Table of Contents
Table 1: Objectives of the Assessment ................................................................. 5
Table 2: Respondents by district by sex .............................................................. 15
Table 3: Respondents by age and sex ................................................................. 16
Table 4: Types of disability by sex ................................................................ 16
Table 5: Respondents by education by sex ....................................................... 16
Table 6: Summary profile of MDAs & CSOs interviewed for the assessment .......... 16
Table 7: Details of MDAs, local government Agencies (LGAs), CSOs, & Special Schools .......... 17
Table 8: Knowledge of mode of HIV transmission ........................................ 21
Table 9: HIV prevention .............................................................................. 22
Table 10: Perceptions of risk of HIV infection for people with disabilities .......... 23
Table 11: Perceptions of personal risk of HIV infection .................................... 24
Table 12: Level of risk by respondents’ disability type ...................................... 24
Table 13: Personal risk by respondents’ disability ............................................ 25
Table 14: Perceived personal risk of HIV by age of respondent ....................... 26
Table 15: Age of sexual debut among boys and girls in the community ............... 26
Table 16: Respondents’ sexual debut ................................................................ 27
Table 17: Multiple partners among people with disabilities ............................. 28
Table 18: Incidences of rape among people with disabilities ............................ 29
Table 19: Knowledge of people with disabilities who have been raped ............. 30
Table 20: Responses by disability of respondents ............................................ 30
Table 21: Attendance of VCT by disability of respondent .................................. 31
Table 22: Use of VCT services by respondents ................................................ 32
Table 23: Sources of information on HIV & AIDS .......................................... 32
Table 24: Obstacles to access to HIV & AIDS services for people with disabilities .......................................................................................................................... 33
Table 25: Areas of focus of OPD .................................................................... 34
Table 26: Core activities of organizations of and for people with disabilities ........ 35
Table 27: Prevalence of drug abuse among people with disabilities ................. 36
Table 28: Access to information for people with disabilities ............................. 38
Table 29: challenges experienced by people with disabilities in services .......... 39
Table 30: Challenges encountered when serving people with disabilities .......... 39
Table 31: Capacity gaps in service provision to people with disabilities ............ 40
Table 32: Collaboration with other service providers ....................................... 41
Table 33: Integration of OPDs plans into the District plans ................................ 42
Table 34: ODP Representation in Social Service Committees and Council Multi-Sectoral AIDS Committees ................................................................................................. 43
Table 35: On whether ODP meet regularly with CHAC & DACC ...................... 44
Table 36: Best practice Example 1 ................................................................... 45
Table 37: Best Practice Example 2 ................................................................... 46
Acknowledgements ............................................................................................................. vi
Abbreviations ................................................................................................................... viii
Executive Summary ............................................................................................................ ix
In conclusion ..................................................................................................................... xii

Chapter 1: Context of the study and background Information .............................. 1
  1.1 Introduction ........................................................................................................ 1
  1.2 Tanzania: Facts and Figures ............................................................................. 1
    1.2.1 Geographical Location ............................................................................... 1
    1.2.2 Population .................................................................................................. 1
    1.2.3 Human Development Index ...................................................................... 2
    1.2.4 Economy .................................................................................................. 2
    1.2.5 Disability and poverty .............................................................................. 3
  1.3 HIV & AIDS in Tanzania: Facts and Figures ..................................................... 3
  1.4 The purpose of the assessment of HIV & AIDS and Disability in Tanzania ....... 5
  1.5 Objectives of the Assessment .......................................................................... 5
  1.6 Study areas ........................................................................................................ 6
  1.7 Significance of the study ................................................................................... 6
  1.8 Organization of the Assessment Report ............................................................ 7

Chapter 2: Review of the literature ................................................................................. 8
  2.1 Introduction ...................................................................................................... 8
  2.2 The situation of people with disabilities with respect to HIV & AIDS .......... 8
  2.3 Recognition of HIV & AIDS as a problem facing disabled people ............... 9
  2.4 Barriers to effective service provision for disabled people with regard to HIV & AIDS 13

Chapter 3: Design and methodological framework .................................................. 14
  3.1 Study Design .................................................................................................. 14
  3.2 Methodology .................................................................................................. 14
  3.3 Selection of study districts ............................................................................... 14
    3.3.1 Morogoro District and Municipality ....................................................... 14
    3.3.2 Temeke Municipality ............................................................................... 15
    3.3.3 Ilala Municipality .................................................................................... 15
    3.3.4 Selection of respondents ......................................................................... 15
  3.5 Focus Group Discussions (FGD) ....................................................................... 18
  3.6 Data collection tools ....................................................................................... 18
    3.6.1 Language used to collect data ................................................................ 18
    3.6.2 Data collection ....................................................................................... 18
    3.6.3 Interviewing people with intellectual disabilities .................................. 18
  3.7 Data Analysis and report writing ...................................................................... 18
  3.8 Limitations of the study ................................................................................. 19

Chapter 4: Presentation and Discussion of the findings ........................................... 20
  4.1 Introduction .................................................................................................. 20
  a) Situation of people with disabilities in respect to HIV & AIDS and STI .... 20
4.2 Level of knowledge of HIV ................................................................. 20
  4.2.1 Knowledge of modes of transmission of HIV ............................... 21
  4.2.2 Knowledge of HIV and STI prevention methods ......................... 21
4.3 Perceptions of risk of HIV infection for people with disabilities ........ 22
4.4 Age of sexual debut in the respondents’ communities ...................... 26
  4.4.1 Respondents’ sexual debut ......................................................... 27
4.5 Use of condoms among people with disabilities ............................. 27
4.6 Multiple sex partners among people with disabilities ....................... 28
4.7 Incidences of rape of people with disabilities ................................. 29
4.8 Respondents’ knowledge of rape cases among people with disabilities ... 30
4.9 Attendance of VCT Centres by disability .......................................... 31
4.10 Respondents’ use of VCT Services ................................................ 32
4.11 Sources of information on HIV & AIDS ......................................... 32
4.12 Obstacles to HIV & AIDS and STI information and prevention services 33

b) Assessment of the extent to which disabled people’s organizations and special schools are involved with teaching people with disabilities about HIV & AIDS ...... 34
  4.13 Disability focus and Core activities of organizations of people with disabilities ........................................................................................................................................... 34
  4.14 Strategies used to reach people with disabilities ............................... 35
  4.15 Prevalence of use of illicit drugs among people with disabilities .......... 36
  4.16 Programmes to combat drug abuse among people with disabilities ...... 37
  4.17 Training and use of peer educators ................................................ 37
  4.18 OPDs’ assessment of how easy it is for people with disabilities to access to information on HIV & AIDS and STI ............................................................... 38
  4.19 OPDs assessment of challenges preventing people with disabilities from accessing services ......................................................................................................................... 38
  4.20 Challenges encountered by OPDs in providing services to people with disabilities ........................................................................................................................................... 39
  4.21 OPDs capacity gaps and obstacles to effective service provision for people with disabilities ........................................................................................................................................... 40
  4.22 Records .......................................................................................... 41
  4.24 Current collaboration/interactions between district HIV & AIDS service providers ................................................................................................................................. 41
  4.25 Areas of collaboration between disability organizations and health and HIV & AIDS service providers ................................................................................................................................. 42
  4.26 Integration of OPDs into district plans .............................................. 42
  4.27 OPDs representation in Social Service Committees and Council Multi-Sectoral AIDS Committees ................................................................................................................................. 43
  4.28 Meetings with Council HIV & AIDS Coordinator (CHAC) and District Aids Control Coordinator (DACC) ................................................................................................................................. 44
  4.29 Reasons for non-collaboration with Local Government Authorities ...... 45
  4.30 Best practices ................................................................................ 45

c) Technical Assessment of the inclusiveness of Tanzanian HIV & AIDS education, communication, VCT treatment and care, and policy strategies ........ 47
  4.31 Technical Assessment of the inclusiveness of Tanzania HIV & AIDS education, communication, VCT treatment and care and policy strategies ........ 47
Acknowledgements

The Consultancy Team consisting of Margaret Morumbasi, Raphael Kukula and Major Gen. (RTD) Herman Lupogo would like to sincerely thank the Steering Committee under the leadership of TACAIDS for the opportunity to tackle this challenging and exciting assignment. Our experience in carrying out the assignment was educative and highlighted the challenges faced by people with disabilities in accessing HIV & AIDS information and services. Comments and suggestions from the Steering Committee enriched the report and we are grateful for their input.

Special thanks go to GTZ for facilitating the study process. Their efficient and friendly bureaucracy enabled the Team to meet its targets in a timely manner.

The Comprehensive Community Based Rehabilitation Tanzania (CCBRT) deserves special gratitude and praise for providing the Team with excellent working facilities. The dedication of its staff to the work of the Team was very commendable. Members of the Team felt that they were part of the CCBRT – in fact they were issued with CCBRT identity cards.

We also register our appreciation to the research assistants; Ms. Speciosa Mwankina, Oscar Mmuni and Paulina Maro who learned quickly and were able to collect reliable data from the field. The research assistants exhibited a wonderful team spirit that won the hearts of the Consultancy Team members through their dedication and professionalism not only in collecting data but also transcribing tapes of interviews and focus group discussions. They went about their assignments with skill and enthusiasm and managed to present facts and figures which provided the core of the findings of the study.

Special thanks also go to the respondents for their willingness to freely share their experiences and make suggestions on how to improve access to HIV & AIDS information and services for people with disabilities. The people with disabilities were disarmingly frank. Their willingness to answer even personally embarrassing questions added to the qualitative aspects of the findings. Their frankness opened for the team many hitherto unknown passages into the world of people with disabilities. It is a pity that most of them will not be able to read the report or to listen to the discussions but it is hoped that in the long run they will all benefit through this work.

We also express our gratitude to government officials who were very cooperative and shared information that gave insight into the policy environment with regard to HIV & AIDS and people with disabilities.

Lastly, the Team would like to thank the authors of research, government and other publications which provided background information to the research.
Margaret Morumbasi
Lead Consultant
Abbreviations
ADD Action on Disability and Development
AIDS Acquired Immune Deficiency Syndrome
AMREF African Medical Research Foundation
CCBRT Comprehensive Community Based Rehabilitation in Tanzania
CHACC Council for HIV & AIDS Coordinator
CHAVITA Chama cha Viziwi Tanzania (deaf)
CHAWATA Chama cha Walemavu Tanzania (physically disabled)
DACC District AIDS Control Coordinator
DOLASED Disabled Organization for Legal Affairs and Economic Development
FBO Faith Based Organization
GTZ Deutsche Gesellschaft fur Technische Zusammenarbeit GmbH
HIV Human Immunodeficiency Virus
HMIS Health Management Information System
HSHSP Health Sector HIV Strategic Plan
M & E Monitoring and Evaluation
NEDIPHA Network for Disabled People Living with HIV and AIDS
NGO Non-Governmental Organization
NGPRs National Strategy for Growth and Reduction of Poverty
NMSF National Multi-Sectoral Strategic Framework on HIV and AIDS
OPD Organization of Persons with Disabilities
PASADA Pastoral Activities and Services for people with AIDS Dar es Salaam Archdiocese
SHDEPHA+ Service Health and Development for People Living with HIV and AIDS
SHIVYAWATA Shirikisho la Vyama vya Walemavu Tanzania
STI Sexually Transmitted Infection
TACAIDS Tanzania Commission for AIDS
TAS Tanzania Albino Society
TASODEB Tanzania Society for the Deaf and Blind
TAYOA Tanzania Youth Alliance
THMIS Tanzania HIV & Malaria Indicator Survey
TOMSHA Tanzania Output Monitoring System for non-medical HIV & AIDS Interventions
TOR Terms of Reference
UNAIDS United Nations Joint Programme for HIV and AIDS
UNICEF United Nations Children’s Foundation
VCT Voluntary Counselling and Testing
Executive Summary

This is the report of an Assessment of HIV & AIDS and Disability in Tanzania that was carried out between December 2008 and March 2009. The pilot study was intended to carry out the following and make appropriate recommendations.

i) Explore the knowledge level of HIV and AIDS and STI among people with disabilities.

ii) Assess the involvement of organizations of and for people with disabilities in educating people with disabilities on HIV & AIDS and other information related to HIV & AIDS.

iii) Examine the disability and HIV & AIDS policy and legislative environment.

iv) Develop a technical plan to improve external collaboration and internal coordination and capacity areas for organizations of people with disabilities.

v) Develop a technical support plan /inter-sectoral plan of action to overcome identified challenges.

Study sites

The study took place in Kibaha, Temeke, Morogoro and Ilala Districts in Tanzania. The selection of the districts ensured representativeness of the Tanzania socio-economic situation in terms of urban and rural populations.

Respondents included i) people with disabilities, ii) organizations of/for people with disabilities, iii) government officials from relevant government ministries and departments, iv) officials from local government authorities, v) organizations working in the area of HIV & AIDS, vi) teachers in special schools, vii) parents and caregivers of people with disabilities.

Methodology: The evaluation adopted a mix of qualitative and quantitative research techniques to ensure gathering of holistic information.

Key findings

On the overall, the study revealed that the policy and legislation environment was not sufficiently supportive of people with disabilities, with evidence that they were not specified as being among vulnerable people groups that need to be reached in HIV & AIDS education. Due to this, HIV & AIDS interventions were geared towards the general population which is mainly non-disabled.

Nevertheless, the study found that people with disabilities had knowledge of HIV, its mode of transmission, prevention, and management. This indicated that initiatives in disseminating information to the general population had been successful. However, when discussing with participants in FGDs concerns were voiced that a) HIV & AIDS education was not reaching people with disabilities in the remote and interior parts of
Tanzania, b) messages were distorted or inaccessible for most people with disabilities due to inappropriate delivery formats that were used.

The findings also demonstrated that although there was an HIV & AIDS policy in the country, it was insensitive to the special and specific needs of people with disabilities. The omission of people with disabilities from policy documents, prevented LGA and other implementers from addressing their in interventions.

The study also established that in general, MDA, LGA and service providers lacked technical and financial capacities as well as inadequate information on disability and were insensitive to the needs of people with disabilities.

There was weak coordination among organizations of and for people with disabilities and LGAs and with other service providers.

The results of the study also revealed that there are many barriers preventing people with disabilities from accessing services. These ranged from physical inaccessibility of facilities, insensitive health workers, inappropriate IEC materials and lack of capacity of service providers.

**Recommendations to improve the policy environment**

1) Review HIV and AIDS policies and strategies to ensure inclusion of people with disabilities.

2) Review and update and disseminate nationally accepted definitions of disability. For example, in SHIVYAWATA members said that their six traditional categories may become seven if people with flaking skins are taken on board.


4) Ensure that the National Demographic and Health Survey include indicators on people with disabilities.

5) Ensure registration of people with disabilities (disaggregated by gender and disability type) at the village level and use the data for planning at all levels.

6) Ensure the capture of information on people with disabilities (disaggregated by gender and disability type) at public and private health facilities.

7) Involve people with disabilities and family members in the design of HIV & AIDS initiatives would be crucial for success since the primary source of information and social and material support is within the family setting.

8) Evaluate TOMSHA’s performance from inception in 2006.

9) Review and edit TOMSHA reporting guidelines to make them more succinct and user friendly.
10) Review and update TOMSHA and HMIS reporting forms to accommodate information on people with disabilities.

Recommendations on improving the situation of people with disabilities

1) Carry out a survey in the remote districts of Tanzania to investigate the situation of people with disabilities in areas where HIV & AIDS and other services may be few.
2) Equip people with disabilities with life-skills.
3) Sensitize people with disabilities on the availability of care, treatment and support in their communities without stigmatization or rejection.
4) Ensure support mechanisms to people with disabilities who have been identified in their communities.
5) Sensitize communities on the specific needs of people with disabilities and the availability of services.
6) Provide information in accessible formats for people with disabilities.
7) Ensure the participation of people with disabilities in HIV & AIDS campaigns.

Recommendations on capacity building

1) Build the capacities of MDAs, LGAs and CSOs to address the needs of PWDs in HIV and AIDS service provision.
2) Train health workers and peer educators in appropriate ways of working with people with disabilities.
3) Identify people with disabilities in the target areas and train them and their families to participate in disseminating HIV & AIDS information.

Recommendations on physical access and IEC Materials

1) Develop appropriate HIV & AIDS information materials in accessible formats to ensure that people with hearing and visual impairments are reached.
2) Provide directional signs to indicate that people with disabilities can be served in VCT centres; it is recommended that such signs be posted at service provision points.
3) Ensure government and private health facilities are physically accessible for people with physical disabilities and other mobility difficulties, by providing ramps, wide doorways, reducing the use of steps/stairs for people with disabilities.
Recommendations for organizations of people with disabilities

1) Enhance technical capacities of OPDs in disability to equip them to serve people with disabilities in HIV and AIDS.
2) Expand services to include HIV and AIDS education and support.
3) Review/strengthen/develop policies on HIV and people with disabilities.
4) Establish internal and external mechanisms to ensure enhanced collaboration with other organizations and LGAs.
5) Establish/strengthen and maintain accurate and up to date records.
6) Explore finance mobilization strategies to improve organizations’ finances.
7) Develop/facilitate development of appropriate IEC materials for people with disabilities.

In conclusion

This assessment has highlighted the multiple challenges that people with disabilities face in HIV & AIDS service provision. Although the study seemed to suggest that HIV & AIDS messages have reached people with disabilities, the concerns of participants regarding people with disabilities in the remote districts of Tanzania should be taken seriously. To this end, it will be necessary as a way forward to carry out a study focusing on people with disabilities in remote districts and explore what HIV & AIDS services are available to them. Investing time and finances in this activity will add immensely to the knowledge of the needs of people with disabilities in hard to reach areas. It is our belief that such a study will be of immense value in efforts to seriously pay attention and design interventions in HIV & AIDS to reach people with disabilities, most of whom are unreached so far.
Chapter 1: Context of the study and background Information

1.1 Introduction
This is the report of the assessment of HIV & AIDS and Disability in Tanzania, which was commissioned by TACAIDS and carried out from 10th December 2008 until March 2009. The assessment is one among the growing number of studies to reduce the knowledge gaps and improve the understanding of the dynamics of HIV and AIDS and STI’s among people with disabilities. The study was necessitated by the increasing recognition that the people with disabilities have been neglected in initiatives and interventions targeting the prevention and management HIV & AIDS and STI.

This chapter will discuss the context of the study including the geographical location of Tanzania in relation to the countries in Africa, its socio-economic situation and relevant facts and figures to enable an understanding of the context in which the study was carried out. It will also provide background information and rationale for the assessment and highlight the key requirements of the terms of reference for the study.

1.2 Tanzania: Facts and Figures

1.2.1 Geographical Location
Tanzania became independent in the early 1960s. It comprises the mainland and Zanzibar (Unguja and Pemba). Tanzania is located on the Eastern coast of the African continent along the along the Indian Ocean between Kenya to the North and Mozambique to the South. Other countries bordering Tanzania are Burundi, Rwanda and Uganda to the North West, the Democratic Republic of the Congo to the West, Malawi and Zambia to the South West.

Tanzania has 26 administrative regions, which are: Arusha, Dar es Salaam, Dodoma, Iringa, Kagera, Kigoma, Kilimanjaro, Lindi, Manyara, Mara, Mbeya, Morogoro, Mtwara, Mwanza, Pemba North, Pemba South, Pwani, Rukwa, Ruvuma, Shinyanga, Singida, Tabora, Tanga, Zanzibar Central/South, Zanzibar North, and Zanzibar Urban/West.

1.2.2 Population
The World Factbook1 estimates Tanzania’s population for 2008 at 40,213,000, up from 38,700,000 as indicated by the Population Reference Bureau in 20072. The population distribution by age and sex is as indicated in the table below:

<table>
<thead>
<tr>
<th>Age group</th>
<th>Males</th>
<th>Females</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-14 years</td>
<td>8,763,471</td>
<td>8,719,198</td>
<td>17,482,669</td>
</tr>
<tr>
<td>15-64 years</td>
<td>10,638,666</td>
<td>10,947,190</td>
<td>21,585,856</td>
</tr>
<tr>
<td>65 years and over</td>
<td>502,368</td>
<td>642,269</td>
<td>1,144,637</td>
</tr>
</tbody>
</table>

2 University of California, San Francisco: HIV InSite (October 2007).
The World Factbook estimates take into account the effects of excess mortality due to AIDS that could result in lower life expectancy, higher infant mortality, higher death rates, and lower population growth rates and distribution by age and sex.

1.2.3 Human Development Index

The HDI measures the average progress of a country in human development. According to the UNDP Human Development Index Statistical update released in 2008, the Human Development Index (HDI)\(^3\) for Tanzania is 0.503, which ranks the country at 152\(^{nd}\) out of 179 countries.

<table>
<thead>
<tr>
<th>HDI value 2006</th>
<th>Life expectancy at birth (years)</th>
<th>Adult literacy rate (% ages 15 and above)</th>
<th>Combined primary, secondary and tertiary gross enrolment ratio (%)</th>
<th>GDP per capita (PPP US$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tanzania (0.503)</td>
<td>158. Tanzania (51.6)</td>
<td>109. Tanzania (72.0)</td>
<td>149. Tanzania (54.3)</td>
<td>156. Tanzania (1,126)</td>
</tr>
</tbody>
</table>

Source: UNDP HDI update 2008

1.2.4 Economy

According to the World Factbook, Tanzania is one of the poorest countries in the world with a 40% of its GDP attributable to agriculture, the country’s mainstay. The industrial production growth rate was estimated in 2007 to be 9.5%. Agriculture, provides 85% of exports, and employs 80% of the total work force in the country.

Industry consists of manufacturing of light consumer goods including sugar, beer, cigarettes, and sisal twine and processing of agricultural products such as coffee, sisal,

tea, cotton, pyrethrum, cashew nuts, tobacco, cloves, corn, wheat, cassava (tapioca), bananas, fruits, vegetables; cattle, sheep, and goats.

Tanzania produces mineral such include diamonds, gold, iron, salt and soda ash. It also produces cement, oil refining, shoes, apparel, wood products, and fertilizer for the agricultural sector.

1.2.5 Disability and poverty
Studies have established a strong correlation between disability and poverty; poverty is both a cause and consequence of disability.

The Human Poverty Index (HPI-1) value for Tanzania is 32.9 %, thus ranking the country 98th among 135 developing countries for which the index has been calculated.

### Human Poverty Index (HPI-1)

The Human Poverty Index for developing countries (HPI-1) focuses on the proportion of people below a threshold level in the same dimensions of human development as the human development index - living a long and healthy life, having access to education, and a decent standard of living. By looking beyond income deprivation, the HPI-1 represents a multi-dimensional alternative to the $1.25 a day (PPP US$) poverty measure.

*Source: UNDP website*

### Table 2: Selected indicators of human poverty for Tanzania ranked among 135 developing countries for which the index has been calculated

<table>
<thead>
<tr>
<th>Human Poverty Index (HPI-1) 2006</th>
<th>Probability of not surviving past age 40 (%) 2005</th>
<th>Adult illiteracy rate (%ages 15 and older 2006)</th>
<th>People without access to an improved water source (%) 2006</th>
<th>Children underweight for age (% ages 0-5) 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>(32.9)</td>
<td>(36.2)</td>
<td>(28.0)</td>
<td>(45)</td>
<td>(22)</td>
</tr>
</tbody>
</table>

1.3 HIV & AIDS in Tanzania: Facts and Figures
Like in most parts of the world and much of sub-Saharan Africa especially, there is a dearth of information on the situation of people with disabilities and HIV & AIDS in Tanzania hence the reason for the study on disability and HIV & AIDS. However, World Health Organization (WHO) estimates that 10 percent of any population is deemed to be living with one type of disability or another. This means Tanzania whose population is 40,212,662, would be having approximately four million people living with disabilities. Although the Tanzania Second National Multi-sectoral Strategic Framework (NMSF) 2008-2012, acknowledges that highly vulnerable groups of people who need specific attention include people with disabilities, no interventions have been done to target them specifically. This is the case despite that fact that it has been established that due to their
vulnerability, people with disabilities could be at greater risk of HIV infection compared to other people in society. Nevertheless, NMSF aims to reduce new HIV/AIDS infections by partnering with key stakeholders at all levels to jointly plan and implement HIV/AIDS interventions targeting vulnerable groups of people. This in keeping with the targets set by the National Strategy for Growth and Poverty Reduction Strategy / NSGPR (2005) 4, under Cluster II “Improved survival, health and well-being” among which are the reduction of the HIV and AIDS prevalence among women and men with disabilities (aged 15-25). However, there are not statistics to indicate the situation on HIV & AIDS for people with disabilities.

The preliminary report of the Tanzania HIV & Malaria Indicator Survey (THMIS) (2007/08) reveals that knowledge of AIDS in Tanzania is ‘nearly universal’. THMIS shows that all men (99 percent) and women (98 percent) aged 15-49 years have heard about AIDS. It is noted, however, that THIMS has not provided information on people with disabilities, so it is not known to what extent people with disabilities, especially those living in remote areas and those with profound disabilities know about HIV & AIDS. HIV prevalence rate among adults (ages 15-49), was as high as 6.2 percent. Adults and children (0-49) living with HIV at the end of 2007 was 1.4 million and AIDS deaths among adults and children in 2007 was 96,000, while AIDS orphans at the end of 2007 stood at 970,000 5.

<table>
<thead>
<tr>
<th>Description</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population, 2008</td>
<td>40,213,000</td>
</tr>
<tr>
<td>People living with HIV/AIDS, 2007</td>
<td>1,400,000</td>
</tr>
<tr>
<td>Women (aged 15+) with HIV/AIDS, 2007</td>
<td>760,000</td>
</tr>
<tr>
<td>Children with HIV/AIDS, 2007</td>
<td>140,000</td>
</tr>
<tr>
<td>Adult HIV prevalence (%), 2007</td>
<td>6.2</td>
</tr>
<tr>
<td>AIDS deaths, 2007</td>
<td>96,000</td>
</tr>
<tr>
<td>New HIV infections, 2005</td>
<td>No data</td>
</tr>
</tbody>
</table>

Source: Population Reference Bureau & UNAIDS

According to the Population Reference Bureau, 2007 6, population of Tanzania stood at 38,700,000. According to the second Tanzania HIV & AIDS and Malaria Indicator Survey (THMIS) 2007/2008, HIV & AIDS prevalence stands at 5.8 percent, down from 7 percent previously. The key findings of the survey are highlighted below:

i) Ninety eight point four (98.4) percent of women and 98.9 percent of men aged 15-49 years in Tanzania have heard of AIDS.

ii) Five point eight (5.8) percent of women and men in the Mainland Tanzania are infected with HIV. Of these, 6.8 percent are women while 4.7 percent are men. HIV prevalence in Zanzibar is less than 1 percent.

iii) In urban areas HIV prevalence is 8.7 percent compared to 4.7 percent in the rural areas.

---

4 National Strategy for Growth and Poverty Reduction Strategy / NSGPR (2005), Vice President Office
5 UNDP 2008 Tanzania Country Profile
6 University of California, San Francisco HIV InSite (October 2007)
iv) Ten point six (10.6) percent of the women residing in urban areas are infected with HIV compared to 5.3 percent of women in rural areas.

v) Six point four (6.4) percent of men residing in urban areas are infected compared to 4.0 percent of men residing in rural areas.

vi) The highest HIV prevalence rates are in Iringa (14.7 percent) and the lowest in the country is Pemba at 0.3 percent. Dar-es-Salaam ranks second in HIV prevalence, which is at 8.9 percent, Mbeya is third with 7.9 percent (in the previous survey prevalence in Mbeya was over 13 percent).

1.4 The purpose of the assessment of HIV & AIDS and Disability in Tanzania

The purpose of the assessment of HIV & AIDS and Disability in Tanzania is to expand the knowledge base on HIV & AIDS and people with disabilities in Tanzania. It is widely acknowledged that there is no single definition for disability. However, in general, some definitions adopt the medical model, while the rights-based perspective views disability as socially constructed. The Tanzania National Policy on Disability defines disability as

‘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’.

The policy document defines a person with disability as

‘An individual whose prospects of obtaining and retaining an employment are greatly reduced due to known physical, mental or social factors’,

The findings will shed light and improve the understanding of the specific challenges that face people with disabilities who are also infected or affected by HIV & AIDS in Tanzania. They will also provide evidence-based information to guide future decision-making in planning and designing approaches and interventions in HIV & AIDS with particular reference to people with disabilities.

1.5 Objectives of the Assessment

The objectives of the consultancy as specified in the TOR were as indicated in the table below:

<table>
<thead>
<tr>
<th>Table 1: Objectives of the Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To identify and assess gaps and obstacles to the HIV/AIDS health services delivery to people with disabilities.</td>
</tr>
</tbody>
</table>

Complete Terms of Reference for the assessment are appended to the report.
2. To conduct a technical needs assessment to address identified gaps and obstacles.

3. To develop Technical Support Action Plans (including respective budget requirements) for the inclusion of people with disabilities in all HIV/AIDS prevention, testing, treatment and care efforts, improving coordination of organizations of and for disabilities and those working in HIV & AIDS, and for improving the policy environment for people with disabilities.

4. To analyze the current M&E systems and available indicators – and possibly propose new ones – for monitoring and evaluating the effectiveness and efficiency of this Plan.

### 1.6 Study areas

Specifically, the assignment involved comprehensive situation analyses with focus on the following three study areas.

1) **Determine the level of knowledge** in terms of infection, prevention, management of HIV/AIDS and STIs among people with different disabilities. This segment of the study also sought to establish the dynamics that fuel and inform people’s attitudes and practice in HIV & AIDS.

2) **Analyse organizations for people with disabilities** in order to determine how far disability organizations /special needs schools are involved in teaching and disseminating information on HIV & AIDS and measures such as practising safe sex, prevention of sexually transmitted infections, impact of drug usage and other topics relevant to HIV/AIDS and STIs.

3) **Analyse organizations (Government, NGOs, NGOs, FBO) working in the area of HIV/AIDS** including assessment of inclusiveness of Tanzanian HIV/AIDS services to people with different disabilities (including HIV/AIDS education, communication, VCT, treatment and care), their policies and strategies.

### 1.7 Significance of the study

Sweeny (2004) argues that ‘Given the lack of precision on disability statistics, it is unsurprising that statistics do not exist on how many people with disabilities are currently living with the virus or have died of AIDS-related diseases’. In this regard, this study will add to the body of knowledge on HIV and AIDS and provide a greater understanding of the situation of people with disabilities in relation to HIV & AIDS for scholars, policy makers, development partners and practitioners in the disability and HIV & AIDS sector. It is worth noting that this study is the first one of its kind in Tanzania and therefore it will provide an important landmark in efforts to address disability and HIV & AIDS.
The findings will provide an evidence platform that could be used to inform policy and practice in the areas of HIV & AIDS in Tanzania.

1.8 Organization of the Assessment Report

A report of the findings covering all the areas of the TOR, incorporating comments from the Technical Committee overseeing the study and other stakeholders will be prepared and submitted to TACAIDS in the agreed format.

The Terms of Reference (TOR) for the assessment will be used to organize the report, which will be divided into chapters as below.

1. Chapter One presents the context of the study and background information.
2. Chapter Two is a review of relevant literature.
3. Chapter Three will discuss the methodological framework for the study
4. Chapter Four will present and discuss the findings.
5. Chapter Five will draw conclusions and recommendations on the way forward.
Chapter 2: Review of the literature

2.1 Introduction

This chapter explores some of the available literature that has investigated the situation of people with disabilities and HIV & AIDS globally and in the region. In general, studies in many parts of the world suggest that people with disabilities continue to lag behind in realizing their human rights. Negative attitudes and discrimination against people with disabilities persist due to ignorance, retrogressive beliefs and practices and lack of information. The persisting exclusion of people with disabilities in many parts of the world, especially in Africa in policy formulation, operational guidelines and interventions in HIV & AIDS information, prevention, care and support have also contributed to preventing people with disabilities from accessing and enjoying their human rights as other citizens.

2.2 The situation of people with disabilities with respect to HIV & AIDS

Disability and HIV & AIDS are human rights and development issues. The United Nations through its Human rights instruments (Conventions and Optional Protocols), has been at the forefront in securing the rights of all people including women, children and more recently, people with disabilities through the UN Convention on Persons with Disabilities that took effect from May 2008. Underlining the role and mandate of UN in promoting the human rights of all people United Nations Enable (Department of Public Information) states that

‘Since its beginning, the United Nations has been committed to realization of universal human rights for all, including the rights of persons with disabilities. This commitment has been translated into international norms and standards, such as international human rights conventions and international, national and local action for making a difference in the lives of people all over the world. 2008 is a significant year for taking action to make this commitment a reality: the entry into force of the Convention on the Rights of Persons with Disabilities and its Optional Protocol, legally binding instruments as well as the commemoration of the 60th anniversary of the Universal Declaration of Human Rights (UDHR).

UN Enable further explains that

The Convention is a human rights instrument with an explicit social development dimension. It reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms on an equal basis with others. It clarifies and qualifies how all categories of rights apply to persons with disabilities and

identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights, where their rights have been violated, and where protection of rights must be reinforced.

By signing and ratifying the Convention, the member states are obligated to ensure that development plans, poverty reduction strategies and HIV & AIDS strategies take on disability as one of the integral components of such plans and strategies. The Convention on the Rights of People with Disabilities (UNCRPWD) has thrust into the international limelight the need to secure and uphold the rights of people with disabilities in all respects. It has stressed the need to recognize disability as a mainstream issue that should be incorporated into national development plans as a means of ensuring that people with disabilities enjoy equal rights with other people.

The UN Development Programme (UNDP), World Health Organization (WHO) and Cordaid (2008) assert that people with disabilities constitute about 10 per cent of the world’s population, or 650 million people. It also states that 80 percent of persons with disabilities live in developing countries. Only about one percent (1%) or two percent (2%) have access to rehabilitation. The majority of disabled people are relegated to the fringes of society where they live in poverty with little access to services and other support. Inclusion International9, an organization working with intellectual disabilities and their families, points out that ‘98% of children with disabilities are not in school and 98% of people with disabilities in developing countries do not have access to rehabilitative and appropriate basic services, and over 80% of people with disabilities are not employed’.

2.3 Recognition of HIV & AIDS as a problem facing disabled people

The notion that urgent measures need to be taken by governments, organizations for and of people with disabilities and development organizations to address the issue of HIV and AIDS among people with disabilities is now widely acknowledged and supported by increasing research in this area. There is relatively scant information in Africa and Tanzania specifically on the situation of people with disabilities with regard to HIV & AIDS. However, evidence increasingly suggests that compared with non-disabled people, people with disabilities may be at a higher risk of HIV infection due to their vulnerability (Groce, 2004; ICAD10: 2008).

People with disabilities are vulnerable due to the impact of their disability and the social constructs that promote discrimination against them. This makes it possible for others to take advantage of people with disabilities, who largely have no recourse for justice. The vulnerability of people with disabilities has been highlighted in the National Campaign HIV & AIDS and disability, of which Handicap International, (2007)11 has been at the forefront, the Global Survey on HIV and Disability by Groce, 2004; a study on Rape of

9 www.Inclusion-international.org
10 Interagency Coalition on AIDS and development (September 2008): HIV, AIDS and Disability.
11 HI Workshop Report of the proceedings of the National Campaign on Disability and HIV & AIDS held at the Pan Afric Hotel, Nairobi from 26th – 27th June 2007
Individuals with Disability in the Age of AIDS by Groce & Trasi, 2004, an article on HIV, AIDS and disability by ICAD, 2008. Key issues in these studies are, among other things, that:

1) People with physical disabilities are vulnerable due to their diminished physical strength to repulse and resist abusers.

2) People with visual impairments are vulnerable since they cannot easily identify perpetrators of abuse.

3) Deaf people, especially the illiterate and those without sign language may not be able to verbalize and report sexual abuse.

4) People with intellectual disability may not be able to realize they have been abused and may not be capable of reporting such abuse.

5) People with profound and multiple disabilities may be at increased vulnerability to abuse and would have diminished ability to ward off abusers and report abuse.

6) People with disabilities depend on others to provide care, guidance, psychosocial support and security and general welfare so they feel beholden to them and would not be willing to resist or even report incidences of abuse, including sexual assault. This dependency increases their vulnerability since the caregivers have been noted to be a source of violence and abuse of disabled people.

7) Due to widespread poverty among disabled people, women with disabilities are at increased risk of contracting HIV as they are likely to engage in risky sexual behaviour with multiple partners in exchange for money as a means of sustenance.

8) In addition, prevalent and persistent negative attitudes towards disabled people, the resulting stigma and negative treatment (Ogden & Nyblade (International Cancer for Research on Women, 2005) coupled with the erroneous belief that they are asexual compound their vulnerability and contribute to their neglect in initiatives addressing HIV & AIDS. HIV & AIDS initiatives include education, prevention, counselling and testing, treatment, care and other necessary support to enhance the quality of life for people living with HIV & AIDS.

9) Groce & Trasi (2004) point out that ‘the belief that sex with an individual who is disabled can rid one of a sexually transmitted disease is old’ (p.1). In their study on Virgin Rape and HIV – the Folk Belief of Virgin Cleansing, Groce & Trasi (2004) reported that ‘interviews with disability advocates and service providers, as well as literature review found reports of "virgin rape" of disabled individuals in association with HIV/AIDS in 14 of the 21 countries reviewed (p.3).

---

12 Groce, Nora Ellen & Reshma Trasi (2004) Rape of Individuals with Disability in the Age of AIDS: The Folk Belief of “Virgin Cleansing”, Global Health Division, Yale School of Public Health
According to a study done by Nora Groce, Aisha Yousafzai, Phindile Dlamini and Shelia Wirz (2003) in Swaziland, the level of knowledge of HIV & AIDS information among deaf people was erroneous.

Significant differences in levels of knowledge about HIV/AIDS were identified between the hearing and deaf respondents. The deaf population was significantly more likely to believe in incorrect modes of HIV transmission, (e.g. hugging, and airborne transmission) and HIV prevention (e.g. avoiding sharing utensils and eating healthy foods). Almost all of the deaf respondents (99%) reported difficulties in communicating with healthcare facility staff, which may result in less use of HIV voluntary counselling and testing services. (p. 2)

Despite the fact that people with disabilities are at the same or increased risk of becoming HIV/AIDS-affected, they have been given little attention in HIV/AIDS prevention, counselling and testing, as well as in treatment and care programmes (Groce, 2004; Sweeny, 2004; IDCS, 2005 & 2007; UNDP, 2008). Although there is a dearth of information regarding HIV & AIDS and people with disabilities, there is growing global concern that HIV & AIDS initiatives have largely neglected the needs of people with disabilities. Underlining the importance of targeting people with disabilities in HIV & AIDS initiatives, the Africa Campaign on Disability and HIV & AIDS (2008: p.5) argues that there are 80 million people with disabilities in Africa and ‘if people with disabilities are not included (in HIV & AIDS interventions), efforts to slow the spread of the (HIV) virus will be unsuccessful.

According to an article released by Interagency on Aids and Disability (September 2008),

There is a growing movement to address the need for increased collaboration in programming between those who advocate for the rights of people with disabilities (PWDs) and those involved in HIV education, prevention, care and treatment. Organizations dedicated to advocating for the rights of PWDs are beginning to develop and implement programming to effectively educate PWDs on HIV treatment and prevention techniques. (p. 1)

This concern has birthed actions/initiatives by various service organizations to ensure that HIV & AIDS services respond to the specific situation and needs of disabled people. Notable among the initiatives in Africa are i) the ‘Africa Campaign on Disability and HIV & AIDS’ which is spearheaded by Handicap International and the African Union of the Blind (AFUB) ii) the ‘HIV & AIDS Awareness and Training Project for Blind and Partially Sighted Persons in Africa’ in 2005, iii) the collaborative venture by Norwegian Church Aid (NCA) and National Council of Churches of Kenya (NCCK) to develop materials and messages in sign language, Braille and audio formats for people with disabilities.


disabilities, v) the Family AIDS Caring Trust (FACT) in Harare, Zimbabwe has started training disabled members on the ‘Stepping Stones’ programme to mitigate the deficit in HIV & AIDS information and communication.

The renowned ‘Global Study on HIV/AIDS and Disability’ (Groce, 2004) argues that although research in North America has revealed that disabled persons are at similar or even greater risk of HIV & AIDS, initiatives in HIV/AIDS education, test, treatment and care rarely address the needs of persons with disability. The study also observes that similar research in Sub-Saharan Africa is rare, with implications that HIV/AIDS information and interventions could similarly be rare, hence the need for research to provide an evidence-base for developing HIV & AIDS policy and interventions. Groce (2004) states that ‘disabled people are up to three times more likely to be victims of physical abuse, sexual abuse or rape as members of the general population, as they are often perceived as easy targets for violence by would-be perpetrators’. This vulnerability pre-disposes them to HIV and other sexually transmitted infections. Groce (2004) reported that, Mulindwa in a study in Uganda ‘found that 38% of women and 35% of men with disabilities reported having had an STD at one time’. At the same time, disabled people have reported being discouraged from seeking medical services on the assumption that they could possibly not have HIV & AIDS (HI, 2007; Yousafzai AK, Dlamini PJ, Groce N, Wirz S. (2004) remarked that:

‘it has been widely reported for individuals with all types of disabilities, and this lack of awareness on the part of HIV/AIDS experts appears to be a major barrier to the inclusion of these populations in HIV/AIDS outreach efforts in a number of countries (p.10).

Sweeny (2004) declares that the ‘lack of international attention to these factors means that questions remain’ (p.8). She further points out that ‘the gap in development theory on disability and HIV/AIDS suggests that there is a less than coherent approach to the topic in development practice today’. This neglect of people with disabilities in HIV & AIDS interventions support the false but prevalent belief that people with disabilities are not sexually active; that having a disability is synonymous with being asexual (DFID, 2000, Handicap International 2007) and therefore HIV/AIDS education need not target disabled people (World Bank, 2004).

15 www.cira.med.yale.edu/globalsurvey.
17 HI Report of the proceedings of the National Campaign on Disability and HIV & AIDS held at the Pan Afric Hotel, Nairobi from 26th – 27th June 2007.
There have been suggestions that disabled people are not capable of making decisions or expressing opinions that can be taken seriously even in court in cases of sexual abuse. For example, discussing interview techniques for people with disabilities, Modell argues that disabled people are at great risk due to misunderstanding, misconceptions on disability and perceptions that disabled people are ‘unreliable witnesses’ thus making it possible for perpetrators of abuse to easily evade punishment. Studies (Groce, 2004) and anecdotal evidence suggest that disabled people are often sexually abused as a form of ‘cleansing’ to get rid of sexually transmitted diseases including HIV & AIDS. Groce & Trasi (2004) report that that

“We have identified numerous reports of rape of individuals who are blind, deaf, physically impaired, intellectually disabled or who have mental health disabilities. These rapes are being perpetrated in the belief that having sex with a disabled individual will transfer the virus from the infected person to the individual with disability. Individuals with disability are apparently being targeted because they are often incorrectly assumed to be sexually inactive – hence virgins. The belief that sex with an individual who is disabled can rid one of a sexually transmitted disease is old. (p.1)

Groce & Trasi (2004) assert that ‘individuals with disability are presumably at risk not only because it is assumed that they are virgins, but also because they are often easy targets’ (p.2).

2.4 Barriers to effective service provision for disabled people with regard to HIV & AIDS

Studies such as those by International Deaf Children’s Society (IDCS) in Kenya in (2007), VSO (2005), Ogden & Nyblade (2005), Handicap International (2008), ICAD (2008) revealed that barriers persist in HIV & AIDS service provision for disabled people. These include: i) physical inaccessibility of VCT and health centres, ii) inappropriate education and information materials for the deaf and those with visual impairments, iii) lack of privacy during consultation with medical personnel that may require interpretation, iv) lack of sign language among service providers, and v) insensitive service providers.

---

23 Handicap International Campaign Report of a Meeting on Disability and HIV & AIDS held at the Pan Afric Hotel, Nairobi in June 2007.
Chapter 3: Design and methodological framework

3.1 Study Design

The study used a mix of qualitative and quantitative research design in order to capture a holistic situation of the HIV & AIDS scenario in the study districts in Tanzania. Technical Committee under the chairmanship of the TACAIDS Director of District and Community Response with representation from partners gave oversight to the whole process.

3.2 Methodology

The process of data collection involved the following:

i) The preparatory part of the assessment included the development and presentation of an inception report to the Technical Steering Committee for comments and adoption as the Road Map for Assessment.

ii) In preparing the inception report, the consultants

   a) Discussed the TOR for the study in order to arrive at a common understanding of the tasks at hand.

   b) Developed the criteria which they used to identify the study areas, the respondents (key people and organizations), and research assistants. The study areas were chosen on the basis of their representativeness of the Tanzania context. In order to achieve a balance, the study sites included both urban and rural areas.

   c) Developed data collection tools that included self-administered questionnaires, focus group discussion guides and in-depth interviews with key respondents.

   d) Identified research assistants and developed and prepared to train them to collect data from the field.

3.3 Selection of study districts

Four districts were selected for the study. The selection took into account the need to represent the socio-economic situation in Tanzania as much as possible. However, due to financial and time constraints, only nearby and accessible districts were selected. The study selected two rural and two urban districts. These were Kibaha District in Pwani Region and Morogoro District in Morogoro Region. The two urban districts were Temeke Municipal Council, and Ilala Municipal Council in Dar-es-Salaam.

3.3.1 Morogoro District and Municipality

Morogoro District has a Municipality and a Rural District Council with shared facilities since the headquarters of the Rural Council is within the Municipality.

---

24 Morogoro Rural District Homepage for the 2002 Tanzania National Census.
Morogoro Municipality has 19 wards with a population of 228,863\textsuperscript{25}, while Morogoro Rural District is divided into 25 administrative wards. It is bordered to the east by Pwani Region, to the South by the Morogoro Urban District, to the West by Mvomero District. Morogoro Rural District had a population of 263,920 according to 2002 Tanzania National Census.

### 3.3.2 Temeke Municipality

Temeke is a municipality that is partly rural and partly urban with a population of 771,500\textsuperscript{26}. It is situated to the South and South West of Dar-es-Salaam city centre. It has 24 wards, seven (7) of which are rural, 15 urban and two (2) are mixed (rural/urban).

### 3.3.3 Ilala Municipality

Ilala Municipality occupies the Eastern, Central and Western area of Dar-es-Salaam and includes the Central Business District (CBD) of Dar-es-Salaam. According to the Tanzania National Website (2003), it has a population of 637,573. It has 22 wards, three (3) being rural wards, 16 urban and three (3) mixed (urban/rural).

### 3.3.4 Selection of respondents

Respondents were purposively selected and included snowballing where some key respondents and members of the consultancy team gave and obtained references to other knowledgeable individuals and organizations in the disability movement and among service providers.

Respondents included female and male adults, youth and children with disabilities disaggregated by district by sex, by disability by age and sex, by disability type and sex and by education and sex as indicated in the following tables:

<table>
<thead>
<tr>
<th></th>
<th>Ilala</th>
<th>Temeke</th>
<th>Kibaha</th>
<th>Morogoro</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>3</td>
<td>7</td>
<td>2</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>12</td>
<td>7</td>
<td>11</td>
<td>40</td>
</tr>
</tbody>
</table>

\textsuperscript{25} Morogororo Urban Homepage (2002) Tanzania National Census

\textsuperscript{26} Source: Tanzania National Website (2003) accessed 23\textsuperscript{rd} February 2009.
Table 3: Respondents by age and sex

<table>
<thead>
<tr>
<th>Years (age range)</th>
<th>Male</th>
<th>Female</th>
<th>Total</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>
<tr>
<td>Total</td>
<td>18</td>
<td>22</td>
<td>40</td>
</tr>
</tbody>
</table>

Table 4: Types of disability by sex

<table>
<thead>
<tr>
<th>Disability</th>
<th>Male</th>
<th>Female</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>Deaf</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>Multiple</td>
<td>5</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Albino</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
<td>22</td>
<td>40</td>
</tr>
</tbody>
</table>

Table 5: Respondents by education by sex

<table>
<thead>
<tr>
<th>Education</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</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>University</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
<td>22</td>
<td>40</td>
</tr>
</tbody>
</table>

Other respondents were: i) parents and caregivers, ii) service providers, iii) teachers in Special Schools, iv) physiotherapists, v) officials in MDAs, LGAs, and Civil Service Organizations (CSOs).

Table 6: Summary profile of MDAs & CSOs interviewed for the assessment

<table>
<thead>
<tr>
<th>Type of organisation</th>
<th>Ilala</th>
<th>Temeke</th>
<th>Kibaha</th>
<th>Morogoro</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ministries, Departments Agencies,</td>
<td>7</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Table 7: Details of MDAs, local government Agencies (LGAs), CSOs, & Special Schools

<table>
<thead>
<tr>
<th>(MDA)</th>
<th>FBO</th>
<th>NGO</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>5</td>
<td>24</td>
</tr>
</tbody>
</table>

**Government ministries, departments and agencies (MDAs)**
- Ministry of Health- Social Welfare Department and National AIDS Control Programme
- Ministry of Community, Gender and Children –Community Department, Folk Development Centres and Training Institute for Deaf
- Ministry of Education and Vocational Training- SNE section
- TACAIDS

**Local Government Authorities**
- District Aids Committees (DACs), CHACs
  - Ilala Municipal Council,
  - Temeke Municipal Council
  - Kinondoni Municipal Council- Sinza VCT dispensary
  - Kibaha District Council
  - Morogoro Municipal Council
  - Morogoro District Council

**Civil Service Organizations (CSOs)**
- Umbrella organizations of/for people with disabilities: SHIVYAWATA, CHAWATA, CHAVITA, Tanzania Albino Society (TAS), TLB, DOLASED,
- Organizations for/of disability: HOPE PROJECT FOR PWD (Temeke and Kibaha), NEDPHA+ (Temeke and Kibaha), SHIVYAWATA (Kibaha),

**Special Schools**
- ILALA: Uhuru Mchanganyiko, Buguruni Shule ya Viziwi, Sinza Maalum,
- KIBAHA: Kongowe School for MH,
- MOROGORO: Kilakala, Mwembesongo Special Schools
### 3.5 Focus Group Discussions (FGD)

Focus group discussions were held as below:

<table>
<thead>
<tr>
<th>District</th>
<th>Respondents</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mbagala in Temeke</td>
<td>Parents of children with intellectual disabilities</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Buguruni School for the Deaf in Ilala</td>
<td>School goers</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Kibaha</td>
<td>People with disabilities and NGO leaders</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Kilakala School Morogoro</td>
<td>Youth</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>SHIVYAWATA in Kinondoni</td>
<td>Officials of SHIVYAWATA members</td>
<td>6</td>
<td>0</td>
</tr>
</tbody>
</table>

### 3.6 Data collection tools

Tools included self administered questionnaires, focus group discussion (FGD) guides, and interview guides.

#### 3.6.1 Language used to collect data

Data collection instruments were translated into Kiswahili which is the national language that is generally used and understood in Tanzania.

#### 3.6.2 Data collection

Data collection was done by three research assistants who were supervised and supported by local consultants following training and coaching on how to use the data collection instruments. The local consultants assisted in setting up the appointments with respondents.

#### 3.6.3 Interviewing people with intellectual disabilities

Interviews with people with intellectual disabilities were carried out in the presence of family members and caregivers who helped to explain the questions and contributed in clarifying the responses given. The study team found that the support of family members was important in facilitating communication between the researcher and the respondent.

### 3.7 Data Analysis and report writing

Completed questionnaires and assistant researchers’ notes were organized and checked for completeness before being keyed into the computer and analysed.
Quantitative data was subjected to quantitative techniques involving the use of a spreadsheet, while qualitative data was analysed using qualitative techniques such as the Grounded Theory espoused by Glaser and Strauss (1967)\(^{27}\) and the matrix of association and emerging themes by Quinn (1990)\(^{28}\), among other qualitative research scholars and practitioners.

### 3.8 Limitations of the study

This was a pilot study intended to provide a first inside view of the situation and was not meant to be a comprehensive study of the situation of people with disabilities in the whole country. In this regard, it is possible that different findings would have been realized in more remote districts of Tanzania. This could be the subject of a follow up study.

---


Chapter 4: Presentation and Discussion of the findings

4.1 Introduction
This chapter presents and discusses the findings in the three study areas as specified in the terms of reference:

1) The situation of people with disabilities in terms of knowledge of HIV & AIDS’ prevention, infection, and management.
2) The involvement of disability organizations in HIV & AIDS, modes of service delivery, key obstacles in service provision and the challenges faced. It also explores the coordination and collaboration situation and discusses the capacity gaps of disability organizations.
3) Lastly, the chapter looks at the relevant government organizations (Ministries, Departments and Agencies (MDAs), Local Government Agencies (LGAs)) and Civil Society Organizations (CSOs). It also examines the inclusiveness of people with disabilities in their policies and strategies, while identifying service gaps.

a) Situation of people with disabilities in respect to HIV & AIDS and STI

4.2 Level of knowledge of HIV
On the overall, the study found that people with disabilities in the study areas had a high level of knowledge of HIV, its infection modes, prevention and treatment. Respondents exhibited a high level of awareness that demonstrated that they had exposure to HIV & AIDS and STI information. Thirty four percent (85%) respondents indicated that they were aware of HIV and only six (15%) respondents with intellectual disabilities did not show an understanding of HIV & AIDS and STI.

Findings from the group discussions provided more insight into the situation of people with disabilities with regard to their level of knowledge. Discussing this issue, a participant captured the sentiments of others when she explained that:

For people with disabilities living in the rural areas, the knowledge of HIV & AIDS is very low. There are very few who get information on HIV & AIDS.
(Member of an organization of people with disabilities, Ilala)

Contributing to the discussions, other participants also noted that HIV & AIDS campaign organizers do not usually involve people with disabilities either. Instead, information is given generally and many people with disabilities do not normally attend such campaigns. As such the respondents indicated that ‘people with disabilities in rural areas are far from getting information on HIV & AIDS’. As one participant put it, ‘wameshaulika kabisa’ (They are completely forgotten). Another participant captured the views of many others when she advised that
‘the government should do sensitization on HIV & AIDS to people with disabilities because many of them are in a black blanket (meaning they are completely in the dark) as far as HIV & AIDS is concerned’.

The key issue arising here is the need for representation/inclusion of people with disabilities in decision making in the design and implementation of HIV and AIDS initiatives, especially in the rural areas. This would enhance participation and a greater ownership of activities on HIV & AIDS and improve awareness.

4.2.1 Knowledge of modes of transmission of HIV

The table below illustrates the respondents’ knowledge of the modes of HIV transmission.

<table>
<thead>
<tr>
<th>Modes of HIV transmission</th>
<th>Yes</th>
<th>%</th>
<th>No</th>
<th>%</th>
<th>Don’t know</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Through having sexual intercourse with an infected person</td>
<td>29</td>
<td>72.5%</td>
<td>8</td>
<td>20%</td>
<td>3</td>
<td>7.5%</td>
</tr>
<tr>
<td>Shaking hands</td>
<td>13</td>
<td>32.5%</td>
<td>24</td>
<td>60%</td>
<td>3</td>
<td>7.5%</td>
</tr>
<tr>
<td>Sharing clothes</td>
<td>12</td>
<td>30%</td>
<td>24</td>
<td>60%</td>
<td>4</td>
<td>10%</td>
</tr>
<tr>
<td>Sharing utensils</td>
<td>4</td>
<td>10%</td>
<td>33</td>
<td>82.5%</td>
<td>3</td>
<td>7.5%</td>
</tr>
<tr>
<td>Sharing needles</td>
<td>20</td>
<td>50%</td>
<td>11</td>
<td>27.5%</td>
<td>9</td>
<td>22.5%</td>
</tr>
<tr>
<td>Living with HIV + person</td>
<td>18</td>
<td>45%</td>
<td>19</td>
<td>47.5%</td>
<td>3</td>
<td>7.5%</td>
</tr>
<tr>
<td>Through breastfeeding</td>
<td>28</td>
<td>70%</td>
<td>11</td>
<td>27.5%</td>
<td>1</td>
<td>2.5%</td>
</tr>
</tbody>
</table>

Discussing the knowledge of HIV transmission among people with disabilities, one respondent in an interview noted that

Some people with disabilities believe that HIV & AIDS 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) exorcised (FGD: Ilala).

4.2.2 Knowledge of HIV and STI prevention methods

The respondents were also knowledgeable on methods used to prevent HIV infection. Faithfulness was cited by 32 (80%) of respondents as a prevention mode while abstinence was cited by 6 (15%) and condom use by 2 (5%).
Table 9: HIV prevention

<table>
<thead>
<tr>
<th>HOW CAN HIV INFECTION BE PREVENTED?</th>
<th>BY BEING FAITHFUL</th>
<th>THROUGH CONDOMS</th>
<th>USE OF THROUGH ABSTINENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. %</td>
<td>No. %</td>
<td>No. %</td>
<td>No. %</td>
</tr>
<tr>
<td>32 80</td>
<td>2 5</td>
<td>6 15</td>
<td></td>
</tr>
</tbody>
</table>

The findings further revealed that most of the respondents were aware that to date, there is no cure for HIV. Sixty two percent (62.5%) of the respondents said that HIV had no cure, 14% (35%) said there was a cure for HIV, while only (1) 2.5% did not know whether HIV had a cure.

The respondents also demonstrated an awareness of the ways of preventing sexually transmitted infections (STI). Twenty eight (70%) mentioned abstinence as a way of preventing STI, 27 (67.5%) mentioned condom use, 24 (60%) mentioned remaining faithful as a prevention measure while 21 (52.5%) indicated that avoiding casual sex was an STI prevention method. However some respondents felt that there is need to teach people with disabilities ‘how to wear condoms using models to demonstrate it’.

The fact that most respondents did not identify use of condoms as an HIV prevention method was surprising. It was also notable that respondents mentioned condom use as a method for preventing STI. These misconceptions justify the concerns of FGD participants on condom use and indicate a need for further education on this matter for people with disabilities.

4.3 Perceptions of risk of HIV infection for people with disabilities

i) Perceptions of risk of HIV infection for people with disabilities irrespective of participants’ conditions

The assessment explored the respondents’ perspectives on the risk of HIV infection for people with disabilities. Thirty two (80%) of the respondents thought that people with disabilities were at risk of HIV infection while two (5%) respondents said people with disabilities were not at risk and six (15%) did not know whether or not people with disabilities are at risk of HIV infection.

The table below illustrates the pattern of responses received on the level of risk of HIV infection for people with disabilities.
Table 10: Perceptions of risk of HIV infection for people with disabilities

<table>
<thead>
<tr>
<th>ARE PWDS AT RISK OF HIV INFECTION?</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>%</td>
<td>NO</td>
<td>%</td>
<td>DON’T KNOW</td>
</tr>
<tr>
<td>32</td>
<td>80</td>
<td>2</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

Participants in interviews and focus group discussions believed that the risk of HIV infection for people with disabilities was prevalent ‘because they cannot defend themselves’ (Morogoro). Many suggested that the level of risk depended on the type and severity of the disability. For example, there were multiple observations that children with intellectual disabilities ranked highest in the level of risk of HIV infection ‘because of their broken mind’ (FGD in a Special School).

One respondent, a young girl with an intellectual disability was interviewed together with her mother. The mother, who appeared resigned to her unfortunate circumstances, dejectedly reported that her daughter was ‘pregnant but I do not know who made her pregnant’. This could be evidence of the helplessness that often accompanies poverty and lack of legal and social support.

In FGDs participants reported that rumours of sexual abuse within the family setting abound and reporting of such abuse is difficult as families maintain secrecy and community members are often reluctant to interfere. Supporting this argument, one person observed that ‘disabled people are at risk that is why many disabled women have children with their fathers’. (Ilala)

Respondents in an FGD seemed suggested that some people with disabilities ‘information on HIV & AIDS does not belong to them. It is for others’ (FGD: Ilala & Temekte). Also, some people were said to ‘believe that people with disabilities do not have sex with many people and therefore they are safe’ (FGD: Ilala Municipality).

Emerging issues in this section include:

1) Lack of adequate knowledge, but more important perhaps, is the lack of negotiation skills and lack of capacity among some people with intellectual disabilities and children to understand what is happening to them when they are abused.

2) Another issue is the violation of the rights of people with disabilities who cannot raise their voices due to fear of rejection from the family. They would also fear punishment for revealing perpetrators of abuse in the family.

3) Secrecy, perhaps due to shame among family members of abuse of people with disabilities is also another issue that emerges from the findings and which merits attention.
4) Lack of community support denotes a breakdown of the traditional social support structures and so there may be need for alternatives when designing interventions. These could be facilitation of support groups.

ii) Participants’ perception of risk of HIV infection For respondents’ age group of respondent and personally
On whether they thought their age group was at risk of HIV infection, 35 (85.5%) of the respondents said ‘Yes’ while four (10%) thought they were not, and one did not know.

When the respondents were asked to state whether they thought they were personally at risk of HIV infection, 23 (57.5%) believed they were at risk while 15 (37.5%) thought they were not.

Table 11: Perceptions of personal risk of HIV infection

<table>
<thead>
<tr>
<th>IS YOUR AGE GROUP AT RISK OF HIV INFECTION?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>35</td>
<td>87.5</td>
</tr>
</tbody>
</table>

| ARE YOU AT RISK OF HIV INFECTION |
|--------------------------|---|---|---|---|---|
| YES %                    | 23 | 57.5 |
| NO %                     | 15 | 37.5 |
| DON’T KNOW %             | 2  | 5   |

These findings suggest that the respondents had their sexual debut later than is the practice in their communities.

It was not clear from the findings why 37% of the participants thought they were personally at a low risk of infection even though the majority of them had indicated that their age groups were at high risk of HIV infection.

iii) Perceived HIV risk for people with disabilities analysed by respondents’ disability
Although most respondents stated that people with disabilities were at risk, further analysis of this item by the disability of the respondents yielded the following results as illustrated in the table below:

Table 12: Level of risk by respondents’ disability type

<table>
<thead>
<tr>
<th>Type of disability</th>
<th>No of respondents</th>
<th>Yes</th>
<th>No</th>
<th>(%) saying people with disabilities were at risk of HIV infection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>11</td>
<td>11</td>
<td>0</td>
<td>100%</td>
</tr>
<tr>
<td>Visual</td>
<td>8</td>
<td>6</td>
<td>2</td>
<td>75%</td>
</tr>
<tr>
<td>Deaf</td>
<td>6</td>
<td>6</td>
<td>0</td>
<td>100%</td>
</tr>
<tr>
<td>Intellectual</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>75%</td>
</tr>
<tr>
<td>Multiple</td>
<td>8</td>
<td>5</td>
<td>3</td>
<td>62.5%</td>
</tr>
<tr>
<td>Albino</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>100%</td>
</tr>
</tbody>
</table>
The findings suggest that all (100%) respondents with physical disabilities, hearing impairments and albinos believed that people with disabilities were at a risk of HIV infection. Seventy five percent (75%) respondents with visual and 75% with intellectual impairments said that people with disabilities were at risk, while 62.5% of those with multiple disabilities said people with disabilities were at risk.

iv) Risk for disabled by respondents’ sex
When the results were differentiated by sex of the respondents, 95% of female respondents stated that people with disabilities were at risk of HIV, while 66.7% males believed that disabled people were at risk of HIV infection.

This finding suggests that females with disabilities may feel more vulnerable and perceive themselves to be at great risk of HIV infection. Is it possible that women were speaking from their own experiences of the number of threats or actual incidences of violation?

v) Perceptions of personal risk by disability of respondent
Analysis of personal risk by respondents’ disability yielded the following results as illustrated in the table below:

<table>
<thead>
<tr>
<th>Type of disability</th>
<th>No of respondents</th>
<th>Yes</th>
<th>No</th>
<th>Level of Risk (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>11</td>
<td>5</td>
<td>6</td>
<td>45.5</td>
</tr>
<tr>
<td>Visual</td>
<td>8</td>
<td>4</td>
<td>4</td>
<td>50</td>
</tr>
<tr>
<td>Deaf</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>66.7</td>
</tr>
<tr>
<td>Intellectual</td>
<td>4</td>
<td>4</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>Multiple</td>
<td>3</td>
<td>3</td>
<td>5</td>
<td>37.5</td>
</tr>
<tr>
<td>Albino</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>Total</td>
<td>40</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The results reveal that people with intellectual disabilities and Albinos felt they were at 100% risk of HIV infection, 66.7% of deaf people said they were at risk, and 50% of respondents with visual impairments were of the opinion that they were at risk of HIV infection.

vi) Perceived personal risk of HIV infection by respondents’ sex and age
The findings suggest that more males thought they had a higher personal risk of HIV infection. Analysis of perceived personal risk by sex of respondent revealed that 10 (61%) out of 18 male respondents believed they were at a higher risk of HIV infection,
while 12 (54.5%) of the 22 female respondents thought they were at a higher risk of HIV infection.

Analysis of perceived personal risk of HIV infection by age of respondent yielded results as shown in the table below:

Table 14: Perceived personal risk of HIV by age of respondent

<table>
<thead>
<tr>
<th>Age group (Yrs)</th>
<th>No of respondents</th>
<th>Yes</th>
<th>No</th>
<th>Level of Risk (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-24</td>
<td>7</td>
<td>7</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>25-29</td>
<td>6</td>
<td>3</td>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>30-39</td>
<td>15</td>
<td>10</td>
<td>5</td>
<td>66.7</td>
</tr>
<tr>
<td>40-49</td>
<td>9</td>
<td>5</td>
<td>4</td>
<td>55.5</td>
</tr>
<tr>
<td>50+</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>33.3</td>
</tr>
</tbody>
</table>

According to the findings, 100% of respondents in the age group 15-24 years perceived themselves to be at a risk of HIV and 66.7% of participants in the 30-39 age range believed they were at a risk of HIV infection. With only 33.3% of participants aged over 50 years reporting that they believed they were at risk of HIV infection, the findings suggest that as they became older, participants believed that their risk of HIV infection diminished.

4.4 Age of sexual debut in the respondents’ communities

The most cited age of sexual debut among both boys and girls in the respondents’ communities was 10-14 years, with a few respondents indicating that young people become sexually active at the age of seven (7 years) in some communities. Thirty one (77.5%) of respondents indicated the age of 10-14 years as the age of sexual debut among girls while 28 (70%) reported the same age group for boys’ sexual debut. These findings reflect that of the general population as found in the THMIS which indicates that 60 percent of young women in Mainland Tanzania have had sex at age 18. The findings negate the prevalent but erroneous belief that people with disabilities are not sexually active and underline the need for policy makers and implementers to pay attention and plan for them in HIV & AIDS education and in designing interventions. The table below indicates the distribution of the responses on the age of sexual debut among boys and girls in the respondents’ communities.

Table 15: Age of sexual debut among boys and girls in the community

<table>
<thead>
<tr>
<th>Girls</th>
<th>Age groups</th>
<th>Number of respondents</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10-14 yrs</td>
<td>31</td>
<td>77.5%</td>
</tr>
<tr>
<td></td>
<td>15-19 yrs</td>
<td>8</td>
<td>20%</td>
</tr>
<tr>
<td></td>
<td>20-24 yrs</td>
<td>1</td>
<td>2.5%</td>
</tr>
<tr>
<td></td>
<td>25-29 yrs</td>
<td>0</td>
<td>0%</td>
</tr>
</tbody>
</table>
4.4.1 Respondents’ sexual debut

Asked about their own sexual debut, 45 percent of respondents indicated that they started having sexual intercourse between of 15-19 years. Eight respondents reported that they had never engaged in sexual intercourse.

<table>
<thead>
<tr>
<th>Age group</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>10-14 yrs</td>
<td>4</td>
<td>10%</td>
</tr>
<tr>
<td>15-19 yrs</td>
<td>18</td>
<td>45%</td>
</tr>
<tr>
<td>20-24 yrs</td>
<td>7</td>
<td>17.5%</td>
</tr>
<tr>
<td>25-29 yrs</td>
<td>3</td>
<td>7.5%</td>
</tr>
</tbody>
</table>

It was not clear why the respondents’ age of sexual debut was later than what they stated for their communities but perhaps respondents felt it would be more appropriate to report that they had sex later than their peers.

An interview with a deaf female respondent in her teenage years provided some interesting information. She stated that she had never had sexual intercourse ‘but when I was young, in nursery school, I remember having sex always but these days I do not have sex’. This finding poses the question of possible abuse of young disabled children in families.

4.5 Use of condoms among people with disabilities

Respondents appeared to have knowledge of HIV infection modes and prevention, regular use of condoms was high. For example, when asked whether they had had sex with a stranger in the past year, 31 (77.5%) of the respondents indicated they had not, while nine (22.5%) responded in the affirmative. Of the nine who reported that they had had sex with a stranger, seven (78%) said they had used a condom. The findings were similar to those of THMIS, which found that condom use among women aged 15-24 having sex with a non-cohabiting partner was at 32 percent while for men, the incidence was 80 percent.
On the frequency of condom use, 20 (50%) of the respondents said they never used condoms during sexual intercourse, 11 (27.5%) used condoms ‘every time’, while nine (22.5%) used condoms ‘some of the time’.

Probed on the reasons for non-use of condoms with their partners, 58.1% of the respondents who had not used condoms stated that they ‘trusted each other’ with the partner. Others ‘never’ used condoms because they were married; while one woman said that she never used condoms ‘because they have side effects’. Twenty eight percent (28%) thought it was the partners’ responsibility or ‘it was not necessary’ to use condoms.

Clearly, a large number of participants used the knowledge gained concerning prevention of HIV through the use of condoms. A concern was also raised during FGDs about knowledge of the proper use of condoms, with participants suggesting that ‘there is need to show/demonstrate to people with disabilities how to wear condoms’. This lends credence to observations made during focus group discussions where participants emphasized that information on HIV & AIDS should be given repeatedly instead of infrequently as it was happening currently. This would ensure that the messages become part of the recipients and might reduce risky sexual behaviour.

4.6 Multiple sex partners among people with disabilities

The study also investigated sexual behaviour of people with disabilities with regard to multiple sexual partners. Twenty six (65%) out of 40 respondents indicated that it was ‘not common’ for people with disabilities to have multiple partners. Twelve (30%) respondents said that the practice of having multiple sex partners was ‘common’ while 2 (5%) respondents did not know.

Probed as to the reasons for people with disabilities having multiple partners, the 12 respondents reporting that it was common for people with disabilities to have multiple partners gave various reasons including ‘to get money’ (66.6%), being ‘forced’ (58%), ‘drunkenness’ (50%), and having ‘no spouse’ (33.3%).

<table>
<thead>
<tr>
<th>Questions</th>
<th>Variables</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is it common for people with disabilities to have many partners?</td>
<td>Yes</td>
<td>12 (30%)</td>
</tr>
<tr>
<td>I don’t know</td>
<td>2 (5%)</td>
<td></td>
</tr>
<tr>
<td>If yes to above, why?</td>
<td>to get money</td>
<td>8</td>
</tr>
<tr>
<td>Forced</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>due to drunkenness</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>no husband/wife</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
The question of ‘involuntarily’ having multiple sexual partners among disabled people emerged from the findings. Women with intellectual disabilities were reported to experience repeated rapes by different people both within and outside the family circle.

According to a respondent, the reasons for this were

’Some people think that people with disabilities do not have sex with many people so they are safe. Therefore, people can follow blind women/men and have sex with them and leave them with HIV & AIDS’ (FGD Kibaha).

### 4.7 Incidences of rape of people with disabilities

The findings suggest that there are low incidences of rape of people with disabilities as indicated in the table below.

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>NUMBER</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>COMMON</td>
<td>10</td>
<td>25%</td>
</tr>
<tr>
<td>NOT COMMON</td>
<td>23</td>
<td>57.5%</td>
</tr>
<tr>
<td>DO NOT KNOW</td>
<td>7</td>
<td>17.5%</td>
</tr>
</tbody>
</table>

Findings from FGDs however, suggest that people with disabilities are raped for the following reasons: i) ‘used as objects of pleasure’, ii) ‘because they are defenceless’, iii) ‘families will keep the information secret’, iv) ‘it does not matter because she is disabled’.

One poignant response from a respondent was captured below:

*Many of the raped are intellectual (with intellectual disability) so when the family finds that someone in the family did that, they do nothing because they say that the person is mental (Kibaha).*

Discussions in FGDs suggest that rape of disabled people could be prevalent among family settings. FGD participants pointed out that ‘rape takes place mostly in secret, so it is difficult to know about it’ (male respondent: FGD, Kibaha). They believed that the greatest risk for people with disabilities came from ‘their family members and local, trusted people’ (Respondent in Temeke).

Agreeing with this observation, another respondent added that it was ‘difficult for the deaf and the intellectually disabled to report incidents of rape against them’ (Female participant: FGD, Ilala).
Contributing to the discussions, a respondent reminded other participants that the rape of people with disabilities could be worse because

‘Some years ago, people were told by witchdoctors that if men had sex with a disabled person, they would become rich. Some of the men even went after those with more severe disabilities arguing that the more extensive the disability, the richer you will become’. (Female participant: FGD, Kibaha).

During interviews, one respondent with an intellectual disability said that she had never had sexual intercourse but she was obviously pregnant. Family members were reluctant to discuss this matter, saying they did not know how it happened. It is therefore reasonable to conclude that rape of people with disabilities could be more prevalent than the statistics in the table above would suggest. This position is similar to the findings of a study by Sweeney that suggest that ‘women with disabilities are more exposed to being sexually exploited than their non-disabled peers and will rarely report the attack’.

4.8 Respondents’ knowledge of rape cases among people with disabilities

When asked whether they knew of any person with disabilities who had been raped, the respondents reported as in the table below:

<table>
<thead>
<tr>
<th>KNOWLEDGE OF RAPE CASES AMONG PEOPLE WITH DISABILITIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
</tr>
<tr>
<td>NO</td>
</tr>
</tbody>
</table>

Although 60% of the respondents reported that they did not know of a disabled person who had been raped, it appeared that FGDs gave opportunity to participants to share their knowledge on this matter. Even a figure of 40% rape cases would be very high.

The number of respondents indicating that they knew of a disabled person who had been raped was highest among the deaf at 66.7% and lowest among blind people and albinos.

---

29 Jacinta M Sweeney (2004): A thesis submitted to the University of Manchester for the degree of MA Poverty, Conflict and Reconstruction in the Faculty of Social Sciences and Law, Institute for Development Policy and Management (IDPM)
4.9 Attendance of VCT Centres by disability
The question on the use of VCT services elicited various responses. In general, participants believed that many people with disabilities did not use VCT services for various reasons including:

- long distances to the VCT centres,
- b) the belief that ‘those services belong to others’,
- c) ‘fear of discrimination, stigma and rejection’,
- d) lack of privacy,
- e) ‘fear of lack of confidentiality of their status,
- f) ‘the impacts of their disability, e.g. the blind, the physically disabled’,
- g) ‘lack of health workers with sign language,
- h) insensitivity and disability friendly service providers.

One response that came up repeatedly and strongly in different forms was the negative attitudes of health service providers where it was said that:

‘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 sinner (sic) (sinful) they do not sympathise that this is a disabled woman and they have made her pregnant’. (Ilala Municipality)

The pattern of respondents stating that people with disabilities attend VCT centres by disability of respondents is as indicated in the table below:

<table>
<thead>
<tr>
<th>Disability of respondent</th>
<th>No of respondents</th>
<th>Yes</th>
<th>No</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>11</td>
<td>7</td>
<td>4</td>
<td>42.7</td>
</tr>
<tr>
<td>Visual</td>
<td>8</td>
<td>7</td>
<td>1</td>
<td>87.5</td>
</tr>
<tr>
<td>Deaf</td>
<td>6</td>
<td>5</td>
<td>1</td>
<td>83.3</td>
</tr>
<tr>
<td>MH</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>87.5</td>
</tr>
<tr>
<td>Multiple</td>
<td>8</td>
<td>5</td>
<td>3</td>
<td>62.5</td>
</tr>
<tr>
<td>Albino</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>66.7</td>
</tr>
</tbody>
</table>

The results indicate that people with visual impairments were most aware that people with disabilities visited VCT centres.
4.10 Respondents’ use of VCT Services

Thirty four (85%) of the respondents indicated a desire to be tested and 22 (55%) of them revealed that they had been tested for HIV but only two (9.1%) had been found to be HIV positive. Before being tested, only 6% thought they were at risk of HIV while 72.75% did not.

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>%</th>
<th>NO</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>DESIRE TO BE TESTED</td>
<td>34</td>
<td>85%</td>
<td>6</td>
<td>15%</td>
</tr>
<tr>
<td>EVER TESTED</td>
<td>22</td>
<td>55%</td>
<td>18</td>
<td>45%</td>
</tr>
<tr>
<td>IF YES, WERE YOU HIV +?</td>
<td>2</td>
<td>9%</td>
<td>20</td>
<td>91%</td>
</tr>
<tr>
<td>*IF YES, DID YOU BELIEVE YOU WERE AT RISK BEFORE TEST?</td>
<td>6</td>
<td>27.3%</td>
<td>16</td>
<td>72.75%</td>
</tr>
</tbody>
</table>

*NB: Even respondents who did not test positive responded to this item

4.11 Sources of information on HIV & AIDS

Respondents identified various sources of information on HIV & AIDS. For the youth, school was significant because they were taught about HIV & AIDS while there. Other respondents learned about it in i) seminars and workshops, ii) in campaigns at church, iii) at health facility iv) through being infected and from friends and family members.

The study noted that information learned from family members and friends tended to be flawed. For example, one respondent said she learned about HIV & AIDS from her mother. She learned that

\[\text{HIV is a very bad disease that one gets through 'umalaya' (prostitution). People with HIV should not be looked after by family members because they would infect other family members with HIV. Therefore, such people should be chased away from home. (Respondent to a questionnaire)}\]

<table>
<thead>
<tr>
<th>HOW/WHERE DID YOU KNOW ABOUT HIV &amp; AIDS and STI? (it is possible to have more than one response to this item)</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>IN SEMINAR/CHURCH/RADIO</td>
<td>15</td>
<td>37.5%</td>
</tr>
<tr>
<td>FROM FRIEND/FAMILY MEMBER</td>
<td>15</td>
<td>37.5%</td>
</tr>
</tbody>
</table>
During focus group discussions, participants mentioned other significant sources of information as the i) radio, ii) pamphlets and iii) flyers, iv) banners, v) bill boards, and in some few cases, vi) television. However, participants also stressed that blind and deaf people would need to have messages in Braille or signed for them. Illiterate deaf people without formal sign language would need another medium as well.

4.12 Obstacles to HIV & AIDS and STI information and prevention services

Twenty one (52.5%) of the 40 respondents thought that it was easy for people with disabilities to access HIV & AIDS and STI information and services, while 19 (47.5%) said it was not. The study found that there were many obstacles to access to HIV & AIDS services. The distribution of the respondents’ answers when asked about the obstacles to accessing HIV & AIDS services are indicated in the table below:

<table>
<thead>
<tr>
<th>Obstacles</th>
<th>Respondents</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>STIGMA</td>
<td>10</td>
<td>53%</td>
</tr>
<tr>
<td>LACK OF INVOLVEMENT IN PROGRAMMING</td>
<td>12</td>
<td>63%</td>
</tr>
<tr>
<td>LOW PRIORITY GIVEN TO PEOPLE WITH DISABILITIES</td>
<td>6</td>
<td>32%</td>
</tr>
<tr>
<td>LACK OF EXPERTS</td>
<td>5</td>
<td>26%</td>
</tr>
<tr>
<td>LACK OF BRAILLE MATERIALS</td>
<td>2</td>
<td>11%</td>
</tr>
<tr>
<td>LONG DISTANCE</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>NO SIGNS</td>
<td>2</td>
<td>10.5%</td>
</tr>
</tbody>
</table>

Twelve (63%) of the respondents mentioned lack of involvement in programming as an obstacle to access to HIV & AIDS services. This lack of involvement appeared to have resulted in lack of ownership of HIV & AIDS services. For example, in an FGD participants said that VCT services were

‘Inaccessible because there were no signs to indicate whether we can be served there. We do not know whether a person with disabilities would be served’. (FGD Morogoro).

Other obstacles to accessing HIV & AIDS information and prevention services as identified in FGDs were i) inaccessible clinics, ii) lack of sign language among service providers, iii) ignorance and the belief that VCT services are not meant for people with disabilities, iv) the fear of people gossip, v) fear of discrimination, rejection and stigma.
b) **Assessment of the extent to which disabled people’s organizations and special schools are involved with teaching people with disabilities about HIV & AIDS**

4.13 **Disability focus and Core activities of organizations of people with disabilities**

The table below summarizes the areas of operation of the 24 organizations of/for people with disabilities. Some organizations focused on more than one disability area.

<table>
<thead>
<tr>
<th>Type of disability</th>
<th>ILALA</th>
<th>TEMEKE</th>
<th>KIBAHA</th>
<th>MOROGORO</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHYSICAL</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>BLIND</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>DEAF</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>MH</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>ALBINO</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

| ALL DISABILITIES   | 2     | 3      | 4      | 0        | 9     |
| TOTAL              | 30*   |        |        |          | 30*   |

*NB: Some organizations focused on more than one area

Sixteen (16) organizations for and of people with disabilities in Ilala, Temeke, Kibaha and Morogoro, and eight (8) Special Schools were visited for the assessment. Ilala District, by virtue of it being the central business district (CBD) of Dar-es-Salaam, also appears to have a large number of MDAs and umbrella CSOs.

The areas of focus of the organizations were: a) nine focused on all disabilities, b) eight focused on the deaf, c) five focused on the blind, d) four focused on the intellectually disabled, e) three on the physically disabled, and f) one focused on people with albinism.

The core activities of the organizations were: i) advocacy, ii) HIV & AIDS education, iii) promoting the starting of support groups, iv) rehabilitation, medical counselling, v) outreach/ home based care, vi) capacity building, vii) legal services, viii) development and ix) income generating activities (IGA).
Table 26: Core activities of organizations of and for people with disabilities

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>ILALA</th>
<th>TEMEKE</th>
<th>KIBAHA</th>
<th>MOROGORO</th>
<th>TOTAL</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADVOCACY</td>
<td>7</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>12</td>
<td>50%</td>
</tr>
<tr>
<td>HIV &amp; AIDS EDUCATION</td>
<td>11</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>20</td>
<td>83.3%</td>
</tr>
<tr>
<td>SUPPORT GRPS</td>
<td>5</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>11</td>
<td>45.8%</td>
</tr>
<tr>
<td>REHABILITATION</td>
<td>8</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>13</td>
<td>54.2%</td>
</tr>
<tr>
<td>MEDICAL COUNSELLING</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>9</td>
<td>37.5%</td>
</tr>
<tr>
<td>OUTREACH/ HOMEBASED CARE</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>10</td>
<td>41.7%</td>
</tr>
<tr>
<td>CAPACITY BUILDING</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>12</td>
<td>50%</td>
</tr>
<tr>
<td>LEGAL SERVICES</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>7</td>
<td>29.2%</td>
</tr>
<tr>
<td>DEVELOPMENT</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>20.8%</td>
</tr>
<tr>
<td>IGA</td>
<td>3</td>
<td>13</td>
<td>2</td>
<td>0</td>
<td>18</td>
<td>49%</td>
</tr>
</tbody>
</table>

As is evident in the table above, 20 (83.3%) of the organizations are involved in HIV & AIDS education for people with disabilities. This possibly explains the high level of knowledge of HIV & AIDS information found among the respondents in the study districts.

The numbers of people served was shown as 178,623 in Ilala, 604,053 in Temeke, 86 in Kibaha and 175 Morogoro. Respondents were not able to disaggregate the figures by gender and type of disability. From their knowledge of the local situation, the local consultants noted that the figures for Temeke and Ilala may be representing national figures but this was difficult to verify due to lack of accurate records.

Maintenance of accurate records is crucial in determining the level of achievement of objectives of any organization. There is therefore need to build the capacity of organizations of and for people with disabilities to maintain proper records of their clients.

4.14 Strategies used to reach people with disabilities

OPDs used various strategies to reach people with disabilities. These included direct implementation of projects, community support, funding activities of other NGOs and counseling, test and treatment.
Below is a summary of the strategies used by organizations of people with disabilities.

i) Two (2) supported government initiatives.
ii) Two (2) supported income generating activities (IGAs) for people with disabilities.
iii) Six (6) provided HIV & AIDS education.
iv) Three (3) participated in development and distribution of materials.
v) Two (2) funded other NGOS.
vi) Two (2) funded communities.
vii) Two (2) provided counseling, testing, treatment and support to people with disabilities.

The study was unable to determine the extent to which OPDs were serving disabled people in terms of dissemination of HIV & AIDS information and materials due to lack of documentation and records. This could be an area of further study, especially in preparation for collaboration interventions with OPDs in future projects/programmes.

4.15 Prevalence of use of illicit drugs among people with disabilities

The study attempted to determine the extent of the awareness of use of illicit drugs among people with disabilities and addressed the question to members of the organizations of/for people with disabilities in all the focus districts. Fifty four point two percent (54.2%) of the respondents reported that there was presence of drug abuse among people with disabilities, while six (25%) said there was no drug abuse among people with disabilities and five (20.8%) did not know.

As to whether drug abuse was common among people with disabilities, the 13 (69.2%) of the respondents reporting the presence of drug abuse stated that it was ‘limited to a few’.

The responses were as indicated in the table below:

<table>
<thead>
<tr>
<th>ARE THERE INCIDENCES OF DRUG ABUSE AMONG PEOPLE WITH DISABILITIES?</th>
<th>YES</th>
<th>%</th>
<th>NO</th>
<th>%</th>
<th>DON’T KNOW</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No of respondents</td>
<td>13</td>
<td>54.2%</td>
<td>6</td>
<td>25%</td>
<td>5</td>
<td>20.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HOW COMMON IS DRUG ABUSE AMONG PWDS (13)?</th>
<th>VERY COMMON</th>
<th>LIMITED TO FEW</th>
</tr>
</thead>
<tbody>
<tr>
<td>No of respondents of</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>30.8%</td>
<td>69.2%</td>
</tr>
</tbody>
</table>

Findings from FGDs seem to confirm the suggestions that drug abuse among people with disabilities was low. FGD participants were able to recall only two cases of drug abuse.
4.16 Programmes to combat drug abuse among people with disabilities

As to whether the organizations had programmes to combat use of illicit drugs among people with disabilities, only eight (33.3%) of the organizations reported that they had while 16 (66.7%) of the 24 organizations did not have programmes on drug abuse targeting people with disabilities as indicated below:

<table>
<thead>
<tr>
<th>DISTRICT</th>
<th>YES</th>
<th>%</th>
<th>NO</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>ILALA</td>
<td>3</td>
<td>10</td>
<td>10</td>
<td>33.3%</td>
</tr>
<tr>
<td>TEMEKE</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>66.7%</td>
</tr>
<tr>
<td>KIBAHA</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>33.3%</td>
</tr>
<tr>
<td>MOROGORO</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>66.7%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>8</td>
<td>33.3%</td>
<td>16</td>
<td>66.7%</td>
</tr>
</tbody>
</table>

Organizations with programmes on drug abuse among people with disabilities focused on i) the health consequences of drug use, ii) education on drugs abuse, iii) counselling and support and iv) legal consequences of drug abuse.

Although the small number of organizations having programmes on HIV & AIDS among people with disabilities could be evidence of the low incidence of drug abuse among people with disabilities, it is a clear indication that there is awareness of the problem of drug addiction and it could grow. It is evident that there is a need to address it more vigorously before the situation gets out of hand.

4.17 Training and use of peer educators

Peer educators have been used effectively in community interventions in areas of HIV & AIDS and disability, for example in Community Based Rehabilitation initiatives. The study therefore explored the extent to which OPDs used peer educators in their work in HIV & AIDS. Regarding the training and use of peer educators, 14 (58.3%) out of the 24 organizations reported that they trained peer educators.

However, more specific questions on the number of peer educators trained and the number of people with disabilities trained by peer educators did not yield meaningful responses because the organizations did not have statistics and other records on this activity.
4.18 **OPDs’ assessment of how easy it is for people with disabilities to access to information on HIV & AIDS and STI**

When asked whether it was easy for people with disabilities to access information on HIV & AIDS, 15 (62.5%) organizations reported that it was easy while eight (33.3%) said it was not easy. The distribution of responses is indicated in the table below:

<table>
<thead>
<tr>
<th>District</th>
<th>YES</th>
<th>%</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>ILALA</td>
<td>8</td>
<td>33.3%</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>TEMEKE</td>
<td>5</td>
<td>20.8%</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>KIBAHA</td>
<td>2</td>
<td>8.3%</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>MOROGORO</td>
<td>0</td>
<td>0%</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>15</td>
<td>62.5%</td>
<td>8</td>
<td>(33.3%)</td>
</tr>
</tbody>
</table>

Although the findings seem to suggest that people with disabilities had no difficulties in accessing information, respondents in FGDs observed that out-of-school youth without reading skills, illiterate people and blind people without knowledge of Braille would be unable to access written information. Similarly, people with severe/profound intellectual and multiple disabilities would have difficulties in accessing information unless it was brought and given to them in accessible formats such as pictorial presentations, dramatization and explanations using mediums of communication used in the family setting. They also argued that deaf people who had never gone to school many not know formal sign language and would need information to be disseminated to them using familiar signs used with family members.

The findings from personal interviews and discussions, suggest that people with disabilities especially in the rural areas had no access to information on HIV & AIDS. According to them, efforts to disseminate information do not usually target people with disabilities, especially in the rural areas, thus making them believe that they do not need to know about HIV & AIDS. At the same time, information is usually disseminated in formats that do not reach the deaf, the blind and people with intellectual, multiple and profound disabilities who might be the most vulnerable of all.

4.19 **OPDs assessment of challenges preventing people with disabilities from accessing services**

Asked to state what obstacles prevented people with disabilities from accessing services the respondents gave their answers as shown below. Sign language was the most cited reason, followed by physical inaccessibility and unfriendly environment in that order.
Respondents in FGDs suggested that the absence or invisibility of people with disabilities as employees in service providing organizations was also an obstacle and their presence would encourage people with disabilities to use the services more than they are doing currently.

Discussing the ‘unfriendly environment’ as a barrier to services, participants also noted that negative attitudes towards people with disabilities were contributing factors to discouraging them from using health facilities and VCT centres. For example, reactions with shock or disdain when people with disabilities present themselves for service could discourage them from repeat visits to the service centres.

4.20 Challenges encountered by OPDs in providing services to people with disabilities

The study sought to understand the challenges experienced by OPDs in providing services to people with disabilities. The table below presents responses obtained in response to this question.

<table>
<thead>
<tr>
<th>Challenges</th>
<th>ILALA</th>
<th>TEMEKE</th>
<th>KIBAHA</th>
<th>MOROGORO</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>No sign language</td>
<td>11</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>Physical inaccessibility</td>
<td>9</td>
<td>3</td>
<td>4</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Unfriendly environment</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Others (lack of directional signs)</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

Service providers indicated that the greatest challenge to serving people with disabilities was long distances to the service centres as mentioned by 13 organizations. They
explained that sometimes the distances were as far as 100km away and with difficult terrain especially for people with physical mobility challenges. Long distances also prevented the organizations from taking outreach activities to people with disabilities in their communities. Therefore they confined their activities to places where they could reach easily and cheaply. Ten (10) organizations identified ‘family reluctance’ to take people with disabilities for services as a major challenge. This was demonstrated during data collection when the research assistants encountered a thirty year old man with disabilities who was critically ill but the family members were not able or unwilling to take him to a medical facility arguing that it was ‘difficult as he was too heavy to carry’. They pointed out that he was already 30 years old. Sadly, the research team was informed of the death of the man a few days later.

From this incident, it is possible to conclude that issues of neglect, poverty, ignorance and care-giver fatigue in caring for people with disabilities are present. This is an area that would need further investigation.

4.21 OPDs capacity gaps and obstacles to effective service provision for people with disabilities

Asked to identify gaps in service provision, the OPDs mentioned the following as indicated in the table below. It was possible to have more than one answer for this item.

<table>
<thead>
<tr>
<th>VARIABLES</th>
<th>ILALA</th>
<th>TEMEKE</th>
<th>KIBAHA</th>
<th>MOROGORO</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>INADEQUATE SKILLED PERSONNEL</td>
<td>7</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>LIMITED FINANCES</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>DELAYS OF MATERIALS</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>LIMITED TRANSPORT</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>LONG DISTANCES</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>RELUCTANCE TO CONDOM USE</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>RELUCTANCE TO TEST</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>HIGH STAFF TURNOVER</td>
<td>2</td>
<td></td>
<td></td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>OTHERS</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
4.22 Records
The study established that OPDs did not have effective systems to register and know specific numbers of people with disabilities served and the disability types. Although this was not mentioned as a barrier to service provision, this is definitely a barrier it is not possible plan effectively for service services without statistics.

The study notes that the question of lack of data came up repeatedly in questionnaires, in interviews and in focus group discussions. This is a serious matter because no meaningful planning can be done without knowing the number of the target group in any intervention. It is a capacity gap that needs to be addressed to improve service delivery.

4.23 Legal assistance for people with disabilities
Thirteen (54.1%) of the organizations indicated that there was legal assistance for people with disabilities, eight said there was none, while three (3) organizations did not know whether there was legal assistance for people with disabilities.

When the question of legal aid for people with disabilities was put to FGD participants, they noted that it was not there. To support their claim, they referred to a case where a person with disability was raped and ‘when the matter was reported to the police the no action has been taken to date’.

4.24 Current collaboration/interactions between district HIV & AIDS service providers
The findings suggest that collaboration with other service providers is rather weak as indicated in the table below. The reasons for this weak collaboration were identified in focus group discussions with OPDs.

Table 32: Collaboration with other service providers

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>ILALA</th>
<th>TEMEKE</th>
<th>KIBAHA</th>
<th>MOROGORO</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaboration with other organizations?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>IF YOU COLLABORATE, HOW MANY ARE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Service Providers (LGAs)?</td>
<td>Yes</td>
<td>5</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>HIV &amp; AIDS Service providers?</td>
<td>No</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

The reasons for non-collaboration were explained during discussions in which participants attributed lack of collaboration to lack of strong leadership and capacity in the disability rights movement to bring the organizations together and coordinate
activities. In FGDs, OPDs were accused of not having close collaborations with one another due to a) ‘competition’, b) ‘secrecy’, c) ‘unwillingness to open up to others, d) ‘mutual distrust’, e) ‘lack of transparency’ and ‘financial reasons’.

The study observes that stronger collaboration between OPDs would ensure improved service delivery to people with disabilities. This is also an intervention opportunity to improve on the areas of weakness among OPDs and civil society organizations (CSOs) in general.

4.25 Areas of collaboration between disability organizations and health and HIV & AIDS service providers

The study noted that there was some collaboration between disability organizations and Health and HIV & AIDS service providers. The major areas of collaboration were:

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>ILALA</th>
<th>TEMEKE</th>
<th>KIBAHA</th>
<th>MOROGORO</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>JOINT MEETINGS</td>
<td>7</td>
<td>3</td>
<td>4</td>
<td>2</td>
<td>16</td>
</tr>
<tr>
<td>JOINT PLANNING</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>INFORMATION SHARE</td>
<td>6</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td>JOINT ADVOCACY</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>JOINT TRAINING</td>
<td>7</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>13</td>
</tr>
</tbody>
</table>

The areas of collaboration identified above are an indication that it is possible to enhance collaboration among disability organizations and HIV & AIDS service providers.

4.26 Integration of OPDs into district plans

When the OPDs were asked whether their activities were integrated into district plans, 12 (50%) of the organizations said yes they were, 10 (41.7%) said no, and 2 (8.3%) did not know as indicated in the table below:

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>YES</th>
<th>%</th>
<th>NO</th>
<th>%</th>
<th>DON'T KNOW</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>ILALA</td>
<td>6</td>
<td>25%</td>
<td>5</td>
<td>20.8%</td>
<td>2</td>
<td>8.3%</td>
</tr>
<tr>
<td>TEMEKE</td>
<td>1</td>
<td>4.2%</td>
<td>4</td>
<td>16.7%</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>KIBAHA</td>
<td>3</td>
<td>12.5%</td>
<td>1</td>
<td>4.2%</td>
<td>0</td>
<td>0%</td>
</tr>
</tbody>
</table>
These findings indicate that the level of integration into district plans is low at around 50%. LGAs (under whom the HIV & AIDS providers operate were reported to be ‘unwilling to incorporate’ OPDs in their plans and activities. MDAs and LGAs was also said to have weak oversight into the activities of OPDs thus indicating a sense of disharmony and lack of strong coordination that is necessary for effective service delivery and monitoring of activities and results.

*There is need for the LGA to ensure a greater participation of OPDs in the local development plans and activities. This would improve coordination, accountability and transparency and reduce unnecessary duplication of effort.*

### 4.27 OPDs representation in Social Service Committees and Council Multi-Sectoral AIDS Committees

The study asked respondents from organizations of people with disabilities to indicate if they were represented in the relevant LGA committees as provided by in the government policy. The findings are as indicated in the table below:

<table>
<thead>
<tr>
<th>ARE YOU REPRESENTED IN COUNCIL SOCIAL SERVICE COMMITTEES?</th>
<th>ILALA</th>
<th>TEMEKE</th>
<th>KIBAHA</th>
<th>MOROGORO</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>NO</td>
<td>8</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>DON’T KNOW</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ARE YOU REPRESENTED IN COUNCIL MULTI-SECTORAL AIDS COMMITTEE?</th>
<th>ILALA</th>
<th>TEMEKE</th>
<th>KIBAHA</th>
<th>MOROGORO</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>NO</td>
<td>9</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>19</td>
</tr>
<tr>
<td>DON’T KNOW</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

The findings indicate that of the 24 organizations of people with disabilities, 18 (75%) were not represented in the Council Social Service Committees although there are guidelines for their representation in the local government committees. Similarly, representation in the Council Multi-Sectoral AIDS Committee was low with 19 (79%) of the organizations reporting that they were not represented.
This is an area of opportunity that LGAs should seize to enhance collaboration and oversight of the activities of OPDs in order to improve on the extent and quality of services provided in the area of HIV & AIDS as well as other community support interventions.

4.28 Meetings with Council HIV & AIDS Coordinator (CHAC) and District AIDS Control Coordinator (DACC)

In trying to further determine and understand the level of involvement of OPDs in LGA, the participants were asked about their participation with CHAC and DACC. The results are indicated below:

Table 35: On whether ODP meet regularly with CHAC & DACC

<table>
<thead>
<tr>
<th></th>
<th>DO YOU MEET REGULARLY WITH CHAC?</th>
<th></th>
<th>DO YOU MEET REGULARLY WITH DACC?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>YES</td>
<td>%</td>
<td>NO</td>
</tr>
<tr>
<td>ILALA</td>
<td>4</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>TEMEKE</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>KIBAHA</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>MOROGORO</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

The study found that eight (33.3%) of the 24 organizations of/for people with disabilities reported that they met regularly with CHAC and DACC while 16 (66.7%) did not. One respondent reported that they had only had one meeting in the period of one year.

This is indicative of weak collaboration mechanisms among the various players in the disability sector. If OPDs related more closely with one another, it is possible that they would have a stronger voice to ensure a greater participation and collaboration with MDAs and LGAs.
4.29 Reasons for non-collaboration with Local Government Authorities
The reasons for non-collaboration were shared by both the OPDs and LGAs. While it emerged that many OPDs were not aware that they should be represented in the LGAs, it also emerged that the LGAs had not informed OPDs of the government policy that CSOs should be represented especially in the Council Multi-Sectoral AIDS Committee (CMAC), which was set up in 2003 to ensure representation of people living with HIV. It was also noted that many CSOs are not proactive in seeking out information and exploring ways of collaboration with LGAs and so their representation remains low.

It essential for LGAs live up to their responsibility to take a leadership role in ensuring collaboration with OPDs as required in the government policy on matters of representation and participation of people with disabilities. Similarly, the OPDs should take a more proactive role in order to ensure that the voice of people with disabilities is heard in the relevant LGA committees.

4.30 Best practices
The study identified two examples of Best Practices in regard to disabled people and HIV & AIDS. The profiles of the Best Practice examples are presented in the table below:

Table 36: Best practice Example 1

<table>
<thead>
<tr>
<th>Best Practice Example 1: Special schools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Buguruni School for the Deaf has mainstreed HIV &amp; AIDS education into its curriculum as do all special schools. However the study noted that their approach was innovative, efficient and effective and its impact went beyond the confines of the school. Buguruni a) mainstreams HIV &amp; AIDS education into school work, b) allows and encourages open discussions of HIV &amp; AIDS and STI among students and teachers in school, c) encourages children to discuss HIV &amp; AIDS information obtained in school with family members.</td>
</tr>
<tr>
<td>The strategies used by Buguruni indicate that the HIV &amp; AIDS information goes beyond the school environment to the homes and into the community. This was an example of good practice that ensures a wide dissemination of accurate information on HIV &amp; AIDS.</td>
</tr>
<tr>
<td>Ingredients of success in Buguruni School for the Deaf</td>
</tr>
<tr>
<td>According to teachers at Buguruni, the ingredients of success in disseminating HIV &amp; AIDS information for learners were: a) commitment of key individuals, i.e. teachers and school authorities, b) sustained activity, c) follow ups, d) monitoring of achievements.</td>
</tr>
<tr>
<td>It would be interesting to further investigate what motivates teachers and school authorities to be so committed and whether this could be replicated.</td>
</tr>
</tbody>
</table>
Table 37: Best Practice Example 2

**Best Practice Example 2: Morogoro Municipality**

The study found that Morogoro Municipality had practical ways of including people with disabilities in HIV & AIDS initiatives. This was through a) ensuring representation of people with disabilities in all the 19 municipal wards, b) training representatives in turn on HIV & AIDS and STI. This was the only Municipality to have used this approach among those who were studied.

**Ingredients for success in Morogoro Municipality**

Success was assured through:

i) committed political leadership,

ii) innovative approaches of ensuring representation,

iii) Cascade training of peers to ensure a large pool of people knowledgeable in HIV & AIDS issues.

**Challenges/omissions/opportunities for Morogoro Municipality**

i) The municipality did not include the deaf among representatives of people with disabilities due to lack of expertise in sign language.

ii) The municipality did not explore the use of sign language experts.

iii) Limited funds reduced the number of disabled members so they picked only a few from each ward but asked them to ‘spread the word to others’.

**Lessons to learn from Buguruni School for the Deaf and Morogoro Municipality**

i) It is possible to involve people with disabilities in HIV & AIDS initiatives as facilitators and not just consumers.

The uptake of knowledge on HIV & AIDS and STI among people with disabilities is good as they are able, keen and willing to learn and use it e.g. in Kilakala Special School) in Morogoro.
c) Technical Assessment of the inclusiveness of Tanzanian HIV & AIDS education, communication, VCT treatment and care, and policy strategies

4.31 Technical Assessment of the inclusiveness of Tanzania HIV & AIDS education, communication, VCT treatment and care and policy strategies

4.32 Introduction
Policies state government positions on issues and provide road maps for the implementation of programmes to achieve national goals and objectives. The National HIV & AIDS policy gives legislative legitimacy to activities in HIV & AIDS control and management. The importance of targeting people with disabilities through policy documents and guidelines was underlined in the findings, which highlighted the continuing vulnerability of people with disabilities in the community. The assessment established that disability still attracts stigma, rejection and discrimination due to prevalent negative attitudes brought about by retrogressive beliefs. Similarly, HIV & AIDS also attract stigma and marginalization as it is widely viewed as a disease of ‘Umalaya’, that is, prostitution and of people that lead immoral lifestyles.

When people are afflicted with the twin problems of HIV & AIDS they suffer double discrimination, stigma, and rejection in the community. This exacerbates their marginalization and policy makers need to respond to reduce marginalization of people with disabilities.

These observations make a strong case for establishing a disability friendly HIV and AIDS policy environment to guide in interventions.

4.33 Inclusiveness of the national policy environment on HIV & AIDS policy for people with disabilities

The Ministry of Health and Social Welfare formulates policies and guidelines on HIV & AIDS control and management in the country. The Council HIV & AIDS Coordinator (CHAC) and the District AIDS Control Coordinator (DACC) are the lead implementers for the Local Government Authorities under the Council Multi sectoral AIDS Committee and the Council Social Services Committee respectively.

A scrutiny of the National Policy on HIV & AIDS (2001) that is currently in use reveals that it does not have specific references to people with disabilities. The study noted that when defining vulnerable groups of people, the policy does not include people with disabilities among them. Owing to this omission, the specific needs of people with disabilities are not addressed sufficiently when planning interventions on HIV & AIDS. Since the policy guidelines do not include people with disabilities, the LGAs who implement Central government policies and strategies similarly do not have programmes designed with the needs of people with disabilities in mind.
An analysis of TOMSHA and interviews with TACAIDS staff indicate that generally, TOMSHA does not specifically mention people with disabilities. However, indicator No. 14 (p.18) which states ‘number of persons reached with HIV prevention programmes by target group’ should be expanded to include people with disabilities and the type of disability. The TOMSHA reporting forms need to be able to accommodate information on people with disabilities.

Discussions with the Ministry of Health officials revealed that the HIV & AIDS and Malaria Indicator Survey (THMIS) has no indicators to capture information on people with disabilities and this should be changed in future.

4.34 Inclusiveness of the policy environment in OPDs
Only five of the six OPDs indicated that they had a policy that guides in addressing HIV & AIDS with regard to people with disabilities. The organizations however, were unable to provide a policy document to support their claims.

4.35 Inclusiveness of HIV & AIDS education for people with disabilities
Local Government Authorities: With the exception of Morogoro Municipality all the other LGAs did not involve people with disabilities in their HIV and AIDS programme. The findings indicated that Morogoro Municipality had inclusive strategies in which they run HIV and AIDS training for people with disabilities in all its 19 wards. Beneficiaries of the training are expected to share the information obtained in the training with others in their communities. The study identified the municipality as an example of ‘Best Practice’ that could be emulated elsewhere in Tanzania. However, the study notes that Morogoro did not include people with hearing impairments in their training and it could improve its inclusiveness to ensure representation of people with hearing impairments by engaging the services of sign language interpreters. With policy guidelines on how to make HIV & AIDS inclusive for people with disabilities, this situation should change for the better.

CHAC & DACC: Interviews with CHAC and DACC revealed that LGAs offer integrated HIV & AIDS interventions but had no strategies to cater for the needs of people with disabilities such as the blind, the deaf and those with intellectual disabilities.

The study respondents observed that when HIV & AIDS services are integrated,

‘We feel excluded and fear to participate because we fear rejection, stigma and discrimination and yet we are even more vulnerable than non-disabled.’ (Male respondent, FGD Kibaha)

Other participants in FGDs agreed with these sentiments and noted that during HIV & AIDS campaigns, no one encourages people with disabilities to attend in spite of the fact that ‘many of them were dying of AIDS because of ignorance of how to protect themselves from HIV’. (FGD participants)
Since they have high risk of HIV infection, people with disabilities need much more encouragement and sensitivity through inclusive policy guidelines and regulations to enable them to use the HIV & AIDS services in a non-threatening manner.

Special Schools: The study established that inclusiveness of HIV & AIDS education was strong in Special Schools since HIV & AIDS education is incorporated into the curriculum. Therefore, pupils were taught about HIV & AIDS from the time they entered school. Due to this inclusiveness, pupils in Special Schools were well informed about HIV & AIDS as discussed in earlier sections of this report.

4.36 Inclusiveness of VCT, treatment and care
The study found that in policy and practice VCT treatment and care did not have policies and guidelines that responded to the specific and special needs of people with disabilities. The findings however, emphasized the need for such policies and guidelines. Participants observed that there is need to ensure the inclusion of people with disabilities in HIV & AIDS education in VCT centres. Since many people with disabilities depend on assistants to take them to places, they fear that the confidentiality of the information they would give at the VCT centres may not be assured. For this reason many of them are reluctant to be seen visiting VCT centres. Participants also noted that already people with disabilities experienced discrimination, stigma and rejection in their communities due to their disability and therefore HIV infection would mean they would experience ‘double trauma’.

People with disabilities need to have their rights to appropriate services through adequate HIV & AIDS policy support in order for them to benefit from HIV & AIDS education. There is therefore need to review the policy environment and provide appropriate guidelines to ensure inclusive and disability friendly policies and practices in VCT Centres.

4.37 Inclusiveness of communication means for people with disabilities
The findings did not identify any policy guidelines among any of the organizations concerning communicating HIV & AIDS information to people with disabilities. As such, the findings indicated that communication materials used by LGAs and CSOs to disseminate HIV and AIDS information are not appropriate and accessible to people with disabilities. For example, there were no communication materials in Braille and sign language.

The study revealed that teachers in special schools employed creative communication strategies by developing their own IEC materials to ensure that all children with various disabilities understood HIV and AIDS information accurately. They also encouraged pupils to share the information with their families.
4.38 Service gaps in VCT and Health facilities, special schools and in OPDs

ii) Lack of adequately trained personnel
There is need to develop the capacity of service providers in health facilities, and organizations to equip them to better response to the needs of people with disabilities in HIV & AIDS education, treatment and care.

iii) Physical inaccessibility
Inaccessible physical facilities were identified as a barrier that needs to be addressed through refurbishment/ modifications.

iv) Organizations’ weak or non-existent policies
Organizations need to develop or update their HIV & AIDS policies to ensure inclusiveness for people with disabilities.

v) Limited finances
Financial constraints among OPDs were identified as gaps in service provision. In order to address this, there is need for capacity building on financial resource mobilization and resource mobilization in general.

vi) Lack of disability responsive IEC materials
Lack of appropriate IEC materials came up repeatedly as a gap and obstacle to effective service provision for people with disabilities.

vii) Weak/non-existent information management systems
The study found that there were weak or non-existent systems for keeping records of clients with disabilities serviced either in health facilities or VCT centres as this is not yet included into the reporting forms.
Chapter 5: Conclusions and Recommendations

5.1 Introduction
The assessment has established that the people with disabilities have a high level of knowledge about infection, prevention and treatment of HIV. It also has revealed that disability organizations and government agencies have some programmes that target people with disabilities. There are still many obstacles however, to ensuring that HIV & AIDS messages reach all people with disabilities. The following sections in this chapter will draw conclusions from the findings of the three study areas and make recommendations.

5.2 Conclusions
On the overall, the study reveals that people with disabilities who were interviewed were knowledgeable about HIV & AIDS, its modes of transmission, prevention methods, and the fact that it has no cure currently. Despite this knowledge, it was noted that condom use was rather low among respondent who indicated that they were sexually active and even among those who had multiple sex partners.

The study notes that many barriers continue to prevent people with disabilities from accessing and using HIV & AIDS services effectively. Some of the barriers have to do with i) physical inaccessibility of service centres, ii) lack of sign language, iii) negative attitudes among service providers, iv) lack of awareness about availability of services and v) inaccessible information formats for blind and deaf people.

The findings also revealed that information on HIV & AIDS and STI from various sources such as special schools, seminars, the print media (pamphlets, flyers), the radio, drama, and family and friends. The study noted that while formally disseminated information in schools and in seminars was accurate, HIV & AIDS information from friends and family tended to be factually flawed.

The study noted that there were no significant differences in levels of vulnerability to HIV & AIDS by disability type. However, analysis of responses from female participants appeared to suggest that the level of vulnerability among women with disabilities could be higher. Similarly the vulnerability levels could be higher for children and people with intellectual disabilities.

5.3 Recommendations on the policy environment

1) Review HIV and AIDS policies and strategies to ensure inclusion of people with disabilities.

2) Review and update and disseminate nationally accepted definitions of disability. For example, in SHIVYAWATA members said that the six traditional categories (people with hearing, visual, physical, intellectual, multiple impairments and Albinos) may become seven if people with flaking skins are taken on board.

4) Ensure that the National Demographic and Health Survey and TOMSHA include indicators on people with disabilities.

5) Ensure registration of people with disabilities (disaggregated by gender and disability type) at the village level and use the data for planning at all levels.

6) Ensure the capture of information on people with disabilities (disaggregated by gender and disability type) at public and private health facilities.

7) Involve people with disabilities and family members in the design of HIV & AIDS initiatives would be crucial for success since the primary source of information and social and material support is within the family setting.

8) Evaluate TOMSHA’s performance from inception in 2006. This would involve its use among the organizations, accuracy and usefulness of information gathered in terms of decision-making, and feedback from users to improve the inclusiveness of indicators. Use the results to review and edit TOMSHA reporting guidelines to make them more succinct and user friendly.

9) Review and update TOMSHA and HMIS reporting forms to accommodate information on people with disabilities.

10) Review THMIS and amend indicators to allow for the collection of information on people with disabilities.

5.4 Recommendations on support of people with disabilities

1) Equip people with disabilities with life-skills.

2) Sensitize people with disabilities on the availability of care, treatment and support in their communities without stigmatization or rejection.

3) Ensure support mechanisms to people with disabilities who have been identified in their communities.

4) Sensitize communities on the specific needs of people with disabilities and the availability of services.

5) Provide information in accessible formats for people with disabilities.

6) Ensure the participation of people with disabilities in HIV & AIDS campaigns.

5.5 Recommendations on capacity building

1) Build the capacities of MDAs, LGAs and CSOs to address the needs of PWDs in HIV and AIDS service provision.

2) Mainstream disability by training health workers and peer educators in appropriate ways of also working with people with disabilities.

3) Identify people with disabilities in the target areas and train them and their families to participate in disseminating HIV & AIDS information.
5.6 Recommendations on physical access and IEC Materials

1) Develop appropriate HIV & AIDS information materials in accessible formats to ensure that people with hearing and visual impairments are reached.

2) Provide directional signs to indicate that people with disabilities can be served in VCT centres; it is recommended that such signs be posted at service provision facilities.

3) Ensure government and private health facilities are physically accessible for people with physical disabilities and other mobility difficulties, by providing ramps, wide doorways, reducing the use of steps/stairs for people with disabilities.

5.7 Recommendations for organizations of people with disabilities

1) Enhance technical capacities of OPDs in disability to equip them to serve people with disabilities in HIV and AIDS.

2) Expand services to include HIV and AIDS education and support.

3) Review/ strengthen/develop policies on HIV and people with disabilities.

4) Establish internal and external mechanisms to ensure enhanced collaboration with other organizations and LGAs.

5) Establish/strengthen and maintain accurate and up to date records.

6) Explore finance mobilization strategies to improve organizations’ finances.

7) Develop/facilitate development of appropriate IEC materials for people with disabilities.

5.8 In conclusion

This assessment has highlighted the multiple challenges that people with disabilities face in HIV & AIDS service provision. Although the study seemed to suggest that HIV & AIDS messages have reached people with disabilities, the concerns of participants regarding people with disabilities in the remote districts of Tanzania should be taken seriously. To this end, it will be necessary as a way forward to carry out a study focusing on people with disabilities in remote districts and explore what HIV & AIDS services are available to them. Investing time and finances in this activity will add immensely to the knowledge of the needs of people with disabilities in hard to reach areas. It is our belief that such a study will be of immense value in efforts to seriously pay attention and design interventions in HIV & AIDS to reach people with disabilities, most of whom are unreached so far.
## Annex 1: Data collection instruments

**Data Collection tool 1: Situation Analysis of People with Disabilities in respect to HIV & AIDS and STIs**

<table>
<thead>
<tr>
<th>Preliminaries</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Date of Interview: ________________________________</td>
</tr>
<tr>
<td>2. Name of Interviewer: ______________________________</td>
</tr>
<tr>
<td>3. District: __________________ Region: ______________</td>
</tr>
<tr>
<td>4. Rural: ___________ Urban: ______________</td>
</tr>
<tr>
<td>5. ____________________</td>
</tr>
<tr>
<td>6. Sex: Female: ___________ Male ______________</td>
</tr>
<tr>
<td>7. Age group (select one)</td>
</tr>
<tr>
<td>8. Type of disability (tick):</td>
</tr>
<tr>
<td>6. Albino: ______________</td>
</tr>
<tr>
<td>9. Level of education</td>
</tr>
<tr>
<td>10. Occupation:</td>
</tr>
<tr>
<td>11. Marital Status</td>
</tr>
</tbody>
</table>
Knowledge and awareness of HIV & AIDS, access to information and services

12. Do you know about HIV & AIDS? Yes: ___________ No. __________

13. If so, what do you know about it?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

14. How did you know about HIV & AIDS?
   1. In a seminar ______________________
   2. From a friend/neighbour ______________
   3. Taught at school ____________________
   4. At the hospital/dispensary/health centre__________
   5. Other (Explain) ___________________________________________________

15. Is it easy to get information on HIV and AIDS in your area?
   1. Yes ___________________
   2. No ___________________
   3. Don’t know _______________

16. If no, why not?
   1. It is not available ___________________
   2. The centre is too far _______________
   3. Some people cannot read _______________
   4. Some people cannot see _______________
   5. Nobody has approached to tell us about it.______________

17. Which disabled people would find it difficult to get/access information on HIV & AIDS (tick)?
   1. Blind people __________________________________________
   2. Deaf people ____________________________________________
   3. Mentally disabled people _________________________________
   4. People with physical disabilities __________________________
   5. None would find it difficult. _____________________________________

18. If difficult, what could be done to make information on HIV & AIDS easily available and accessible to disabled people?
   1. Blind people____________________________________________
   2. Deaf people______________________________________________
   3. Intellectually disabled people_______________________________
   4. People with physical disabilities____________________________

19. Can HIV be spread through having sexual intercourse with a person infected by HIV?
   1. Yes. ______
   2. No. ______
   3. Don’t know ______

20. Can HIV be spread by shaking hands with an HIV infected person?
   1. Yes ______
   2. No ______
   3. Don’t Know ______

21. Can HIV be spread by sharing clothes with an HIV infected person?
   1. Yes ______
   2. No ______
   3. Don’t know ______
22. Can HIV be spread by sharing utensils (eating from the same plate and using same spoons, cups, etc) with an HIV infected person?
   1. Yes _______
   2. No _______
   3. Don’t know _______

23. Can HIV be spread by sharing injection needles with an HIV infected person?
   1. Yes _______
   2. No _______
   3. Don’t know _______

24. Can HIV be spread by living with an HIV infected person?
   1. Yes _______
   2. No _______
   3. Don’t know _______

25. Can HIV be spread through breastfeeding?
   1. Yes _______
   2. No _______
   3. Don’t know _______

26. Is there a cure for HIV/AIDS?
   1. Yes _______
   2. No _______
   3. Don’t know _______

27. Do you think disabled people can be at risk of getting HIV?
   1. Yes _______
   2. No _______
   3. Don’t know _______

28. Do you think you are at risk of getting HIV?
   1. Yes _______
   2. No _______
   3. Don’t know _______

29. How can a person avoid getting HIV?
   1. by being faithful to one non-infected partner
   2. by using condoms every time during sex encounter
   3. by abstaining from sex

30. Do you know any person who has been tested and found with HIV?
   1. Yes _______
   2. No _______

31. Do you think people of your age group can get infected with HIV?
   1. Yes _______
   2. No _______
   3. Don’t know _______

32. Do you know a disabled person who is infected with HIV?
   1. Yes _______
   2. No _______

33. If a friend or family member had HIV, should this information remain secret?
   1. Yes _______
   2. No _______
   3. Don’t know _______

34. If yes, why should the status remain secret?
   1. Family will shun/avoid him/her. _______
   2. The neighbours will avoid him/her _______
   3. It is not important for others to know _______
4. Other reasons (Specify) ________________________________________________

35. Should family members care for persons affected by AIDS?
   1. yes __________
   2. no __________
   3. I don’t know __________

36. Is there a centre for testing HIV in your area?
   1. Yes __________
   2. No __________
   3. Don’t know __________

37. Do disabled people attend the centre?
   1. Yes __________
   2. No __________
   3. Don’t know __________

38. Is it easy for disabled people to access HIV/AIDS services?
   1. Yes __________
   2. No __________

39. If no, why is it difficult for disabled people to access services?
   1. No sign language for the deaf. __________
   2. not accessible for wheelchairs __________
   3. no information in Braille __________
   4. fear of discrimination __________
   5. no expertise for people with intellectual disability __________

40. Would you like to be tested for HIV?
   1. Yes __________
   2. No __________

41. Have you ever had an HIV test?
   1. Yes __________
   2. No __________

42. If yes, were you HIV positive?
   1. Yes __________
   2. No __________

43. If yes, did you think you were at risk of getting HIV infection?
   1. Yes __________
   2. No __________

44. At what age do girls in your community have their first sexual encounter?
   1. 10-14 yrs __________
   2. 15-19 yrs __________
   3. 20-24 yrs __________
   4. 25-29 yrs __________

45. At what age do boys in your community have their first sexual encounter?
   1. 10-14 yrs __________
   2. 15-19 yrs __________
   3. 20-24 yrs __________
   4. 25-29 yrs __________

46. At what age did you have your first sexual encounter?
   1. 10-14 yrs __________
   2. 15-19 yrs __________
   3. 20-24 yrs __________
   4. 25-29 yrs __________

47. Do you know about sexually transmitted infections (STIs)?
   1. Yes: __________
2. No.

48. If yes, How did you learn about STI?
   1. In a seminar/course/training in year ________
   2. From a friend/neighbour ________
   3. Taught at school ________
   4. At the hospital/dispensary/health centre ________
   5. from being infected ________

49. How does a person avoid sexually transmitted infections? (its possible to have more than one answer)
   1. Using a condom during sexual intercourse ________
   2. Abstaining from sex ________
   3. Being faithful to one uninfected partner ________
   4. Avoid casual sex with many people ________

50. Have you engaged in sexual relations with another person who was not your wife/husband/partner/girlfriend/boyfriend?
   1. Yes ________
   2. No ________

51. If yes, did you use a condom?
   1. Yes ________
   2. No ________

52. How often do you use condoms?
   1. All the time when having sexual intercourse ________
   2. Some of the time when having sexual intercourse ________
   3. Never ________

53. If no, why don’t you use condoms?
   1. It is not necessary to use condoms ________
   2. It is the responsibility of my partner/spouse ________
   3. I am married so I do not need to use protection ________
   4. I find it difficult to insist that my partner and I use protection ________
   5. My partner and I trust each other ________
   6. Don’t know where to get protection. ________
   7. Too expensive to buy. ________
   8. Don’t know there is protection ________
   9. condoms reduce sexual pleasure ________
   10. My religion does not approve of the use of condoms ________

54. Which of the following are signs and symptoms of STI? (Tick three)
   1. Ulcer or sore in the genital area ________
   2. Frequent urination ________
   3. Unusual genital discharge ________
   4. Frequent diarrhoea ________
   5. Swelling and inflammation of the genital parts ________
   6. No symptoms ________

55. Have you ever had a sexually transmitted infection (STI)
   1. Yes ________
   2. No ________
   3. Don’t Know ________

56. If yes, where did you seek treatment from?
   1. Health facility. ________
   2. Self-medication ________
   3. Traditional healer ________
   4. From my friend ________
57. If you did not seek treatment, what was the reason?
   1. Did not know where to get treatment ______
   2. Symptoms went away ______________
   3. Was ashamed ______________
   4. Hospital too far ______________
   5. Did not have money to seek treatment __
   6. Doctors do not speak my language (e.g. sign language)____

58. Is it common for disabled people to have sexual intercourse with many partners?
   1. Yes __________
   2. No __________
   3. Don’t know __________

59. If yes, what are some of the reasons for having sexual intercourse with many people?
   1. To get money __________
   2. Being forced (Rape) __________
   3. Due to drunkenness __________
   4. No husband/wife __________
   5. Don’t know __________

60. Is rape of disabled people common in your area?
   1. Yes __________
   2. No __________
   3. Don’t know __________

61. Do you know any disabled person who has been raped?
   1. Yes __________
   2. No __________

Sources and means of Information used by disabled people:

62. Is there a programme on HIV & AIDS and STI focusing on disabled people in your area?
   1. Yes __________
   2. No __________
   3. Don’t know __________

63. If yes, what means are used to give the information?
   1. training seminars/workshops/schools _______
   2. drama (radio & TV) _______
   3. print media (Newspapers, flyers, billboards, posters)_____
   4. traditional media (initiation ceremonies, weddings, drama___

Obstacles to access HIV/AIDS information, prevention services:

64. Do you find it easy to access information on HIV & AIDS?
   1. Yes __________
   2. No. __________

65. If not, what are the obstacles to getting information on HIV & AIDS?
   1 __________________________
   2 __________________________
   3 __________________________
   4 __________________________
   5 __________________________
   6 __________________________
Data Collection tool for Area 2: Situation Analysis of organizations for and of people with Disabilities in respect to HIV & AIDS and STI'S

<table>
<thead>
<tr>
<th>Preliminaries</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Date of Interview: ____________________________</td>
</tr>
<tr>
<td>2. Name of Interviewer: __________________________</td>
</tr>
<tr>
<td>3. District: __________________ Region: __________________</td>
</tr>
<tr>
<td>4. Rural: ___________ Urban: ___________</td>
</tr>
<tr>
<td>5. Name of Organization __________________________________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type of organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Organization of/for Disabled People’s ____________</td>
</tr>
<tr>
<td>• Health and HIV/AIDS Organization ____________</td>
</tr>
<tr>
<td>• DISTRICT Health &amp; HIV/AIDS Service provider ____________</td>
</tr>
<tr>
<td>• Special school</td>
</tr>
</tbody>
</table>

| Name of Respondent __________________________________ |
| Female: ___________ Male: __________________ |
| Designation: ____________________________________ |

<table>
<thead>
<tr>
<th>Disability focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) physically disabled ____________</td>
</tr>
<tr>
<td>b) blind/low vision</td>
</tr>
<tr>
<td>c) deaf/hard of hearing ____________</td>
</tr>
<tr>
<td>d) intellectually disabled ____________</td>
</tr>
<tr>
<td>e) Albino</td>
</tr>
<tr>
<td>f) all disability groups ____________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Capacity of schools</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Number of staff: males ___________ females ___________</td>
</tr>
<tr>
<td>2. Educational background.</td>
</tr>
<tr>
<td>a) Number of staff with e.g. Deaf sign language; Men ____ female:</td>
</tr>
<tr>
<td>b) Braille; Male: ___________ female ___________</td>
</tr>
<tr>
<td>c) Therapists: (OT, PT)</td>
</tr>
<tr>
<td>d) Assessors: Male: ___________ female ___________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Core activities/programmes/services provided:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. advocacy ___________</td>
</tr>
<tr>
<td>2. education ___________</td>
</tr>
<tr>
<td>3. support group ___________</td>
</tr>
<tr>
<td>4. rehabilitation ___________</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>5.</td>
</tr>
<tr>
<td>6.</td>
</tr>
<tr>
<td>7.</td>
</tr>
<tr>
<td>8.</td>
</tr>
<tr>
<td>9.</td>
</tr>
<tr>
<td>10.</td>
</tr>
</tbody>
</table>

11. **Years/months in operation**

12. **Sources of income**
   1. International donors
   2. Government grants
   3. Members’ contributions
   4. Income generating activities (name them)

13. **Membership/number of people served**

   - **Number of members**
   - **Clients served:**
     1. Number of Adult Males with disabilities
     2. Number of Adult Females with disabilities
     3. Number of Adult Males without disabilities
     4. Number of Adult Females without disabilities
     5. Number of Male Youth with disabilities
     6. Number of Female youth with disabilities
     7. Number of Number of families

How far disability organizations / special needs schools are involved in teaching people with disabilities about HIV/AIDS, drug addiction / substance abuse:

14. Do you think that disabled people are at risk of HIV infections?
   1. Yes
   2. No
   3. Don’t know

15. Compared to non-disabled people, would you say disabled people are more at risk of HIV infection?
   1. Yes
   2. No
   3. Don’t know

16. If yes, why?

17. If no, why?

18. Which group of disabled people are more at risk of HIV infection?
   1. physically disabled
   2. blind/low vision deaf/hard of hearing
   3. intellectually disabled
4. people with multiple disability  
5. all disability groups are at equal risk  

19. Do disabled people believe they are at risk of HIV infection?  
   1. Yes,  
   2. No  
   3. Don’t know  

20. If they think they are at risk, what support have they asked for?  
   1. testing services  
   2. condoms  
   3. training  
   4. information  

21. What prevents disabled people from seeking HIV & AIDS information and services?  
   1. Fear of being stigmatized and rejected  
   2. HIV is not talked about in this community  
   3. They do not know they can ask for help  
   4. They seek traditional healers  
   5. Don’t know  

22. Do people in this community think that disabled people are at risk of HIV?  
   1. Yes,  
   2. No,  
   3. Don’t know  

23. Are disabled children more at risk of HIV than disabled adults?  
   1. Yes,  
   2. No,  
   3. Don’t know.  

24. Does your organization have any HIV & AIDS programmes/projects targeting the disabled?  
   1. Yes  
   2. No  

25. Does your organization have any outreach programmes for disabled people infected with HIV?  
   1. Yes  
   2. No  
   3. Don’t know  

26. If yes, what are the activities of the outreach programme?  
   1. HIV/AIDS education  
   2. advocacy & sensitization  
   3. home based care (hygiene, nutrition, physiotherapy, treatment of opportunistic infections, delivery of medication) and support  
   4. income generating activities  
   5. counselling  

27. How many disabled people have accessed your services in the past year?  
(Records)  
   1. between 1-50 (males _____ females _____)  
   2. between 51-100 (males _____ females _____)
3. between 101-150 (males _____ females _____)
4. between 151-300 (males _____ females _____)
5. over 301 (Males _______ females _____)

28. How many disabled people are targeted by the programme?
   1. Males _______
   2. females ______

29. How many adults have been reached in the programme?
   1. Males _____
   2. females _____

30. How many youth aged 15-19, have been reached in the programme in the past year?
   1. Males ______
   2. Females ______

**Obstacles between disability organizations and health and HIV/AIDS service providers:**

31. What difficulties do the disabled encounter at the HIV test and treatment centres?
   1. Inaccessible clinics __________
   2. No sign language interpretation____
   3. Unfriendly officials __________
   4. Other barriers (explain) __________

32. Do you know disabled people who have not been able to access HIV & AIDS services because of their disability?
   1. Yes _______
   2. No _______
   3. Don’t know _______

33. Do you know disabled people who have not sought services because they do not know the symptoms of HIV & AIDS?
   1. Yes _______
   2. No _______
   3. Don’t know _______

34. Do you know disabled people who have not sought services because they are afraid of being rejected, stigmatized?
   1. Yes _______
   2. No _______
   3. Don’t know _______

35. Is there any substance abuse/drug abuse among disabled people?
   1. Yes _______
   2. No _______
   3. don’t know _______

36. If yes, do you think
   1. it is very common _______
   2. it is limited to a few _______

37. What challenges do you encounter when working with disabled people in the programme/project?
1. the disabled find it difficult to come to the centre due to long distances____
2. the disabled cannot afford our service fees_______
3. there are few experts
4. the disabled are reluctant to come to the centres____
5. the caregivers/family members are not willing to bring the disabled to the centres____

38. Do disabled people access information on HIV & AIDS?
   1. Yes
   2. No
   3. Don’t know

39. If yes, do you ensure that HIV & AIDS information was accessible to:
   • The blind?
     1. Yes
     2. No
   • The deaf?
     1. Yes
     2. No
   • Intellectually disabled?
     1. Yes
     2. No

40. If no, how can access to HIV information be improved for disabled people?
   1. Material should be delivered using appropriate media (sign language, Braille, radio, posters,) ______
   2. use of drama ______
   3. make information available to rural communities_____
   4. use locally accepted means and people_____
   5. Don’t know ______

Current collaboration / interactions between district HIV/AIDS services and HIV/AIDS organizations.

41. Do you collaborate with health and HIV & AIDS service providers?
   1. Yes
   2. No

42. If yes, how many do you collaborate with?
   1. Health service providers
   2. HIV & AIDS Service providers

43. Do you collaborate with other organizations of/for disabled people?
   1. Yes
   2. No

44. Do you collaborate in any of the following areas?
   1. joint meetings
   2. joint planning
   3. sharing information
45. Are your activities integrated in the district plans?
   1. Yes
   2. No
   3. Don’t know

46. Are you represented in the Council Social Service Committee?
   1. Yes
   2. No
   3. Don’t know

47. Are you represented in the Council Multi-sectoral AIDS Committee?
   1. Yes
   2. No
   3. Don’t know

48. Do you meet regularly with Council HIV & AIDS coordinator?
   1. Yes
   2. No

49. Do you meet regularly with District AIDS Control Coordinator?
   1. Yes
   2. No

50. Are you aware of disabled people who have been raped in the past one year?
   1. Yes
   2. No

51. If so, how many?
   1. adult male
   2. adult female
   3. female child
   4. male child

52. Do you know any disabled people who have been tested for HIV?
   1. Yes
   2. No

53. If yes, how many were HIV positive?
   1. males
   2. females

54. In your programme, do you have training and information on illicit drugs and substance abuse?
   1. Yes
   2. No

55. If yes, what areas does the programme address?
   1. knowledge of illicit drug and substance abuse
   2. legal consequences of drug and substance abuse
   3. health consequences – recognition of signs and symptoms
   4. prevention of drug and substance abuse
   5. counselling and support services for drug abusers

56. Who conducts the training?
   1. in-house staff
2. civil society organizations
3. government officers

57. Have you identified and trained peer educators for HIV & AIDS with respect to disabled people?
   1. Yes
   2. No

58. If yes, how many people were trained by peer educators since the programme started?
   1. adult males
   2. adult females
   3. young men
   4. Young women

59. How many of the peer educators are disabled?
   1. Adult males
   2. Adult females

60. How many of the peer educators are infected with HIV?
   1. Adult males
   2. Adult females
   3. Young men
   4. Young women

61. Do you think drug traffickers use disabled people to transport and sell illicit drugs?
   1. Yes
   2. No
   3. Don’t know

62. How many organizations promoting information on HIV & AIDS targeting disabled people are in your area?
   1. Number
   2. None

63. How many organizations promoting illicit drugs and substance abuse information targeting disabled people are in your area?
   1. Number
   2. None

64. Is legal assistance available for disabled people?
   1. Yes
   2. No
   3. don’t know

65. In order to enhance your effectiveness to reach out to disabled people whom might be at risk of HIV, or who might be infected, list what would be your requirements in the following:
   1. Human resources

   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________

   2. Equipments and supplies

   ____________________________________________________________
3. Others
Area 3: Organizations dealing with HIV/AIDS (Government, NGOs, FBOs, private sector)

<table>
<thead>
<tr>
<th>Data Collection tool for Area 3: organizations dealing with Disabilities HIV &amp; AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Preliminaries</strong></td>
</tr>
<tr>
<td>1. Date of Interview: ____________________________</td>
</tr>
<tr>
<td>2. Name of Interviewer: ____________________________</td>
</tr>
<tr>
<td>3. District: __________________ Region: __________________</td>
</tr>
<tr>
<td>4. Rural: ___________ Urban: ___________</td>
</tr>
<tr>
<td>5. Name of Organization ____________________________</td>
</tr>
<tr>
<td><strong>Type of organization</strong></td>
</tr>
<tr>
<td>• Government</td>
</tr>
<tr>
<td>• NGO</td>
</tr>
<tr>
<td>• FBO</td>
</tr>
<tr>
<td>• Private</td>
</tr>
<tr>
<td>6. Name of Respondent ____________________________</td>
</tr>
<tr>
<td>Female: ___________ Male: ___________</td>
</tr>
<tr>
<td>Designation: ____________________________</td>
</tr>
<tr>
<td><strong>Disability focus</strong></td>
</tr>
<tr>
<td>g) physically disabled ___________</td>
</tr>
<tr>
<td>h) blind/low vision deaf/hard of hearing ___________</td>
</tr>
<tr>
<td>i) intellectually disabled ___________</td>
</tr>
<tr>
<td>j) multiply disabled (describe) _______________________</td>
</tr>
<tr>
<td>k) epileptic ___________</td>
</tr>
<tr>
<td>l) chronic disease ___________</td>
</tr>
<tr>
<td>m) all disability groups ___________</td>
</tr>
<tr>
<td>n) Other (describe) ____________________________</td>
</tr>
<tr>
<td><strong>Age of clients</strong></td>
</tr>
<tr>
<td>a) school age (age range from: ___________ to age ___________)</td>
</tr>
<tr>
<td>b) Young adults (females) ___________</td>
</tr>
<tr>
<td>c) Young adults (males) ___________</td>
</tr>
<tr>
<td>d) Adults: males ___________ females ___________</td>
</tr>
<tr>
<td>e) Total number catered for: Males ___________ Females ___________</td>
</tr>
<tr>
<td><strong>Core activities/programmes/services provided:</strong></td>
</tr>
<tr>
<td>a) advocacy ___________</td>
</tr>
<tr>
<td>b) education ___________</td>
</tr>
<tr>
<td>c) support group ___________</td>
</tr>
<tr>
<td>d) rehabilitation ___________</td>
</tr>
<tr>
<td>e) medical/counselling ___________</td>
</tr>
<tr>
<td>f) outreach ___________</td>
</tr>
<tr>
<td>g) capacity building/training ___________</td>
</tr>
<tr>
<td>h) legal / rights ___________</td>
</tr>
<tr>
<td>i) development ___________</td>
</tr>
<tr>
<td>j) income generation/economic ___________</td>
</tr>
</tbody>
</table>
11. **Years/months in operation** _________________

12. **Sources of income**
   - International donors __________
   - Government grants ______________
   - Members’ contributions __________
   - Income generating activities (name them)
     ______________________________________________________________________
     ______________________________________________________________________

13. **Membership/number of people served**
    Number of members ________________

    Clients served:
    - Number of Adult Males with disabilities ____________
    - Number of Adult Females with disabilities __________
    - Number of Adult Males without disabilities _________
    - Number of Adult Females without disabilities ________
    - Number of Male Youth with disabilities ____________
    - Number of Female youth with disabilities __________
    - Number of Number of families ______________________

**Information from government**

14. Do you use the national Policy on HIV/AIDS to plan intervention activities on HIV/AIDS?
    1. Yes
    2. No.

15. If yes, do you include people with disabilities in HIV/AIDS services?
    1. yes
    2. No

16. If yes, what specific services do you provide for disabled people with HIV/AIDS?
    1. Training of peer educators male: ___ female _____
    2. number of disabled receiving advocacy/sensitization activities: Male ___
       female ____
    3. number of disabled receiving counselling and testing: males ____ females __
    4. No of disabled receiving treatment: males ____ females ______
    5. number of disabled receiving home-based services: males ___ females __
    6. number of follow up (monitoring and support) visits: __________________
    7. Frequency of distribution of appropriate materials for disabled (e.g. Braille, sign language, etc): Monthly ____ Quarterly ____ half yearly ______
    8. Distribution of condoms: Monthly _____ Quarterly ____ half yearly _____

17. What challenges do you face in giving the above services?
    1. inadequate number of skilled personnel
    2. limited financial resources
    3. delays in receiving materials
4. limited means of transportation
5. long distances
6. reluctance of disabled people to use the services (e.g. condoms)
7. reluctance of disabled people to use HIV/AIDS counselling and testing services
8. high turnover of skilled staff
9. any other

18. If disabled are not included in the plans, do you plan to include them in the next plan?
   1. yes
   2. no

19. if yes, specify

_____________________________________________________________
_____________________________________________________________
_____________________________________________________________

20. Do you have personnel specifically trained to work with disabled people with HIV/AIDS?
   1. yes
   2. no

21. If yes, what specific skills do they have to work with disabled people?
   1. sign language
   2. counselling
   3. use of Braille materials
   4. recognition of disability and care of disabled people
   5. assessment and referral of disabled people

22. Do you have a policy to include people with disabilities in your programmes/activities?
   1. yes
   2. no

23. If yes, specify.

24. What strategies do you use in your programmes to reach disabled people with HIV&AIDS information and services?
   1. supporting government initiatives
   2. supporting income generating
   3. HIV/AIDS education
   4. development and distribution of materials
   5. funding/supporting other NGOs in HIV/AIDS education and prevention
   6. Funding/support community mobilization and advocacy campaigns.
   7. counselling, test, treatment and support

25. If you do not currently focus on disabled people, do you plan to include them in your future activities/programmes?
   1. yes
   2. no
26. What challenges are there in the provision of services for disabled people with HIV/AIDS?
   1. physical accessibility to buildings
   2. access to information
   3. access to services (counselling, test, and treatment)
   4. access to care and support
   5. limited finances
   6. limited facilities
### Annex 2: Work Plan

<table>
<thead>
<tr>
<th>Item No</th>
<th>Dates</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1)</td>
<td>19th Dec. 2008</td>
<td><strong>Activity</strong></td>
</tr>
<tr>
<td></td>
<td>Morning</td>
<td>Train research assistants</td>
</tr>
<tr>
<td></td>
<td>Afternoon</td>
<td>Pre-test tools at Temeke (Local Govt, disability organizations, disabled people, parents, caregivers, community members)</td>
</tr>
<tr>
<td>2)</td>
<td>22nd Dec.–31st Dec. 2008</td>
<td><strong>Data Collection starts as indicated below:</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Ministry of Health (NACP)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Social Welfare Dept</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Min of Education and Vocational Training (Special Schools Dept.)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Min of Community Development, Gender and Children</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• PMO – Regional Administration and Local Govt. (TACAIDS, Commissioner for Local Govt)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Local Govt. (Temeke Municipal Council, Ilala Municipal Council.)</td>
</tr>
<tr>
<td>3)</td>
<td>2nd Jan – 21st Jan 2009</td>
<td><strong>Data collection continues at Ilala, Kibaha District Council, Morogoro District</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Organizations for and of people with disabilities.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• NGOs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Disabled people, parents, caregivers, community members</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Local Govt authorities</td>
</tr>
<tr>
<td>4)</td>
<td>7th, 8th, 9th, 12th Jan 2009</td>
<td>Monitoring and supervision of data collection by local consultants</td>
</tr>
<tr>
<td>5)</td>
<td>22nd January – 27th January 2009</td>
<td>• Data entry (2 days)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Data analysis and compilation of report (2 days)</td>
</tr>
<tr>
<td>6)</td>
<td>28th January 2009</td>
<td>First Draft report of Findings</td>
</tr>
<tr>
<td>7)</td>
<td>28th January – 9th February 2009</td>
<td>Development of Technical Support Plan</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Review of documents (3 days)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Develop/Write Technical Support Plan (6 days)</td>
</tr>
<tr>
<td></td>
<td>Date Range</td>
<td>Activity</td>
</tr>
<tr>
<td>---</td>
<td>------------</td>
<td>----------</td>
</tr>
<tr>
<td>8)</td>
<td>10th Feb – 13th Feb 2009</td>
<td>Develop an M &amp; E System</td>
</tr>
</tbody>
</table>
| 9) | 16th Feb – 17th Feb 2009 | • Prepare findings (1 day)  
• Present findings to Technical Steering Committee (1 day) |
| 10) | 18th Feb – 19th Feb 2009 | Finalize all reports (2 days)  
• Findings of Assessment  
• Road Map Support Plan  
• Monitoring and Evaluation |
| 11) | 20th February 2009 | Submission of Reports to the Technical Steering Committee |
| 12) | 23rd, 24th, 25th, 26th Feb 2009 | Contingency days for adjustments, completion, final revisions, etc |