‘The Forgotten’
HIV and Disability in Tanzania

Technical and Financial Assistance was provided by:
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According to the World Health Organization (WHO), one person in every ten or 677 million people across the globe, live with a disability; however, until recently the impact of the AIDS pandemic upon people with disabilities has received little attention. In the absence of data, it has commonly and incorrectly been assumed that people with disabilities are less vulnerable to HIV infection because they are unlikely to be sexually active or engaging in high-risk behaviours. Yet increasingly, there has been a growing body of literature which indicates that these assumptions are far from true; that people with disabilities face and share all the known sorts of vulnerabilities in HIV and AIDS, and are at equal or increased risk of infection.

In Tanzania an estimated four million people were living with a disability in 2008, half of whom were children; however, little is known about their needs and even less about those who are affected or infected with HIV and AIDS. Reaching them with education and healthcare services is a challenge as resources are scarce; they often need special services for information and other interventions. In other words, very few of them have access to basic services or even know the existing resources.

It is for this reason that an assessment was carried out in early 2009 in selected districts of Tanzania mainland in order to highlight the multiple challenges that people with disabilities face in HIV & AIDS service provision.

This document presents the findings of that assessment. The key recommendations of the study include: the need to overcome stigma and discrimination at the family, community and national levels; to build a disability-friendly environment and strengthen community support for people with disabilities; to strengthen the capacity of HIV and disability service providers; to improve data collection on disability; to strengthen the policy environment; and to work towards overcoming the many obstacles to health and related service access. Critical to the latter will be the need to ensure HIV information is available in formats which are appropriate to those with learning, visual and hearing difficulties.

Key recommendations from the study will be taken forward by the Comprehensive Community Based Rehabilitation in Tanzania (CCBRT) and the CBM in their new project initiative on: Making HIV and AIDS services inclusive for People with Disabilities in Tanzania. The findings will also inform HIV and AIDS related strategies and service guidelines.

This is an important step towards achieving the national commitments and targets, stipulated in MKUKUTA, and the new Health Sector Strategic Plan on HIV and AIDS (2008-2012).

Mrs. Blandina Nyoni
Permanent Secretary
MOHSW
Acknowledgements

This publication is based on the study carried out to assess the needs of people living with disabilities in Tanzania which was conducted under the leadership of Tanzania Commission for AIDS (TACAIDS) in 2009. It is the first of its kind in the country and it provides an insight into the situation of Tanzanians living with disabilities, particularly assessing their vulnerability in terms of risks of contracting HIV and AIDS.

The document is an outcome of the efforts of many individuals and institutions who we are indebted to acknowledge. We would like extend our gratitude to Comprehensive Community Based Rehabilitation in Tanzania (CCBRT) for the vast experience in providing rehabilitation services for people living with disabilities which was very central in shaping the direction of the study.

TACAIDS acknowledges the continued technical support by the Deutsche Gesellschaft fuer Technische Zusammenarbeit (GTZ) GmbH during the entire process without forgetting the financial resources provided by the German BACKUP Initiative, implemented by GTZ, to conduct the study and publish the results. As an international cooperation enterprise for sustainable development with worldwide operations, the federally owned GTZ supports the German Government in achieving its development-policy objectives.

TACAIDS expresses sincere gratitude to the Department of National Response, for pioneering this study, the commitment and guidance provided has contributed significantly to the outcome of this study possible. Special thanks go to Mrs Annika Unterpertinger at CCBRT and all consultants and researchers who were involved in the assessment and the resulting publication, namely Ms. Margaret Morumbasi, Major Gen. (Rtd) Herman Lupogo, and Mr. Raphael Kukula. Furthermore, TACAIDS appreciates the work of the research assistants: Ms. Speciosa Mwankina, Mr. Oscar Mmuni and Ms. Paulina Maro for their tireless work.

TACAIDS is also deeply indebted to the respondents of the interviews for their willingness in sharing their experiences and in making suggestions on how to improve access to HIV and AIDS information and services for people with disabilities. Their responses have significantly informed the outcome of this report.

This publication is an important step towards the integration of people living with disabilities into the HIV and AIDS response in Tanzania.

Dr. Fatma Mrisho
Executive Chairperson
TACAIDS
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>CBM</td>
<td>Christian Blind Mission</td>
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<td>CCBRT</td>
<td>Comprehensive Community Based Rehabilitation in Tanzania</td>
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<td>CHAVITA</td>
<td>Chama cha Viziwi Tanzania</td>
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<td>CHAWATA</td>
<td>Chama cha Walemavu Tanzania</td>
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<tr>
<td>CSO</td>
<td>Civil Society Organisation</td>
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<td>DHS</td>
<td>Demographic and Health Survey</td>
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<tr>
<td>DOLASED</td>
<td>Disabled Organization for Legal Affairs &amp; Economic Development</td>
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<td>FBO</td>
<td>Faith-Based Organisation</td>
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<tr>
<td>GTZ</td>
<td>Deutsche Gesellschaft fuer Technische Zusammenarbeit</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>LGA</td>
<td>Local Government Authority</td>
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<tr>
<td>MDA</td>
<td>Ministries, Departments and Agencies</td>
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<tr>
<td>MKUKUTA</td>
<td>National Strategy for Economic Growth and Reduction of Poverty</td>
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<td>NGO</td>
<td>Non-Governmental Organization</td>
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<td>NMSF</td>
<td>National Multi-Sectoral Strategic Framework on HIV and AIDS</td>
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<tr>
<td>OPD</td>
<td>Organisation of – and for – people living with disabilities</td>
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<td>SHIVYAWATA</td>
<td>Shirikisho la Vyama vya Walemavu Tanzania</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<td>TACAIDS</td>
<td>Tanzania Commission for AIDS</td>
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<td>THMIS</td>
<td>Tanzania HIV &amp; Malaria Indicator Survey</td>
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<tr>
<td>TOMSHA</td>
<td>Tanzania Output Monitoring System for Non-medical HIV &amp; AIDS Interventions</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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Global Overview:
According to the World Health Organization (WHO), one person in every ten - or 677 million people across the globe - live with a disability significant enough to make a difference to their daily lives. Until recently, however, the impact of the HIV/AIDS pandemic upon those living with a disability has received little attention. In the absence of data, it has been commonly – and incorrectly – assumed that people with disabilities are not vulnerable to HIV infection because they are unlikely to be sexually active or engaging in high-risk behaviours. Yet since the Millennium, there has been a growing body of literature which indicates that these assumptions are far from true; that people with disabilities face all the known vulnerability factors for HIV/AIDS, and are at equal or - increased risk - of HIV infection.

Tanzanian Overview:
Although people living with disabilities are considered a vulnerable group in national HIV policy documents, to date HIV initiatives have rarely targeted the country’s four million or so disabled individuals, or taken into account their unique circumstances and needs.

Background, Rationale and Objectives:
The purpose of this study was to carry out an assessment of HIV and disability in Tanzania. It was necessitated by a lack of information about these issues, and guided by the desire to reduce HIV infections and fulfil the rights of all people to access proper and appropriate health information. It is the first study of its kind in Tanzania and will be used to guide future programming.

The study was commissioned by TACAIDS, funded by the German BACKUP Initiative, implemented by GTZ of the German Development Cooperation, and overseen by a Technical Committee led by TACAIDS. It aimed to;

- Assess the impact of HIV and AIDS on people with disabilities;
- Evaluate disabled people's access to HIV information, testing and services;
- Provide recommendations for overcoming obstacles and barriers to the above in order to increase access to HIV services.

The survey gathered information from three key groups: people with disabilities, organisations of - and for - people with disabilities, and HIV organisations. Quantitative and qualitative information was gathered by questionnaire surveys, focal group discussions and in-depth interviews. The survey was carried out in four districts close to Dar es Salaam.

Key Findings:
People with disabilities are sexually active, and engaging in high-risk sexual activities. Yet they are less educated about HIV than their peers and more likely to be excluded from critical HIV services. Specifically, the survey found that of the 40 respondents who were living with a disability:

- Less than half said they ‘knew about’ HIV and AIDS. Even those who did know about it had misconceptions about its transmission.
- Half had had sex by the age of 19.
- Almost a quarter had had sex with a non-regular partner, and most of those (78%) did not use a condom when doing so.
● A quarter of those who were sexually active said they ‘never’ used condoms.
● 15 per cent had had an STI.
● 9 per cent of those tested were HIV positive.
● 40 per cent said they knew a disabled person who had been raped.
● The majority thought it was not easy to access HIV services.
● Stigma and discrimination were reported as key barriers to accessing services.

The study also interviewed Government and civil society organisations involved with delivering services to people living with disabilities and found that:

● Most organisations thought there were key capacity challenges to delivering effective HIV services to those living with a disability.
● The policy and legislation environment was not considered sufficiently supportive of facilitating disabled people’s access to HIV services.
● Collaboration between key HIV and disability organisations was poor.

**Key Recommendations:**
Most HIV and AIDS interventions are geared towards the general population and don’t take into account the special needs of disabled people. Tanzania will need to adjust and adapt its current HIV and AIDS response in order to reach them. The study findings suggest the need to:

● Build a disability-friendly environment;
● Improve access to information;
● Build the capacity of health facilities and providers, as well as that of HIV organisations and those working with people with disabilities;
● Improve coordination between organisations working in the fields of HIV and disability;
● Improve the database on disability and HIV;
● Ensure national minimum policy guidelines are in place to ensure the inclusion of people living with disabilities;
● Ensure guidelines are supported by the responsible national bodies.

**Way Forward:**
The report’s key recommendations will be taken forward by civil society organisations under the auspices of a new project initiative: ‘Making HIV/AIDS Services Inclusive for People with Disabilities in Tanzania.’ The latter will be supported by the Governments of Tanzania and the United States, and begins in 2009.
Disability and HIV: The Global, Continental and National Situation

Global HIV and Disability Statistics

- In 2007, an estimated 33 million people in the world were living with HIV.
- More than two-thirds (25 million) were living in Sub-Saharan Africa.
- In 2009, around 677 million people globally were living with a disability.
- It is not known how many people with disabilities are infected or affected by HIV, but they appear to be more at risk of infection than their non-disabled peers.

According to the World Health Organization (WHO), one person in every ten - or 677 million people across the globe - live with a disability significant enough to make a difference to their daily lives. Most (70 per cent) live in the developing world, and in rural rather than urban locations. They are among the poorest, least educated, and most stigmatized of all the world’s citizens.¹

Until recently, the impact of the HIV epidemic upon people with disabilities has received little attention. Of the 10,000 scientific papers presented at the Bangkok AIDS conference, for example, only twenty focused on HIV and disability (Jansen et al, 2004). The most comprehensive assessment of HIV to date – UNAIDS 2008 Report on the Global AIDS Epidemic – looked at the impact of the virus on many different sections of society but not on the disabled. And a recent report on HIV in the Great Lakes Region failed to identify people with disabilities as a particularly vulnerable group.² In short, the research context in the area of HIV and disability is - with some notable exceptions³ - categorised by neglect.

¹ Based on global population estimates from www.census.gov, May 2009. Other data from WHO, UNESCO and UNDP.
³ E.g. In 2009, UNAIDS published a policy brief on HIV and disability. The links between the two were also a focus of attention at the International Conference on AIDS and STDs in Africa (ICASA) in December 2008 held in Dakar, Senegal.
In the absence of data, it has been commonly - and incorrectly - assumed that people living with a disability are not at high risk of HIV infection because they are unlikely to be sexually active, use drugs or alcohol, or be sexually abused or raped. Yet since the Millennium, there has been a growing body of literature which indicates that these assumptions are far from true.

The 2004 Global Study on HIV and AIDS and Disability, for example, the largest study of its kind, found that people with disabilities face all the known vulnerability factors for HIV and AIDS (poverty, illiteracy, stigma and marginalisation), and are at equal or - increased risk - of HIV infection compared to their non-disabled peers. Sub-groups, such as women, adolescents and minorities, were seen to be at even greater risk. To date, however, HIV and AIDS initiatives have rarely targeted individuals with disabilities or taken into account their unique circumstances and needs. 4

Definitions of Disability

There is no single definition of disability. WHO defines it as a "physical, sensory, intellectual, or mental health impairment that has a significant and long-lasting effect on the individual’s daily life and activities". Tanzania’s National Disability Policy (2004) defines it as “the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, mental or social factors”. Disability is defined in this document in accordance with the latter and therefore includes people with albinism.

People with Disabilities: At Increased Risk of HIV Infection?

There are several reasons why people living with disabilities may be more vulnerable to being infected or affected by HIV:

1: Reduced Access to Information:

People with disabilities are widely shut out of formal education: an estimated 98 per cent of the world's disabled children are not in school and 97 per cent of people living with a disability are illiterate.5 In addition, information, including HIV information, is rarely circulated in an accessible format for this vulnerable group (such as in Braille or using pictorial/simplified formats).

2: Stigma and Discrimination:

Parents, caregivers and health staff often assume people with disabilities do not have sex, or disapprove of them being sexually active. This can result in caregivers refusing to escort them to the clinic; health staff turning them away; or them being missed during HIV outreach work.

3: Inaccessible Health Services:

Most of the world's people living with a disability reside in rural areas, which may be some distance from health facilities. They are less likely than their non-disabled peers to have money for transport or health service costs. Physical limitations (blindness, paralysis etc) may further complicate access. Once at the clinic, they may face environmental obstacles (missing ramps, steep steps) and communication difficulties (few health staff know sign language; lack of information in appropriate formats). The negative attitude of health staff (presumed or actual) is frequently seen as a barrier to accessing health services: service providers may lack knowledge of the special needs of people with disabilities, or have misinformed or stigmatizing attitudes towards them. They may also consider them to be a low priority for their care, attention or treatment. 5

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4 The Global Study was supported by Yale University and the World Bank. It surveyed disabled individuals, organisations and programmes representing 100,000 people from 57 countries (43% of whom were from sub-Saharan Africa). Its findings are found in: Capturing Hidden Voices (Groce, 2004). Full details of all references can be found at the end of this report.

5 DFID (2000): Disability, Poverty and Development.

6 Information is a digest of multiple studies, including UNAIDS policy brief, and the Global Study, 2004.
4: High Incidence of Sexual Abuse:
People who live with a disability are up to three times more likely to be victims of physical and sexual abuse. They are often perceived as easy targets, unable to fight off, recognise, or report their perpetrators. Women and girls who are intellectually challenged and those in special school and care facilities are particularly at risk. Since people with disabilities are widely thought to be sexually inactive, they have become victims of the ‘cleansing myth’ of ‘virgin rape’ (i.e. the notion that you can pass your own HIV infection on if you sleep with a virgin). Groce found evidence of the virgin rape practice in two thirds of the countries studied for the Global Study. Dependency, isolation and a general environment of discrimination also mean that people with disabilities are less likely to report abuse or seek (or gain) legal recourse.

5: High Risk Behaviours:
A number of factors influence high-risk sexual behaviour. For example, the intellectually challenged may not understand about the use of condoms; people with disabilities are more likely to be poor and may engage in transactional or paid sex; sexual abuse is known to make it more likely that you will engage in high risk behaviour.

6: Affected by HIV:
Having a child with a disability makes you more vulnerable to infection. For example, test results compiled in Tanzania’s disability hospital in 2001/2 showed that mothers with a disabled child were twice as likely to be infected with HIV. Giving birth to a child with a disability may make you more likely to be abandoned by your husband, move rapidly through a series of relationships, or engage in transactional or paid sex in order to survive. In turn, having a parent who is HIV positive is likely to reduce the quality of your care: a vicious cycle of disability and HIV/AIDS.

Disability and HIV: The African Context

An estimated 100 million people were living with a disability in Africa in 2009, and an estimated 25 million people in the continent were living with HIV. How many live with both is not known. A handful of small scale studies have indicated that – like elsewhere - HIV prevalence among people with disabilities may be equal to - if not greater - than infection rates among the non-disabled population. For example, a 2003 study in Uganda found that over a third of people with disabilities had had a sexually transmitted infection. The high prevalence of STIs - as a proxy indicator for HIV - has huge implications for programming in the continent at the epicentre of the HIV epidemic.

Stigma and discrimination: Studies in South Africa suggest that stigma exposes people with disabilities to a particularly high risk of HIV infection. Findings from the ‘Forgotten Tribe’ (Progression Zimbabwe, 2006) indicate that widespread discrimination from all levels of society may prevent people with disabilities from accessing health services. A study in Malawi in 2006 found that insensitive and abusive attitudes in schools (including for example, hiding their white canes, leading them to the wrong classroom, relentless teasing) were a key factor in disabled girls dropping out of formal education.

Knowledge: In Swaziland, a 2003 study showed significant differences in HIV knowledge between the hearing and hearing-impaired population, with the latter significantly more likely to believe in erroneous methods of transmissions (e.g. that HIV could be caught by hugging). Almost all the hearing-impaired

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7 Groce (2004): Capturing Hidden Voices.
9 Groce & Trasi (2004): Rape of Individuals with Disability in the Age of AIDS: The Folk Belief of “Virgin Cleansing.”
10 Tanzania’s disability hospital (CCBRT) regularly offers VCT during training weeks for mothers of disabled children. These findings were the results of compiling and analyzing test results over 2001/2.
12 Based on 10% of population (WHO estimate), and using May 2009 population figures.
14 Hanass-Hancock, Jill (2005–8): Invisible: the notion of disability in the connect of HIV/AIDS.
15 Abigail Suka: Violence against Girls who are Blind and Visually Impaired in Schools in Malawi.
respondents of the study said that they had difficulty communicating with healthcare staff, findings echoed by a study by the same authors in Nigeria in 2007.

**Access VCT:** People with disabilities may not access Voluntary Counselling and Testing (VCT) services, even when their level of knowledge and awareness of HIV is high. A survey in Malawi found that although 94 per cent of respondents ‘knew about’ HIV, only 10 per cent had been tested. Respondents gave a variety of reasons for not being tested, including ‘thinking they would be okay’, and difficulties getting to the testing centre.

**Abuse:** A study in Ethiopia found that 46 per cent of respondents living with a disability had been the victims of sexual violence. Other surveys (e.g. Nganzi et al, 2004, Zimbabwe) found evidence of the targeted abuse of children with disabilities, in part as a result of the ‘virgin cleansing’ myth.

**Legal protection:** Studies in South Africa have shown that people with disabilities are less likely to report abuse, be considered reliable witnesses, or be understood in court. They also have less recourse to medical or legal protection. Family members and people with disabilities may be disincentivised to stop or report rape and sexual abuse thinking that they would not be believed, or that - even if they were - action would not be taken.

**Low esteem:** Studies in Rwanda and Uganda indicate that feelings of dependency and low self-esteem among young people with disabilities make them less likely to be able to negotiate safe sex.

**SUMMARY:** The findings detailed above indicate that African people living with a disability are likely to be at higher risk of HIV infection than their non-disabled peers.

**African Policy Level Commitments**

African Governments, policy makers, and civil society organisations are far from blind to the situation of people with disabilities, and have not been deaf to their pleas for assistance in accessing HIV services. The Africa Campaign on Disability and HIV/AIDS - spearheaded by Handicap International and the African Union of the Blind - aims to provide equal access to HIV information and services, and the Secretariat of the African Decade of Persons with Disabilities (2002-2009), opened its office in Cape Town in 2004 to continue raising awareness of the special needs of the continent’s disabled people, including in relation to HIV. In 2005, the ‘HIV/AIDS Awareness and Training Project for Blind and Partially Sighted Persons in Africa’ began and in 2008, the African Network of Women with Disabilities was formed. In practical terms, there have also been attempts to develop materials in formats accessible to the disabled (Kenya), to improve HIV communications (Zimbabwe), and to train staff at VCT centres to serve hearing impaired people (Kenya). However to date, these efforts have been uncoordinated and piecemeal. In general, Ministries of Health expect people with disabilities to access services like the rest of the population in HIV initiatives best categorised as ‘one size fits all’.

**Disability and HIV: The Tanzanian Picture**

**Disability in Tanzania: The Facts**

- An estimated 4 million people in Tanzania live with a disability;
- Almost half of them are children;
- Less than 2 percent are believed to have access to rehabilitation services;
- Most are excluded from school.

In 2008 an estimated four million Tanzanians were living with a disability, half of whom were children. In a poor country like Tanzania, people with disabilities are considered a low priority for the scarce and precious resources of schooling and healthcare. As a result,
very few have access to basic services or even know they exist. The majority of people with disabilities are relegated to the fringes of society, where they live in poverty with little access to services and other support. Very little is known about people with disabilities in Tanzania, still less about those who are affected or infected with HIV. SHIVYAWATA – an umbrella organisation which represents six different disabled people's organisations – conducted participatory poverty assessments across the entire country in 2002/3, and found that people with disabilities are among the poorest of Tanzania's poor.

Policy environment: The policy environment in Tanzania is strong, and the Government has signed a number of international, continental, and national commitments to disability, including the recent United Nations Convention on the Rights of Persons with Disabilities (2006). It is also a signatory to continental action plans, and took a significant step to address the issue at a policy level through its 2004 National Policy on Disability. Despite these policy commitments, people with disabilities are not specifically mentioned as a vulnerable group in the National Policy on HIV/AIDS (2001). And although the current poverty reduction strategy (MKUKUTA) and Tanzania's second National Multi-sectoral Strategic Framework on HIV/AIDS (2008-2012), acknowledges that people with disabilities make up a highly vulnerable group needing special attention, no nation wide interventions have yet been made to actually address their needs.

Tanzania: Key Facts

- Tanzania is one of the poorest countries in the world, and was ranked 152 out of 179 on the Human Development Index in 2008.
- Although the economy is growing, household poverty levels are very high, and over a third of Tanzanians live below the basic needs poverty line.
- The first case of AIDS was diagnosed in Tanzania in 1983.
- Since then, over one million Tanzanian are thought to have died as a result of the epidemic. Recent figures indicate that almost six out of every 100 adults (15-49 years) are HIV positive on the mainland of Tanzania.
- Women are more infected than men (6.8% compared to 4.7%), and rates are higher in urban than rural areas (8.7% compared to 4.7%) and in particular locations. Iringa, has the highest prevalence (14.7%) and Pemba Island the lowest (0.3%).
- More than 1 million Tanzanian children have been orphaned or made otherwise vulnerable as a result of the epidemic.

Data on disability: Although a question on disability was included in the last Population Census (2002), other key surveys have failed to ask or generate information about people with disabilities. For example, the most recent Tanzania HIV & Malaria Indicator Survey (THMIS, 2008) and Demographic and Health Survey did not mention people with disabilities. As a result little is known on a national level about the breadth and depth of disability issues in Tanzania. The National Bureau of Statistics will release a new report on disability later in 2009, which should go some way to addressing these data gaps.

HIV initiatives addressing disability: To date efforts to make HIV initiatives accessible to people with disabilities have been fragmented, with limited geographical reach. A survey in Tanzania in 2006 indicated that the vast majority of HIV/
AIDS organizations in Tanzania have not set up any programmes targeting people with disabilities and that only a fraction have focused on the latter in their work. Only a few organizations have developed disability-friendly HIV and AIDS educational resources, and efforts to train people with disabilities to be peer educators failed through lack of funding and resources.

Disability and HIV organisations: The disability movement in Tanzania is fragmented with little coordination between the existing organisations. Key organisations include SHIVYAWATA, the Disabled Organization for Legal Affairs and Social Economic Development, the Information Centre on Disability, the Tanzania Association for Albinos and the Tanzania Society for the Blind. The Comprehensive Community Rehabilitation Tanzania (CCBRT) is an NGO which was established in 1994 to support people living with disabilities, and has since expanded its focus to those with HIV. It is currently the largest provider of disability and rehabilitation services in the country, and serves around 120,000 people annually primarily from Dar es Salaam and the surrounding regions.

**International and National Commitments to People with Disabilities in Tanzania**

At an international level, Tanzania has signed:
- The United Nations Convention on the Rights of Persons with Disabilities (2006), which obliges member states to integrate disability issues into development plans, including HIV and AIDS and poverty reduction strategies.
- The UN Convention on the Rights of the Child (1990) which outlines commitments to disabled children.
- The Declaration on the Rights of Disabled Persons (1975).

At a continental level:
- The Plan of Action for the African Decade of Persons with Disabilities.

At a national level:
- The National Policy on Disability (2004) which acknowledges the need to reach people with disabilities in HIV and AIDS initiatives, and provides guidelines - and sets parameters - for service delivery.
- The current national Poverty Reduction Strategy (MKUKUTA, 2005-2010) which considers persons with disabilities in a number of sectors (education, health etc) and has the reduction of HIV infections among young people living with disabilities (15-25 years) as a target.
- In 2005, the Department of Social Welfare and the Tanzanian Disability Organisations formed the MKUKUTA Disability Network to follow up MKUKUTA action points.
- The new Health Sector HIV/AIDS Strategy Plan (2008-2012) recognises people with disabilities as a highly vulnerable group, and aims to reduce infections and target interventions to address their specific needs.
The Study: Background, Objectives, Design and Methodology

Background and Purpose: The purpose of the study was to carry out an assessment of HIV and disability in Tanzania. It was necessitated by a lack of information about these issues, and guided by the desire to fulfil the rights of all people to access appropriate health information. The study was commissioned by TACAIDS, funded by the German BACKUP Initiative, implemented by GTZ of the German Development Cooperation, and overseen by a Technical Committee led by TACAIDS (and with representatives from UNAIDS, PEPFAR, GTZ and CCBRT). The report’s key recommendations will be taken forward by CCBRT and CBM in their new project initiative: ‘Making HIV/AIDS Services Inclusive for People with Disabilities in Tanzania’.

Overall Objectives:
The study aimed to:

- Assess the impact of HIV and AIDS on people with disabilities;
- Evaluate disabled people’s access to HIV information, testing and services;
- Provide recommendations for overcoming barriers and obstacles to accessing HIV services.

The survey gathered information from three key groups:

People with disabilities, to establish:

- Awareness among people living with disabilities about HIV and AIDS services;
- Access – and obstacles - to HIV information, testing and services;
- HIV behavioural indicators (e.g. high-risk sex, condom use).

Organisations for/of people with disabilities, to establish:

- The capacity of organisations working with persons with disabilities;
- Current activities related to HIV and AIDS and disability in the four sample districts;

- Obstacles and challenges to delivering HIV services to people with disabilities;
- Collaboration between HIV and disability service providers (including local government).

Organisations dealing with HIV and AIDS, to establish:

- Policies, programmes, and interventions currently in place to ensure inclusion of individuals with disabilities;
- Gaps in policy documents and guidelines where people with disabilities are overlooked;
- Obstacles and challenges to delivering HIV services to people with disabilities and recommendations to overcome them.

Methodology:
The study provided quantitative and qualitative information on disability and HIV in Tanzania through:

- Three questionnaire surveys (one specially designed for people living with disabilities, one for organisations working with persons with disabilities, and one for HIV organisations);
- Focus group discussions with people in the four selected districts, targeting people with disabilities (including young people), and their carers (parents, teachers, service providers);
- In-depth interviews with key players at the district level, including health and HIV staff, teachers, rehabilitative/technical staff and district HIV coordinators.

Four districts were selected for the study to provide a balance between rural and urban locations. Due to financial and time constraints, only nearby and accessible districts were selected. Characteristics of the four districts are seen in the table overleaf.
Characteristics of the four districts chosen for the study

<table>
<thead>
<tr>
<th>District</th>
<th>Region</th>
<th>Population *</th>
<th>Wards</th>
<th>Type of district</th>
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<tbody>
<tr>
<td>Morogoro Rural</td>
<td>Morogoro</td>
<td>492,783</td>
<td>44</td>
<td>Rural</td>
</tr>
<tr>
<td>Kibaha</td>
<td>Pwani</td>
<td>132,045</td>
<td>9</td>
<td>Rural</td>
</tr>
<tr>
<td>Temeke</td>
<td>Dar es Salaam</td>
<td>771,500</td>
<td>24</td>
<td>Primarily urban (15 of 24 wards)</td>
</tr>
<tr>
<td>Ilala</td>
<td>Dar es Salaam</td>
<td>637,573</td>
<td>22</td>
<td>Primarily urban (16 of 22 wards)</td>
</tr>
</tbody>
</table>

*According to 2002 Census

**Data collection:** Data was collected by research assistants trained by the study consultants and guided by data collection tools. Questionnaires were translated into Kiswahili and filled out directly by individuals except in cases where respondents were unable to write (because illiterate, blind, physically incapable etc), then they were filled out by researchers. Interviews with people with communication difficulties or intellectual impairments were carried out in the presence of caregivers who assisted the researchers to communicate more fully.

**Focus group discussions:** Focus group discussions were held with 32 people (17 men/boys and 15 women/girls), including children with disabilities, young people, parents, caregivers, NGO leaders and staff from SHIVYAWATA.

**Limitations of the study:** This study provides a preliminary insight into the situation of people with disabilities in Tanzania. To provide a good statistical base for programming, a much larger sample size would need to be taken (recommended 1% of total disabled population), across all areas of the country, age groups, educational levels and disability types.

**Group 1: People living with Disabilities**
A questionnaire containing 65 questions was completed by 40 people with disabilities (18 men and 22 women). The median age was 30-39. Half had only received primary education and 13 had received no education at all. Over a quarter had physical impairments. Detailed characteristics of the respondents are shown in the table below.

Profiles of 40 people with disabilities interviewed for this survey disaggregated by age, sex, education, location and type of impairment.

<table>
<thead>
<tr>
<th>Type of impairment</th>
<th>Men</th>
<th>Women</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>3</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Visual</td>
<td>5</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Hearing</td>
<td>1</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Intellectual</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Albinism</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Multiple</td>
<td>5</td>
<td>3</td>
<td>8</td>
</tr>
</tbody>
</table>
Group 2: Civil Society Organisations of - and for - People with Disabilities

Twenty four civil society organisations – including non-government organisations, organisations of - and for - people with disabilities, and special schools - filled in a survey questionnaire. Of the total, nine organisations worked with all people of all disability types, eight worked specifically with the hearing impaired, five with the visually impaired, four with the intellectually impaired, three with the physically impaired, and one with people with albinism. (Some worked in more than one focal area). The respondents themselves worked in - or with - the organisations in multiple capacities, including as teachers, physiotherapists, and parents/caregivers.

<table>
<thead>
<tr>
<th>Age</th>
<th>Men</th>
<th>Women</th>
<th>Total by age group</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-19</td>
<td>0</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>20-24</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>25-29</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>30-39</td>
<td>7</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>40-49</td>
<td>3</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>50+</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>District</th>
<th>Men</th>
<th>Women</th>
<th>Total by district</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ilala</td>
<td>3</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Temeke</td>
<td>7</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>Kibaha</td>
<td>2</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Morogoro</td>
<td>6</td>
<td>5</td>
<td>11</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th>Men</th>
<th>Women</th>
<th>Total by education</th>
</tr>
</thead>
<tbody>
<tr>
<td>None and illiterate</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>None but can read</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Primary</td>
<td>6</td>
<td>14</td>
<td>20</td>
</tr>
<tr>
<td>Secondary</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Tertiary</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

| TOTAL     | 18 men | 22 women | 40 disabled people |

Group 3: Organisations dealing with HIV

The survey also targeted organisations dealing with HIV, including Government Ministries, Department and Agencies (MDAs) and civil society organisations (CSOs). Of the 24 organisations surveyed, 23 said they also worked with people with disabilities in the course of their HIV work.

Partners interviewed for questionnaire 2 and 3 included: seven Government Ministries, Departments and Agencies; district and municipals councils in all four districts (as well as in Kinondoni District); Council HIV and AIDS coordinators (CHAC/ Social Welfare Department) and District AIDS Coordinators (DACC/ Health Sector); umbrella organizations; and civil society organisations including NGOs and FBOs. For a full list of all organizations interviewed, please see Annex.
Study Findings: From People with Disabilities

Awareness of HIV and AIDS, and Exposure to HIV messages

The survey included a series of questions about HIV and AIDS knowledge, and exposure to HIV and AIDS-related messages and information.

According to the Tanzania HIV/AIDS & Malaria Indicator Survey (THMIS), almost all adults in Tanzania (>98 per cent), say they have heard of HIV. However, less than half of the people with disabilities interviewed for this study said they knew about HIV, suggesting that they are substantially less aware about the epidemic than the general population.

Do you know about HIV? Responses from 40 people living with disabilities

![Do you know about HIV? Responses from 40 people living with disabilities](image)

A much higher percentage of people (85 per cent) said that they knew about sexually transmitted infections (STIs), indicating that many people in the sample group were not aware that HIV was an STI. Of the eighteen who said they did know about HIV, thirteen said they had heard about it from a friend or neighbour, eleven from a school or at a seminar or training session, eight through a hospital/dispensary/health centre, and nine through a radio or other means. (Interviewees could mention more than one source).

Interviewees were divided about whether they thought people with disabilities had easy access to HIV information, with roughly half (21) saying yes and half (19) saying no.

Do you find it easy to access HIV and AIDS information? Responses from 40 people living with disabilities

![Do you find it easy to access HIV and AIDS information? Responses from 40 people living with disabilities](image)

Of the people who thought it was not easy to access information, no-one thought it was because information was not available. Stigma and discrimination towards people with disabilities was mentioned by well over a third of respondents (16) as a key obstacle. Other key challenges cited included the physical difficulties of accessing information (such as not being able to read, see or hear), the lack of information in appropriate formats (e.g. signs for people with hearing impairments, Braille for people with visual impairments), and the distance of health and information centres. A quarter of respondents thought that the lack of involvement of people with disabilities in HIV services (specifically, the fact that

25 The question do you know about HIV and have you heard about HIV are, of course, slightly different, so results cannot be directly compared.

26 Similar information sources were cited as providing STI education. 3 people also said that they had learnt about STIs through being infected.
they were not working in health facilities) was a key impediment to accessing information.

Focal group discussions (involving people with and without disabilities) produced starker comments on the plight of people with disabilities in terms of access to information.

**Focal Group Comments on Access to Information:**
- People with disabilities in rural areas are far from getting information on HIV and AIDS. They are “wamesahaulika kabisa.” [completely forgotten]
- “Disabilities ... are in a black blanket [i.e. completely in the dark] as far as HIV is concerned.”
- “Information on HIV & AIDS does not belong to [the disabled]. It is for others.”

Most respondents living with a disability (70 per cent) did not think there was an HIV/STI programme in their area which focused on the special needs of the disabled. The ten people (25 per cent) who thought there was one, reported that the programme used drama, printed and traditional media (e.g. folk dances, songs, poems, and parables), to communicate HIV information to the disabled.

**SUMMARY:**
Less than half of the respondents said they 'knew about' HIV and AIDS. Even those who 'knew about it' had misconceptions about its transmission. People with disabilities consider their access to HIV information is limited.

**Knowledge of HIV and AIDS among People with Disabilities**
The study findings indicate that people with disabilities are not only less likely to be aware of HIV, they are also less likely to have comprehensive knowledge of the virus. For example, around a third of the respondents did not know that you could avoid HIV by wearing a condom or by being faithful. According to the THMIS findings, over 85 per cent of men and women in Tanzania know that abstaining from sex can prevent HIV, whereas only 57 per cent of the disabled focal group knew it.

**Knowledge of ways to prevent HIV and other STIs as identified by 40 people living with a disability**

<table>
<thead>
<tr>
<th>How can one avoid HIV?</th>
<th>How can one avoid STIs?</th>
</tr>
</thead>
<tbody>
<tr>
<td>% who answered ‘Yes’</td>
<td>% who answered ‘Yes’</td>
</tr>
<tr>
<td>Abstaining from sex?</td>
<td>23 (57.5%)</td>
</tr>
<tr>
<td>Being faithful?</td>
<td>28 (70%)</td>
</tr>
<tr>
<td>By using Condoms?</td>
<td>25 (62.5%)</td>
</tr>
<tr>
<td>Avoiding casual sex?</td>
<td>Not asked</td>
</tr>
</tbody>
</table>

Although existing educational initiatives appear to be having some success (demonstrated, for example, by the fact that almost three quarters of the respondents knew HIV could be transmitted by having sex with an infected partner), there is still a long way to go. Almost a third of the people with disabilities interviewed thought you could become infected by shaking hands or sharing clothes, and almost half thought you could get HIV by living with an infected person. Over a third thought there was a cure for HIV and AIDS.

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27 It must be remembered that this is only a preliminary survey providing a snapshot of the situation for people with disabilities, and that the sample size (40) is very small, especially when compared to the THMIS (15,000+).
Knowledge of ways of transmitting HIV as identified by 40 people living with a disability

<table>
<thead>
<tr>
<th>How can HIV be transmitted?</th>
<th>% saying ‘Yes’</th>
<th>% saying ‘No’</th>
<th>‘Don’t know’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Through sex with an infected person?</td>
<td>72.5%</td>
<td>20%</td>
<td>7.5%</td>
</tr>
<tr>
<td>Shaking hands?</td>
<td>32.5%</td>
<td>60%</td>
<td>7.5%</td>
</tr>
<tr>
<td>Sharing clothes?</td>
<td>30%</td>
<td>60%</td>
<td>10%</td>
</tr>
<tr>
<td>Sharing utensils?</td>
<td>10%</td>
<td>82.5</td>
<td>7.5%</td>
</tr>
<tr>
<td>Sharing needles?</td>
<td>50%</td>
<td>27.5%</td>
<td>22.5%</td>
</tr>
<tr>
<td>Living with HIV + person?</td>
<td>45%</td>
<td>47.5%</td>
<td>7.5%</td>
</tr>
<tr>
<td>Through breastfeeding?</td>
<td>70%</td>
<td>27.5%</td>
<td>2.5%</td>
</tr>
</tbody>
</table>

Erroneous knowledge: Focal group comments on how HIV is spread

- “HIV is a very bad disease that one gets through umalaya [prostitution]. People with HIV should not be looked after by family members because they would infect other family members. Therefore, such people should be chased away from home.”
- “Some people with disabilities believe that HIV is transmitted through witchcraft and can be healed by traditional healers. Others believe that HIV is transmitted through demon possession and that is why they go to church to have the demons removed.”

SUMMARY:
People with disabilities are less aware about HIV than the general population. Current education is not adequate.

HIV Testing, Counselling and Prevalence
Knowledge of one's HIV status can empower individuals to take precautions to protect against acquiring and transmitting the disease. To assess the awareness and coverage of HIV testing services, respondents were asked whether there was a VCT centre in their area; if they thought people with disabilities used the centre; if they would like to be tested; and whether they had been tested. Those who had been tested were asked about their results.

Sixty five percent of respondents were aware that there was a centre nearby where they could be tested for HIV. Awareness is lower than among the general population as measured by the THMIS (where > 80 per cent said they knew where they could be tested). Respondents were divided over whether people with disabilities attended the centres, with just over half (52 per cent) saying that they did. Most respondents (>57 per cent) thought it was not easy for people with disabilities to access HIV services. The key reported barriers to VCT were lack of sign language, lack of information in Braille, fear of discrimination, lack of expertise in dealing with intellectual disabilities, and lack of wheelchair access (mentioned by 17, 15, 14, 13 and 12 people respectively).

Perceived barriers were reflected in actual behaviour. For although 85 per cent of people interviewed said they would like to be tested for HIV, only 55 per cent (22 people) had been tested. Of those, 2 people (or 9 per cent of those tested) were found to be HIV positive. Although this sample size is very small, it is worth pointing out that a higher percentage of people living with disabilities had been tested, and prevalence among those tested was higher than among the general population. 28

SUMMARY:
The majority of respondents with a disability thought it was not easy to access HIV services. Nevertheless over half had been tested – 9 per cent of whom were HIV positive.

28 According to the THMIS, prevalence among the general population is 5.7 per cent (compared to 9%) and 37% of women and 27% of men who have been tested (compared to 55%).
HIV Related Behaviour Indicators

This section explores the prevalence of behaviours that relate to and influence the AIDS epidemic and other sexual infections. Issues discussed include perception of risk, age at sexual debut, multiple sexual partners, condom use, drug use, and sexual abuse, all of which can influence the spread of HIV and other STIs.

Perception of HIV Risk

The study explored respondents’ perception of HIV risks. Although 80 per cent agreed that people with disabilities could be at risk of getting HIV, and >87 per cent agreed that their age group was at risk of HIV infection, only 57 per cent felt themselves to be personally at risk. Young people were most likely to think they were at risk. The study indicates, that people with disabilities think they themselves are less at risk of being infected with HIV than other people of a similar age, sex or disability type. Over a third of respondents (37 per cent) knew a person with disability living with HIV.

Do you think you are at risk of HIV? Responses from 40 people living with disabilities

<table>
<thead>
<tr>
<th>Response</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>22</td>
</tr>
<tr>
<td>No</td>
<td>14</td>
</tr>
<tr>
<td>Don't know</td>
<td>4</td>
</tr>
</tbody>
</table>

SUMMARY: Over half the respondents felt themselves to be at risk.

Age of sexual debut as reported by 40 people living with a disability

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>10-14 yrs</td>
<td>10%</td>
</tr>
<tr>
<td>15-19 yrs</td>
<td>50%</td>
</tr>
<tr>
<td>20-24 yrs</td>
<td>20%</td>
</tr>
<tr>
<td>25-29 yrs</td>
<td>10%</td>
</tr>
<tr>
<td>Never</td>
<td>6%</td>
</tr>
</tbody>
</table>

SUMMARY: People with disabilities are sexually active; half have had sex by the age of 19.

Use of Condoms

People with disabilities were asked about their condom use. Of the 30 respondents who said that they had had sex, eleven people said they used condoms ‘every time’ and nine ‘some of the time’. The remainder of the people who had had sex (10 people or 25 per cent) never used condoms. When asked why not, half said because “my partner and I trust each other”. Other reasons were “because I am married” or “it is the responsibility of my partner”, “my religion doesn’t approve” or “condoms reduce sexual pleasure”. No one mentioned the reason for non-use as “not knowing where to get them”, “expense”, or “the difficulties of persuading partners to use them.”

29 2.1% of women aged between 20–49 said they had never had sex, and 5.1% of men. THMIS, 2008.
Condoms use as reported by 40 people living with a disability: How often do you use condoms?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every time</td>
<td>30%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>40%</td>
</tr>
<tr>
<td>Never</td>
<td>30%</td>
</tr>
</tbody>
</table>

SUMMARY: A quarter of sexually active respondents said they never used condoms, and nearly a quarter use them only ‘some of the time’.

Incidence of STIs
The prevalence of STIs is often used as a proxy indicator for HIV, and having an STI also makes you more likely to be infected with HIV. People with disabilities were therefore asked whether they had ever had a STI. Six of the forty respondents (15 per cent) said that they had. All six sought treatment for their illness: four went to a health facility, one to a traditional healer, and one self-medicated.

The majority of respondents could name some of the key symptoms of sexually transmitted illnesses. Between 26 and 32 respondents mentioned: swelling and inflammation, genital ulcers and sores, and unusual genital discharges. Overall, respondents were better informed about STIs as a whole than about HIV.

Have you ever had an STI? Responses from 40 people living with disabilities.

<table>
<thead>
<tr>
<th>Response</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15%</td>
</tr>
<tr>
<td>No</td>
<td>85%</td>
</tr>
</tbody>
</table>

SUMMARY: 15 per cent of respondents said they had had an STI

Sex with Multiple and Non-Regular Partners
The survey included questions about respondents’ sexual partners to allow the researchers to look at the extent of higher risk sexual behaviour. Nine out of the forty people interviewed (>22 per cent) said they themselves had had sexual relations with someone other than their spouse or regular partner. Seven of those nine (78 per cent) had not used a condom on the occasion.30

Twelve of the forty people (30 per cent) interviewed thought it was ‘common’ for people living with disability to have sex with many partners. When asked why it was common, eight people ticked “to get money”, seven marked “being forced (raped)”, six “due to drunkenness” and four people put it down to having “no spouse”.

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30 The THMIS 2008 asks different questions so it is hard to make a direct comparison between this focal group and the general population. The THMIS question is time specific. It found that 16% of women and 29% of men reported having sex in the 12 months before the survey with someone who was not a husband/wife or cohabiting partner. 22% of men who said they had two or more partners in the past 12 months, said they used a condom the last time they had sex.
Is it common for people living with disabilities to have sexual intercourse with many partners?

Do you know any disabled person who has been raped?

**SUMMARY:**
Almost a quarter of respondents had had sex with a non-regular partner and most of those (78 per cent) did not use a condom when doing so.

**Incidence of Rape**
A quarter of respondents believed that rape of people living with disabilities was "common" in their community. An even higher number (40 per cent) reported knowing a person living with a disability who had been raped. These figures are alarmingly high, but chime with data from the Global Study and elsewhere, as well as qualitative information from this study's focal group discussions (see box below).

Worth mentioning here, is that over half the respondents from disabled people's organisations (see next section) also said they knew of people with disabilities who had been raped. The latter identified twenty-four people who they believed had been forced to have sex, of which young disabled girls were the largest subcategory (9 out of the 24 reported).

**SUMMARY:**
40 per cent of respondents knew a disabled person who has been raped. Rape and sexual abuse of people with disabilities is considered 'common'.

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Rape and Sexual Abuse of People with Disabilities: Opinions and anecdotes from Focal Group Discussions

Participants in focal group discussions tended to think that sexual abuse of people with disabilities was common, that intellectually challenged women were especially vulnerable, and that much abuse took place within the home. A sample of the opinions and quotes from the four districts include:

- People with disabilities are at risk of HIV “because they cannot defend themselves”.
- The intellectually impaired are most at risk “because of their broken minds”.
- People with disabilities are commonly abused by members of their own family and “many disabled women have children with their fathers”.
- The greatest risk for people with disabilities comes from “their family members and local, trusted people”.
- People with disabilities are often fearful of reporting abuse in case they are thrown out of their home, rejected by their families or punished.
- Abuse is shrouded in secrecy, because it “takes place in secret”, because families do not talk of incest, and community members are reluctant to interfere.
- Some people believe that you can rid yourself of HIV by having sex with a virgin and passing it on to them. People with disabilities are commonly believed to be virgins and are therefore targeted. People with visual impairments are thought to be at particular risk.
- “Some years ago, people were told by witchdoctors that if men had sex with a disabled person, they would become rich. Some men even went after those with more severe disabilities arguing that the more extensive the disability, the richer they would become.”
- Perpetrators of abuse are protected by the disability of the person they abuse. For example, people with hearing and intellectual impairments finding it “difficult... to report incidents of rape against them”.
- If an intellectually challenged person reports that they have been abused within the family “they do nothing because they say that the person is mental.”
- The intellectually impaired do not always know that they have been abused or understand what sex is.  

Use of Illegal Drugs

Research has shown that intoxicants can reduce inhibitions and increase risky behaviour. Although people with disabilities themselves were not asked about their use of illegal drugs, it is worth noting that of the twenty-four respondents from disability organisations (see next section), thirteen (54 per cent) thought that there was drug abuse among people with disabilities, and four thought it was “very common”. A third (8) said they provided training on drug abuse, primarily focusing on the health and legal consequences of drug use, education, counselling and support. Less than a third thought that drug traffickers might use people with disabilities to transport and sell illegal drugs. (See next section for more detailed responses from disability organisations).

32 One intellectually challenged woman, for example, told the study team she had never had sexual intercourse, though she was clearly pregnant.
Study Findings: Organisations of - and for - People with Disabilities (OPD)

This report has so far detailed the perceptions of 40 people with disabilities who were interviewed for this study. It will now go on to look at the findings from questioning 24 organisations working with people with disabilities in four focus districts.

Profile of Organisations: Core Activities, Funding and Reach

Income generating activities was mentioned by almost all organisations as a key part of their work. Most organisations (20) also stated that HIV education was one of their core activities. Other mentioned (in descending order) rehabilitation, advocacy, capacity building, running support groups, outreach, and medical/counselling. Legal counselling was mentioned as a core activity by seven of the organisations.

Legal Aid:
Participants in focal group discussions tended to believe that there was no legal aid for people with disabilities. However, seven out of the organizations of – and for – people with disabilities said that legal assistance was available for them.

Sixteen of the organisations mentioned development partners as a source of funding and 13 mentioned Government grants. Eight said they received some funding from members, and seven organisations that funding was supported through income-generating activities.

Poor record-keeping was apparent in all institutions, and it was not possible to determine how many people living with disabilities were being reached by services, still less to disaggregate data by sex, age or type of disability. It was also not possible to determine the quantity or quality of educational materials which had been disseminated on HIV and AIDS or the breadth of dissemination. It is worth noting, however, that none of the institutions had materials available at the time of the researchers’ visits.

Perceptions of Risk

The vast majority of the respondents from the organisations of – and for - people with disabilities (23 out of 24) thought that people with disabilities were at risk of HIV, and most thought they were more vulnerable to infection than non-disabled people. Children with disabilities were considered to be particularly at risk.

Availability of HIV Programming for People with Disabilities

Almost two thirds of the respondents (including representatives from special schools, and organisations with a disability or HIV focus) said that they had an HIV or AIDS programme which specifically targeted people with disabilities (ten had an outreach programme). Key HIV services included HIV education, VCT, home-based care, advocacy, sensitization and income-generation. Support to other NGOs and Government initiatives were also mentioned. The services most commonly requested by people living with disabilities, according to Government and non-government representatives, were - in descending order - training, information, condoms and testing.

It is worth mentioning here that only 25% of the people living with disabilities surveyed knew of an HIV programme targeting them (see above), which begs the question of whether HIV programming was poorly communicated, poorly accessed or poorly actualised.

33 The numbers of people living with disabilities reached by HIV services (as reported/guessed by organisations) are almost certainly inaccurate and have therefore not been included. For example, the five institutions in Temeke estimated they were serving 604,053 people, whereas the total population of Temeke is not much more than that. The seven institutions in Kibaha on the other hand estimated they were serving just 86 people.
Access to Information
Fourteen out of the 24 organisations of – and for – people with disabilities who responded to this question thought that their clients did access HIV information. However, most thought the quality of information could be improved. Nine agreed that circulating information in more appropriate formats (e.g. Braille, pictorial/simplified) would improve access to information, especially if it was circulated through non-formal channels, that is, not just through schools from which most people with disabilities are excluded. Seven organisations thought that parcelling information in dramatic performances would improve education, and around the same number agreed that information should be disseminated to - and in a format acceptable to - rural communities. Other commented that those with physical disabilities and without wheelchairs may need to have information taken to their homes.

Do people living with disabilities have access to information on HIV and AIDS? Responses from organisations.

Training and Use of Peer Educators
The survey sought to determine the extent to which organisations were using peer educators to provide information and advice on HIV and AIDS to their clients. Over half reported that they trained peer educators (though very few had reported training or capacity building as one of their core activities). However, poor record keeping meant that neither the numbers of peer educators trained - nor the number of people living with disabilities trained by them - could be determined.

Obstacles to Accessing HIV Information and Services
Organisations reported that fear of discrimination was one of the main barriers to their clients accessing HIV services (mentioned by eleven). Representatives of sixteen organisations said that they knew of people living with disabilities who had not been able to access services as a result of their impairment. Key difficulties encountered at VCT centres were (in descending order of times mentioned): lack of sign language specialists, inaccessible clinics, and unfriendly officials (mentioned by 20, 18 and 14 organisations respectively). Other reported obstacles to accessing services were ‘they do not know they can ask for help’, ‘HIV is not talked about in this community’ and ‘they seek traditional healers’ (the latter mentioned by only one organisation).

Do you know people living with disabilities who have not been able to access HIV and AIDS services because of their impairment? Responses from organisations of – and for - people with disabilities.

Challenges of Working with Disabled People
Government and non-government organisations identified similar barrier to accessing services as disabled people themselves (see next section). However, they identified slightly different obstacles when asked about the challenges faced in providing services to people with disabilities. In relation to this question, thirteen mentioned that the “disabled find it difficult to come to the centre due to long distances”, ten that “families are not willing to bring their disabled relations to the centre”, eight that “there are few disability experts”, seven that “the disabled cannot afford our service fees”, and three that the “disabled are reluctant to come to our centres”.

Yes
No
Don't know
Harmonisation and Alignment
Most organisations (20) said that they collaborated with other disability organisations, and over half (13) said that they collaborated with other health and HIV and AIDS service providers. When asked how they collaborated with other disability organisations, sixteen reported conducting joint meetings, thirteen joint training, twelve information sharing, and eleven joint planning and advocacy.

Collaboration and alignment with local government authorities:
Organisations of - and for - people with disabilities were asked about collaboration and integration with their local government authorities. Although twelve said that their activities had been integrated into district plans, over three quarters said that they were not represented on their local Council Social Services Committee or Multisectoral AIDS Committee (contrary to what was advised in the 2001 National HIV/AIDS Policy), and two thirds said that they did NOT meet regularly with either the local Council HIV/AIDS Coordinator (Social Welfare) or the District Aids Control Coordinator (Health).

Are you represented in your Council Social Services Committee, or in your Council Multi-Sectoral AIDS Committee? Responses from 24 organisations.

Do you meet regularly with the District Aids Control Coordinator (DACC) or the Council HIV & AIDS Coordinator (CHAC)? Responses from 24 organisations.

Reasons for non-collaboration:
Many organisations of - and for - people with disabilities were not aware that they should be represented in local government authority (LGA) structures such as Council Multi-Sectoral AIDS Committees, and did not actively seek to collaborate with LGAs. Lack of collaboration was attributed to 'mutual distrust', characterised by 'competition', 'secrecy', and an 'unwillingness to open up'. Organisations of - and for - the disabled were nervous about letting others (including Government) know what they were doing. Focal group participants also stated that the disability rights movement was currently lacking strong leadership, as well as the capacity to bring organisations together and coordinate activities. (It is worth noting that lack of collaboration between LGAs and Civil Society Organisations (CSO) is widespread in Tanzania. To improve HIV collaboration, TACAIDS has developed the CSO assessment tool to allow representatives of both parties to work together.)

SUMMARY:
Collaboration between organisations of and for people with disabilities and other health and HIV service providers is strong. However, organisations of and for people with disabilities are not collaborating with LGAs.
Study Findings: Organisations Dealing with HIV

Information from Government Ministries, Departments and Agencies

Two thirds of the 24 HIV organisations interviewed said that they used the National Policy on HIV/AIDS to plan interventions. Although the latter does not provide policy guidance on programming for disabled people, two thirds said that they included people with disabilities in the HIV/AIDS services they offered. The services offered included advocacy, treatment, home based care, condom provision, and follow up visits (but not peer education or testing services).

HIV organisations said that they faced a number of key challenges in providing services for people with disabilities, including inadequate numbers of skilled personnel (mentioned by 11 organisations), limited financial resources (10), delays in receiving materials (6); limited means of transportation (6); long distances (3); and the reluctance of people living with disabilities to use HIV services (5). None had personnel specifically trained to work with HIV infected individuals who were also disabled. However, five had a staff member who knew sign language.

Information from NGOs and FBOs

Of the NGOs and FBOs who filled out the third questionnaire, five said that they had a policy that specifically guided them on how to address HIV issues with people with disabilities. None, however, had a policy document to support their claims.

Key challenges identified by CSOs in providing services for people living with disabilities and with HIV and AIDS included: limited finances (mentioned by 5), limited facilities or physical accessibility to buildings (4); difficulties accessing services (3) and in accessing care and support (2).

Inclusiveness of the National Policy Environment

The survey team tried to establish if the HIV and AIDS policy environment was inclusive of people with disabilities. However, no policy was found in any organisations which addressed the specific challenges of people living with disabilities, or provided guidelines for communicating HIV information to them.

Overview of policy guidelines in organisations surveyed:

- The National HIV/AIDS Policy does not provide guidelines for reaching people with disabilities.
- The National Policy on Disability does not include guidelines on improving disabled people's access to HIV services.
- VCT centres do not have policies or guidelines to address the special needs of people with disabilities.
- LGAs offer integrated HIV and AIDS interventions but have no strategies to cater for the needs of people with disabilities, and - with the notable exception of Morogoro Municipality - people living with disabilities are not involved in local HIV and AIDS programmes.
- Disability data is lacking, because key monitoring surveys and tools (e.g. DHS, THMIS, TOMSHA) do not have disability-sensitive indicators.
- Although HIV and AIDS education is theoretically mainstreamed as part of the curriculum at special schools, standardised disability-friendly materials are not yet available.

Two Best Practice Examples

1. HIV and AIDS education is mainstreamed into the curriculum at special schools. However, Buguruni School for the Deaf goes one step further. It uses an innovative approach to increase the spread of school-based education to the wider community. It positively encourages open discussion about HIV and AIDS in the school environment (between pupils, and between pupils and teachers), and encourages pupils to discuss what they have learnt with their own families, thus taking HIV education beyond the school room and into community homes.

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34 Although the study team found teachers in special schools were using creative communication strategies (including their own IEC materials) to teach pupils about HIV, at the moment communication methods depends on the commitment and creativity of individual teachers.
Morogoro Municipality was the only local government authority surveyed which included people living with disabilities in its HIV and AIDS initiatives. In all 19 wards of the district an individual living with a disability had been put forward to represent the interests and concerns of people living with disabilities in their area. All representatives had been trained on issues relating to HIV and AIDS, and were expected to share their knowledge with others in the community through cascade training. Although inclusivity was not absolute (people with hearing impairment, for example, were excluded from training because of a lack of sign language specialists), the district has shown that it is possible to involve people with disabilities in HIV and AIDS initiatives not just as consumers but as teachers and facilitators. These examples of good practice might be emulated elsewhere in Tanzania.

Summary of Key Findings from the Study

People with disabilities are sexually active, and engaging in high-risk sexual activities. Yet they are less educated about HIV than their peers and more likely to be excluded from critical HIV services. Specifically, the survey found that of the 40 respondents who were living with a disability:

- Less than half said they ‘knew about’ HIV and AIDS. Even those who did know about it had misconceptions about its transmission.
- Half had had sex by the age of 19.
- Almost a quarter had had sex with a non-regular partner, and most of those (78%) did not use a condom when doing so.
- A quarter of those who were sexually active said they ‘never’ used condoms.
- 15 per cent had had a STI.
- 9 per cent of those tested were HIV positive.
- 40 per cent said they knew a disabled person who had been raped.

- The majority thought it was not easy to access HIV services.
- Only a quarter knew of an HIV programme that specifically targeted the disabled.
- Stigma and discrimination were reported as key barriers to accessing services.

The study also interviewed Government and civil society organisations involved with delivering services (including HIV education) to people living with disabilities and found that:

- Most organisations thought there were key capacity challenges to delivering effective HIV services to those living with a disability.
- The policy and legislation environment was not considered sufficiently supportive of facilitating disabled people’s access to HIV services.
- Collaboration between key HIV and disability organisations was poor.

“When a pregnant person with disability goes to a health centre, the service providers wonder that it is possible for a disabled woman to carry a pregnancy. They exclaim and say ‘O God, men are very sinful’.”
Comment from Focal Group Discussion
Summary of Key Barriers to accessing HIV Information and Services

‘There are no signs to indicate whether we can be served there [in the VCT clinic]. We do not know whether a person with disabilities would be served.’
Comment from Focal Group Discussion

People living with disabilities face specific challenges relating to:
- Being reached by HIV and AIDS messages;
- Accessing HIV prevention educational materials and condoms;
- Accessing HIV related services, including VCT, antiretroviral therapy etc.

The key barriers identified in this survey (by people with disabilities, disability organisations, and HIV service providers) are similar to those observed in international studies and include:

**Barriers created by Stigma, Discrimination and Ignorance:**
- Erroneous beliefs, such as that people with disabilities do not (or should not) have sex mean that they may be turned away by service providers, or their caregivers may not wish or see the point of take them to the clinic;
- The negative attitude of family, society and service providers makes persons with disabilities fear that they will be turned away, ridiculed or otherwise rejected and belittled;
- The low value attached to people living with disabilities make them less likely to be prioritised for services (such as antiretroviral therapy) in resource-stretched settings;
- Lack of understanding of the unique needs of people with disabilities and impatience and/or fear of them make them less likely to be able to access information and services.

**Environmental Barriers:**
- Physical difficulties of getting to facilities;
- Long distances to facilities;
- Lack of transport to reach facilities;
- Lack of physical access to facilities (e.g. restricted wheelchair access, lack of ramps);
- Lack of directional signs at facilities;
- Lack of privacy (e.g. for those who need a translator);
- Physical dependency – attendance may depend on the goodwill of a caretaker/escorter.

**Communication Barriers:**
- Difficulties processing/understanding information (e.g. for the intellectually impaired);
- Restricted access to certain forms of information (e.g. because of hearing or visual impairments);
- Illiteracy (as a result of exclusion from formal or informal education);
- Lack of information in accessible formats (e.g. Braille, sign language, pictorial etc);
- Lack of skilled health staff (e.g. none able to use sign language).

**HIV and AIDS Service Provider Barriers:**
- Lack of adequately trained staff and understanding of how to work with people with disabilities;
- Negative/insensitive attitude of health care providers towards persons with disabilities;
- Fear that HIV testing results would not be kept confidential (a particular worry for people who need an interpreter);
- Feeling of exclusion - “these services are not meant for the disabled” - reinforced by an absence of service providers with an impairment, and a lack of involvement in HIV initiatives;
- Poverty - people with disabilities are less likely to be able to afford services.

**Policy, Resources, Infrastructure Barriers:**
- Inadequate resources (finance and human) for disability/HIV issues;
- Inadequate service provision in health facilities, including lack of outreach;
- Inadequate policy frameworks to guide the delivery of HIV services to people with a disability.

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Recommendations

Key Recommendations

Many of the country’s four million people currently living with a disability are excluded from accessing health information and critical HIV services. Tanzania will need to adjust and adapt its current HIV and AIDS response in order to reach them. The following recommendations provide a broad overview of what needs to be done. The findings of this survey suggest the need to:

Build a Disability Friendly Environment:

- Specifically: Increase public awareness about the rights of people with disabilities, their special needs, lifestyle and vulnerability, using multiple media (radio, TV, newspapers, fliers, campaigns, special events). Counter popular myths, e.g. that people with disabilities don’t have sex, and that HIV can be cured by sleeping with a virgin.
- Lobby for increased political commitment to disability issues, including the possibility of a high-profile disability ambassador.
- Lobby for the increased commitment of Government, policy and decision-makers to improve the policy environment.
- Develop guidelines to increase the access to HIV information and services; disseminate to health providers, VCT centres and organisations of – and for – people with disabilities.
- Ensure people with disabilities are represented in appropriate local government authority fora.
- Promote the involvement and participation of people with disabilities in decision-making, and in the design of HIV programmes and interventions.

Policy Recommendations:

HIV and AIDS services will only become available to people living with disabilities if national minimum guidelines are in place and supported by the responsible bodies. To this end it is suggested that:

- The National Policy on HIV/AIDS (2001) and the National Policy on Disability (2004) need to be updated to include specific planning to increase the access of people living with disabilities to HIV services.
- Health facilities and staff need improved policy frameworks to guide and increase the access of people living with disabilities to HIV services.
- Minimum guidelines for inclusive VCT and Care and Treatment services need to be developed.
- A manual for health facilities should be developed to make their services and facilities accessible to people with disabilities.
- CSOs need to update their HIV and AIDS policies, as well as strengthen implementation and monitoring mechanisms to ensure people with disabilities are reached.

Improve Access to Information:

- Advocate to get more children with disabilities into school.
- Ensure Special Schools have HIV and AIDS education effectively mainstreamed (as per government guidelines) through development of disability-friendly educational formats and teacher training.
- Support CSOs to provide literary classes.
- Redesign HIV information materials in appropriate formats to respond to the special HIV needs of people living with disabilities, and involve people with different impairments in their design. Information should include: how to access testing, care, treatment, and support in local communities.
- The Global Report on Disability and HIV (www.globalsurvey.med.yale.edu) suggests a three-pronged strategy for reaching disabled people with health materials. This can provide a phased approach, and be adjusted according to available financial resources.

Build Capacity of Health Facilities and Providers:

- Build awareness among health care providers of the special needs of people living with disabilities. Address issues of discrimination and stigma.
- Train health staff, VCT staff and peer educators to serve people with disabilities more effectively.

36 The multiple international resources available on the Global Study website can provide the base for developing disability-friendly IEC materials in Tanzania.
including by improving their communication skills.

- Support the development of appropriate materials in accessible formats to provide HIV information and broader information about clinic / health services.
- Support the development of policy level guidelines which promote the inclusion of people living with disabilities in health and HIV services, and detail specific ways of targeting and meeting their needs.
- Strengthen collaboration between VCT/health service providers and organisations of and for people with disabilities.
- Support improved access to facility buildings (i.e. ramps, wide doorways, reduced steps), and improved directional signs in appropriate formats and media.

Building Capacity of Organisations of and for People with Disabilities:

Umbrella organisations and national disability partners should focus on building the capacity of local service providers to adequately provide services for people with disabilities. Specifically, they should build the capacity of organisations of – and for – people with disabilities to:

- Raise awareness and understanding of disabilities in their communities through teaching and information-sharing. Target in particular: health care providers, VCT staff and schools.
- Support disability organisations to expand and strengthen their work in HIV education.
- Train people living with disabilities to become peer HIV educators.
- Support people living with disabilities to become representatives in relevant LGA committees.
- Keep accurate records of peoples reached by services (including disaggregated data).
- Mobilise resources - both human and financial - to provide critical services (e.g. transport, staff pay and training, awareness raising).

Harmonisation and alignment:

- LGAs should provide greater oversight of the activities of organisations of – and for – people with disabilities and ensure people living with disabilities are represented and participating in district-level decision-making fora.
- LGAs should inform relevant partners in a timely manner of Government policies in relation to HIV and disability matters.
- HIV and disability partners at all levels should improve information-sharing and collaboration.
- HIV and disability partners need to increase their capacity through training. They also need to examine the barriers to service provision and explore ways to overcome them.

Improve Data Base:

- Disability partners should lobby for the inclusion of disability indicators in key national surveys including the next Census, THMIS and DHS, and for the revision of the TOMSHA to include appropriate indicators.
- Strengthen information management systems in health facilities, VCT centres and among non-government and disabled people’s organisations.

Further study:

This report provides a brief snap shot of a small focal group of people living with disabilities and disability and HIV partners close to Dar es Salaam. It has provided important ways to frame the work ahead. However, it is suggested that a larger survey would provide a much more accurate picture of the challenges faced by people living with disabilities in Tanzania. A statistically valid sample (i.e. 1 per cent) would involve interviewing around 40,000 people living with disabilities from across Tanzania, in both rural and urban locations, accessible and hard-to-reach places, and spread over age, sex and disability type.37 If time and financial constraints limit the possibility of a further survey, it is suggested that findings from existing large scale studies (including the Global Survey on HIV and Disability in which 43 per cent of respondents were from Sub-Saharan Africa) could be used to further guide programme implementation.

37 If such a study could be funded, it is suggested that the researchers should ask some of the same questions as those asked in national surveys (e.g. DHS and THMIS) so that exact correlations can be drawn between disabled and national populations. For example, it would have been useful to directly compare sexual behaviour between disabled populations but the questions asked in the sample survey were often slightly – or even very - different.
Conclusion

Many of the four million people living with a disability in Tanzania are currently excluded from accessing health information and critical HIV services. Tanzania will need to adjust and adapt its current HIV and AIDS response in order to reach them.

The key recommendations from this report will be taken forward by CCBRT and CBM in their new project initiative to make ‘HIV/AIDS Services Inclusive for People with Disabilities in Tanzania’. The latter will be supported by the Government of Tanzania and the financial support from the Government of the United States. The project begins in May 2009 for an initial period of three years.
Bibliography & Further Reading

International Studies


- De Vries, C (2004): *Disabled people are more vulnerable to HIV*. Dutch Coalition on Disability and Development, DCDD Newsletter No 9.


- Inclusion International (2006): “Fact Sheet on Poverty and Disability”


African Studies


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• UNAIDS (2007) Sub-Saharan Africa AIDS epidemic update: Regional Summary


Websites

www.cira.med.yale.edu/globalsurvey

www.worldbank.org/disability

www.unaids.org
Profile of Non Governmental institutions and organisations interviewed for the survey

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Profile of Government Ministries, Departments Agencies (MDAs), Non-Government Organisations (NGOs) and Faith-based Organisations (FBOs) interviewed for the survey

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* Two organizations of – and for – the disabled were based in the capital.

Partners interviewed for questionnaire 2 and 3 included: seven Government Ministries, Departments and Agencies; 38 district and municipals councils in all four districts (as well as in Kinondoni District); Council HIV and AIDS coordinators (CHAC/ Social Welfare Department) and District AIDS Coordinators (DACC/ Health Sector); umbrella organisations 39, and civil society organisations including NGOs and FBOs. 40

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38 Tanzania Commission on HIV/AIDS (TACAIDS), National AIDS Control Program (NACP), Department of Social Welfare under the Ministry of Health and Social Welfare, the Ministry of Education and Vocational Training’s Special Needs Education Department, the Ministry of Community, Gender and Children (including the Community Department, Folk Development Centres and Training Institute for Deaf).

39 Including, CHAWATA (for the physically disabled), CHAVITA (for the deaf), TAS (for albinos) and DOLASED (for legal affairs and economic development), Hope Project for People Living with Disabilities, Network for Disabled People Living with HIV and AIDS (NEDPHA+).

40 NGOs: CCBRT, the Tanzania Youth Alliance (TAYOA), and the Service Health and Development for People Living with HIV and AIDS (SHDEPHA+), Pastoral Activities and Services for people with AIDS (PASADA), Dar es Salaam Archdiocese, Action Aid. FBO: Salvation Army. Sinza VCT dispensary was also surveyed.
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