A HANDBOOK ON BEST PRACTICES REGARDING HIV AND AIDS FOR PEOPLE WITH DISABILITIES

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FOREWORD

In spite of the remarkable increase of global awareness on HIV, there is still a huge amount of work to do to stop the AIDS epidemic. Even though the spread of the epidemic may have stabilised in 2008 (2008 Report on the global AIDS epidemic, UNAIDS), it has done so at a very high level of HIV infections. Therefore, there is urgent need for more action to move towards the 2010 UN target to achieve Universal Access to HIV prevention, treatment, care and support.

According to the World Health Organization 650 million people or 10% of the world's population have a disability and four out of every five disabled persons live in developing countries (Disability and Rehabilitation WHO Action Plan 2006-2011). Within every social group - class, caste, ethnicity, gender, religion, and sexual orientation – people with disabilities are represented. In the context of HIV, they are also found within every high risk group such as sex workers and their clients, injecting drug users, men having sex with men, orphans and prisoners. People with disabilities are therefore exposed to the same risk factors for HIV as every non-disabled person. Moreover, due to their often marginalised and vulnerable position in the community (e.g. lack of access to information, low literacy rate and stigma), people with disabilities are at an even higher risk of contracting HIV.

Awareness of disability as a crosscutting issue in development - and subsequently in the HIV response - is increasing. The publication of the UNAIDS, WHO and OHCHR policy brief: DISABILITY and HIV (April 2009) was a first milestone in this respect. Still, awareness of exclusion of people with disabilities from HIV policies and programmes has not yet reached the level that is needed to influence policymakers in the HIV response sufficiently. Moreover, studies on this subject are limited and concrete data on the contribution in numbers of disabled people to the high levels of HIV infections are scarce.

This handbook aims to fill this gap. It aims to further increase awareness of this subject, to share knowledge and to give examples of best practices. It also invites to study the impact of the AIDS epidemic on people with disabilities and it seeks to incite a wider action to achieve universal access for people with disabilities to HIV prevention, treatment, care and support. Without this action the Millennium Development Goal of halting and beginning to reverse the spread of HIV by 2015 will not be met. Expanding the response to the AIDS epidemic by including people with disabilities is nothing less than adhering to the principles and standards of human rights, in particular to the UN Convention on the Rights of Persons with Disabilities (December 2006).

We sincerely hope that this handbook will inspire you and your colleagues in a practical way to work towards a truly inclusive HIV response.

Froukje Pronk
Programme Officer
Dutch Coalition on Disability and Development

ACKNOWLEDGEMENTS

ACRONYMS

AIDS	*Acquired Immune Deficiency Syndrome*
APDK	*Association for the Physically Disabled of Kenya*
ARVS	*Anti Retro Viral Drugs*
BLINK	*Blind and Low vision Network*
DASCO	*District AIDS and STI Coordinator*
DFID	*Department for International Development*
DPO	*Disabled People's Organization*
HI	*Handicap International*
HIV	*Human Immunodeficiency Virus*
HOH	*Hard of Hearing*
HTC	*HIV Testing and Counselling*
IEC	*Information Education Communication*
KNAD	*Kenya National Association of the Deaf*
KSL	*Kenyan Sign Language*
LVCT	*Liverpool VCT, Care and Treatment*
MDG	*Millennium Development Goal*
NACC	*National AIDS Control Council*
NASCOP	*National AIDS and STI Control Programme*
PASCO	*Provincial AIDS and STI Coordinator*
PLHIV	*People Living with HIV*
PMO	*Programme Management Office*
PWD	*People with Disabilities*
PWID	*People with Intellectual Disabilities*
SRH	*Sexual and Reproductive Health*
TOT	*Trainer of Trainer*
UNAIDS	*United Nations Joint Programme on HIV/AIDS*
VCT	*Voluntary Counselling and Testing*
VSO	*Voluntary Service Overseas*
WHO	*World Health Organization*

CONTENTS

OPERATIONAL DEFINITIONS

Best Practices – This has been defined as "knowledge about what works in specific situations and contexts, without using inordinate resources to achieve the desired results, and which can be used to develop and implement solutions adapted to similar health problems in other situations and contexts (WHO, 2008).It refers to the process of gathering and applying knowledge about what is working and what is not working in different situations and contexts through feedback learning and reflection. As such, the documentation of best practices includes the identification and contextualization of both lessons learned, the continued process of learning, feedback, reflection, analysis and re-strategizing on what works, how and why.

Disability – The United Nations Convention on the Rights of Persons with Disabilities defines disability as 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (United Nations Enable, 2006).

HIV/AIDS – For the purposes of this handbook HIV/AIDS has been used to mean HIV and AIDS.

Visually Impaired – Refers to anyone who is totally blind or has low vision.

Deaf- Refers to a person who is deaf or hard of hearing. This definition includes pre-lingual and post-lingual deafness. For the purposes of this handbook, this term has been used interchangeably with the term "Hearing impaired".

Intellectual Disability – The term intellectual disability refers to a lower than average ability to process new or complex information, learn new skills, and cope independently. It involves limitations in intellectual functioning and adaptive behaviour (OSHI, 2005).

Disability-friendly Interventions – This refers to interventions aimed at making the existing services more easily accessible to persons with disability. Examples are: use of Information, Education and Communication (IEC) materials, sign language and interpreters for the deaf, Braille materials, large print and tape aid for the blind and mobility aid for the physically challenged.

PREFACE

The goal of this handbook is to highlight some of the best practices around the world in HIV/AIDS services, programmes and policies for people with disabilities. As described in chapter 1 of the handbook, systematic efforts were made to identify case studies from various countries.

However, the numbers of case studies obtained were smaller than expected. This could be an indication that there is little documentation of practice in HIV/AIDS and disability. It could also be that organizations primarily working with/on disabilities have given minimal attention to HIV/AIDS, and similarly little attention is paid to disability by mainstream HIV/AIDS organizations.

Intended Audience:

This handbook is primarily aimed at organizations involved in or intending to be involved in programming and advocacy to influence or to develop policy and programmes in HIV/AIDS service delivery for Persons with Disabilities (PWDs). This includes both mainstream HIV/AIDS organizations, and those working primarily with/for people with disabilities. Other audiences who will benefit from this handbook include but are not limited to:

- HIV/AIDS service providers and experts;

- Policy makers;

- Disabled Persons Organisations (DPOs);

- Donors funding HIV/AIDS programs that support PWDs and those funding disability programs that address HIV/AIDS.

How to use this Handbook:

This handbook is divided into four chapters, each addressing a particular broad topic in reference to best practices for Disability and HIV/AIDS. The categories of disabilities covered in the handbook are the Deaf, visually impaired, physically and intellectually challenged. Each chapter outlines best practices for each category of disability. For each of these categories, a case study outlining successful strategies in the delivery of services, formulation of policies, in programming and advocacy has been provided. Similarly, case studies describing key characteristics of outstanding mechanisms used in the formulation and implementation of policies as well as in the inclusion of disability and HIV/AIDS in programmes have been provided. The case studies describe the following:

- Strategies that were employed;

- Achievements recorded by the project;

- Lessons learned;

- What worked well.

The methodology used to develop this handbook has also been described in each section. Pictures and illustrations depicting characteristics of successful interventions have been added where relevant.

Outline of the Handbook:

This handbook is divided into the following chapters:

- Chapter 1

  This includes background information and rationale for the production of this handbook.

- Chapter 2

  Highlights the best practices in the delivery of HIV/AIDS services to PWDs. The strategies used to deliver HIV/AIDS services in terms of prevention, care and treatment, are discussed.

- Chapter 3

  Highlights best practices in policy and advocacy with regards to HIV/AIDS across the broad spectrum of disabilities.

- Chapter 4

  Describes best practices in programming for HIV/AIDS across the four disabilities in focus. Practical and successful strategies of disability and HIV programming at different levels with potential for replication have been discussed. A minimum criterion to consider when setting up HIV/AIDS programmes for PWDs has been highlighted.

- Chapter 5

  Conclusion

CHAPTER 1

INTRODUCTION

INTRODUCTION

1.1. Why a Best Practices Handbook on Disability and HIV/AIDS

The World Health Organization estimates that there are at least 650 million People with Disabilities (PWDs) worldwide (United Nations Enable, 2006). Despite the growing number of PWDs, little is known about HIV/AIDS in populations with pre-existing disabilities. As such, it is commonly assumed that individuals with physical, sensory (deafness, blindness) or intellectual disabilities are not at high risk of HIV infection.

Literacy rates for PWDs are exceptionally low – one estimate cites an adult literacy rate of only 3% globally thus making communication of information and messages about HIV/AIDS all the more difficult (Cambridge P, 1997). In terms of gender, disabled women face unique challenges because they run a high risk of gender-based violence; they lack access to sexual and reproductive health (SRH) services such as family planning and maternal health, are not aware of mother-to-child HIV transmission and have lesser access to rehabilitation services (ESCAP, 1995).

Vulnerability to HIV/AIDS is further compounded by the social exclusion of PWDs from mainstream HIV/AIDS services and poor access to treatment. For instance, majority of existing HIV Testing and Counselling (HTC) services are physically inaccessible; do not offer counselling using sign language; IEC materials on HIV/AIDS are not availed in Braille for the visually impaired; complex or vague messages do not reach those with intellectual impairments, while the physically handicapped people often depend on their sexual partners to put on condoms. Importantly, most PWDs are not aware of their reproductive health rights and the existing sexual and reproductive health (SRH) services are often inaccessible to them (UNFPA, 2003).

Most organizations working in the area of HIV have not included PWDs in their programmes, or do not know how to do this while disability targeted organizations rarely have HIV on their agenda, or do not know how to develop HIV/AIDS programs and projects. Consequently, sex education programmes for those with disability are rare (Collins P. et al, 2001). Almost no general campaigns about HIV/AIDS focus on the needs of, or include disabled populations, and there are few rehabilitation services, especially in rural areas with an estimate of only 3% of disabled individuals getting access to the rehabilitation services they need (UNICEF, 1999).

Globally, there is a growing momentum for addressing the human rights of PWDs. However, governments and policy makers have rarely considered the needs of disabled people when formulating their HIV/AIDS policies. As such, PWDs are often excluded from consultation processes while major HIV/AIDS donors, aid agencies and specialised NGOs do not consider disability a concern that should be prioritized in the allocation of funding.

Where HIV/AIDS interventions have been inclusive of PWDs, governments, civil society and the private sector have rolled-out programs at regional, national and community levels. Many of these have generated vital lessons learnt and evidence of success in their implementation. However, detailed documentation of such initiatives, outlining core measures of good

programming taking into account their effectiveness; cost-effectiveness; relevance; ethical soundness; replicability; innovativeness; and sustainability, remains limited (SAFAIDS, 2009). Documenting and disseminating best practices in HIV/AIDS and disability programmes provides a good description of the constructive and creative programmes that people and organizations around the world are implementing. This is important because without access to existing knowledge and experience from the field of things that work, whether fully or in part, mistakes may be repeated and valuable time lost.

This handbook fills this gap by documenting case studies of best practices in HIV/AIDS policies, programs, and services for PWD. The aim is to share knowledge, experiences and practices that can be replicated by other organisations.

1.2. Methodology used in compiling this handbook

The information used to develop this handbook was sourced primarily from existing literature and primary data from interviews with key informants in the area of HIV/AIDS and disability globally. A narrative synthesis of the best practices for HIV/AIDS service delivery, policy advocacy and programming for the hearing impaired, visually impaired, physically and mentally challenged people derived from the secondary search and primary sources was done.

(Photo courtesy of Association of the Physically Disabled on Kenya- APDK)

1.2.1 Secondary Literature Review

A systematic review of published and unpublished literature on HIV/AIDS and disability was done to:

- Describe best practices in programming, advocacy and delivery of HIV/AIDS services to PWDs.

- Identify and review existing policy frameworks around HIV/AIDS Programming among PWDs.

- Document what works well and identify enabling factors in the delivery of HIV/AIDS services, implementation of programs and advocacy for PWDs

The materials reviewed included journal articles, reports, websites and book chapters in English language produced between 1999 and 2009. Google search engine was also used to identify existing programs and interventions on HIV/AIDS and disability. Numerous internet searches were done and data extracted was recorded on a data capture form.

1.2.2 Primary data

Where programme work had not been documented, interviews were conducted with resource persons in organizations involved in the provision of HIV/AIDS services to PWDs, and Disabled People Organizations (DPOs) that offer HIV/AIDS services. These organizations were identified through LVCT's Disability Programme and Voluntary Services Overseas (VSO) networks, as well as snowballing through international organizations such as Handicap International and associations of PWDs. The procedure that was followed to enhance collection of data from the key informants was as follows:

- A list of organizations working with PWDs around the world was compiled.

- A data submission form was sent via e-mail to 136 directors, heads of programmes and people working with PWDs around the globe. [See annex 1]

- A letter of introduction written by VSO was attached to the data submission form and sent to the selected key informants.

- Follow up of the data form and request for information was done by telephone after two weeks.

- Out of the 136 e- mails sent out, 28 e-mails recorded delivery failure, 68 e-mails had information regarding the organizations' inability to complete the form because they did not have HIV/AIDS programs targeting PWDs and vice versa or their programs had not recorded achievements as they were newly implemented. 18 submissions had relevant information which was used to compile this handbook.

- In Kenya, 16 face to face interviews with key informants from selected DPOs were done.

The following 3 chapters of this handbook outline selected best practices in HIV/AIDS services, policies and programming, and for PWDs compiled from the existing literature and interviews.

CHAPTER 2

BEST PRACTICES FOR HIV/AIDS SERVICE DELIVERY

BEST PRACTICES FOR HIV/AIDS SERVICE DELIVERY

2.1. Delivery of HIV/AIDS Services to the Deaf and Hearing Impaired

This section focuses on the strategies that have been utilized by various organizations working with PWDs in ensuring the delivery of HIV/AIDS services to the hearing impaired.

Introduction

A study conducted in Maryland USA shows that Deaf people are 2 to 10 times as likely as their hearing counterparts to be HIV positive. This has been attributed to the challenges deaf people experience including poor access to information about HIV/AIDS and safe sex, inadequate treatment programs, and issues such as confidentiality within the community, difficulty in getting information from the media and lack of prevention programs aimed specifically at them (Gaskins S, 1999; Monaghan L, 2003).

Some of the techniques that have been employed by different stakeholders to deliver required HIV/AIDS services to the hearing impaired include:

- Participatory approach in HIV/AIDS awareness

- Deaf friendly HIV Testing, Counselling, Care and Treatment services

2.1.1. Enhancing HIV/AIDS Awareness through participatory approaches

Education and awareness on HIV/AIDS enables people with hearing impairments to make informed decisions in relation to living positively or negatively. The use of participatory strategies enables them to share ideas, engage in the construction of messages, activities and come to a consensus as to what they understand by the concepts being explored.

During the compilation of this handbook, organizations working for and with disabled people were found to utilize outreach forums such as workshops, seminars, home visits and mobilization to disseminate information regarding HIV/AIDS transmission, prevention, care and treatment. In these forums PWDs were involved in dissemination of HIV/AIDS information. Successful approaches utilized by various programmes to enhance awareness include:

a)   Peer education

b)   Behaviour change communication (BCC)

a) Peer Education

Peer education has proven to be an effective strategy in global HIV/AIDS prevention. Successful programmes have used both formal and informal approaches to gather and teach the hearing impaired on the intersections between sexuality, and HIV/AIDS at individual, group and community levels. Through peer education, training on use of condoms, transmission, care and treatment of HIV/AIDS, counselling and empowerment on communication skills have been facilitated.

The key strategies that have been used in carrying out peer education sessions include:

- Peer led informal discussions on sexuality, decision-making and sex negotiation skills.

- Use of diverse techniques, for example through condom demonstrations, to prove information on the associations between risky sexual behaviour and HIV/AIDS.

Highlighted below is a case study of an organization in Kenya that has demonstrated best practice in the utilization of peer education as a strategy for enhancing HIV/AIDS awareness among the hearing impaired.

Deaf

Case study of an HIV Awareness Project for the Deaf

Name of Organisation: Sahaya Deaf
Tel: +254-0720-695-072
E- mail: sahayadeaf@yahoo.com
Website: http://www.sahaya.org/deaf/hiv.html

Background:

The HIV Awareness Project of the Deaf in Nairobi, Kenya was started in 2004 under the wings of Sahaya International, Inc (www.sahaya.org) in partnership with GRACE Africa and Liverpool VCT Care and Treatment. The project was funded by World Bank with key implementers from Sahaya Deaf Kenya and 3 primary schools for the deaf in Western Kenya. The project was informed by a preliminary survey done in 2003 that demonstrated limited awareness on health and HIV issues among the Deaf youth, with the assumption that the limited knowledge was due to too little responsibility and leadership entrusted to the Deaf youth. Underscoring this situation was the apparent lack of Deaf-friendly supporting tools, activities, and educational materials.

Objective:

The project set out to introduce peer activities to enhance HIV/AIDS awareness among the Deaf through schools for the Deaf.

Strategies Used:

- Community Involvement in Programme design where by:
  - 3 rural schools for the Deaf in Western Kenya were involved as a pilot group for the project. These schools were selected upon consultation with stakeholders working with the Deaf in the identified regions.

- Peer led education:
  - 5 deaf master educators who were teachers in the Deaf schools selected during the pilot were trained on HIV/AIDS. They were then assigned to Deaf schools where they trained local Deaf youth on how to become effective peer educators on matters of HIV/AIDS.

- Utilization of local financial and human resources:
  - As part of the project's experiment to design Deaf-friendly tools, activities, and educational materials, the awareness project partnered with a local group of professional puppeteers and trained deaf individuals to become puppeteers in three weeks. The puppets use sign language to convey important messages on HIV and AIDS to the audience.

Achievements:

- A peer education system incorporating schools, churches, and self-help groups of the Deaf has been developed through the use of a sign language vocabulary, interactive group games and puppetry show.

- Deaf peer networks with a population of 1300 Deaf peers drawn from 23 schools of the Deaf and Deaf adults' centres with a population of 4,000, 4 churches, 3 self-help groups, and one association of parents with Deaf children have been established. Through these networks, the project recorded increased:
  - Awareness on HIV/AIDS,
  - Health seeking behaviour; and
  - Ability for Deaf to share information with other Deaf peers.

- Members of a deaf puppetry group have been trained and certified by the programme to offer outreach services with a focus on HIV/AIDS awareness creation.

- Two training handbooks for master educators and peer educators were developed and distributed to local and international deaf communities. The purpose of these handbooks was to provide Deaf youth and adults, teachers, parents and guardians with a tool for addressing basic health awareness within an independent framework utilizing optimal communication. The Deaf peer education handbook is appropriate for various ages, communities, cultures, religions, and literacy levels. It has been distributed to schools for the Deaf, Deaf adult centres and other stakeholders working directly with Deaf groups.
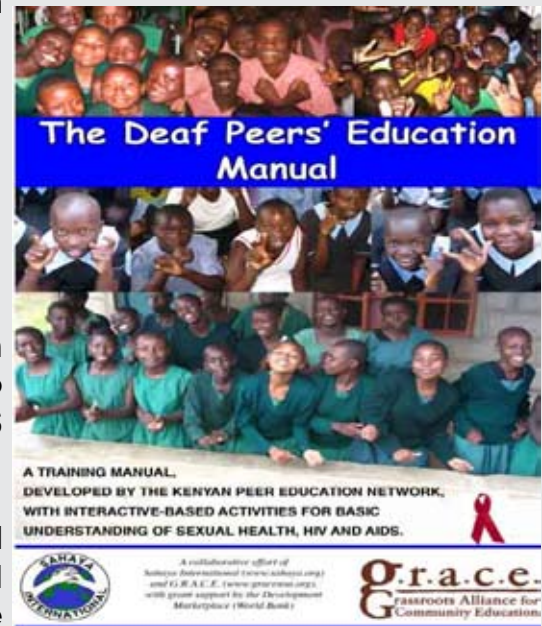
What worked well:

- Continuous monitoring, evaluation and supervision of peer education sessions, that has contributed to the improvement of ways in which information is disseminated to the hearing impaired.
  - The project was evaluated through a post program survey which was done through focus group discussions, in sign language.

Lessons learnt:

- Use of sign language alone without participatory interactive activities reduces levels of receptiveness of information by persons with hearing impairment.

- Deaf-friendly materials take quite a considerable amount of time to design thus ample time should be factored in the planning.

b) Behaviour change communication

Some organisations have zeroed in on the creation of HIV/AIDS prevention and awareness through the development of Deaf friendly educational tools such as posters, flyers, policy briefs, newsletters, brochures, banners, drawings and pictorial illustrations such as cartoons with HIV messages.

Innovative approaches aimed at enabling HIV/AIDS awareness such as the use of magnetic theatres have also been utilized. Magnetic theatres are short dramas and skits acted by disabled people. They are premised on the edutainment approach which combines education and entertainment and therefore often attract large crowds.

Some of the organizations that have used the BCC approach include:

1. Jamaica Council of Persons with disabilities (JCPD).
   Available at http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2008/20080905_disability_hiv_jamaica.asp

2. Kenya Disabled Action Network (KEDAN)
   Telephone /+254 020 2324589/ +254 720 786 621
   E- mail: kedan2@gmail.com
   Website: http://www.kedan.or.ke/pages/what_we_do.html

The following is a case study that has demonstrated best practice in the delivery of HIV/AIDS information through innovative methods.

Case study of the Jamaica Council of Persons with Disabilities (JCPD) – Responding to HIV programme

Tel: (876) 968-8373 & 968-0623
Email: jcpd@cwjamaica.com
Website: http://myjcpd.org/

Background:

JCPD developed innovative information and economic empowerment programme to include PWDs in HIV related public education that is being implemented as part of the national response to HIV.

Objective:

To ensure that public health information disseminated through television id also done using sign language.

Strategies Used:

🎗 Utilization of mobile phone and television
Through this approach, the programme directly addresses the disabled community on the subject of HIV, by:

- Customizing messages and information and delivering it in accessible formats to suit their disabilities such as sending HIV prevention messages through the short text messaging service on mobile phones.

- Ensuring that public health information on television has the necessary sign language for the deaf community.

🎗 Use of Videos and Compact Discs(CDs):
Video and CD documentaries with HIV/AIDS and STI information have also been produced to teach the hearing impaired on issues pertaining HIV/AIDS. Sign language interpretation has been used to make the video accessible to the deaf audience.

🎗 Income generation:
The programme is coupled with an income generation component to assist people in accessing business skills and small grants to initiate and manage their own business, thus potentially reducing their vulnerability to HIV.

🎗 Empowering deaf women and girls:
The program has a specific focus on Deaf women and girls, and their service providers. They are educated about HIV and on gender relations as a whole. Within the project women are empowered with skills to strengthen their economic independence.

Lessons learnt:

Through a ripple-on effect, the education and economic empowerment programme for persons with disabilities have facilitated a positive impact on the lives of Deaf and hence reduced their vulnerability to HIV.

Conclusion:

Organizations working with the Deaf need to devise strategies on how best to utilise participatory approaches in awareness creation. This will in turn help address the existing HIV related knowledge gaps and also sensitise people on the available HIV counselling, care and treatment services.

2.1.2. Deaf friendly HIV Testing, Counselling, Care and Treatment services

Knowledge of HIV status is a significant factor in HIV prevention and the delivery of care and treatment services. Approaches through which HIV Testing and Counselling (HTC) for the deaf has been achieved is through Deaf specific stand alone Voluntary Counselling and Testing (VCT) sites and provision of mobile VCT in schools, communities and public forums.

Two main strategies have been utilized by some of the stakeholders working with the hearing impaired to provide HTC services, namely:

- Utilizing Deaf HIV counsellors and peer educators , as the main service providers in mobile and stand alone VCT sites for the deaf; and

- Training hearing counsellors in sign language and on how to provide services to the deaf so that HTC services targeted at the deaf can be integrated in VCT sites aimed at the general population.

In addition to the above strategies, HIV/AIDS organizations around the world have utilised diverse ways through which access to HIV care and treatment by the hearing impaired can be enhanced. This has been mainly through:

- Post test clubs and support groups for PWDs, where health talks on HIV are given. These health talks have greatly increased HIV awareness levels among the hearing impaired and have also acted as an entry point to care and treatment for HIV/AIDS, in addition to facilitating disclosure of HIV status among its members.

Summary of strategies that have been used by diverse organizations to enhance access to HIV care, treatment and psychosocial support:

- Home based care where service providers do routine follow up of their clients who are on HIV care and treatment but are unable to visit the clinics on their own.

- Post test clubs that have weekly or monthly meetings.

- Special programmes targeting children with disabilities.

- Integration of deaf friendly HTC services in mainstream service delivery point through training of non-deaf service providers on sign language.

The following is a case study of an organization that has portrayed best practice in the delivery of HTC services to the Deaf.

Case Study of Liverpool VCT, Care and Treatment

Name of Organisation: Liverpool VCT, Care and Treatment (LVCT)
Telephone: + 254 20 2714590, 2715308
E- Mail: enquiries@liverpoolvct.org
Website: www.liverpoolvct.org

Background:

In 2003, the provision of HIV/AIDS care and treatment services for Kenya's Deaf population was limited and the attitude of health service providers was a big barrier for Deaf people to access HIV testing and counselling (HTC) and related services. Service providers lacked the knowledge to deal with Deaf clients and heavily depended either on interpreters who were school teachers and who were always assumed to be experts on deaf issues; or unqualified interpreters to provide HIV services to Deaf people.

With the introduction of VCT as an HIV prevention strategy, several HIV workshops were organized by deaf people themselves and an increased number of Deaf clients were visiting VCT sites to access HIV testing services. However, many had negative experiences as the communication barriers meant that they did not feel that their needs were met and utilization of interpreters' breached confidentiality. These reports and feedback were made to the Kenya National Association of the Deaf (KNAD). KNAD recognized the need to set up a Deaf specific or friendly testing and counselling site. KNAD, together with other Deaf stakeholders, approached Liverpool VCT, Care and Treatment (LVCT) to set up a Deaf VCT service.

A Deaf VCT Programme was established at LVCT with the following objectives:

- Raise awareness of HIV/AIDS and STI among the Deaf community in Kenya

- Increase access to quality VCT, Care and treatment services to the deaf community

- Involvement of Deaf people in policy dialogue and development

Strategies used:

- Stakeholder and target community involvement and consultation
  - This was achieved through meetings between LVCT, KNAD, The Kenya Society of the Deaf, Nairobi Association of the Deaf and Nairobi Deaf Women to discuss strategies for setting up a VCT centre for Deaf people.

  - LVCT, and other stakeholders, organized an HIV awareness workshop for Deaf people in Nairobi, to examine the level of HIV knowledge among the Deaf community. Through this workshop, LVCT selected 16 potential Deaf trainees to undertake VCT training.

  - The selection of Deaf trainees, who are now counsellors and peer educators, was done by LVCT and a technical working group comprising various Deaf stakeholders. The selection criteria included: fluency in Kenya Sign Language (KSL), high school certificate with grade D+ and general experience/ Interest in counselling, ability to read and write good English.

- Revision of curriculum to meet Deaf trainees needs
  - The 3 weeks national VCT training curriculum was revised to meet the training needs of the 16 Deaf trainees. The training of the Deaf took four weeks.

  - The Deaf trainees, who qualified to be counsellors, were employed and certified to offer HIV testing and counselling services in stand alone and integrated VCT sites.

- Sign language interpreters trained on VCT
  - Two sign language interpreters were trained as VCT counsellors so as to provide better quality interpretation services during the training of the deaf trainees and subsequent follow up. The qualification of these interpreters was a high school certificate, certificate in counselling and guidance, 3-year experiences in interpretation and fluency in KSL.

- Peer led support groups

Achievements:

- In 2003, LVCT established the Nairobi Deaf VCT as the first site for Deaf people run by deaf counsellors. After 8 months, two additional sites were opened in Kisumu and Mombasa.

- In 2004, a National Deaf mobile VCT Campaign was initiated to bring VCT services closer to the deaf community

- More than 12,000 Deaf clients have received VCT through the 3 stand-alone sites for the Deaf between 2003 and 2008.

- 200 mobile VCT outreaches for PWDs have been done between 2003 and 2008 through the use of deaf peer educators.

- 53 Hearing HIV service providers have been trained on basic KSL to improve VCT services up take by the deaf without using an interpreter.

- A "Signs for Sexuality and Reproductive health" handbook aimed at building the capacity of service providers to improve their communication with Deaf clients was developed and printed. The handbook is designed to help improve the quality of health delivery in terms of communication during counselling, diagnosis, prescription, peer education and various health education, curative and rehabilitative services.

- In 2009, the successful LVCT peer led Deaf programme was expanded to include other groups of PWDs and renamed the Disability Programme.

Lessons learnt:

- Involving deaf people in the delivery of HTC has meant that adoption of comprehensive and quality services for the deaf have not only been inclusive but also sustainable.

- The involvement of all the key Deaf stakeholders from the public and private sectors is important from the initiation of the programme and ultimately service delivery.

- Peer led community mobilization and mobile VCT are crucial for sustainability of Deaf VCT services.

- Capacity building of sign language interpreters and health service providers is necessary to ensure that deaf clients receive quality, non-stigmatizing and affirming HIV services.

- Training health service providers in basic sign language is important for increasing uptake of HTC services among the Deaf.

A deaf counselling Session

(Photo courtesy of Liverpool VCT, Care and Treatment)

Factors that contributed to the success of LVCT's Deaf VCT Program

- Involvement and consultation with a wide range of stakeholders
- Support from a national association for the Deaf
- Inclusion of Deaf counsellors in the broader LVCT HCT programme
- Adaptation of the national training curriculum to suit the deaf trainees
- Training of sign language interpreters
- The programme is led by a deaf manager

Conclusion:

There is need for all stakeholders involved in HIV/AIDS service delivery to:

Talk   about   HIV/AIDS   with   the deaf

Photo obtained from Strengthening the AIDS Response Zambia' – STARZ Programme
Available at www.hlsp.org/files/page/278207/Disabilities_paper_web.pdf

2.2. Delivery of HIV/AIDS Services to the Visually Impaired

This section focuses on the strategies that have been utilized by various organizations working with PWDs in ensuring the delivery of HIV/AIDS services to those with visual impairment.

Introduction

Globally, programmes and campaigns to create awareness on how to prevent, manage and live positively with HIV/AIDS have rarely been made accessible to visually impaired persons. Most of the information on HIV/AIDS and related topics is not available in Braille or large print hence inaccessible to visually impaired people. Though some DPOs have developed IEC materials in Braille, not all blind people can read Braille.

The blind persons also experience challenges in accessing medical care due to factors like inability to read IEC materials including instructions on medication prescribed for them. They also face a challenge in determining the expiry date printed on condom covers and other necessary information regarding the correct use of condoms for HIV prevention and this makes them dependant on others for assistance.

Below are comments by Jean Pierre an 18 year old High School student in Rwanda, who attended a HIV/AIDS awareness workshop conducted by a facilitator, named Rahab:

"I attended a training session in my home area but I did not enjoy it because they used a video which I didn't understand because nobody explained what was going on; they also gave me a print booklet to read. But after I attended the training by Rahab, I understood better because I touched a condom and learned how to use it. Things were explained to me much better"

In addition, there is almost no research that has been carried out on the intersections between blindness and HIV. A lack of information means that visually impaired people have limited knowledge on how to protect themselves from infections; for those already infected, how to live positively with HIV/AIDS and/or how to care for others living with HIV. This situation is further compounded by the stigma blind people suffer from society and the negative attitudes from service providers which inhibit their uptake of HIV/AIDS services. This is best described in the quote below;

"…I once went to be tested for HIV at the clinic. This female counsellor I met there asked if I knew how to perform sex. I answered in amazement would you like me to show you how it is done?"

(This was the experience of Jacque Mogisho a young man from Rwanda.)

Organizations working with the blind have thus taken the initiative to educate visually impaired people through the use of friendly formats and languages, namely: Peer education, Screen reader programs, Talking books, audio CDs and cassettes among others. Some of the organizations working with the visually impaired have also initiated HIV/AIDS awareness programs utilizing workshops, outreach seminars, and mobile HTC through which information on transmission, prevention as well as care and treatment of HIV/AIDS is disseminated. Some of the successful the techniques that have been employed include:

- Participatory approach for HIV/AIDS awareness

- HIV testing, counselling, care and treatment services friendly to the visually impaired

2.2.1. Enhancing HIV/AIDS awareness through participatory approaches

The section focuses on the 2 main approaches that have been used by organizations delivering services to foster HIV/AIDS awareness among the visually impaired. These include:

a)   Peer Education

b)   Development of IEC materials

During the peer education sessions, peer educators use tactile oriented approaches to deliver HIV/AIDS information. This is demonstrated by use of special training tools for touch to elicit procedural mannerisms of delivering information such as procedural condom demonstration where the blind practically feel and are taught how to use condoms. When administering the tactile approach, teaching is individualized and the information is broken down into simple understandable terms.

The African Union for the Blind is one of the organisations that has utilised this approach to create awareness among its members. By touching the condoms, the visually impaired get more empowered in terms of knowing how to protect themselves from STI/HIV. An association for disabled people in Zimbabwe is demanding that condom packs be written in Braille to help its blind members to engage in "safe sex".

The use of peer education as an awareness creation approach is demonstrated in the photos below

A Visually Impaired peer educator conducting a HIV/AIDS awareness session in Ethiopia (Photo- courtesy of AFUB)

A blind participant familiarises herself with a female condom in a HIV/AIDS workshop (Photo- courtesy of AFUB)

One-to-one condom demonstration among the blind (Photo- courtesy of AFUB

Visually Impaired

b) Development of IEC materials

Organisations have diversified on the formats utilized to create HIV/AIDS awareness among the visually impaired to include the include use of Braille, large print, audio compact discs, cassettes, and the electronic media.

Braille and large print:

Production of IEC materials in Braille and large sized letters to create HIV awareness among the blind and visually impaired community, have been a successful medium of delivery HIV/AIDS messages to this population.

The following are some of the organisations that have used this strategy:

Blind and Low Vision Network –Kenya (BLINK)
Telephone: +254 20 21 31 556
E- mail: blinkenya@yahoo.com

BLINK provides HIV information in large print/font for the visually impaired and this is facilitated by using different colours and colour contrast to make the letters more visible and legible to persons with low vision.

> African Union of the Blind (AFUB)
> E-mail: sally@afub-uafa.org
> Telephone: +254 20 823989
> Website: www.afub-uafa.org

AFUB focuses on the development of resource materials for blind and partially sighted people. These include brochures prepared in braille and or large print containing HIV related information.

Audio Compact Discs:

Education and resource materials such as audio CD and cassettes which contain HIV/AIDS information and messages are also produced. These CDs and cassettes are further translated into local dialects to make them more user friendly to the blind people. Below are case studies of two organizations that have demonstrated best practice in the use of this strategy, namely

- African Union of the Blind (AFUB),and

- Zambia National Library and Cultural Centre for the Blind

Case study of African Union of the Blind (AFUB)-HIV/AIDS Awareness, training and Advocacy Program

Name of Organisation: African Union of the Blind
Tel: +254 20 823989
Website: www.afub-uafa.org

Background:

African Union of the Blind is an international umbrella organisation of associations of and for blind persons in Africa. 55 National associations of the blind in 50 countries across Africa are members of AFUB.

In 2005, upon receiving financial support from the Canadian International Development Agency (CIDA) and the Canadian National Institute for the Blind (CNIB), AFUB began to implement the HIV/AIDS Awareness, Training and Advocacy Program with her member associations of the blind. During the first phase, the program was implemented in six countries, i.e. Cameroon, Ghana, Kenya, Malawi, Rwanda and Tanzania. Subsequently, due to the successes recorded from this phase, in 2008, the program was rolled out to Benin, Eritrea, Ethiopia, Lesotho, Liberia, Mali, South Africa and Zambia.

In 2010, AFUB hopes to extend the program to Botswana, Burkina Faso and Togo.

Objective:

The program's overall goal is to reduce the incidence of HIV/AIDS among blind and partially sighted people in Africa through promoting their inclusion and participation in HIV awareness and control programmes in their communities.

Strategies Used:

Development of resource materials for blind and partially sighted people.

- 20 different HIV/AIDS resource materials friendly to visually impaired persons have been developed.

- The materials have been produced in French but are translated to the particular national languages of the various countries and for some into local dialects depending on the ethnic inclination. The responsibility to translate such materials is taken up by the national organizations of the blind in the respective countries.

- Such materials include hard copies/brochures with information in Braille, large print, videos and audio CDs and tapes with a recording of HIV information.

- The CDs and cassettes produced are also labelled in Braille to help blind people identify and differentiate those with HIV/AIDS information from any other that they may have.

Development of an HIV/AIDS advocacy and training model

- The model includes: a TOT handbook for training peer educators, a grassroots training guide for peer educators to use at the grassroots training, and a guide that outlines the minimum criteria that AIDS service providers need to know.

- It comprises seven modules that centre on sexuality, HIV prevention, management of HIV and care & support for those living with the virus.

Achievements:

An easy to read booklet written in simplified language has been developed. The booklet puts together a number of themes relating to HIV/AIDS and incorporates recent developments such as human rights issues.

Training handbooks and guidelines developed for the peer educators to use in workshops and at grassroots level have ensured that all the relevant HIV related information is well disseminated

Case study of the Zambia National Library and Cultural Centre for the Blind

Tel: +260 1-260516

Background:

The Zambia National Library and Cultural Centre for the Blind is an affiliate of the Zambia National Federation of the Blind. It was founded in 1993 with funding from the Finnish Federation of the Blind. The centre has a multipurpose library with lending and borrowing facilities, a recording studio and a transcription service. It has 35 corresponding centers countrywide that are either housed in city council libraries and are run by the city councils or are attached to schools and colleges.

Strategies used:

Innovative information management practices

- Braille Transcription
  – The centre transcribes and prints HIV and AIDS information in Braille books.

- Audio books are produced for use by the blind learners in colleges and schools.

- Video Cassettes with HIV/AIDS information are also produced

Provision of Brailled HIV and AIDS resources
- The centre is stocked with different types of information targeting visually-impaired people. Such materials include hardcopies and audio recordings of the following;

  o Introduction to Antiretroviral therapy (ART)
  o Antiretroviral therapy (ART):
  o ART may help you feel strong even if your immune system is weak;
  o Side effects of ARV drugs;
  o Men and HIV in Zambia and HIV and AIDS basic handbook for entrepreneurs.
  o Food for people living with HIV/AIDS

Lessons learnt:

The information disseminated should be availed in local languages, in a manner that can be easily understood by target readers especially in terms of functional literacy.

Information needs to be culturally-appropriate and be in the right format for the visually-impaired

It is imperative to involve PWDs in the design and implementation of information programmes that are meant to benefit them.

What worked well:

Provision of HIV and AIDS information in both print and audio formats enables the visually impaired to have varied choices on what resources they want to use.

Use of Radio

Some organizations have managed to set public awareness programmes through the use of local and international media, for example through radio talk shows to raise awareness on HIV/AIDS. The radio has been instrumental for the blind as it is easily accessible even in the most resource poor settings. The talk shows are usually made in national languages as well as local dialects and hence are able to reach a large population within their convenient proximity.

"……people like us [visually impaired], we normally get the information (HIV/AIDS) from the radio easily even if you cannot go to the baraza (meetings such as those called by chief) but you can listen them in the radio, yes, because there are programmes……."

Quote from a blind woman in Kenya

The above quote demonstrates how the use of audio messages has been instrumental in reaching out to the visually impaired.

Use of computer via screen reader programs

A screen reader program for blind people known as Job Access With Speech (JAWS) has been adopted where the blind are able to access audio oriented HIV/AIDS information. This program provides the user with access to the information displayed on the screen via text-to- speech or by means of a Braille display and allows for more comprehensive keyboard interaction with the computer. This screen-reader software has Braille, speech synthesizer and screen magnification, and is compatible with computer applications such as Microsoft Office, Internet Explorer, Firefox, Corel, Word Perfect and Adobe Acrobat Reader, among other applications hence a wide range of user preference.

An example of an organisation that has successfully implemented the use of the JAWS programme is the Blind and low vision Network (BLINK), Kenya whose case study is described below:

Case study of Blind and Low Vision Network- Blink

Telephone: +254 20 21 31 556
E- mail: blinkenya@yahoo.com

Background:

Blind and low vision Network (BLINK) is an NGO registered in 2003 and whose membership constitutes community based groupings of visually impaired persons. With support from ABILIS Foundation, Handicap International and AMREF Maanisha program, the organization has majored in HIV and AIDS education/awareness among the blind and partially blind (low vision) persons. Blink works with other partners both in government, civil society and private sector to extend HIV and AIDS services to its beneficiaries. These include but not limited to the National AIDS Control Council, Ministry of Education, Ministry of Agriculture, Ministry of Culture and Social services, Kenyatta University, and various learning institutions for the visually impaired persons.

Objective:

To provide accessible HIV/AIDS services to visually impaired persons and to strengthen community responses to mainstreaming visually impaired persons in HIV/AIDS activities.

Strategies used:

Community sensitization

- BLINK holds workshops and outreach forums where sensitization on HIV/AIDS to the visually impaired community is done. In these forums, approaches such as interactive sessions are utilized where professional/ community trainers are invited to talk to the audience on matters related to HIV/AIDS. The main mode of dissemination of messages in these training is through tactile oriented approaches facilitated through sense of touch and verbal communication.

- Peer education is the main mode of teaching utilized in learning institutions where trained peers are used to disseminate HIV and AIDS information to their peers through family cells and peer clubs.

Offering HTC services

- BLINK utilizes government structures such as National AIDS and STI Control Programme (NASCOP) structures to provide mobile VCT services to the blind and visually impaired at the grassroots. VCT attendants are first trained on special intervention skills required when serving persons with visual impairment.

- During outreach workshops the sighted guides for the blind benefit from training on HIV AIDS and are provided with HTC services. Sighted guides play crucial roles in passing on information to blind persons and their involvement is key in any efforts to reach out to blind persons.

Production of resource materials friendly to visually impaired

- This is achieved by translating and producing HIV/AIDS messages in Braille.

- Audio HIV messages are also produced in CDs and cassettes/tapes which are then given to visually impaired people to listen to.

- BLINK has a resource centre where visually impaired persons access HIV/AIDS resource materials. Within the resource centre are computers which enhance learning for the visually impaired persons. The computers have a screen reader program known as JAWS, which has a software/application that enables the blind people to access HIV/AIDS information. JAWS enable blind people to manoeuvre the computer through sound synthesizers.

Achievements:

- Over 2000 visually impaired persons have been sensitized through this program.

- More than 700 visually impaired persons have accessed HTC services.

- 800 CDs with different messages have been produced and disseminated. These audio CDs have been produced using local dialects and disseminated; Approximately 700 cassettes have been produced and disseminated.

- 1500 Braille materials have been produced. These materials are in form of leaflets and brochures carrying different messages such as using a condom (both male and female), living positively, nutrition, transmission of HIV, Opportunistic infections, benefits of VCT services

What worked well:

- The use of tactile oriented approaches to deliver HIV/AIDS information. For this, demonstrations through touch work well. During the trainings, the trainers use special training tools for touch to elicit procedural mannerisms of delivering HIV AIDS information for example condom demonstrations.

Lessons learnt:

- Blind people need a specialized approach for them to understand information. Hence teaching should be individualized or made to a one a one to one basis.

- Tactile oriented approaches make information more consumable for the visually impaired.

- There is need to break down HIV/AIDS information into simple understandable terms for the blind people to comprehend

Conclusion:

IEC materials created and used by different organisations working with the visually impaired can be utilised to enhance access to HIV information. The HIV/AIDS related IEC materials targeting the general population can also be converted into the formats that are user friendly to the visually impaired. Increased in knowledge levels on HIV by the visually impaired could also contribute to increased accessibility of HIV CT, care and treatment services.

2.2.2. HIV Testing, Counselling, Care and Treatment Services friendly to Visually Impaired People

HTC service providers from HIV mainstreamed programmes utilize opportunities presented by organizations working with the visually impaired people to provide mobile HTC services. Organisations working with the visually impaired have also devised innovative approaches to enhance delivery and uptake of HIV/AIDS related services by the visually impaired. These include:

- Setting up of support groups and post test clubs for the VI where those with HIV share their experiences on how they have managed to cope with their status, encourage their colleagues to go for HIV testing as well as give advice on proper nutrition and coping mechanisms.

- Development of large font generic leaflet on condom use to enable the blind read the condom instructions given on the packets.

- Development of alternative packaging for medicines prescribed to the blind as indicated in the case study below:

Case Study of the South African National Council for the Blind

Email: admin@sancb.org.za
Website: http://www.sancb.org.za/about.html

Background:

The South African National Council for the Blind (SANCB) is a Non-Government Organisation (NGO) striving to meet the needs of all blind and partially sighted people in South Africa. Since its establishment in 1929, SANCB has been the umbrella organization for over 90 organizations for and of the blind in South Africa. As such, it represents over 600 000 blind and partially sighted people.

Its support includes rehabilitation, education and training, the provision of assistive devices, social and economic development and programmes promoting the prevention of blindness and the restoration of sight. SANCB is a member of the African Union of the Blind.

Mission Statement:

- To foster and promote conditions that enable all blind and partially sighted people to live dignified, productive and meaningful lives through which they contribute to a society in which blind people and their seeing counterparts thrive together.

- Helping organizations for and of the blind to deliver effective and relevant services to blind and partially sighted people and their families or other stakeholders.

- To initiate, develop and implement projects that benefit blind and partially sighed people of all ages.

The South African National Council for the Blind has been successful in obtaining alternatively labelled containers which are accessible for blind people through their resource center. These containers are imported from Royal National Institute for the Blind in the UK or from the MAxiaids in the USA for between US $ 3 to about US $ 6 plus postage.

For the purposes of ensuring that the special packaging reaches the visually impaired who need them, the SANCB has a network of organizations in all the provinces. These organizations purchase the packaging from the SANCB, or advise individuals to contact the SANCB resource centre.

The picture below shows how the containers have been labelled for each day of the week and the particular times when the drugs should be taken (morning, noon, bedtime and evening). To indicate the day when the drug is to taken, the first letter of the day has been raised above the package surface for easy touch and recognition by blind people. This enables everyone to take full responsibility for their own health. The containers are also re-usable.

Available at www.icdr.utoronto.ca/Files/PDF/94a3663acf97d5f.pdf 1.

2.3. Best Practices for HIV/AIDS Service Delivery to the Physically Challenged

This section focuses on the strategies that have been utilized by various organizations working with PWDs in ensuring the delivery of HIV/AIDS services to those who are physically challenged.

Introduction

The links between physical disability and HIV are two pronged: people with physical disabilities may become infected with HIV, due to risky behaviour, and, people with HIV may at times become physically disabled due to some of the opportunistic infections (OI). Health care and rehabilitation providers do not commonly address these issues. Persons living with HIV who in turn become disabled rarely get the required support or information from service care providers on how to deal with the double stigmatisation arising from HIV infection and disability.

Organizations targeting the physically challenged have adopted different approaches to enhance delivery of HIV information and services. These include:

- Participatory approaches in enhancing HIV/AIDS awareness

- Structural modifications in existing HIV service delivery stations to facilitate ease of movement.

2.3.1. HIV/AIDS awareness through the use of participatory approaches

During the compilation of this handbook, organisations were found to use diverse peer led approaches in an effort to disseminate HIV/AIDS related information to those individuals who fall within this population group.

The formation of peer led support groups and post test clubs have significantly provided an enabling environment for the physically disabled people to benefit from counselling and sharing experiences of their peers who are living with HIV/AIDS. In these groups and clubs, information on nutrition as well as referral to care and treatment is given. DPOs working with the physically disabled have also made efforts to organize mobile outreaches and free medical check ups where services such as VCT are offered.

Organizations working with physically disabled have also embraced creativity in how they carry out peer education programmes using dramas and skits acted by the physically disabled people to relay HIV/AIDS information and messages to large groups of people. Through these gatherings, time and opportunity are given for community groups to discuss issues relating to HIV/AIDS transmission, prevention, testing, care and treatment.

The key strategies that have been employed in carrying out peer education sessions by different stakeholders include:

- Involvement of the physically challenged as peer educators

- Implementation of peer education activities, for examples dramas, in locations that can be easily accessed by the physically challenged.

Trainer facilitating session at the Disabled people's federation meeting/training in Bolangir district, Orissa- (Photo courtesy of VSO India)

The following is case study of an organization that has demonstrated best practice in delivery of peer education to the physically challenged in Kenya.

Case study of Association for the Physically Disabled of Kenya (APDK)

Telephone: +254 (20) - 4451523
 Email: apdknbi@africaonline.co.ke
Website: apdk.org

Background:

The Association for the Physically Disabled of Kenya (APDK) is an NGO that has been actively supporting initiatives to address the needs of Kenyans who have disabilities and was first established in 1958 as an umbrella organization for groups working with the physically disabled in Kenya and with aim of rehabilitating PWDs. APDK provides technical support to 193 DPOs in Kenya by helping them to mobilize resources, deliver new information in HIV AIDS, and to develop IEC materials, APDK 's work revolves around; advocacy, medical rehabilitation, community based programmes, vocational training, sheltered employment, provision of appliances and mobility aids, economic empowerment (employment and micro-finance programmes), counselling, educational programmes, sensitization and community training. HIV/ AIDS is a cross cutting theme and hence given a special focus in all the key areas of involvement.

Objectives:

- To create awareness on causes, prevention and management of various disabilities with the aim of reducing prevalence and to overcome prejudices and traditional beliefs towards PWDs.

- To promote quality rehabilitation services through medical rehabilitation, social rehabilitation and economic empowerment.

- To develop low-cost supportive appliances through appropriate technology to meet the needs of persons with disability especially in the rural community.

- To promote formation of grassroots groups of persons with disabilities with the aim of increasing their self confidence to achieve full participation in their communities and attain equal rights

Strategies Used:

Formation of support groups and delivery of HTC services

- Through these groups, APDK has provided forums through which PWDs have been mentored on HIV/AIDS through open discussions and talks on ARVs and from experiences of PLHIV.

- APDK Nairobi branch, works closely with LVCT through its comprehensive community based rehabilitation programme based mukuru with the goal of mainstreaming HIV & AIDS programmes into CCBR programmes.

Empowering of PWDs

- This is achieved through workshops organized for peer educators which also target the larger community in a bid to reduce stigma. During these workshops peer educators are given information on HIV/AIDS transmission, prevention, care and treatment. Condom demonstration is also done and practical procedures on using alternative methods in putting on condoms such as the use of the mouth for those whose limbs are disabled.

Community participation

- APDK works with the community through its Comprehensive Community Based Rehabilitation (CCBR) and outreach programs. 3 districts namely Kisii, Kisumu and Embu are implementing Disability, HIV/AIDS programs in the community.

- APDK partners with other organizations in order to pay visits to schools of PWDs where they offer sanitary towels and through these forums, discussion on HIV/AIDS is done.

- APDK Nairobi branch is also working closely with LVCT through its comprehensive community based rehabilitation programme based (CCBR), Mukuru with the goal of mainstreaming HIV & AIDS programmes into CCBR programmes.

Development of resource materials

- These are availed in different formats for the different groups of disability.

- In conjunction with Handicap International, APDK developed a training handbook on HIV/AIDS & Disability to be used by PWD trainers in various trainings. The handbook was also translated into Braille.

2.3.2. Structural modifications in existing HIV service delivery stations to facilitate ease of movement.

Structural challenges experienced by the physically disabled persons in accessing HIV related services from public health facilities are well documented in the existing literature. Strategies that have been put in place by different organizations to facilitate delivery of HIV/AIDS and SRH services to the physically challenged include mobile HTC and home based care services. The construction of wheel chair ramps and functional escalators in health facilities has been found to improve mobility within the health facilities hence easier access to SRH services.

(Photos courtesy of Association of the Physically Disabled on Kenya)

Conclusion:

During the compilations of this handbook, no organisations was found to have come up with a best practice that would ease access to HIV care by the physically challenged other than making the required structural modifications to the existing health facilities.

The following case study below highlight the achievements made by one organisation in Kenya, whose VCT services have factored in the needs of the Deaf, visually impaired and the physically challenged clients

Case study of the Kenya Institute of Special Education Disability Friendly VCT

Background:

The Kenya Institute of Special Education (KISE) was established in 1986. KISE's mandate is to training teachers and other personnel in the field of Special Needs Education, run an educational and Functional Assessment Centre for Early Intervention for persons with special needs and disabilities, design, produce and maintain educational resources and assistive devices for persons with special needs and disabilities and conduct research in the areas of special needs amongst others. In November 2008, KISE, LVCT and DPOs such as HI and APDK among others got into a partnership to set a Disability friendly VCT in KISE's premises.

Objective:

To provide quality and friendly HTC services and referral to PWDs

Strategies used:

Offering HTC services

- HTC services are offered to PWDs. The HTC services have been accustomed to serve all categories of disability.

- Referrals for HIV care and treatment are also done.

- Involvement of PWDs as service providers

Training service providers on special skills

- HTC counsellors offering services in the site were trained on how to handle PWDs because they are a group that has special needs.

- Hearing HTC providers were also trained on sign language so that they could offer services to the deaf community.

Designing and building of Ramps

- A ramp was built for ease of accessibility by people with physical impairments. This makes it easy for persons on wheel chairs and those on crutches.

Provision of HIV and AIDS services in accessible formats

- Information on HIV/AIDS is availed in Braille for the visually impaired clients

- Deaf clients receive services with direct contact with the service providers.

Achievements:

- Over 2000 PWDs have accessed HTC services and information since the establishment of this VCT.

Lessons learnt:

- With the location of the facility far away from the main road and public transport, it has been a bit challenging for PWDs to access the VCT. Organizations intending to establish static VCT sites should take this into consideration, but better still invest in outreach services as elaborated in the LVCT case study (pg 12) as these increase accessibility and service uptake.

Conclusion:

It is vital that all HTC centers are made friendly for PWDs. The following are the minimum standards that should be observed by organizations seeking to set up disability friendly HIV testing and counselling centres.

Minimum Standards for setting up a Disability friendly HTC Site

Structure:

- Consider setting up the VCT the ground floor for ease of accessibility.

- Where necessary, build ramps at the entrance of the testing centers or provide lifts where possible.

- Ensure that the doors to the counselling rooms are large enough to accommodate a wheel chair

- The service provider's room should have adequate space and well equipped to accommodate a wheel chair, an interpreter and or a carer/guardian

- Ensure that the rooms are well lit to facilitate communication with deaf (sign language and writing) and persons with low vision.

Communication:

- There should be a sign language interpreter.

- Service providers should have basic sign language and or a deaf counsellor/ interpreter should be available at the site upon request.

- The HTC site should be located in an environment where there is minimal interference with the counselling session.

- HIV/AIDS IEC materials catering for all groups of PWDs should be availed at the reception desks, waiting bay and the testing room. This should include materials in Braille and large font as well as in sign language; for example posters and leaflets done in sign language.

- The IECs developed should be simplified for all PWDs.

- Drawings and illustrations with focus on HIV/AIDS should be provided for the intellectually challenged persons.

Service provision:

- HIV services providers should have basic knowledge on disability and HIV issues.

- HIV service providers should be trained on how to provide quality and non-stigmatized services to PWDs.

- Service providers should develop innovative approaches that will involve taking HIV services closer to PWDs. Such may include, mobile HTC and Home based Testing and Counselling.

- Clear referral mechanisms from the HTC site to HIV care & treatment services that are disability friendly should be established where possible service should be offered at no cost or a waiver made for PWDs who might not be in a position to cater for the expenses incurred in accessing HTC services.

- Initiate peer led support groups where disabled clients can join for psychosocial support.

- PWDs can be involved either as mobilizers, peer educators, or counsellors in the delivery of HTC services.

2.4. Delivery of HIV/AIDS Services to Persons with Intellectual Disabilities (PWID)

This section describes the strategies that have been utilized by organizations working with PWID in ensuring that they access HIV/AIDS related information and services.

Introduction

Studies have demonstrated a high sero-prevalence of HIV infection in people with serious chronic mental illnesses. For example, prevalence rates in mentally ill inpatients and outpatients have been reported to be between 5% and 23%, compared with a range of 0.3% to 0.4% in the general population in the United States of America over comparable time periods (WHO, 2008). Other studies have reported behavioural risk factors for transmission of HIV between 30% and 60% of people with severe mental illnesses. These risks include high rates of sexual contact with multiple partners, injecting drug use, sexual contact with injecting drug users, sexual abuse (in which women are particularly vulnerable to HIV infection), unprotected sex between men and low use of condoms. Depending on the severity of the disability, people with intellectual disabilities are often placed at a disadvantage in sexual relationships. Besides these behavioural risks, mental disorders may also interfere with the ability to acquire and or use information about HIV/AIDS.

The diagnosis of mental health problems in HIV-infected individuals is in most cases problematic due to myriad reasons which include:

- Lack of disclosure by patients of their psychological state to health-care professionals for fear of being stigmatized further.

- Health-care professionals are often not skilled in detecting psychological symptoms and, even when they do, they often fail to take the necessary action for further assessment, management and referral.

A number of strategies that have been adopted by organizations that offer HIV/AIDS services for the mentally challenged communities are described in this chapter with a focus on HIV prevention.

2.4.1. Enhancing HIV /AIDS prevention among PWIDs

HIV prevention strategies are often two pronged, that is; those that focus on helping prevent a HIV negative person from getting infected; and those that focus on prevention of re-infection among those who are already HIV infected.

Primary data collected from resource persons during the development of this handbook indicated that DPOs and other HIV program implementers focus on the use of two key strategies in their work with PWIDs:

a) Interactive awareness creation

b) Development of IEC materials

a) Interactive awareness creation sessions

This is achieved through role playing and recreation where games on HIV are used in furthering awareness. Within these forums, teachers, parents and other care givers of intellectually challenged people are sensitised on how to pass on these messages to them. Some organisation were through the secondary literature review found to host AIDS talks for those with intellectual impairments that are simple, straightforward and that emphasize repetition of key themes.

Case study of Young Adult Institute (YAI)

Website: www.yai.org

Background:

YAI network is a not-for-profit health and human services organization serving people with developmental and learning disabilities and their families.

Objective:

To create hope and opportunities for people with developmental and learning forms of disability, including their families.

Strategies Used:

An individualistic perspective

- Through this approach, the intellectually challenged are set in control on the learning situation while the AIDS educators facilitate the discovery process, continuously ensuring that the information is understood and retained by use of role playing and visual aids.

- HIV/AIDS messages are simplified made into very straight forward key themes. The critical difference in AIDS-prevention education for the intellectually challenged is that the facilitator or the AIDS educator must really be sure that the person understands the information and is not merely compliantly agreeing with the educator.

- The AIDS educators start by establishing what the persons with mental disability already know about HIV/AIDS. This is because unlike the assumption that intellectually challenged people do not have the knowledge, they have access to this information from TV shows, news programs, posters and magazines just like everyone else.

Visual AIDS and role playing

- To help the intellectually challenged to retain the information, AIDS educators make use of visual AIDS and role playing. Visual AIDS assist the facilitator in illustrating important points about prevention while role playing provides enables PWID s to practice what they have learnt.

Repetition

- The AIDS educators have to keep on repeating the messages so that the intellectually impaired can register them in their minds.

b) Development of IEC materials

This has been done by different organisations through the use of IEC materials such as pictorials and illustrations containing different messages on HIV/STI prevention, HIV & sexual abuse, among others.

Below is a case study of a national association for the mentally handicapped in Africa that has made efforts is ensuring the various groups of people who interact with persons who are intellectually challenged are sensitised on matters regarding HIV/AIDS prevention.

Case study of Kenya Association of the Intellectually Handicapped

Telephone: + 254 0722 407 240
Email: kaihid2004@yahoo.com

Background:

Kenya Association for the Intellectually Handicapped (KAIH) is a local Non- profit making, Non –Governmental Organization for parents and friends of the intellectually challenged. KAIH as an organization of Parents of children with intellectual disabilities has over years realized the vulnerability of the intellectual disabled children to sexual abuses and their lack of knowledge as parents in identifying and taking prompt action on such cases. The KAIH program on HIV and AIDS was started in 2008.

Objective:

KAIH's mission is to promote and create awareness on the rights of Persons with Intellectual Disability (PWID) through empowering the parents and the community.

Strategies Used:

Intensive community education and parent's sensitization on HIV and AIDS and sexuality issues through workshops.

Training and inclusion of PWID as peer educators on issues around sexuality and HIV/ AIDS.

Use of role-play, skits, videos and IEC materials that are visualized and user friendly to PWID.

Convening of a special unit teacher's workshop to address the concerns of parents of children with intellectual disabilities on sexuality, HIV and AIDS.

Quarterly parents meetings with held where a resource person is usually hired to give talks on HIV and AIDS as relates to Intellectual disability.

PLHIV who have disclosed their status are invited to give health talks on behaviour

change, and their experience in the community. During these meetings parents have been able to come out and ask questions relevant to HIV and AIDS.

🎗 Setting up of support groups for HIV positive PWID and their parents

Achievements:

🎗 Peer Educators from among PWID have been trained on self-awareness, drugs and substance abuse, STDs, STIs, Sexuality and HIV and AIDS.

KAIH has been able to create an environment through which PWID and their parents have been able to access HIV counselling and testing services.

Lessons Learnt:

Support groups involving PIWD and their parents are important as they act as forum where they share HIV/AIDS information especially on parenting issues.

Summary of some of the approaches that have been used by organisations delivering HIV prevention messages to PWID:

- Individualized approach by establishing what the person already knows about HIV/AIDS.
- HIV messages simplified for easy understanding.
- HIV messages delivered repetitively for the mentally handicapped to register in their minds.
- AIDS talks done in seminars and workshops where parents of mentally challenged children are addressed on HIV/AIDS.
- Education on HIV/AIDS done in institutions and rehabilitation homes of the mentally challenged.
- IEC materials such as pictorials and illustrations on HIV/AIDS developed.
- Simplified Videos and posters developed for HIV awareness.

Conclusion:

HIV services targeting this population have been initiated and extended in different countries. Some of the programs have focused on:

- Provision of case management services to the intellectually challenged;

- Training of special testing counsellors; and

- Training of case managers who can provide follow up care to the intellectually challenged with focus on post HIV testing diagnosis, and how to live positively with HIV/AIDS.

It was however evident during the compilation of this handbook that there are very limited organizations that are working with the PWID either directly or through the care givers to ensure that they also receive HIV related information and services. No case study was identified on the delivery of HIV testing, counselling, care and treatment services to PWID.

Photo courtesy of Kenya Association of the Intelectually Handicapped

CHAPTER 3

BEST PRACTICES FOR HIV/AIDS AND DISABILITY POLICY ADVOCACY

BEST PRACTICES FOR HIV/AIDS AND DISABILITY POLICY ADVOCACY

This section focuses on the mechanisms that have been applied by various organizations working with PWDs to ensure that disability related concerns are included in the existing HIV/AIDS policies.

Introduction

The global trends on HIV/AIDS have shown that it is paramount for governments to formulate relevant and critical policies that shall mitigate the impact of the HIV/AIDS pandemic. Progress has been made in the last decades in solid foundation for deepening the struggle against the HIV/AIDS pandemic and registering more success stories. Particularly, the impetus towards the process of scaling-up HIV prevention, treatment and care in the globe through continuous formulation, revision, advocacy and implementation of policies specifically to enhance the inclusion of disabled people in HIV/AIDS service delivery has been seen. The integration and reinforcement of prevention, treatment and care for HIV/AIDS unfolds as a bold action exercised across all sectors and levels of governments to address the burden of HIV/AIDS for the disabled population in the attainment of the MDGs specifically, 'universal access to affordable health services for all who need it.'

There can be no single policy or guideline that blankets over the whole population of PWDs but rather have policies tailored for each group as they have diverse needs. In addition, for Disability to be mainstreamed well into existing HIV/AIDS programmes and to make an impact, collective efforts of magnitude are required. The policy making and implementation process should have a wide range of stakeholders as well as PWDs and better still PWDs who are also living positively with HIV to meet the goal of having universal access to HIV prevention, care and treatment by the year 2010. The stakeholders including various actors in the disability sector, AIDS service organizations, government sectors, disabled people's organizations and non-governmental organizations working with and for PWDs should be included in the policy development and implementation phases.

Efforts on policy advocacy have been evidenced by the development of legislation on disability, guidelines for service delivery, national strategic
and operational plans, national AIDS councils amongst other policy frameworks by different players in the HIV/AIDS field.

The United Nations Convention on the Rights of persons with disabilities offers a universal, legally binding and standardized means through which the rights and dignity of persons with disabilities are guaranteed globally. The following is a case study that highlights the key measures put in place in its execution and implementation.

UN Convention on the Rights of Persons with Disabilities

This was developed in 2006 and it marked a "paradigm shift" in attitudes and approaches to PWDs. The Convention was intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of PWDs reaffirming that all PWDs must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to PWDs, identifies areas where adaptations have to be made for PWDs to effectively exercise their rights ,areas where their rights have been violated, and where protection of rights must be reinforced (United Nations Enable, 2006).

The convention covers all human rights areas such as the rights to life, access to justice, to personal mobility, to education, to work and to health; where HIV/AIDS remains an important agenda.

The Convention further commits State Parties, that is, those countries who have enacted Disability Acts through their legislature and who have ratified the UN Convention by including or contemplating inclusion of disabled people in their policy agenda to: "provide PWDs with the same range, quality and standard of free or affordable health care and programmes as provided to other people, including in the area of SRH and population-based programmes" (Article 25) and to "take appropriate measures, including through peer support, to enable PWDs attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life" (Article 26), (UNAIDS, 2009).

Out of the 194 countries in the world, there have been 143 signatories to the Convention. At the same, there have been 87 signatories to the Optional Protocol, 71 ratifications of the Convention and 45 ratifications of the Optional Protocol.

Available at http://www.un.org/disabilities/default.asp?id=150

The UN Convention on the rights of people with disabilities, the HIV/AIDS & Disability Policy brief, the Persons with Disabilities Act are among some of few existing, policy legislature in many countries. Additionally, different countries have different policy legislature systems in place. Highlighted below are some of the provisions of these documents based on the UN convention on the rights of PWDs:

The provisions of the UN convention have been utilised in developing the following mechanisms or policy documents:

- Regional campaigns to advocate for the health related rights of PWDs

- Enactment of national policies to include disability in the health agenda

3.1. Regional Campaign on HIV/AIDS and Disability

To further campaigns on HIV/AIDS and disability while drawing from the UN convention, a number of countries have joined regional campaigns to advocate for the inclusion of disabled people and their rights into existing health related protocols. The objective of these campaigns is to ensure equal access to HIV information and services, and to coordinate national HIV/AIDS policies and programmes.

For instance in Africa, the African Campaign on HIV/AIDS and disability has been established to advocate for the inclusion of disabled people in health related matters. This campaign has brought together a number of African countries including Algeria, Cameroon, Congo, Ethiopia, Kenya, Malawi, Namibia, Nigeria, Rwanda, South Africa, Swaziland, Tanzania, Uganda and Zimbabwe. The following is a case study of the campaign.

Case study of the African Campaign on HIV/AIDS and Disability

Website: Available at http://www.africacampaign.info/

Background:

The Africa Campaign is a unifying umbrella under which disabled people's organizations, organizations of people living with HIV & AIDS, non-governmental organizations, AIDS services organizations, researchers, activists, and other citizens work collectively to achieve two main objectives:

- A coordinated response involving persons with disabilities in African countries to achieve inclusive national HIV & AIDS policies and programmes

- Equal access for persons with disabilities in Africa to information and services on HIV & AIDS.

The Africa Campaign strategic objectives cover a five year period from 2007 – 2011. A minimum of 12 countries are expected to achieve both objectives given policy makers' willingness to collaborate, Campaign partners' operational presence in-country as well as the strength of the Disability and HIV & AIDS movements.

Strategies Used:

Planning and implementations of research on HIV/AIDS and disability
- Findings to be used to inform policy and practice

- DPOs and disabled persons living with HIV to be involved as a valuable resource in the conception, planning, implementation, and analysis of research studies

- Research consortia's encouraged to collaborate with relevant government departments and policy makers to ensure greater utilisations of results generated through research.

Awareness creation

- The campaign communications policy outlines the key messages to be used by partners whenever opportunities arise.

Resource mobilisation through:

- Development of resource mobilisation strategies by the different In-country campaign networks.

- Use of international partners to advocate for the mainstreaming of disability in major HIV/AIDS strategies and initiatives.

- Campaign partners advocating to have HIV/AIDS donors include requirements for disability inclusive programs and policies as part of their funding criteria.

- Use of the campaign website to coordinate all fundraising activities

Capacity building and skills training for effective advocacy

Building of strategic alliances with HIV-specialised groups, NGOs, community based organisations, faith based organisations, people living with HIV, research institutions among others.

- The slogan "Nothing about us without us" highlights the spirit behind the approaches used by the campaign to strengthen in-country and international partnerships by those who champion for the case of PWDs needs of the PWDs.

Monitoring of campaign activities

- The campaign is monitored and guided by the Campaign Steering Group which has representation from the Disability community and the HIV/AIDS community of whom 51% are PWDs.

- The campaign is coordinated by the Campaign Management Team, which includes the Secretariat of the African Decade of Persons with Disabilities and Handicap International.

What worked well:

- The campaigns have built the capacity of DPOs following the formation of declarations.

- The Kampala declaration is now used as an advocacy tool for DPOs in the region.

Lessons Learnt:

- Involvement of people with disabilities in the development of declarations and policy directions is essential.

Some of the stakeholders during the campaign
Photo retrieved from http://www.africacampaign.info/

Conclusion:

These campaigns have been successful because groups of DPOs, NGOs, AIDS service organizations, faith and community based organizations, researchers and activists in the field of HIV and disability have developed and ratified agreements and declarations on the roles and responsibilities of each of them in ensuring that the enacted policies adequately address the needs of the PWDs. Some of the declarations made include:

- **Manila Declaration 2009**
  Available at http://wecando.wordpress.com/2009/06/01/ manila declaration-crpd/

- **Mombasa Declaration on Disability & HIV/AIDS in Kenya,2008**

- **Kampala declaration 2005**
  Available at http://www.who.int/health_financing/documents/cov kampala/en/index.html

Regional Campaigns

3.2. National Responses

Members of the African Campaign on Disability and HIV/AIDS have launched national campaigns following the ratification of declarations aimed at furthering the campaign's agenda. These national campaigns are geared towards exploring barriers faced by PWDs in accessing information and treatment on HIV and AIDS and how these barriers could be overcome through concerted efforts from lobby partners within the particular countries.

The following is a case study that describes the experience of Kenya in implementing a national response aimed at policy formulation, adoption and ratification to foster inclusion and recognition of disability issues in all aspects of life.

Case study of the Kenya Campaign on Disability and HIV/AIDS

Background:

The Disability and HIV and AIDS Campaign is a follow-up to a continental campaign (Africa Campaign on HIV/AIDS and Disability) which took place in South Africa in January 2007, urging African States to conduct national campaigns to create awareness among citizens on the effects of HIV and AIDS on Persons with Disabilities. The Kenya Campaign on Disability and HIV and AIDS is a loose Coalition of organizations in the disability sector and mainstream HIV and AIDS organizations. Its implementing partners include the following organizations; United Disabled Persons of Kenya (UDPK), Handicap International, VSO-Jitolee, United Civil Society Coalition on HIV, TB and Malaria (UCCATM), Liverpool VCT Care and Treatment (LVCT), Association of the Physically Disabled of Kenya (APDK), Sight Savers International, Leonard Cheshire Disability (LCD), African Braille Center (ABC), Kenya Institute of Special Education (KISE), Kenya Consortium of HIV, TB and Malaria (KECOFATUMA), Kenya Association of the Intellectually Handicapped (KAIH), St. Judes Counselling Center, Blind and Low Vision Network (BLINK), Kenya Paraplegic Organization (KPO), Regional Advocacy and Training Center (RATN), Life skills Promoters and Brian Resource Center.

Goal:

To reduce the vulnerability of persons with disabilities to the impact of HIV&AIDS in Kenya

Theme:

The campaign's theme is 'Breaking Barriers'

Objectives:

- Create awareness of the vulnerability of persons with disabilities to the impact of HIV&AIDS.

- Broaden and strengthen the knowledge and skills of persons with disabilities in Kenya to participate in the response to HIV&AIDS both locally and nationally.

- Advocate for the mainstreaming of HIV&AIDS in all areas of the Disability sector

🎗 Campaign for the mainstreaming of disability in HIV&AIDS policies, programmes, legislative documents and guidelines both nationally and internationally, and lobby for the active participation of persons with disabilities in the processes.

🎗 Ensure equal access to HIV prevention, treatment, care and support services for persons with disabilities.

Anticipated outcomes:

🎗 A coordinated response involving persons with disabilities in Kenya to achieve inclusive national HIV & AIDS policies and programmes

🎗 Equal access for persons with disabilities in Kenya to information and services on HIV and AIDS

Activities:

🎗 Creating awareness and educating stakeholders on disability and HIV and AIDS

🎗 Evidence-based research and documentation of issues in disability and HIV and AIDS

🎗 Dissemination of appropriate training tools and good practice

🎗 Resource mobilization

🎗 Capacity building and advocacy skills training

🎗 Network and collaborate with stakeholders in the disability and HIV&AIDS movement

What has worked well:

🎗 Participation of stakeholders in developing the Kampala Declaration.

🎗 Development of the Mombasa Declaration to make it Kenya Specific.

🎗 Translation of the Mombasa Declaration into Swahili which is Kenya's national language.

🎗 Development of strong advocates in the mainstreaming of disability in HIV and AIDS interventions.

🎗 Currently reviewing policies and laws to identify gaps in prevention, treatment care and support of persons with disabilities who are infected by HIV.

In line with the international conventions, many governments have enacted laws dubbed "Persons with Disability Acts" to provide for the rights and rehabilitation of PWDs; to achieve equalization of opportunities for PWDs; to establish the National Councils for PWDs; and for connected purposes.

Listed below are examples of countries that have made legal frameworks that clearly give definitions and laws which, explicitly or through interpretation, prohibit discrimination on the basis of disability or perceived HIV-positive status or AIDS diagnosis. They include:

- Australia, the Commonwealth Disability Discrimination Act (1992)

- Hong Kong Disability Discrimination Ordinance (1995)

- Mauritius, the HIV and AIDS Bill (2006)

- Kenya: The Persons with Disabilities Act (2003)

- United Kingdom, Disability Discrimination Act 1995, amended 2005

- United States, the Americans with Disabilities Act (1990)

In addition to harnessing the legal frameworks for addressing HIV in the context of disability, most governments have established National AIDS Councils (NACs), which are tasked to mobilize resources to fight the pandemic. Organisations working with PWDs in different countries have participated in the committees geared towards informing the development of national HIV/AIDS response agenda. Moreover, some countries have also developed Guidelines for HIV Testing and Counselling which clearly indicate how HTC should be administered to populations, with specifics for PWDs.

Some of the countries where organisations working with PWDs have lobbied to ensure that the national HIV strategic documents or policies are inclusive of the most at risk population, with focus on the disabled are:

- South Africa National AIDS Strategic Plan (NSP) in 2007–2011.

- The Ugandan National strategic plan for HIV/AIDS (2007/8 – 2011/12)

- The Kenya National AIDS strategic plan (2009/10-2012/13)

National Responses

Key strategies that have been used to achieve representation of PWDs interests in national documents include:

- **Participation in review of national HIV/AIDS strategic plans. This involves:**

  - Being actively involved in national strategic committees and sub-committees
  - Attending meetings regularly
  - Being included in the e-mailing lists
  - Being flexible to host or sponsor such meetings
  - Perseverance and patience, as this process is time engaging

- **Lobbying of various stakeholders to garner the required support in the policy formulation process. For this to be effective, members are required to have:**

  - Dedicated financial resources to support this process
  - Have strategic meetings with partners who are also pushing for the same agenda to be incorporated in national documents
  - Identify champions from the government or private sectors who can support in this lobbying process.

- **Advocacy campaigns through:**

  - Using the media as an advocacy tool
  - Having meetings with donors who can support the implementation of the proposed activities once incorporated into the National Plans of Operations
  - Having meetings with policy makers and other stakeholders to highlight the need of mainstreaming disability in all health programmes and policies

Conclusion:

There is need to emphasize on the role NGOs and Governments play in policy formulation. However this process cannot be successful in instances where disabled people and disability advocacy groups are not involved. As the saying goes, "*Nothing about us without us*" -disabled people need to be involved in order to identify their needs properly and decide how these needs can be addressed through the policies. Organisations working with the PWDs therefore have to ensure that the PWDs are directly involved in the national and regional policy review and/or formulation processes.

CHAPTER 4

BEST PRACTICES FOR HIV/AIDS PROGRAMMING

BEST PRACTICES FOR HIV/AIDS PROGRAMMING

Programming turns policy into reality. Programming basically refers to the distinct interventions or activities needed to meet the objectives outlined in the policy. In order for a programme to be successfully implemented, its activities ought to be planned in detail.

There are myriad reasons that make a program successful in meeting the needs of PWDs. These could include:

- Involvement of PWDs in planning and implementation of interventions and services.

- Provision of a comprehensive range of well-coordinated and flexible services.

- Ensuring adequate coverage of the population of PWD with information and services related to the program.

- Implementation of interventions that seek to reduce the risk of HIV/AIDS on an ongoing and sustained basis.

- Creation of political willingness for a supportive and enabling environment.

According to UNAIDS, the criteria for whether program qualifies as a best practice are:

- Effectiveness (an activity's overall success in producing desired outcomes)

- Ethical soundness (follows principles of social and professional conduct)

- Relevance (how closely useful is the activity)

- Efficiency and Cost-Effectiveness (an activity's capacity to produce desired results with a minimum of expenditure)

- Replicable (ability of a program to be adapted to meet similar needs in other settings)

- Sustainability (the ability of a program or project to continue being effective in the future)

Types of Programs:

The initiative of including PWDs in HIV/AIDS programmes has been categorized into 3 levels of inclusion. These levels include:

• Level 1: Inclusion as part of general population

Inclusion as part of general HIV/AIDS outreach with no adaptations whereby individuals with disability are reached by the same aids education messages and services as members of the general public.

• Level 2: Minor adaptations to general programs that foster inclusion

Within this level, adaptations are made to aids outreach campaigns to ensure that individuals with disability are included as members of the general public.

• Level 3: Disability specific programminggramming

Disability-specific adaptations of existing HIV/AIDS materials are made to reach individuals with disability outside the bounds of the general public, targeting harder to reach individuals and populations.

The table below provides a summary of the types of actions used in the inclusion of PWDs in HIV and AIDS prevention and care. This table has been adapted from the Yale/World Bank on global survey on HIV/AIDS and disability Report, 2004 by Nora Groce) with minor additions and references to some of the case studies contained in this handbook.

Type of Action	Methods	Examples of interventions	Case study
Type I: Inclusion as Part of General HIV/AIDS Outreach with No Adaptations	Ensure that AIDS education outreach and services available to the general population include individuals with disability. Use materials already available to the general public, incorporating simple adaptations to ensure accessibility by all. Train AIDS educators, outreach workers, clinical and social service staff on disability issues. Train individuals with disability to be AIDS educators.	AIDS posters and billboards depict individuals with disability (i.e. wheelchair users, blind and deaf individuals) as part of group scenes. *(Refer to case study on APDK, Pg 28)* Move AIDS education, testing and care service delivery programs, as well as drug, alcohol and domestic violence programs to accessible meeting places. *(Refer to case studies on KAIH, Pg 36, LVCT ,Pg 12)* Make simple adaptations such as allowing blind individuals to feel a condom rather than just talking to them about it. *(Refer to case study on BLINK, Pg 22)* Make simple and straightforward HIV messages to allow intellectually disabled individuals to understand and memorize the words. *(Refer to case study on YAI, Pg 35)*	

Type of Action	Methods	Examples of interventions	Case study
Type II: Minor Adaptations to General Programs that Foster Inclusion	Adapt already existing HIV materials to ensure inclusion of disabled people. Make simple alternations to facilities to increase inclusion. During general training programs, train HIV and AIDS educators and clinicians about disability in general and that there are differences in the needs of individuals' with different types of disabilities. Train individuals with disability to be AIDS educators.	Caption AIDS public service announcements on TV for deaf people. Make AIDS materials available for blind people in inexpensive cassette formats and in Braille. *(Refer to case studies on AFUB,Pg 19, BLINK,Pg 22)* Build ramps into meeting halls or clinics (ramps can be made of mud, stone, bamboo, wood, etc). *(Refer to case study on APDK, Pg 28)* Ensure that HIV/AIDS information in disseminated in a variety of formats: radio, billboards, to ensure that specific groups (deaf, blind) to not miss out. *(Refer to case study on JCPD, Pg 10)*	FARD (Case study)
Type III: Disability Specific Programming	Develop disability-specific outreach efforts. Develop new materials to use in outreach efforts. Train AIDS educators, hire staff specializing in the issues related to serving the specific disabled population targeted; train disability advocates being AIDS educators with the disability community as well as the overall community.	Videos in Sign Language for Deaf Target schools, institutions and organizations serving populations of disabled people for specials programs to ensure that students, residents of participating members have been informed. Re-write training materials in simpler language/easy to understand format for those with intellectual impairments, or how disabled individuals who are illiterate or low literacy. *(Refer to case studies on YAI, Pg 35; S. African National Council for the Blind, Pg 25)* Have a Sign Language interpreter available at clinics/hospitals to explain complicated regimes of AIDS drugs and follow-up. *(Refer to the case study on LVCT, Pg 12)*	African Union of the Blind (Case study)

Programming

Highlighted below are some of the case studies that speak to successful programming for PWDs

Case study: Foundation Agency for Rural Development (FARD) -NGO, Nairobi, Kenya

Telephone numbers: 254 2 342767(landline); and 254 722 886 165(Mobile).
Website: http://www.kardcares.org/whowehelp/fard.html

Background:

In June 2002, the Foundation Agency for Rural Development (FARD)/Kenya and the Makueni Disabled Persons Organisation (MADIPO) forged a partnership to address HIV/AIDS among the disabled in this region.

Strategies Used:

Training special needs teachers on basic facts around HIV/AIDS

- Over 45 members of DPOs have been trained on HIV/AIDS peer education, counseling and home based care.

Extensive HIV/AIDS awareness and education campaign

- The DPOs have formed their own theatre groups to sensitize other members and the public on HIV/AIDS.

Lessons learnt:

- The disabled like other groups are also at the risk of contracting HIV/AIDS and therefore should be targeted.

- Involving the disabled adds value to the programs as they not only become beneficiaries but also players. This realizes a greater impact especially when disabled person are seen in the forefront in the fight against HIV/AIDS.

- Persons with disabilities need not to be just beneficiaries but essential players in HIV/AIDS programs as this makes such programs more acceptable and effective.

- Many programs do not seem to recognize the role disabled persons can play in the fight against HIV/AIDS. This is in particular relevance to rural communities where awareness on persons with disabilities with still not high.

- The Government and other institutions need to extend their support and assistance to programs that involve and work with the persons with disabilities. Such support will enhance sustainability and effectiveness in implementing HIV/AIDS programs.

Case study: African Union of the Blind-HIV/AIDS Awareness, Training and Advocacy Program

Telephone: +254 721 250 678
E-mail: sally@afub-uafa.org
Website: www.afub-uafa.org

Background:

The African Union of the Blind (AFUB) has taken a great initiative to promote the inclusion of issues on blindness into HIV/AIDS programs. In October 2005, AFUB launched the HIV&AIDS Awareness and Training Program for Blind and partially sighted people in Africa. This program is/has been implemented in the following countries: Cameroon, Ghana, Kenya, Malawi, Rwanda, Tanzania, Benin, Eritrea, Ethiopia, Lesotho, Liberia, Mali, South Africa and Zambia. In 2010, the program will be rolled out to Botswana, Burkina Faso and Togo.

Objective:

To reduce the incidence of HIV/AIDS among blind and partially sighted people in Africa through promoting their inclusion and participation in HIV awareness and control programmes in their communities.

Strategies Used:

- Establishment of National Lobby Committees comprising of representatives of national organizations of the blind, VCT service providers, medical practitioners, networks of people living with HIV/AIDS, community based service providers, NGOs, the government through National AIDS Control councils and National AIDS Commissions.

- Development of training and resource materials for blind and partially sighted people.

- Implementation of public education programs through media and by other means with an aim of raising awareness on HIV&AIDS as a problem facing blind and partially sighted persons, and to encourage blind persons and their families to access the services and programs available to them.

- Recruitment and training of blind and partially sighted as peer trainers/ educators and counsellors.

- Conducting grass root training workshops for blind and partially sighted persons.

Achievements:

- 14 National Lobby Committees have been established in 10 countries to advocate for access to HIV related services by visually impaired persons in their respective countries.

- 14 Trainers of trainer (TOT) workshops for the Blind and partially sighted trainers have been conducted in various countries so as to increase their skills as well as to create a resource for ongoing HIV/AIDS training and networking.

- 311 blind & partially sighted persons have been trained as peer educators in relation to HIV/AIDS causes, prevention and management.

- At least 5,243 blind and partially sighted persons have directly received training on the modes of HIV transmission, prevention and management of HIV/AIDS related conditions in the ten countries.

- Development of a model on HIV/AIDS training and advocacy.

- 20 different HIV/AIDS resource materials friendly to visually impaired persons have been developed. The materials have been produced in French but are translated to the particular national languages of the various countries.

What worked well:

- Customizing of HIV/AIDS messages to formats friendly to blind and visually impaired (Braille, digital, large print and audio formats).

  The establishment of lobby committees that include HIV/AIDS service providers ensured that underlying issues and concerns in terms of service delivery to the blind and low visioned people were aired and addressed at the national level in the various countries.

- Empowering blind and partially sighted people through Peer Education training has led to their increased confidence in participating in HIV programs in their communities.

- Networking with other DPOs has helped AFUB to share her experiences with other DPOs as well as learn from others on how to implement successful disability specific programs.

Lessons learnt:

- Involving mainstream AIDS service organizations and service providers in the development of handbooks and HIV resources makes it easier to communicate ensures that the needs of blind and partially sighted people are in as far as HIV/AIDS programmes and services are concerned are well addressed.

- Continuous and systematic data collection and record keeping on the experiences of blind women and men regarding HIV/AIDS is important as it assists in implementing evidence-based HIV programmes.

Quote from a participant of an AFUB Training

"The ideas I got from the workshop were great. The materials, the tape I got and the Braille booklet I got have certainly been useful for me. I have used this information to reach 36 other visually impaired persons in my region….."

This is the experience of Hussein Hurqato; a visually impaired (peer educator) man from Ethiopia. He is also the Chairperson of Ethiopia Association of the Blind (ENAB) in Awassa.

Case Study of Handicap International - HI Kenya Disability Program

Tel: + 254-20-2716445; +254-20-271-6500
Email: hikenya@handicap-international.or.ke
Website: http://www.handicap-international.org.uk

Background:

Handicap International (HI) is an international NGO that has been serving PWDs worldwide for 27 years and its services have been pivoted on the principle of equalization of opportunities, inclusion and social integration. HI-Kenya program was established in 1994 and since then it has been implementing comprehensive programmes on disabilities and chronic illnesses such as HIV/AIDS through combined efforts of people living with disabilities, their families and communities and the appropriate health, educational, vocational and social services. Its key implementers in rights and policy include the Ministry of Health, National Aids and STI Control Programme (NASCOP) and National Aids Control Council (NACC). Other partners include the DPOs that it supports namely: Deaf Empowerment Kenya, Blind and Low Vision Network in Kenya (BLINK), (United Disabled Persons of Kenya (UDPK), Kenya Disability Action Network (KEDAN), Disabled Group of Trans Nova (DIGROT), Nairobi Family Support Services (NFSS), Kenya Association of the Intellectually Handicapped (KAIH) and Kenya Sign language Research Project.

Mission:

To empower people in disabling situations in Kenya to lead better lives

Objective:

To see PWDs mainstreamed into HIV/AIDS policies, preventive, treatment and care interventions

Strategies used:

Institutional strengthening

- Through sub-granting, HI Kenya has capacity built 5 DPOs in Kenya whose activities focus on all categories of disability. The work of these DPOs revolve around key thematic areas which are: policy advocacy, behaviour change communication, production of appropriate IEC materials for PWDS and stigma reduction. HI is involved in providing support in the identification and filling of gaps within programs and technical support by overseeing success of HIV disability projects.

- As a strategy of capacity building, HI introduced a new tool 'participatory assessment tool' which was designed to assist organizations to recognize their own potential and decide for themselves how best to address the challenges they face.

Development of a Kenyan Disability Directory

- HI steered the development, compilation and publication of the Kenya disability Directory. This was achieved through consultative meetings with government ministries, CBOs, rehabilitation suppliers, special schools and DPOs. This directory contains a list of organizations offering disability friendly HIV/AIDS services. It is a resource tool that is envisioned to help its users in their routine tasks by strengthening the reference base, enhancing coordination and networking, as well as diversifying intervention measures in disability work. This directory was first published in 2003 and two editions have been done so far.

Policy advocacy

- In May 2007, HI-Kenya in collaboration with local based organizations launched the Kenya Campaign on HIV/AIDS and Disability. This Campaign aims at the formulation, adoption and ratification of a declaration that would aim at affecting policy towards disability and HIV/AIDS in Kenya.

Community involvement

- Community outreaches aimed at promoting HIV/AIDS prevention through behaviour change communication have been done.

Achievements:

Successful running of activities of 5 autonomous DPOs with support of the AED Capable Partners Kenya Programme focusing on all categories of disabilities.

Policy advocacy for inclusion of disability needs in the HIV/AIDS policies with the launch of the Kenya Campaign on HIV/AIDS and Disability.

Disability friendly IEC materials on HIV/AIDS produced and distributed.

A documentary in sign language with voice over produced, demonstrating the HIV/AIDS activities of Deaf Empowerment Kenya. It specifically highlighted challenges faced by deaf women and girls in accessing HIV/AIDS information and services.

Public awareness campaigns done through airing of documentary and features on three television and radio stations. Newspaper articles and commentaries on how HIV/AIDS impacts on people with disabilities have been published.

Lessons Learnt

Disability issues should be mainstreamed into HIV/AIDS interventions and policies.

HIV/AIDS information and services need to be in an appropriate format that is readily available and understood by the disabled and non disabled populations

Service providers need sensitization on the needs of PWDs.

What worked well:

The 5 supported DPOs have evolved significantly from inception of the disability and HIV/AIDS project to a degree where much of their structure is stronger therefore more sustainable.

Where initially HI carried out its capacity building initiative with more attention to the short-term needs of the DPO, it now recognizes and appreciates the need to build ownership of the growing process within the organization. Needs assessments, as a result, have evolved to be self-guided and dictated by DPOs themselves, therefore putting them in a position to make the hard decisions necessary for enhancing better access to HIV/AIDS services.

CHAPTER 5
CONCLUSION

CONCLUSION

People with disabilities have an increased vulnerability to HIV/AIDS. There is need to approach the HIV/AIDS pandemic as a developmental challenge that demand multifaceted, concerted and strategically designed responses. The documentation of best practices demonstrates that with technical support, systematic and consultative engagement of PWD and their organizations positive results can be achieved.

Most significant is cognizance that all interventions and responses to HIV/AIDS prevention, care and treatment should be made accessible to all persons including PWDs. To facilitate this, information should thus be packaged in appropriate formats that are easy to use and which accommodate specific disabilities and localized for easier consumption so as to respond to the different needs of PWDs. There is still need for invention of technology so as enhance the production of disability friendly materials such as brailled condoms. Moreover there is need for continued monitoring and documentation of programmes that provide HIV/AIDS services to PWDs so as to identify and address challenges, and to build on and disseminate lessons learned so that other stakeholders can learn from them.

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ANNEX

DISABILITY AND HIV STUDY - KEY INFORMANT SUBMISSION FORM

Liverpool VCT, Care and Treatment in collaboration with Voluntary Services Overseas (VSO) – Jitolee are in the process of compiling a Best Practice handbook on the delivery of HIV/AIDS services to People With Disabilities – specifically the Blind, Deaf and Hard of Hearing, Physically challenged and Mentally challenged. The following guideline provides steps that will be used by organizations in submitting information on their successful projects

Name	**Name of the project/programme/organization?**
Location	**Country? District? State?**
Contact information	**Name, designation, email, postal address, telephone, fax, website?**
Background information	**Brief program/project history – showing the context in which the program/project was carried out? When did it start, end or plan to end?**
Scope of program/project	**Program mission and objectives? Target population? How is the problem impacting on the population?**
Program/project implementation	**Main activities being carried out towards achieving the objectives? How are they done? Who does what? When and where were the activities carried out? Is there a particular order in which the activities are carried out?**
Partners	**The key implementers, partners and collaborators? At what stage were they involved/ brought on board?**
Resources	**Resource implications – human, material, time, finances, etc? Who provided the funding?**
Policy	**Was this program/project aimed at improving service delivery or changing/influencing policy? Were the results able to change/influence policy? If so, who were the key players in this process? How was this done – what steps were carried out that resulted in change? How long did this take? Were there any resource implications during this process? If so, how and if you can – please let us know how much?**
Evaluation	**Was an evaluation of the program/project carried out? If so, how was it done (methodology)? What were the findings?**

Achievements	What are the achievements in terms of measurable outputs and practical outcomes?
Lessons learnt	Was an evaluation of the program/project carried out? If so, how was it done (methodology)? What were the findings?
Challenges	What challenges were encountered? How were they or – could they be overcome?
Conclusion	Benefits of this program to the population? Would you advice others to follow your model in implementing a similar program? If so, why? What recommendations would you give on this issue?

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