Accessibility and Utilization of HIV and Aids Services among the Visually Impaired Persons in Kenya

Dr. Yungungu Alice

A. Songok

Mulinge Patrick

Moi University
School of Education
Department of Curriculum Instruction and Educational Media
P.O.Box 3900-30100
Eldoret
Kenya.

Abstract

HIV and AIDS has had a devastating social and economic impact in Africa. The continent is losing a lot of resources in form of reduced work productivity, absenteeism from work, deaths and funeral expenses, replacements and training of new personnel. The situation regarding the disabled and HIV and AIDS in Africa is in need of more attention because they are more susceptible to contracting HIV and AIDS compared to their non-disabled peers. Many programmes and campaigns to create awareness on how to prevent, manage and live positively with HIV and AIDS have been set up in Kenya by the government, international agencies, nongovernmental organizations, faith-based organizations and community based organizations. These programmes and campaigns however are rarely made accessible to the visually impaired persons for instance, information is not provided in accessible formats like Braille and large print, and they have limited or no knowledge of how to live with HIV and AIDS or how to care for others with the disease. It is also evident that there are cases of illiteracy among visually impaired persons particularly in rural settings. Lack of skills is also an impediment to health practitioners in providing HIV and AIDS services to the visually impaired. As a result, support services are not modified to suit the needs of the visually impaired. Additionally, the infected persons receive little support from the community due to social stigmatization thus accelerating their immunity deficiency. In some circumstances, the vulnerability of the visually impaired persons to HIV is exacerbated by traditional beliefs and myths which presume visually impaired persons to be at no risk of contracting HIV and as a result they are excluded from voluntary counseling, testing and treatment facilities. This paper therefore seeks to address the plight of the visually impaired persons in accessing and utilizing HIV and AIDS services in Kenya. Based on these challenges, recommendations will be made on the ways and means of making these services more accessible to the visually impaired persons. As a result, it is expected that this will increase the degree of utilization of the available HIV and AIDS services by the visually impaired persons with the intent of eradicating the HIV and AIDS scourge in Africa and Kenya in particular.

Keywords: HIV, visually impaired persons

Introduction

HIV and AIDS has had a devastating social and economic impact in Africa. The continent is losing a lot of resources in form of reduced work productivity, absenteeism from work, deaths and funeral expenses, replacements and training of new personnel.

In Kenya, many programmes and campaigns to create awareness on how to prevent, manage and live positively with HIV and AIDS have been set up by the Government, International Agencies, Non Governmental Organizations, Community Based Organizations, and Faith Based Organizations. These programmes and campaigns however are rarely made accessible to the Visually Impaired Persons and therefore they are not able to utilize these services.

This paper therefore seeks to address the plight of the VIPs in accessing and utilizing HIV and AIDS services in Kenya. Based on these challenges, recommendations will be made on the ways and means of making these services more accessible to the VIPs. As a result, it is expected that this will increase their degree of utilization of the available HIV and AIDS services with the intent of eradicating the HIV and AIDS scourge in Africa and Kenya in particular.

HIV and AIDS Policy Issues and Disability in Kenya

The African Decade of Disabled People which is an initiative of the non-governmental community of Africa in cooperation with member States and Governments of the African Unity was formed to further equalization of opportunities for persons with disabilities. The decision to proclaim the Decade was as a result of a recommendation by the Labour and Social Affairs Commission of OAU during its twenty-second session at Windhoek (19-24 April 1999) and adopted by the OAU Assembly of Heads of States and Governments' meeting at Algiers (12-14 July 1999). Governments were urged to:

- Formulate or reformulate policies and national programmes that encourage the full participation of persons with disabilities in social and economic development;
- Create or reinforce national disability coordination committees and ensure effective representation of disabled persons and their organizations;
- Support community-based service delivery, in collaboration with international development agencies and organizations;
- Promote more efforts that encourage positive attitudes towards children, youth, women and adults with disabilities, and the implementation of measures to ensure their access to rehabilitation, education, training and employment, as well as to cultural and sports activities and access to the physical environment;
- Develop programmes that alleviate poverty amongst disabled people and their families;
- Put in place programmes that create greater awareness conscientiousness of communities and Governments relating to disability;
- Prevent disability by promoting peace and paying attention to other causes of disability;
- Mainstream disability on the social economic and political agendas of African governments;
- Spearhead the implementation of the UN Standard Rules on the Equalization of Opportunities for People with Disabilities, and ensure the use of the Standard Rules as a basis for policy and legislation to protect the interests of disabled people in Africa;
- Apply all UN and OAU human rights instruments to promote and monitor the rights of persons with disabilities.

In response to these recommendations, the Persons with Disabilities ACT (2003) was enacted in Kenya. One of its roles is to create and develop a conducive environment for the various disabled organizations and partners to provide access to quality HIV and AIDS services for the disabled persons. As a result of this, there are various disability organizations and projects that have successfully organized disability friendly interventions. Kenya Programmes of Disabled Persons, Kenya Disabled Action Network, National Council for People with Disability, Liverpool Deaf VCT programme, Kenya Union of the Blind, Kenya National Deaf AIDS Education Programme, Dandora Deaf Self help group are among the existing programmes that have been relatively adjusted to meet the direct needs of the disabled. The Persons with Disabilities Strategic Plan 2006 – 2009 which is in line with The Kenya National AIDS Control Strategic plan 2006-2009 also outlines access to health facilities as of the one the strategic issues that should be tackled amongst the disabled persons . It identifies various priority areas that should be implemented to make HIV and AIDS management disability-friendly. These priority areas include: prevention of new infections, improve quality of life of the disabled people infected and affected with HIV and AIDS by improving treatment and care, protection of rights, access to effective services and mitigation of socio-economic impact. These can be achieved by adopting existing programmes and developing innovative responses to reduce the impact of the epidemic on the disabled communities and their access to social services and economic productivity.

Despite these efforts by the Government, NGOs, CBOs, FBOs and other partners, the persons with disabilities are still the poorest of the poor, the most marginalized of the marginalized and the most voiceless of the voiceless.

They are still kept at the very margin of society even in HIV and AIDS preventive, management and supportive services.

There has also been a major difference between what has existed in the policies, public speeches on HIV and AIDS and the reality on the ground. This paper therefore seeks to address the plight of the visually impaired persons as one of the disabled groups in accessing and utilizing HIV and AIDS services in Kenya.

Factors that Militate against the Accessibility and Utilization of HIV and AIDS Services to the Visually Impaired Persons in Kenya

The visually impaired people need services on HIV and AIDS in a manner accessible to them yet there are limited policies, strategies or guidelines to mobilize stakeholders in a coordinated manner to incorporate this population of the disabled. Policy makers have rarely considered the needs of the visually impaired when formulating the HIV and AIDS policies. Additionally, a number of HIV and AIDS donors, aid agencies and specialized NGOs do not consider the particular needs of the VIPs in their programmes. Further, organizations of and for the disabled persons sometimes fail to recognize the specific needs of the VIPs. Consequently, they lack services that best address their special needs.

Training organizations lack training facilities and qualified personnel on HIV and AIDS and therefore are not able to support training programmes for the trainers or even for the VIPs effectively. As a result, health practitioners lack skills that are necessary in dealing with the blind and the low vision persons. For instance, they have been accused of asking offensive questions and even 'wonder loudly' whether the VIPs can ever engage in sexual intercourse. Further, more often than not, they are left out during the sensitization and service provision on issues of HIV and AIDS, mainly because service providers do not know how to integrate them into their service interventions. Negative attitude by some professionals towards the visually impaired persons also renders them reluctant to access and utilize HIV and AIDS services. Some professionals for instance often incorrectly view the visually impaired as sexually inactive and therefore not in need of the services.

The most powerful weapon in the human rights arsenal is information. Armed with information, VIPs are able to access and utilize HIV/AIDS services. Inaccessibility to information, education and communication (IEC) for the blind and the low vision persons however means that they have limited knowledge on how to live positively with HIV and AIDS or how to care for others who are either infected and the affected. Traditional methods used to disseminate HIV and AIDS information are not visual impairment-friendly. For instance, the lack of brailed information and/or talking books and large print materials prevent people with visual challenges from accessing HIV and AIDS information. Further, traditional methods which include textbooks in print, diagrams, billboards, video shows, newspapers, magazines and television adverts do not make much sense to the VIPs. The 'safe use of a condom' is for instance diagrammatically expressed and only meant for those with sight. Imparting of certain skills to the visually impaired can only succeed through an individualized, one-to-one training process for example in the demonstration of safe use of condoms. As a result of this deficiency, majority of the VIPs know very little about HIV and AIDS related issues and consequently do not utilize the limited available HIV and AIDS services.

Although information, education and communication and condom use have been spelt out as the most effective tools in preventing the spread of HIV/AIDS and other STDs, frustrating factors like negative attitudes and perception from the community may restrict one from using a condom as in the case of the blind who may not see and make a choice of the type of the condom to use, determine whether the condom is expired or not, are all factors that are not in conformity with IEC strategies and therefore making the VIPs more susceptible to the disease.

In Kenya, facilities from which the visually impaired rural-based people might otherwise benefit are located mainly in the urban areas where transport costs to such places are often prohibitive. It is also evident that there are cases of illiteracy among the VIPs in the rural setting. This means that they have not been adequately educated about this deadly disease and a reasonable number of them die of illnesses similar or incidental to HIV/AIDS. Because of their socio- economic situation, some VIPs cannot read or write and as a result cannot address available literature on HIV and AIDS. For those who are educated, there are still other limitations for instance the blind can only read Braille. Additionally, some families believe that it is not worthy to spend any money on the education of the visually impaired persons as they will not function in anyway.

They prefer to send all sighted children to school but the visually impaired child to stay at home. This is why many of the visually impaired persons do not receive any education and therefore are not able to access and utilize HIV/AIDS services.

The vulnerability of the blind and low vision persons to HIV and AIDS is further exacerbated by traditional beliefs and myths that presume them to be at no risk of contracting HIV and AIDS and as a result they are excluded from Voluntary Counseling, Testing, treatment facilities and other supportive services. The Samburu tribe for instance, takes visually impaired persons as an outcast. They further belief, keeping this person may bring a bad fortune to the community. This is why persons with visual impairments are not accepted and have to live in isolation. Other tribes take visual impairment as a spell of somebody. The spell comes about because the person him/herself or a family member has not done right to another person. In such communities visual impaired persons are hidden in the houses hence cannot access and utilize HIV/AIDS information and services.

The infected VIPs also often face multiple discriminations from being disabled, poor and HIV-positive. As a result of this, HIV and AIDS services efforts seldom reach them and therefore they receive little support from the community due to social stigma which may accelerate immunity deficiency thus shortening the life of the individual. Such discrimination further compels the VIPs to seek acceptance from their peers consequently feeling content thus failing to utilize the available HIV/AIDS services.

Due to cultural factors, ignorance and superstition, persons with visual imparements are largely perceived as a curse or punishment from God, sub-human and unfit to participate in society's mainstream activities. Most families with children with visual impairments are ashamed of them, tend to hide them and do not offer them any opportunities for personal development such as access to education or employment in family business or land.

Apparent also is the dependence of some of the visually impaired persons on others for financial support which leaves them at a greater risk of not accessing and utilizing HIV/AIDS services. Even when access to the services is available, it is not always confidential. For instance dependency on the use of a guide is an issue that breaches the right of confidentiality a blatant rejection of Article 17 of the International Covenant on Civil and Political Rights (UNHCR, 1976). Some of the visually impaired people reportedly also fail to go to hospitals for Anti-retroviral drugs, condoms, counseling and other services and to VCT centres for counseling and testing because they would need a guide who will in turn charge them for the service which may not be affordable. Consequently, this suggests that accessibility and hence the use of HIV and AIDS services is greatly undermined.

Finally, the VIPs exhibit elements of self-stigmatization which is aggravated by poverty, illiteracy, lack of self confidence and low self esteem. This makes them feel discriminated against and therefore they fail to confidently come out to utilize the already existing HIV and AIDS services. The situation has not been made any better or easier by the attitudes, behaviors and practices of VIPs themselves and generally a pathetic attitude from the general public.

Recommendations

1) There is need for a policy framework that effectively integrates the VIPs into national health and HIV and AIDS programming. This requires specific adjustments of the current policy interventions. There is need for a coordinating policy framework to mobilize and guide various stakeholders and resources. We need specific guidelines on how to apply policy issues to various cases of visual impairment.
2) The Kenya Government, NGOs, CBOs, FBOs and other service providers should make it their policy to mainstream the visually impaired by actively involving them and their organizations in the design and implementation of HIV and AIDS mitigation programmes and services.
3) The Kenya Government through its organ NACC needs to allocate resources towards the provision of HIV and AIDS services that target the VIPs.
4) There should be a continuous review of the HIV and AIDS mitigation programmes and training methods with a view of adapting and modifying them as necessary to reach the VIPs.

5) There is need to expand HIV and AIDS related training for all health care workers and other professionals to enable them to better understand the needs and the concerns of the visually impaired persons to promote confidentiality especially in Voluntary Counseling and Testing situations and to develop positive attitude towards the VIPs in quest of HIV and AIDS services.
6) There is need for Capacity building amongst the VIPs through HIV and AIDS awareness campaigns in order to create and develop self confidence and self esteem. This will in turn help in the fight aganist self stigmatization.
7) Many programmes do not seem to recognize the role that the visually impaired persons can play in the fight against HIV/AIDS. VIPs need not just be beneficiaries but essential players in HIV/AIDS programmes as this makes such programmes more acceptable and effective. This is in particular relevant to rural communities where awareness on VIPs is still not high. The government and other institutions need to extend their support and assistance to programmes that involve and work with the VIPs. Such support will enhance sustainability and effectiveness in implementing HIV/AIDS programmes.
8) There is need to intensify the fight against stigmatization and discrimination of the VIPs.
9) There is need to adopt appropriate and disability-sensitive channels of communication to disseminate HIV/AIDS information to the VIPs

Conclusion

In order to enhance the integration of the VIPs in the fight against the AIDS scourge, it is required that they are actively and effectively involved in programmes of prevention, management, care and supportive services that relate to HIV and AIDS. There is also the need for the VIPs themselves to openly acknowledge that HIV and AIDS concern them. This will help them to develop self confidence and self esteem thus be able to fight against self discrimination. Failure to this, it would mean that a significant number of the disabled population in Kenya will continue to be exposed to the HIV virus.

References

Allafrica.com (2003) 'Disabled People at Significantly Increased Risk of HIV Infection' HYPERLINK: http://allafrica.com/stories/printable/200312020521.html http://allafrica.com/stories/printable/200312020521.html

Banda, I. (2003) 'Disability, Poverty and HIV and AIDS among Disabled Peoples' International 2002 HYPERLINK:http://www.dpi.org/en/resources/articles/06-23-04_hivaids.htm" www.dpi.org/en/resources/articles/06-23-04_hivaids.htm

GOK (1989) 'Kenya special national census on persons with disability' Government printer, Nairobi

GOK (1999) 'Kenta national HIV and AIDS strategic plan 2005-2009 National AIDS Control council' Government printer, Nairobi

GOK (2003) 'Persons with Disabilities Act 2003' Office of the Attorney General Government printer, Nairobi

Groce N. (2003) 'Global Survey on HIV and AIDS and Disability' HYPERLINK: http://globalsurvey.med.yale

Kiraithe, G. (2004) Personal Communication via e-mail kiraitheg@yahoo.com

MOH (2001) 'National Condom Policy and Strategy 2001-2005 Republic of Kenya' Ministry of Health in Collaboration with the National AIDS Control Council, Government printer, Nairobi

Tororei, S. (2006) 'The Social, Economic and Policy Factors Influencing Access to, and Utilization of HIV/AIDS Services by Persons with Disabilities in Kericho District, Kenya D Phil Thesis-Moi University'(Unpublished)

UNAIDS (2000) 'HIV/AIDS Related Stigmatization, Discrimination and Denial: Forms, Contexts and Determinants' Joint United Nations Programme, Geneva

UNAIDS (2001) 'The global strategy framework on HIV/AIDS' Joint United Nations Programme, Geneva

UNAIDS (2002) 'Report on the Global HIV/AIDS Epidemic, UNAIDS, Geneva

UNAIDS (2003) UNAIDS in Kenya HYPERLINK: http://www.unaids.org/en/geographical+area/by+country/kenya.asp

UNAIDS (2004) 'A Joint Response to HIV/AIDS Joint United Nations Programme on HIV/AIDS' Geneva HYPERLINK: http://www.unaids.org

UNAIDS (2004) 'Executive Summary: 2004 Report on the Global AIDS Epidemic' Geneva HYPERLINK: http://www.unaids.org

UNDP (2002) 'Human Development Report 2006 Kenya' HYPERLINK http://www.undp.org/hdr2002/indicator/cty_f_KEN.html

UNDP (2003) 'Kenya Programmes of Disabled Persons: The Voice of Persons with Disabilities in Kenya' HYPERLINK: http://www.undp.kabissa.org/objectives.htm" www.kpdp.kabissa.org/objectives.htm
UNESCO (2004) 'Guidelines for Inclusion: Ensuring Access to Education for all' UNESCO, PARIS
UNHCR (1976) 'International Covenant on Civil and Political Rights General Assembly resolution' UNHCR, Geneva.
WHO (1980) International Classifications of Impairments, Disabilities and Handicaps. World Health Organization, Geneva
WHO (1999) Annual World Health Report, World Health Organizations, Geneva
WHO (2001) 'HIV/AIDS Strategy in the African Region – A Framework for Implementation' World Health Organization, Regional Office for Africa, Harare, Zimbabwe
http://www.au2002.gov.za/docs/summit_council/aureg.pdf >.

Appendix

Acronyms and Abbreviations

ADDP- Africa Decade of Disabled People
AIDS -Acquired Immune Deficiency Syndrome
CBOs-Community-Based Organizations
DPOs -Disabled Peoples Organizations
FBOs- Faith-Based Organizations
HIV-Human Immunodeficiency Virus
IEC- Information Education Communication
MOH- Ministry of Health
NACC- National AIDS Control Council
NCPD-National Council for Persons with Disability
NGOs- Non-Governmental Organizations
OAU- Organization of African Union
PWDs-Persons with Disabilities
STI- Sexually Transmitted Infection
UN- United Nations
UNHCR- United Nations High Commission for Refugees
VCT- Voluntary Counselling and Testing
WHO- Word Health Organization

Definitions of Key Terms

Blindness: It means inability to see
Braille is a system of touch reading for the blind which employs embossed dots evenly arranged in quadrangular letter spaces or cells
Disability: WHO (1999) defines disability as any restriction or lack of ability to perform activity in a manner within the range, which is considered normal.
Low vision is a term that denotes a level of vision that is 20/70 or worse and cannot be fully corrected with conventional glasses. Unlike a person who is blind, a person with low vision has some useful sight (WHO, 1980)
Persons with Disability: In accordance with WHO (1999) Persons with Disability may be defined as individuals with physical, sensory, intellectual or mental impairments that have significant and long-lasting effects on the individual's daily life and activities.
Visually Impaired Persons are those persons whose visual acuity is 3/60 or less after correction or whose visual field subtends an angle not greater than 20 degrees, in the better eye. They suffer from a reduction in ability to interact with the environment within which they live (WHO, 1980)