigation.

2. To make an assessment of DPOs capacity in identifying Organisation's key HIV and AIDS national response activities and developing appropriate processes and standards to deliver and improve them

The little material our pre-research review found seemed to be supportive of the point that DPOs should have capacity to identify their key HIV & AIDS issues and determine appropriate measures in implementing such activities along with other organisational general activities as a facilitative factor for a flow of preventive and treatment measures to their constituency which is normally excluded from the general education. Nonetheless, we were determinedly open-minded and ready 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 develop such a signage between disability and HIV and AIDS.

3. To test DPOs capacity in networking and partnership working with other organisations through sharing national response related information, providing complementary services, joint work and influencing change.

We were therefore interested to determine the extent to which DPOs are empowered with knowledge and practical alliance building and networking skills in the field of disability and HIV and AIDS. It was important to reach an accurate assessment, as the findings would have implications for the coming stages of Lesotho Disability and HIV and AIDS project.

4. To establish the organisational ability to recognise and value its users/beneficiaries in HIV and AIDS project, and build good relationships with them

We were highly determined to make an analysis of DPOs capacity in identifying their target as that was important to ensure PWDs enjoy their rights in the field of HIV & AIDS and to attack their ignorance and exclusion in this field.

5. To assess capacity of DPOs in collecting and analysing relevant disability and HIV and AIDS information appropriately and systematically and using it to evaluate and improve the organisation and its national response activities

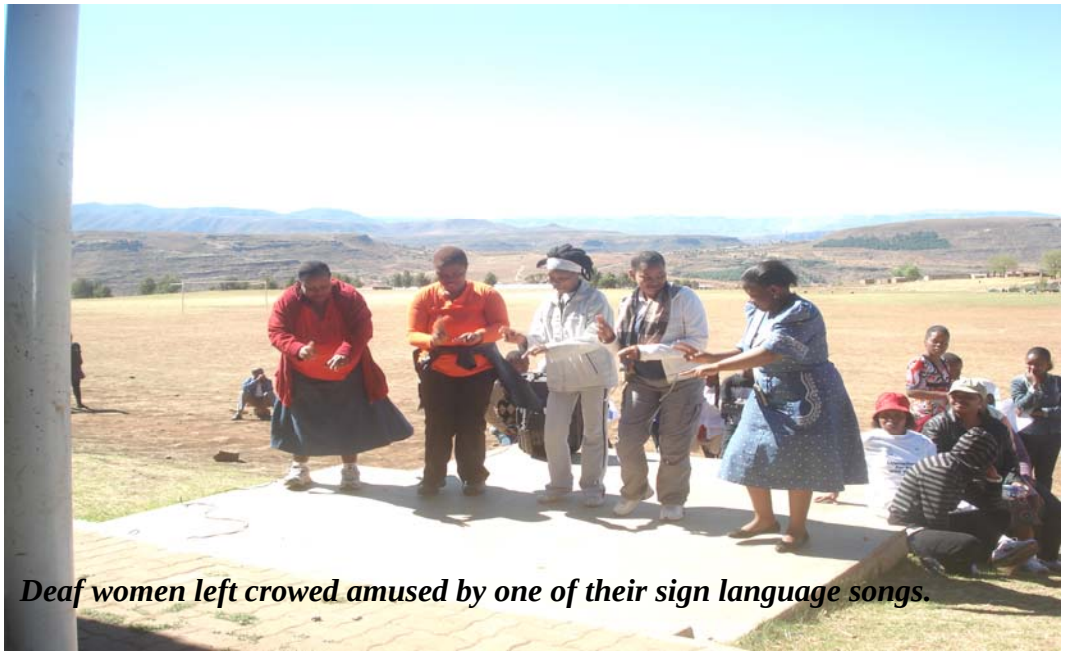
The little material reviewed demonstrated extreme incapacity on the part of DPOs in conducting systematic monitoring of changes and application of appropriate tracking of success indicators necessary in the life of any HIV & AIDS project. However, we were widely open towards receipt of any converse data to this respect.

6. To enquire into DPOs knowledge and ability in collecting and analysing relevant disability and HIV and AIDS data, and appropriately and systematically applying it to policy and project analysis

7. To examine the level of DPOs recognition and valuing the political environment in which it operates, and capacity to proactively seek to improve this environment on behalf of and to the benefit of its constituency.

The research was determined to derive a refined analysis on the aspect of the existing laws and policies in Lesotho that have a bearing on the advocacy work of DPOs. An in-depth analysis of the political factors that affect the success in mainstreaming and including people with disabilities and their organized groups in the HIV & AIDS policies and programmes was highly essential. As an a national federation of DPOs that works in partnership with NGOs and different government sectors, LNFOD often finds that disabled people are ignored in mainstream development initiatives hence, instructive to enquire into the attitudes of the policy makers and AIDS service givers to delivering their services to PWDs.

Our starting point would be to test DPOs' opinions as to whether they have a role to play in HIV and AIDS national response activities. This would enable us better to understand not only the degree of lack of capacity (if any) but also the precise mechanisms fomenting that incapacity. We anticipated examples of groups of PWDs included in the community HIV& AIDS projects and of course having some plans that they are implementing. However we took a caution to actually determine the methodology of that inclusion and the strategic nature of those plans taking into account Lesotho's culture that renders PWDs as mere passive receivers of services, converse to the notion of disability as a development issue upholding the importance of PWDs as active participants in development activities.



Deaf women left crowed amused by one of their sign language songs.

5.2 Methodology

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

One of the key resources revealed by the desk study was the survey format on DPO capacity self-assessment[12]. Following discussions within the survey team, a decision was made to adapt the format to suit the requirements of the present research. Our survey template 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 consistency.

HIV & AIDS needs assessment team interviewing focus group in Tebang

The survey therefore sought to satisfy objectives 1-7 above. The most straightforward element was eliciting responses to achieve the objectives by conducting face-to-face interviews with representatives of the organisations listed below. The participation of the

[12]www.iadb.org/sds/doc/soc-OrganisationalCapacitySelf-AssessmentTool-e.pd.

DPOs– enquiring into whether they had experience in HIV & AIDS planning and examples of their related advocacy goal and monitoring and evaluation systems. The interviews lasted between one 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 some instance, in particular community DPOs, the interviews were prolonged principally because it took participants some time before they could actually have appreciation of what was required of them. Despite, some of the most useful qualitative data emerged from these less structured sessions and we were even more ready to give further information which deemed necessary to enlighten the leadership.

Participating organisations

• Lesotho National Association of the Physically Disabled (LNAPD), Maseru, Mafeteng – Tebang and Matelile community DPOs, Qacha's Nek district branch

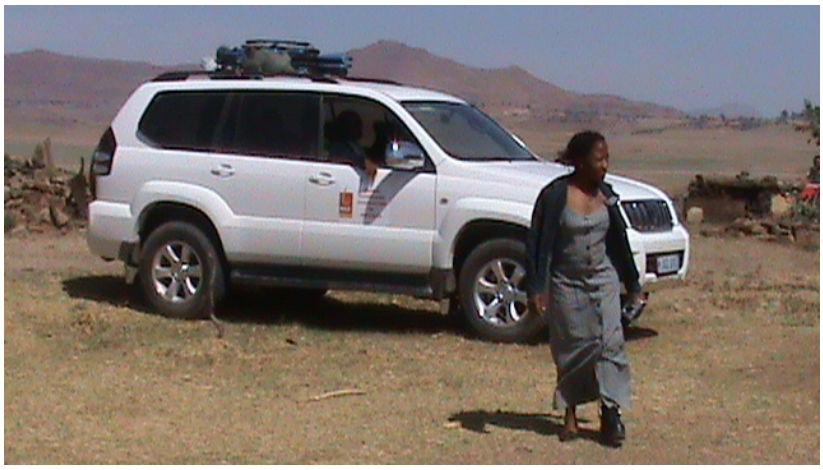
• Lesotho National League of the Visually Impaired Persons (LNLVIP), Maseru, Mafeteng Matelile and Tebang community dpos, Qacha's Nek district branch.

• Lesotho Society of the Mentally Handicapped Persons (LSMHP) Maseru, Mafeteng Matelile and Tebang community dpos, Leribe Ha Mokhoa branch.

• National Association of the Deaf Lesotho (NADL) Maseru, Mafeteng Matelile and Tebang community dpos, Leribe Hlotse branch.

- Ministry of Health and Social Welfare
- National AIDS Commission (NAC
- AIDS NGO and INGOs

Objectives 5 and 6 were more difficult to achieve. We became aware very early of the need to apply simplistic interview methodology for purposes of deriving accuracy and attracting the best of the participants' interest in freely giving out the information needed. Additionally, we sought to obtain data through modified appreciative enquiry techniques, focusing on group animation and the stimulation of discussion among disabled people as opposed to direct enquiry. Through these means, we surveyed 32 disabled people. Our sample included people with visual impairments, physical disabilities, deaf and those with intellectual disabilities. 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, DPO representatives within the survey team led in their particular group discussions to gather village level data. Most of the data hence, supports the overall scenario that was established.



5.2.1 Methodology – General Notes

The decision to concentrate the research in the districts of Maseru, Mafeteng, Leribe and Qacha's Nek was governed by the knowledge of the relatively high HIV prevalence rates among the general population there, existence of ongoing broad national response strategic activities and existence of Disabled People's Organisations. 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 LNFOD perceives disability organisation inevitably affected the research methodology and consequently the findings. One of LNFOD's guiding

principles is that a DPO should be an organisation that views disability merely as a development issue and upholds effective participation of PWDs in the planning, implementation and monitoring of any project's impact as opposed to being subjects of charity only receiving services from the non-disabled members of the organisation. This affected the research by influencing its focus on agencies and institutions in a deterministic manner, setting perimeters of selection of participants. However, 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. The researchers report that disabled people were stimulated to seek further HIV & AIDS information as a result of participating in group sessions, and organisations that were broad in the survey were in many cases exposed to the concept of disabled people's vulnerability to HIV for the first time.

Finally, the desk research explored the issue of disability and HIV & AIDS in Zambia which is cited as a model of the effective disability and HIV & AIDS project in Sub-Saharan Africa[13]. It is certainly true that, through organisations such as the Zambian Federation of Organisations of the Disabled (ZAFOD), groups and organisations of the disabled genuinely receive capacity building in running HIV & AIDS response activities. Individual PWDs get trained as professionals in HIV & AIDS[14]. Further, Zambia experiences a consistent increase in participation of DPOs in the national response activities since 2007 hence, growing numbers of PWDs receiving treatment and livelihood opportunities[15] to mitigate the impact of the pandemic. However, as regards the methodology of this research, the differences between Zambia and Lesotho were judged more significant than the similarities: the disability movement in Zambia is considerably stronger than in Lesotho, with the concomitant effect that disability issues are relatively mainstreamed, and the political will to recognise disabled people's rights is

[13] www.dfid.gov.uk/casestudies/files/africa/zambia- disability.asp - 17k -
[14] (Supra) www.dfid.gov.uk casestudies /files/africa/zambia- disability.asp - 17k -
[15] Help the forgotten minority: Disability and HIV& AIDS in Zambia, 13 January, 2007: (Supra) www.dfid.gov.uk/casestudies /files/africa/zambia-disability.asp - 17k -

reinforced by the national disability legislation[16] and resource inputs[17] far in excess of those able to be mobilized in Lesotho.

[16] Zambia disability Act, 1996, Number 33
[17] www.disability.net/karreport/summer2004/mappingdfid.html - 32k -

CHAPTER 6

6.0 FINDINGS:

6.1 Research Hypotheses

Our hypotheses were informed by some 9 years' experience of working with national disability organisations and HIV & AIDS NGOs, INGOs and relevant government departments in Lesotho and were developed through all caution, in consideration of factors such as Lesotho's poverty, the link between poverty and disability, and the general weakness of DPOs. Our supposition was that we would find the national AIDS strategy implementation largely exclusive of people with disabilities and DPOs' extremely low capacity in identification and implementation of their roles in the HIV and AIDS strategy. 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. LNFOD's experience coupled with empirical evidence concerning DPOs' capacities and disabled people's access to educating information and other variables further led us to infer that we would find low levels of participation by DPOs in the national response activities and poor HIV & AIDS awareness within their membership.

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 those organisations of the disabled need to take active part in the national response activities equal to that taken by other civil society organisations in order to ensure reduction of vulnerability of their constituency to HIV & AIDS.

1. To discover the extent of DPOs' capacity in formulating clearly stated long-term organisational HIV and AIDS purpose, and plans for the medium and short term.

Our trawl of the internet found a qualitatively exemplary literature. Foremost among these is the work of Lina Lindblom who is of the opinion that, because AIDS organisations and governments' HIV responses are not reaching out to persons with disabilities, disability organisations should take matters into their own hands[18]. In several African countries like Botswana, Ethiopia, Kenya, Rwanda, South Africa and Uganda they have come a long way in establishing their own HIV programs that include training, advocacy and development of information in formats accessible to blind, deaf persons[19] and those with intellectual disabilities.

These initiatives are needed because they fill a gap in the official approach to HIV in Africa. DPOs should run their own programs to cater for the knowledge and advocacy needs of their members becoming HIV positive. Their members are ignorant of prevention measures and not reached by national education and control programs.

The African Union of the Blind (AFUB) has developed HIV training and resource materials that address the needs of blind and partially sighted persons, and adapted these into accessible formats for visually impaired persons, i.e. Braille, large print and audio. So far they have trained 1,500 visually impaired persons in their regions on HIV & AIDS and related issues such as counseling and testing and where to get this service, HIV & AIDS management and Anti-retroviral Therapy, sexually transmitted infections and home-based care[20].

The DPOs in Lesotho have just embarked on disability and HIV & AIDS response program so as to promote access to HIV & AIDS services by their members. In Uganda, the disability movement has formed a committee that brings all disability organisations together to work collectively on HIV. The national association of women with disabilities in Ethiopia runs their own HIV program with awareness raising, training, counseling and research. A network of organisations similar to the Ugandan committee is being built in

[18] Lina Lindblom. DPOs fill a gap in the official response to HIV, Cape Times, 29 March, 2007.
[19] www.capetimes.co.za
[20] www.capetimes.co.za

Ethiopia now[21]. These are only but a few examples of a new wave of DPOs initiatives on disability and HIV.

a continental approach was launched that aims to learn from the existing activities and bring together disability organisations, AIDS organisations, governments and other development and funding agencies to work together to improve the situation. The initiative is led by the Secretariat of the African Decade of Persons with Disabilities in collaboration with Handicap International. It is called the Africa Campaign on Disability and HIV & AIDS.

Large AIDS organisations and governments do not include persons with disabilities in their programs[22] and that developed into a need for DPOs to take a critical role in identifying and planning relevant activities, implementing and monitoring the response measures they have put in place. But, the DPOs lack a great deal of the capacity in identifying HIV & AIDS responsive issues and planning strategically to meet those issues[23].

The review however, could not give accurate evidence as to the situation of DPOs in Lesotho hence, instructive to bring the issue to group discussions in order to come up with some tangible samples.

6.2.0 MANAGEMENT AND ADVOCACY

6.2.1 Planning

In the four districts where the survey was implemented, the participants demonstrated almost zero capacity of DPOs and community DPOs in formulating HIV & AIDS strategic long and short term plan to fill a gap in the national response approach.

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[21] www.capetimes.co.za

[22] Lindbom (Supra)

[23]www.disabilitykar.net/mozambique.doc.Mozambican DPOs stated clearly that for them, capacity building means strengthening their organisations to be effective in their work and to achieve results for their members. They understand capacity building to be a process that gives them “legs with which to walk or on which to stand”. They felt clear that the processes of capacity building should increase their skills to plan, implement, monitor and evaluate their work.

Out of 16 community DPOs only 14 had a clear HIV & AIDS mission statement and out of these 14 responses, 4 DPO community DPOs have long term strategies which fit in well within the national response plans. Three of these 4 use management approach while 1 goes for participatory approach in planning. These four community DPOs incorporate finances, education and training on HIV & AIDS in their planning. These are the four headquarters showing clearly the need to improve level of participation of community DPOs.

The researchers made a safe observation that, 62.5 % of the respondents expressed a need for support and improvement of their efforts to plan for the long term. Though participation as a means of planning was not seen as an area in need of improvement, it became clear that the DPOs did not use participation as a means to inform long-term goals and planning, and knowledge of inclusive approaches to planning evolved as a key priority area to be addressed in the training.

6.2.2 Managing Activities

To make an assessment of DPOs capacity in identifying organisation's key HIV and AIDS national response activities and developing appropriate processes and standards to deliver and improve them

The literature recommends that HIV & AIDS activities be managed through a four-fold process ranging from Development and Support of Partnerships and Project Structure; New Knowledge Development; Knowledge Translation; and then Pilot Project Development[24]. The importance of undergoing these stages is mainly to facilitate identification of project activities. However, the practical application of these fundamental principles of project management appears to be complex and difficult[25]. The survey reveals that 81.25 % of the interviewed DPOs have identified their HIV & AIDS activities although there is no evidence regarding application of the stages previously

[24] www.cupe.bc.ca/files/episodic_disabilities.pdf
[25] http://www.africacampaign.info/uploads/media/PRA-Zim-PWD.pdf.

alluded to[26]. It is a generally accepted norm that activities so identified should be effectively implemented to meet the needs of the DPOs' users. On the contrary, many DPOs which are run and led by PWDs are being forced to close down, or are less effectively functioning because of the substantial barriers they face including difficulties obtaining funding and attracting suitably experienced disabled people to take on key leadership roles[27] in the work procedures. It is submitted that at present DPOs are caught in a Catch 22 situation where their needs are not being met, which then hinders their activity implementation ability rendering their needs unmet[28]. This situation is also reflected by the study indicating zero mechanisms in place to manage and ensure effective implementation of HIV & AIDS activities. In this vain, DPOs are faced with a challenge of failure to meet plans and targets and of course, failure to meet the deadline.

Researchers observed that, many of the DPOs especially those in the districts are small organisations with a less developed ability to adjust to new circumstances in finalizing reports, adjusting HIV & AIDS policy and national response strategy and mobilizing resources. Through training, the DPOs could strengthen their activity management and increase effectiveness in delivering and improved ability to identify appropriate HIV & AIDS activities. DPOs should initiate HIV & AIDS and reproductive health programmes that will focus on issues like STIs, family planning, prevention, care, support and mitigation for the PWDs. At the core of these programmes should be an effective advocacy plan for mainstreaming disability in HIV & AIDS programming.

6.2.3 Relationships with Other Organisations

To test DPOs capacity in networking and partnership working with other organisations through sharing national response related information, providing complementary services, joint work and influencing change.

[26] www.africacampaign.info (Supra)

[27] Scope, "National Report", Disability History Timeline, July 2008.

[28] Scope (Supra)

Our desk research on AIDS advocacy highlights the significance of cultivating the relationships between DPOs and AIDS organisations and service providers that is normally said to have a lasting and positive impact on how policy makers respond to AIDS. Relationships amongst stakeholders and appropriate mechanisms should be in place to inform policy makers and programmers on issues of disability and HIV & AIDS. Different surveys and studies conducted in different countries such as Uganda indicate that advocacy for inclusion of persons with disabilities in the mainstream HIV & AIDS programming mostly effective through formation of networks even if informal, partnerships and coalitions with other organisations. Most of the DPOs demonstrate discrimination as their real stumbling block to effective networking with other relevant stakeholders. DPOs' inability to maintain alliances should be additional reason for poor relationships. During the survey, 7 out of 16 DPOs ensure networking, 3 of which demonstrated some form of networking with the support groups. The other 4 network with other stakeholders such as NAC, LENEPWA, Global fund and world vision on HIV & AIDS issues. This might be seen as a fair percentage of DPOs networking with other relevant stakeholders for the same course however, 43.75 % networking is still too low based on how networking is important in HIV & AIDS advocacy issues. The findings reveal that formal partnership occurs only at the national level DPOs. These are planned partnerships addressing organisational development and financial support.

Further, the study show that 7 out of 14 DPOs do nothing to obtain recognition and good working relations with local government where a whooping 10 out of 14 DPOs were unable to advocate either government or any local authorities effectively on issues of disability and HIV & AIDS. This implies that there is still a need for capacity on advocacy for the DPOs as it is of vital importance for them to advocate government or local authorities on combating HIV & AIDS.

From the assessment responses, there seems to be a general lack of understanding of the importance of networking and partnerships to reaching advocacy goals. However, the study expressed by the DPOs was the lack of networking between themselves on HIV & AIDS related issues. Strategies to forming strong relationships were seen as a priority.

Researchers noted the significance of the training on advocacy in the area of disability and HIV & AIDS.

6.2.4 Constituency, Audience, and Advocacy

To establish the organisational ability to recognise and value its users/beneficiaries in HIV and AIDS project, and build good relationships with them

A pool of literature reviewed indicated poor capacity of DPOs in recognizing their users and to build relations with them in order to be able to identify their needs. As a result, large needs of PWDs remain unmet perhaps because DPOs' ability to meet these challenges and to fulfill both an advocacy and service delivery function has been undermined by their limited institutional capacity[29]. Despite this however, and of course with particular reference to Jackie Davies' work on disability and inclusive communication, DPOs should have capacity to share lessons, experiences and identify good practices[30]. DPOs like NGOs, should demonstrate ability to identify their users as PWDs, their families and communities. Additionally, lot of emphasis is seemingly put on the significance of an improved understanding of how to communicate effectively amongst DPOs and PWDs in order to understand both sides' perspectives, and how they can work together for a common purpose[31]. Although the literature reviewed falls short of specific information relating to the situation of DPOs in Lesotho, we were as much as it was necessary, cautioned not to pre-empt the end results of the survey.

In the 4 districts where the survey was implemented, NADL and LNLVIP demonstrated weakness in their user identification mechanisms but however continued to underscore

[29] tools.froogleweb.com/downloadFile.php?ID=247 -

[30] Http:/ /www.healthlink.org.uk/projects/disability/eu_mapping.html - 18k -

[31] http://www.healthlink.org.uk/projects/disability/eu_mapping.html - 18k -

the use of data collection strategy and monitoring interviews and questionnaires to obtain information on the needs of their constituencies. On this basis, it is undoubtedly safe to conclude that the DPOs in Lesotho lack capacity in identification of their constituency and their members' needs and as such, cannot meet PWDs' HIV & AIDS challenges.

In relation to this is DPOs' capacity to meet their targets and HIV & AIDS advocacy goal. In referring to information given out by participants in inclusive communication study, Davies has safely come to a conclusion that both the NGOs and DPOs on one hand need to be able to understand the needs of PWDs so that they are better able to assist them, not only in terms of advocating with them but also working with their families and the communities to identifying their advocacy goal and create suitable and supportive environments[32]. On the other hand, both NGOs and DPOs should establish a communication framework to facilitate sharing of learning and a network essential for meeting advocacy targets and goals. DPOs have a lot to benefit from such networks and communication framework so as NGOs. On the basis of lack of literature pertaining to the actual situation in Lesotho, it was of course significant for us to remain absolutely neutral in a search for the related factual situation.

14 of 16 DPOs interviewed showed demonstrable knowledge on their target audience as local government authorities, national government and service providers. The practical challenge indicated concerned the channels of influence to reaching the target. This therefore, establishes a fact that DPOs greatly lack capacity in advocacy and could rightly be said to having no HIV & AIDS advocacy strategy which certainly should illustrate the project influence map. Nevertheless, there some activities carried out by DPOs aiming at presenting their issues before their targets and those include meetings, public dialogues and media. But since there is a general challenge of non-existence of a clear HIV & AIDS advocacy strategy, one could not by any imagination conclude to the sufficiency of such efforts to meeting the needs of PWDs and to influencing the targets. During the study, it was greatly appreciated that the lack of communication hindered sharing of

[32] http://www.healthlink.org.uk/projects/disability/eu_mapping.html - 18k -

information, networking with stakeholders, and reaching advocacy goals. It was also believed that media campaigns to sensitise the public on disability issues could help reach advocacy goals. Improving communication between DPOs and the media was a key priority. The researchers in this made a general observation of poor capacity in meeting DPOs' constituency needs and in identifying and meeting advocacy goals.

6.2.5 Monitoring and Evaluation

To assess capacity of DPOs in collecting and analysing relevant disability and HIV and AIDS information appropriately and systematically and using it to evaluate and improve the organisation and its national response activities

There is a range of literature on the area of project monitoring and capacity of DPOs to put in place appropriate systems and perform accordingly. The most important is the work of Dube emphasizing a need to capacitate DPOs in setting up monitoring and evaluation systems that would enable them to use the results in a particular DPO policy work and improving on the project performance[33]. However, both national and community DPOs interviewed during the survey demonstrated a serious practical challenge in this instance. 5 of 16 DPOs attempted this question and 3 indicated existence of some sort of monitoring and evaluation plan in their respective DPOs. The fundamental statement put emphasis on poor monitoring and evaluation plans and a need for an established plan for the progress within DPOs. The 2 DPOs who did not have any form of such plans, made a special appeal for capacity building in this area for future development of such plans. In the absence of clear monitoring and evaluation plans, DPOs do not have capacity or even a set practice of incorporating monitoring and evaluations plan in any project design, no indicators developed and obviously no information resulting from monitoring used to improve the program.

[33] Dube, A., 2005, 'Participation of Disabled People in the PRSP/PEAP Process in Uganda', Disability Knowledge and Research, South Africa

The researchers in consideration of all responses received made a general observation that, M&E is a means of good NGO management and that basic training in M&E concepts would benefit the entire community and DPOs.

6.3.0 DATA AND POLICY

6.3.1 Data

To enquire into DPOs knowledge and ability in collecting and analysing relevant disability and HIV and AIDS data, and appropriately and systematically applying it to policy and project analysis

In terms of the literature reviewed during the study, DPOs have an extremely important role to play in collecting data, accessing data and applying it in their advocacy work to respond to data needs of PWDs[34]. However it is actually acknowledged that there is a huge lack of epidemiological data on the incidence and prevalence of HIV & AIDS among PWDs, which is needed to substantiate interventions aimed at fostering PWD's healthcare-seeking behaviour and quality of life[35]. This situation also reflects apparently in Lesotho's DPO who demonstrate the rationale behind that weakness as no capacity and experience in responding to PWDs' needs in this instance. The survey results illustrate zero existence of processes within DPOs to identify data needs of their constituency. None of the 16 DPOs attempted the question relating to these processes perhaps because there was no understanding at all of what was demanded of the question or because there are no such processes at all as confirmed by different DPO plans[36].

It became clear that only 1 DPO, i.e. NADL is engaging in some data collection to be used to inform their future responsive plans and there has never been any national survey on disability to guide their work and inform political arguments. Lack of DPO knowledge

[34]Strategic guidelines for HIV and AIDS, http://www.aidsnet.dk/Admin/Public/DWSDownload.aspx?File=%2FFiles%2FFiler%2FAidsnet%2FStrategi+og+Metode+II%2F10068-08_v1_HIV_strategi_19%5B1%5D.08.08.DOC.
[35] Strategic guidelines on HIV and AIDS (supra)
[36] NADL HIV & AIDS plan, 2008 – 2010.
LSMHP HIV & AIDS plan, 2008 – 2010.
LNLVIP HIV & AIDS plan, 2008- 2010.

and capacity in this instance, lack of human capital to support their data work and general lack of data with respect to disability in HIV & AIDS creates a sufficient conclusion towards a need of capacity building for promotion of attention and response to the needs of PWDs. The researchers broadly recognized that data is a valuable means of forming advocacy arguments, and is vital for changing the political climate and attracting funding resources.

6.3.2 Public Policy and Planning

To examine the level of DPOs recognition and valuing the political environment in which it operates, and capacity to proactively seek to improve this environment on behalf of and to the benefit of its constituency.

There is an extensive literature on this subject and foremost is the report on disability by Hissa Al Thani, whom in upholding the development principle of participation of DPOs in setting policy, managing, administering and delivering programmes, expresses an observation that the participation of DPOs remains lower than it should be in many societies[37]. Failure to take a stake in any of these renders it difficult for these organisations to access the existing policies programmes and even projects. Representation of PWDs' interests in this kind of situation remain as a dream with lots of limitations to materialize. Poor access leads directly to incapacity to influence policy formulation and program and project implementation towards including and meeting disability issues. Additionally, an existing terrible Lack of political power and influence among a majority of DPOs in the world countries often limits their ability to make their issues a priority on government development agendas[38]. Through this survey, Lesotho has appeared to be no exception to this challenge. Out of the 16 DPOs interviewed only 1 attempted this section of the questionnaire. LSMHP Ha Makhoa demonstrated lack of participation in decision making processes of the local government resulting to exclusion of issues of people with disabilities in the planning and implementation of the community development projects. However, some of the responses given by other DPOs in different

[37] Thani H.A, Report of the Special Rapporteur on Disability **"**the 43rd Session of Commission for Social Development", February 8-18, 2005.
[38] Thani H.A, (Supra).

other sections confirmed that DPOs usually are not aware of policy and program planning going on in their different communities and therefore could by no means have opportunity and even capability to influence the policy formulation to be inclusive of disability issues. There is very limited knowledge on the part of DPOs regarding points of contact in the local government authorities thus indicating lack of access to public policy and planning.

The survey revealed an absolute interest amongst DPOs to improve their ability to influence public policy and planning. Besides improving DPOs planning, communication, networking, and use of data, the researchers further acknowledged the importance of an increased DPOs' understanding of the political environment and how decisions are made, and knowledge of how to access information on public planning as key elements to building their capacity in this area. DPO advocacy for political change was found to be of an extremely low level and a need to addressing this in the future capacity development program was noted.

CHAPTER 7

7.0 CONCLUSION:

Recent national initiatives in HIV & AIDS notwithstanding, it is reasonable to conclude that, DPOs suffer great inefficiency and terribly low capacity resulting to the longstanding and continuing neglect of people with disabilities from participating in the national response mainstream programming. This research has identified two possible explanations for this. The slow development within disability movement in Lesotho ever since its birth during the 1980s could be said to be the underlying explanation. There is almost a zero growth within our different national DPOs consequent to progressive financial, technical and political constraints. Despite the DPO successful struggle to winning a local fund support from NAC, DPOs in Lesotho depend heavily on external donor fund which demand satisfaction of certain conditionalities such as a restricted project scope and are tied to some short term projects bound to phase out in a limited period of time. The non-existence of DPOs' sustainability plan addressing financial hardships experienced during expiration period of these donor funded projects renders our DPOs stagnant. Ultimately, we happen to have relatively active DPOs in the capital city while their role is desperately needed by the country's remotest communities.

The majority of people with disabilities in Lesotho are uneducated and thus not knowledgeable of technical issues essential for growth and development in HIV & AIDS discipline [39]. This situation stems from a longstanding and progressive marginalization usually pasted on PWDs by the customary reaction that HIV & AIDS does not affect disabled people or does so to a lesser degree. This may well derive from mistaken assumptions regarding disabled people as sexual beings that has its roots within a moral consensus. These 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 inferior to that of people without disabilities. In

[39] World millenium Summit, "Millenium Development Goals 2000 – 2015", 6th MDG, 2000.

application of this therefore, people with disabilities are denied opportunities to any form of education including HIV & AIDS education.

This circumstance, coupled with the fact that most of our DPOs are led by disabled people themselves, renders disability movement less efficient, ignorant of development issues relevant to influence policy and planning and generally poor capacity to meeting the needs of its constituency. In recognition of some level of knowledge and enlightenment of DPOs in the city, it is safe to conclude that the interest of the majority of PWDs still remain unmet and unrepresented in policy and planning[40] since with the birth of local government phenomenon in the country, planning commences within communities where DPOs are even more weak and of course largely non-existent. Therefore, the growth in the level of neglect and marginalisation of PWDs is seemingly obtaining an increasing momentum.

A possible responsive measure, it is concluded, should be through the application of the principle of 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.

There are some political factors that in one way or the other withhold growth of DPOs and these are characterized within power struggles in different DPOs. Despite their commitment and resilience in the face of seemingly perpetual resource, technical and

[40]National response HIV & AIDS Strategic plan 2006 – 2011.

political constraints, DPOs in Lesotho 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 [41] as opposed to the factionalism sometimes observed, as well as a platform to support capacity development and resource enhancement.

The second explanation, for DPOs' great inefficiency and terribly low capacity, illustrates or symptomises application of the medical model conceptualizing disability as illness that needs medical attention. This stems from believes and attitudes devaluing disabled people and thus rendering them less valuable and inferior to their non-disabled counterparts. According to this kind of thinking, PWDs have a diminished status and in analogy, the DPOs formed by them are relatively less important taking into account the significant role that other civil society NGOs carry out in development issues such as the national response programmes. Consequently, DPOs remain excluded from the mainstream networks, general civil society development programmes and existing HIV & AIDS partnerships.

It is submitted that the DPOs' underdevelopment and the existing application of the medical model to disability will for ever constitute a foundation and a rationale behind inefficiency and lack of capacity of DPOs in meeting the development and HIV & AIDS needs of their constituency. This results in neglect of PWDs from the general national response activities. The study reflected a relatively low percentage of DPOs understanding project planning and this expressed a need for capacity development on planning. Where there is little planning done, full participation of stakeholders and DPO members being a fundamental aspect in planning was not adopted. Many DPOs do not adjust easily to new circumstances in political, technical and financial spheres. Therefore, it is essential to develop management skills and increase efficiency in DPOs.

[41] UN Convention on the Rights of Persons with Disabilities, 2006, Art.29 (b) II.

CHAPTER 8

8.0 RECOMMENDATIONS:

1.

To recognise the urgent need to tackle incapacity and inefficiency of DPOs to fully participate in HIV & AIDS policies and programmes in Lesotho.

As it has been shown above, all of the available evidence points to DPOs' low effectiveness and poor capacity in managing their activities and advocacy in HIV & AIDS programming. At the same time, recognition of this phenomenon is severely limited, which means that HIV & AIDS agencies providing skills development to civil society organisations 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 developing DPOs' capacity and efficiency in project management and policy and advocacy work in HIV & AIDS programming, should be formulation of a comprehensive DPO HIV & AIDS capacity development program. This will be in a form of a strategy addressing skills development within DPOs' role in managing HIV & AIDS project and actively working on policy and advocacy focusing on the 4 thematic areas of the national response strategy [42]. The application of this strategy is practical with the adoption of a General Framework for Inclusion of Disabled People in HIV & AIDS Efforts implementable in a three part typology [43].

I) inclusion of individuals with disability at little or no additional expense to current HIV & AIDS programs:

HIV & AIDS NGOs and CBOs should be educated on nature and roles of DPOs in HIV & AIDS issues to enable collaboration amongst these institutions. The value of this type

[42] National Response Strategy 2006 – 2011 (Supra).
[43] Groce N.E. Guidelines for inclusion of individuals with disability in HIV/AIDS, 2006.

of collaboration is demonstrable through inclusion of DPOs in the mainstream NGO capacity building activities on HIV & AIDS national response. In this instance, extra resources for inclusion of people with disabilities, through their groups and organisations, are not necessary. The organisation providing capacity building service to civil organisation and CBOs simply ensures participation of DPOs in that particular general program. As previously indicated that DPOs in the communities are the most in difficulty, local government and NGOs working in the communities should apply this part of the typology to mainstream DPOs development in their general capacity building programs. A lot of awareness raising and sensitization is necessary to AIDS agencies working on promoting civil society participation in national response activities to provide an understanding on inclusion of DPOs.

II) programs where modifications are made to existing HIV & AIDS programs to ensure greater participation of individuals with disability:

In terms of the evidence gathered, the question of disability and HIV & AIDS is simply too young as a result, HIV & AIDS strategies and policies lack indicators on disability. Hence, where necessary, little modifications providing for specific needs of the disabled should be catered for by AIDS agencies in their functions of developing and promoting capacity of AIDS NGOs in managing their HIV & AIDS and advocacy activities. This part of the typology requires that only simple modifications can be set up to accommodate people with disabilities in the mainstream program. A lot of education needs to be done to build understanding amongst AIDS capacity building agencies on inclusion of DPOs in the trainings they carry out for HIV & AIDS NGOs and CBOs.

III) outreach efforts that are specifically targeted to disabled audiences and that would cost more because of the need for specialized knowledge, time and materials:

As shown previously by evidence collected through the survey, DPOs extremely lack capacity in HIV & AIDS national response strategy. This finding informs formulation of a specific capacity development framework for DPOs both at the national and the community levels. These specific programs should address skills on identification of a

problem and objectives with regard to disability and HIV & AIDS. DPOs should also be capacitated on disability and HIV & AIDS strategic planning, implementation and monitoring and evaluation. As disability advocates, DPOs need to be empowered on planning, implementing and monitoring and evaluating disability and HIV & AIDS advocacy strategy. Lastly, though not limited to , and of course not least, should be capacity building on data use in advocacy work of DPOs and training on influencing policy and public planning for inclusion and meeting the needs of PWDs. This part of the typology requires specificity on disability and a lot of modification to ensure accommodation of people with different extent of disabilities.

2.

Concomitant to this typology is the immediate need for the development of an advocacy network program explicitly acknowledging and tackling the inclusion restrictions of different DPOs and collaboration difficulties with other AIDS NGOs.

It is evident through the findings as rightly captured in Chapter 6 that DPOs have little understanding on building and maintaining networks to promote mainstreaming and recognition of disability as demanding attention and provision at all levels. At the community level, DPOs need to be empowered on research skills necessary to gather information on the existing organisations, institutions, programmes and strategies working on the issue of commonality such as development and HIV & AIDS. That would improve networking, alliance building and ultimately, DPO advocacy for mainstreaming and recognition of their constituency as also vulnerable to the pandemic and its effect.

At the national level, LNFOD is in the process of establishing a disability advocacy coalition with over 40 NGOs. With her participation in the national response programmes, it is reasonably expected that the coalition would inter alia, extend the scope to focusing on advocacy issues in disability and HIV & AIDS. It should however be noted that the coalition is just in its inception stage and has had only two meetings so far with the first in July 2008. On the contrary, it has been indicated in Chapter 6 that DPOs do not have any form of an advocacy network except for the financial and

development partnerships they currently maintain purely for funding purposes. Capacity building in this instance is highly essential to improve DPO advocacy work. More networking with AIDS NGOs, institutions, programmes and strategies is most important and there should be training to give capacity to DPOs and those organisations to form and maintain the network. There is a national AIDS partnership forum that convenes regularly on monthly basis, LNFOD and DPOs should improve their participation and activeness therein, in order to win participants thereof, to mainstreaming and including PWDs and their organisations.

3.

As noted above in Chapters 4 and 6, a challenge of non-availability of data on incidence and prevalence of HIV & AIDS in disability, and DPOs' lack of capacity on identification of data needs and its application in developing HIV & AIDS plans should be tackled with urgency to allow for inclusion of the needs of the disabled in the HIV & AIDS programmes.

Data forms a very important component of any project so far as it gives a baseline on the population, geographic area and constituency demands. In the absence of the data informing DPOs' planning, it is absolutely difficult to justify the responsiveness of their strategies to what constitutes the actual needs of PWDs in a particular area. DPOs should be skilled in identifying their data needs and in applying data to building their projects and planning advocacy. As if it is not enough, it has been noted in explicit terms that there are no official statistics on the population of PWDs in Lesotho and it is instructive that LNFOD engages in a survey to gather data relating to the population of PWDs, the incidence of HIV & AIDS in disability, and the level of their access to treatment, care and support services.

4.

Finally, the beacon of hope that is the considerable improvement in HIV rates in Uganda no doubt offers salutary lessons for Lesotho. 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 Lesotho 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. A major part of these activities should involve combating stigma and discrimination connected to both disability and HIV & AIDS status.

There are key roles here for both DPOs and LNFOD. For all 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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