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Towards universal Access to HIV/AIDS Services for Older Persons in Uganda

HIV/AIDS AND AGEING

**A Review of Key National HIV/AIDS POLICIES, PLANS
AND STRATEGIES IN UGANDA**



Uganda Reach the Aged Association

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CEO

Uganda Reach the Aged Association

Abbreviations

ACP	:	AIDS Control Program
AIDS	:	Acquired Immune Deficiency Syndrome
CBHC	:	Community Based Home Care
CBO	:	Community Based Organisation
CBV	:	Community Based Volunteer
FBO	:	Faith based Organizations
H BC	:	Community Based Care
H BCP	:	Community Based Care Policy
HIV	:	Human Immuno-deficiency Virus
MoH	:	Ministry of Health
NDP	:	National Development Plan
NGO	:	Non Governmental organization
OPLHWA	:	Older Persons Living with HIV/AIDS
OP	:	Older Persons
PEP	:	Post Exposure Prophylaxis
PLHWA	:	People living with HIV/AIDS
PMTCT	:	Prevention of Mother To Child Transmission of HIV
TB	:	Tuberculosis
UNAIDS	:	Joint United Nations Program on HIV/AIDS
UNHS	:	Uganda National Household Survey
VCT	:	Voluntary Counselling and Testing

Executive Summary

The consequences of HIV/AIDS pandemic among different categories of the population in Uganda and other countries cannot be over-emphasized. Although the actual HIV prevalence rate for older persons is not scientifically known, evidence shows that the rate of infection among people that are 50-59 years is higher than that of the age group of 15-49 years. With increased efficiency of HIV Anti-Retroviral treatment, the number of people over 55 years of age that are positive is definitely going to increase. In addition, the HIV/AIDS pandemic has placed great strain on older persons to provide care to PLHIVs and HIV/AIDS orphaned children. HIV/AIDS information, care, support and treatment services are provided within in a national HIV/AIDS response guided by different policies and frameworks.

Over time, URAA and her local and international partners had noted with great concern that older persons' access to HIV/AIDS services such as VCT, ART and information is very limited. Inadequate access to these services is mainly caused by clear policy guidelines which stipulate older persons as a special category in service delivery and access.

It is against this background that URAA with support from HelpAge International (HAI) commissioned a policy analysis/monitoring study to examine different national HIV/AIDS policies and strategies to ascertain inclusion or exclusion of older persons. It is anticipated that this effort will contribute to ensuring, "A range of National HIV policies and programmes to fully reflect the prevention, care, support and treatment needs of older people." Below are key revelations from the review and monitoring study:

The policy review reveals that there are several policies, strategies and programme that have been formulated within the framework of the National HIV/AIDS policy. Many of these policies make reference to older persons as a special category of the population affected by the AIDS scourge. Their references to older persons provide opportunity for access to different services and also advocacy for improving access to HIV/AIDS services by older persons in Uganda. However, most of these interventions fall short in specifying specific entitlements and defining specific strategies for addressing the AIDS pandemic and its effects on older peoples.

Prevention of HIV transmission

- The National HIV/AIDS policy does not specify older people as a risk and special group which require special attention in the fight against HIV/AIDS
- The NSP does not specifically spell out prevention, care and treatment, social support and HBC services for older persons.
- The HCT policy for instance discusses PEP but does not discuss it in the context of the elderly, who may be exposed to the risk of infection in the process of care giving. Similarly, the HCT Policy is silent on this population group, failing to acknowledge that they are at risk, like all the others.
- Overall, the PEP Guideline focuses primarily on PEP for health workers and does not address the need for PEP for older persons yet the latter are exposed to risks of HIV infection in their role as carers of orphans and their relatives infected with HIV as well as HIV infected mothers who deliver under the support of traditional birth attendants (TBAs).

Mitigation of adverse health impact of HIV and AIDS

Some of the policies and strategies reviewed provide room for access to HIV/AIDS prevention, care and treatment services albeit with no specific mechanism for facilitating older persons' access to such services. Key gaps in line with mitigating adverse health effects of HIV/AIDS in reference to older persons include:

- ü ART guidelines do not provide directions to health workers on how to respond to older persons, provide counselling and follow up.
- ü HBC Training manuals for the Community Based Volunteers are silent about offering such care to older persons and there are no specific guidelines on HBC for older persons.
- ü NSP operational documents such as the PMMP, NPAP Operational Handbook and the NPAP are not explicit about HIV/AIDS services targeting older persons.

Impact mitigation at individual and community levels

The different policy guidelines acknowledge the impact of HIV/AIDS on older persons. Older persons are explicitly specified as a special category for different income generating activities as part of the support to infected and affected households. Older persons are identified as a target for social support interventions. The NSP further proposes income generating activities for elderly caregivers. However, the evidence from Kasese shows that older persons have limited access to such support. Many of them (older persons) have no access to appropriate counselling services while others are struggling to support infected and affected persons with basic necessities such as food, soap and clothing.

Address key populations at higher risk

There is an apparent lack of discussion of elderly persons' specific risks and vulnerabilities within policies under the scope of the study. The HIV-specific policies and guidelines reviewed and highlighted herein do not include any discussion of elderly persons' specific HIV risks and vulnerabilities and don't recognize that older persons are susceptible to the risk of HIV transmission like other age groups.

Gender, HIV and AIDS

Inadequate focus on prevention for older persons' needs: The policies and guidelines reviewed pay inadequate attention to elderly persons' gender-specific prevention needs. Although there is wide spread evidence that make older persons, especially elderly women susceptible to HIV infections due to age related changes, no policies have explicit reference to this aspect.

Research and Utilization of Research Products

There is a dearth of information on ageing and HIV/AIDS in Uganda. This absence of information is attributed to lack of inclusion of age specific performance indicators for HIV/AIDS and lack of HIV/AIDS and gerontology research agenda. Although the NAP outlines research needs and lays out a national research agenda on HIV/AIDS, it does not include gerontology and HIV as a research priority. It can be deduced absence on age group of 60 years and above in the USBS report that could be attributed to lack of research agenda on HIV/AIDS and ageing in Uganda.

Recommendation

It is recommended that current HIV/AIDS response policies and strategies are reviewed to reflect magnitude of the HIV/AIDS pandemic among older persons, special entitlements are defined to enable older persons have sufficient access to HIV/AIDS information, care, support and treatment services provided at national and lower levels. There is also need to carry out research on how antiretroviral treatment interacts with age related illnesses among older persons.

Chapter 1: Introduction

1.1 Background

Like other developing countries, the population of older persons in Uganda is increasing. According to the 1991 Uganda Population and Housing Census, the population of older persons was 686,260 (4.1%) of the total population of 16,671,705. This population increased to 1,101,039 (4.6%) as per Uganda Population and Housing Census results of 2002. The Uganda National Household Survey (UNHS) Report 2005/06 estimated the population of older persons at 1,200,000 of which 53 percent were females while 47 percent were males. This population increase has profound consequences at individual, community and national level.

Many of the older persons lack food, money, water, and healthcare. Besides, many older persons in Uganda have lost their children to HIV/AIDS and war, and cannot rely on traditional family support. In fact, many older persons are using their meagre resources to care for their own orphaned grandchildren. About 50 percent of orphans in Uganda are being cared for by older persons.

Everyone has a right to access HIV and AIDS information and services they need - including older men and women. HIV and AIDS affects older persons in a number of ways:

- Growing number of older persons as evidenced by people aged 50 years and above who are HIV positive are living with HIV but they rarely receive adequate prevention, treatment, care and support.
- Older persons support and care for loved ones living with HIV and children orphaned as a result of AIDS. This has a huge impact on their economic, health and emotional well being.
- Although it is often assumed that older persons are no longer sexually active and therefore not at risk of HIV, they are at risk of infection through the same routes as anyone else but are rarely included in HIV and AIDS awareness education.

While much of the public's attention is focused on young people comprising almost half of all new HIV and AIDS cases, there's a growing HIV/AIDS problem developing among the older persons. The continued increase in HIV among the older persons can also be attributed to their living longer as a result of advanced HIV therapy and the perception that the older persons aren't sexually active. The number of HIV/AIDS clients over 50 years of age is expected to increase as people of all ages survive longer due to Anti retroviral therapy and other treatment advances¹. Interface with peer educators indicated that discussions of sex among the elderly generation are regarded as under-the-table things and nobody wants to discuss sexual habits of older persons with the perception that older persons stopped having sex, and yet this is far from a reality. Besides, older persons don't consider themselves at risk and yet they are. For example, a baseline survey conducted by URAA and HAI in Kasese revealed that 64 percent of older people were sexually active, of which 91 percent never used condoms during sexual intercourse².

The Mildmay Centre (2008) indicated that older people often have medical problems (for example, high cholesterol, triglyceride, or blood sugar levels, and/or liver or kidney disease) that disqualify them from participating in many clinical trials. Because of a general lack of awareness among the older persons,

¹ HIV/AIDS among older adults of 50 years and above: coping with the challenges of HIV/AIDS. A case study of The Mildmay centre Uganda (2008)

² URAA (Not dated), IEC Materials Report

they have often been omitted from research, trials, prevention and intervention efforts. As the number of older adults with HIV is growing, research studies and clinical trials should either be modified to include older people, or have separate studies designed specifically for them. Nonetheless, because of their age, they may be more at risk than young people.

Not only are older persons at risk, but the symptoms of HIV are hard to detect because of ageing. Sometimes it's difficult for physicians to determine if a person has flu or is infected with the virus. Many of the early symptoms such as night sweats, chronic fatigue, weight loss, dementia and swollen lymph nodes mimic the natural ageing process. A study by The Mildmay Centre (2008) indicated that as people grow older, they become more susceptible to various illnesses such as diabetes, breast or prostate cancer, high blood pressure, and vision or hearing impairment. Many of these diseases share common symptoms with HIV/AIDS. Lack of discussion about HIV risk factors and HIV-related symptoms can lead to either a misdiagnosis or a delayed diagnosis of HIV with a potentially critical lag in beginning anti-retroviral treatment. This calls for implementation of specific programs targeting older persons who need to be informed about the transmission and prevention of HIV, more research to study older persons' sexual and drug-using behaviours to determine HIV disease progression and treatments and support groups and more. A study conducted by The Mildmay Centre (2008) recommended that since programs aimed at reaching health care and service providers to include misdiagnoses, treatments,

older people are rarely included in controlled clinical trials, little is known about age-specific drug reactions and possibly dangerous interactions with other medications, or side effects.

12 A Review of Key Emerging issues on HIV/AIDS and Ageing

Older people provide care to over 50% of the 1.7million HIV/AIDS orphans, and an average of 3 HIV/AIDS orphans per older person³. The brief of the emerging issues hereunder are aimed at government, URAA and her partners. It sets out the need to strengthen the response to HIV in Uganda by providing interventions on the basis of genuine need rather than age. It highlights the ways in which older persons can be infected with HIV and the vital support that many offer to their children and grandchildren. It also cites examples of interventions that have changed the lives of older persons and those who depend on them.

Risk of contracting HIV

In 2006, UNAIDS stated that a 'substantial proportion of people living with HIV and AIDS are 50 years and older and estimated that 2.8 million people aged 50 and over were living with HIV. Figures from UNAIDS in 2005 revealed that in Botswana, the prevalence rate for people in their early 50s was 21 per cent, compared with 25 per cent of people aged 15-49; and that in Uganda, the rate for men aged 50-59 was 7 per cent – the same as the national adult rate.

Nevertheless, older persons continue to be excluded from HIV prevention, care and treatment services⁴. HIV programmes often discriminate against older persons because of a misconception that older persons are no longer sexually active and therefore not at risk of HIV. In fact, they are very much at risk, predominantly through heterosexual sexual contact. For example, out of 100 older people interviewed in Masaka, Mpigi and Rakai, 96 percent did not mention getting in contact with the blood of an infected

³ URAA Presentation on HIV/AIDS and Older people as presented in URAA & HAI (Nov. 2008), Report on the Uganda National Consultative Meeting on Older Carers of Orphans and Vulnerable Children/People Living with HIV/AIDS.

⁴ AIDS epidemic update, UNAIDS and WHO, December 2007

person as a way of contracting HIV⁵, 67 percent did not mention avoiding multiple partners and 56 percent did not mention abstinence as preventive measures for HIV.

In certain respects, older persons are at greater risk of HIV than younger adults. For example, among elderly women, menopause causes a natural thinning of the vaginal walls, leading to an increased risk of internal injury during sex and subsequent exposure to HIV. Meanwhile, customs such as widow inheritance (which increases vulnerability to non-consensual sex) and ritual cleansing (in which widows are expected to have sex with family or community members following their husband's death) increase older women's risk of exposure to the virus.

New caring duties

HIV is causing a shift in household structure and responsibilities. At a time in their lives when many older persons might expect to be supported and cared for by their own children, a growing number are increasingly taking on caring roles for younger adults living with HIV, and for the orphans and vulnerable children they leave behind. About 40 percent of OVC and an average of 2 PLHIVs are under the care of older people⁶.

Sick adults

Sons and daughters often come home to their parents when they become ill, and older persons find themselves caring for them and their children. Surveys in seven countries in sub-Saharan Africa revealed that around 40 per cent of people living with HIV were being cared for by older persons, with each older carer supporting an average of two people living with HIV. Despite the epidemic's effects, the number of adults over the age 60 in Africa is projected to rise by 55 percent between 2010 and 2025, a 135 percent increase since 1995⁷.

Vulnerable children

Many older persons also play a vital role in caring for children whose parents are sick or have died of AIDS. A recent UNICEF report refers to 'the enormous burden that orphaning is exerting on the extended family in general and grandparents – often grandmothers – in particular'. These new roles are having a huge impact on older persons' lives, adding to the challenges they already face, including health problems, low income and discrimination. With a few exceptions, formal arrangements for elderly care do not yet exist in sub-Saharan Africa. Instead, family members continue to play a vital role in supporting aging kin⁸.

Economic impact

Illnesses can cause catastrophic effects on household income. The cost of caring for people living with HIV is great, but HIV responses rarely calculate or budget for the full cost of providing for a sick dependant. The needs of any children also fall to the carer. Many older persons affected by HIV have to meet extra expenses such as healthcare, school fees and burial costs despite having no regular income. However, older persons have averagely low monthly income. From this point of view it is clear that most elderly people simply cannot meet all the costs of even one child in their care – let alone several children plus adults living with chronic diseases. This economic burden comes at a time of life when

⁵ KEN WILL Social development Indicator Data base (not published)

⁶ HelpAge International (Not dated) Mind the gap; HIV/AIDS and Older people in Africa, HelpAge Briefing paper

⁷ UNAIDS (2010)

⁸ Ssengonzi R. The plight of older persons as caregivers to people infected/affected by HIV/AIDS: evidence from Uganda. J Cross Cult Gerontol 2007;22:339-53.

people's earning potential is much reduced – partly due to the physical impact of ageing, but also to age discrimination. Elderly people with productive assets, such as land, are often forced to sell these to meet the costs of caring for a son or daughter with HIV. This leaves them with nothing to fall back on to support their own needs and those of their orphaned grandchildren. Unlike many other diseases, HIV/AIDS causes deaths primarily among working age adults, who often serve as primary caregivers for dependent elderly family members⁹.

Health and wellbeing

Older carers may already be trying to cope with declining health related to the ageing process, leaving them physically exhausted by caring and more susceptible to the opportunistic infections of those in their care. The emotional distress of caring for one's dying child also takes its toll¹⁰.

Prevention programmes

Elderly people are generally excluded from prevention programmes. The UNAIDS position paper *Intensifying HIV prevention* omits older persons from the list of key groups that it recommends prevention programmes to target¹¹. Excluding older persons from prevention programmes not only increases their own risk of exposure to HIV, but also prevents them from informing the young people they care for.

Voluntary Counselling and Testing

Little is known about whether older persons are accessing these services and what the barriers to access may be. In one small-scale study, older persons said they felt that many services were aimed at younger people, and voiced fears about discussing their sexuality with younger staff. They were concerned about a lack of confidentiality, especially if they were hard of hearing and the counsellor had to raise their voice, or if they were unable to read the results for themselves¹².

Treatment

Many elderly people need access to treatment for HIV and related conditions, either for themselves or for those under their care. But with data on anti-retroviral treatment rarely disaggregated by age, it is not clear how many older persons are obtaining treatment or what prevents them from doing so.

Care and support services

Elderly people who are sick, or caring for others, need home-based support to meet their economic, health and psychosocial needs. However, few home-based care policies, programmes and guidelines address the specific needs of older persons. Meanwhile, national standards are often clinically based. Some make reference to outreach with community care, but none address the needs of older persons caring for others in their homes¹³.

Exclusion from HIV data

⁹ Barrientos A, Gorman M, Heslop A. Old age and poverty in developing countries: contributions and dependence in later life. *World Dev* 2003;31:555-70.

¹⁰ Help Age International (Mind the Gap :HIV and AIDS and Older Persons in Africa)

¹¹ UNAIDS Position Paper: Intensifying HIV Prevention(2005)

¹² Mubisi M, 'Addressing barriers to voluntary counselling and testing for HIV among older persons in Kenya', *Older People and HIV/AIDS in Africa 2*, Nairobi, HelpAge International, February 2008

¹³ Counting carers: how to improve data collection and information on households affected by AIDS and reduce the poverty of carers, people living with HIV and vulnerable children, London, HelpAge International, 2006

Elderly people are widely excluded from systems that track the HIV epidemic and the responses to it. In 2006 UNAIDS changed its global monitoring and reporting of HIV and AIDS, moving away from the conventionally used 15-49 year age group to focus on people aged 15 years and older, with no upper age limit. Today, its annual global epidemic updates and reports provide data on AIDS deaths, new infections and numbers of people living with HIV for all adults over the age of 15.

However, UNAIDS still collects HIV prevalence data (percentage of the population with HIV) for those aged 15-49 only. Similarly, core indicators used to track progress in the HIV response, including access to voluntary counselling and testing, sexual behaviour and condom use, exclude those aged 50 and above.

Monitoring

Focusing monitoring on such a narrow age bracket perpetuates the myth that elderly people are not sexually active, and suggests that increasing access to condoms and broader prevention efforts, including testing, is not a priority for people above the age of 49.

Indicators of health and wellbeing, and measures of income and support, are vital to enable government and NGOs to respond more effectively to the impact of HIV and AIDS. If we are to gain a comprehensive picture of the impact of the epidemic at the national and international level, data must be collected for all people and disaggregated by age, sex and socio-economic status – particularly in high-prevalence areas.

There is also limited data available on who is providing care to people living with HIV or to vulnerable children, and on what support carers need and are receiving. Several cross-country studies describe where orphans live, offering some insight into who provides care. However, they seldom include a complete description of household composition.

Because older persons are extensively excluded from HIV monitoring and reporting, the following details are still largely unknown:

- Country-level HIV prevalence among those aged 50 years and above
- Access to voluntary counselling and testing for those aged 50 and over
- Sexual behaviour and condom use among those aged 50 and over the number of 'skipped-generation' households, where older persons and children live together
- Within skipped-generation households, the economic status, age and sex of the household head
- The number of households with only one or few adults caring for a large number of dependants
- The percentage of older-person-headed households, in which older persons are caring for others living with HIV and AIDS, and for orphans and vulnerable children.

1.3 Policy Monitoring Study and its Objectives

The consequences of HIV/AIDS pandemic among different categories of the population in Uganda and other countries cannot be over-emphasized. Although the actual HIV prevalence rate for older persons is not scientifically known, evidence shows that the rate of infection among people that are 50-59 years is higher than that of the age group of 15-49 years. With increased efficiency of HIV Anti-Retroviral treatment, the number of people over 55 years of age that are positive is definitely going to increase. In addition, the HIV/AIDS pandemic has placed great strain on older persons to provide care to PLHIVs and HIV/AIDS orphaned children. Under the leadership of Uganda AIDS Commission (UAC), a range of policies, guidelines and strategies have been developed to slow-down the spread of HIV/AIDS and

manage its effects within the population. HIV/AIDS service delivery is performed within the framework of different policies and strategies.

Over time, URAA and her local and international partners have noted with great concern that older persons' access to HIV/AIDS services such as VCT, ART and information is very limited. The exclusion of older persons from such services is mainly attributed to absence of specific entitlements for older persons specified by different policy instruments and strategies. While age focused NGOs are undertaking different interventions to improve access to these services, a more sustainable and strategic approach to address these gaps requires mainstreaming of ageing or older persons' needs into different key national policies and strategies. Policies which have clear references and define specific entitlements for older persons would provide good framework for improving access to different HIV/AIDS services in Uganda.

It is against this background that URAA with support from HelpAge International (HAI) commissioned a policy analysis/monitoring study to examine different national HIV/AIDS policies and strategies to ascertain inclusion or exclusion of older persons. It is envisaged that ascertaining status of different policies on aging would enable URAA and her partners to undertake protracted advocacy campaigns on mainstreaming ageing into such policy documents with a view of improving service delivery in Uganda. It is anticipated that this effort will contribute to ensuring, "A range of National HIV policies and programmes to fully reflect the prevention, care, support and treatment needs of older people."

The specific objectives of the policy monitoring study were:

- i. Identify key opportunities for inclusion of ageing issues in HIV/AIDS service delivery in Uganda.
- ii. Identify gaps in different HIV/AIDS policies which ought to be addressed to improve access to HIV/AIDS services by older persons.

1.4 Study Methodology

This section presents information on adopted policy assessment framework and data collection methodology.

1.4.1 Policy Assessment Framework

The policy analysis or appraisal was guided by a set of questions which provided a framework against which each policy, strategy or guideline was subjected to gauge opportunities and gaps in mainstreaming ageing issues in such instrument. Below is a list of questions which formed the assessment framework:

U What was the intervention being analysed?

U What was the definition for the older persons as specified by policy to enable policy makers exercise judgements during implementation? Was policy defined in terms of scope and target group?

U What were the key objectives of the intervention under analysis? Who were the target groups of the policy?

U Did the intervention make any reference to, or mention older persons its special target group or stakeholder?

U What kind of older persons was the policy referring to? Terminally ill? Active? Carers of HIV/AIDS patients and orphans?

U Did the policy reflect the past, present and future forecast in reference to the older persons? (Examine future consequences of the policy)

- ü Does the policy give relevant services to older persons?
- ü What provisions or entitlements did the intervention define in favour of older persons?
- ü What roles did the intervention prescribe for older persons?
- ü To what extent did the policy address values or cultural attachments?
- ü To what extent did the policy provide space and extent of participation of older persons in its development, implementation, review and evaluation? In other words, what opportunities did a given intervention under review provide to older persons?
- ü In what areas of the policy should older people be mentioned or included? Is it in objectives, target group, entitlements or management of interventions?
- ü What ought to be done for older persons to enable them access HIV/AIDS services and prevention information?
- ü What opportunities did the interventions provide for participation or the benefit of older persons?
- ü How easy was it for older persons to participate in specific interventions even if they were not mentioned?
- ü What was the actual policy practice as mirrored by level of access to HIV/AIDS services at community level?

1.4.2 Data Collection

Data collection involved undertaking policy document review in line with the assessment framework and conducting some in-depth interviews and focus group discussions with service providers and older persons. Key informant interviews and focus group discussions were aimed at establishing the actual HIV/AIDS service delivery practice. A total of 5 key informant interviews were held with Ministry of Health (ACP), The Mildmay Centre, URAA and African Palliative Care Association, The URAA Advocacy Team and Kasese District HIV/AIDS Focal Point Person. In addition, four FGDs were conducted in Kasese district with older persons living with HIV/AIDS, older persons providing care to PLHIVs (Older carers) and older person Peer Educators. FGDs and Key informant interviews provided a valuable opportunity for validating policy practice and documenting older persons' experiences in accessing different HIV/AIDS services at district and community level.

CHAPTER 2: A REVIEW OF POLICY COMMITMENTS

A number of national policy instruments and commitments for tackling HIV include older persons, but few of these are being met. This chapter presents policy appraisal findings on different national policies and strategies. For each policy, its position on older persons is stated in clear terms, followed by identification of opportunities and gaps which need to be addressed to make such instruments sensitive and therefore create an enabling environment for access to HIV/AIDS services by older persons in Uganda.

2.1 Constitution of the Republic of Uganda

The 1995 Constitution of the Republic of Uganda recognizes the rights of older persons and provides the basis for the enactment of laws to address their rights and needs. Under the National Objectives and Directive Principles of State Policy of the Constitution, Article 32 states that; *“The state shall make reasonable provision for the welfare and maintenance of the aged.”*

Article 32 of the Constitution stipulates that; *“ Notwithstanding anything in this Constitution the state shall take affirmative action in favour of groups marginalized on the basis of gender, age, disability or any other reason created by history, tradition or custom, for the purpose of redressing imbalances which exist against them.”*¹⁴

Opportunity

The constitution therefore provides room for formulation of policies and enactment of laws which would promote access to HIV/AIDS services by older persons in Uganda.

2.2 The National Development Plan (NDP 2010/11-2014/15)

The National Development Plan (NDP) is the primary Government national strategic plan, aimed at guiding the allocation of resources, decision making and implementation of government programmes. It recognizes that HIV/AIDS is a major development challenge that burdens the country’s health and social systems and undermines national capacity to reduce poverty and income inequalities.

The plan provides an overarching framework to guide public action to eradicate poverty. It spells out priority action areas to support, mobilize and empower vulnerable groups to participate in the economic growth and social development process. In reference to the UNHS 2005/06 report, the NDP document reveals that more than 2.1 million vulnerable children (13.7% of the young people) were under the care of older persons aged 60 years and above. This percentage constitutes 4.6% of the population corresponding to nearly 1.4 million, putting a lot of stress and further impoverishing them.¹⁵ The majority of older persons live in abject poverty and currently only 7.1 % have access to pension of whom 60 percent are males¹⁶. The rest require social protection or some kind of assistance to enable them cope with vulnerability. The burden of looking after orphans coupled with limited activity has put a lot of stress on older persons and almost impoverished them to the extent of destitution. In light of the critical role played by older persons in society, it is important that their efforts are complimented by both the state and private sectors. Strategy 1 of objective 3 under the Social Development Sector, the NDP

¹⁵ UNHS 2005/06

¹⁶ National Development Plan 2010/11-2014/15

¹⁴ The Constitution of the Republic of Uganda (1995)

recognizes the need to diversify and extend social protection measures to all categories of the population which include community based rehabilitation for the older persons.¹⁷

Opportunity

While the NDP does not acknowledge any specific issues related to HIV/AIDS and older persons, it promises to expand community based rehabilitation services for older persons in all districts within the country. The existence of NDP provides an opportunity for the line ministry and its partners to meaningfully plan and design interventions for the elderly within the NDP broader framework.

Within the broader planning frameworks, the NDP provide opportunities for developing interventions and allocating resources to address older persons' HIV and AIDS concerns. The plan also acknowledges the role of older persons in caring for those orphaned and relatives infected by HIV and AIDS.

2.3 The Uganda National AIDS Policy 2008

The Draft Uganda National AIDS Policy (NAP) provides broad guidelines for HIV interventions in Uganda and addresses stigma and discrimination. The NAP does acknowledge the impact of HIV/AIDS on older persons. The policy states that *"The impact of the disease has been wide spread, affecting the elderly, women, men, youth and children, with considerable long and short term implications for each population category."*

Opportunity

The different policy objectives and corresponding operationalisation strategies would provide room for hinging different efforts aimed at improving access to HIV/AIDS services in Uganda by older persons. Besides, the NAP is still in draft form and this provides room for inclusion of older persons.

Gap

However, no specific or explicit policy entitlements or strategies are prescribed to promote access to HIV/AIDS services by older persons. All HIV/AIDS policy guidelines, strategies and plans are grounded within the framework of the NAP. It is therefore important to examine each of these different strategies as presented in the forthcoming sections.

2.4 The National HIV/AIDS Strategic Plan (2007/8-2011/12)

Uganda's national response is guided by a five year National HIV/AIDS Strategic Plan (NSP) 2007/8 – 2011/12, which operationalises the National HIV/AIDS Policy. The NSP recognises that the HIV/AIDS epidemic has geographic, socio-demographic and socio-economic heterogeneity. It emphasizes that as the epidemic matures, the population groups most severely affected have shifted from young unmarried individuals to older and married or formerly married individuals. Higher HIV prevalence peaks are among women aged 30-34 years and men aged 40-44 years, indicating a shift of five to ten years later from the pattern in the early 1990s.

The NSP acknowledges the role of older person populations in caring for orphans and recognises the diminished capacity to sustainably rely on older persons to provide care for the large number of orphans. Older persons are identified as a target for social support interventions which include addressing the legal and political environment; promotion of social rights including education;

¹⁷ Ibid

counselling and psychosocial support; food security and social protection initiatives for key populations at higher risk. The NSP further proposes income generating activities for elderly caregivers.

Opportunity

Within the broader planning frameworks, the NSP provides an opportunity for developing interventions and allocating resources to address older persons' HIV and AIDS concerns. It acknowledges the role of older persons in caring for those orphaned by HIV and AIDS and recognises the diminished capacity to sustainably rely on older persons to provide care for the large number of orphans. Older persons are identified as a target for social support interventions which include addressing the legal and political environment; provision of social rights including education; counselling and psychosocial support; food security and social protection initiatives for key populations at higher risk. The existence of the NSP is an opportunity for the line ministry and its partners to meaningfully plan and design interventions for older persons within the NSP broader framework.

Gaps

The NSP does not specifically spell out prevention, care and treatment, social support and HBC services for older persons. Older persons are not targeted by prevention and care and treatment strategies because there is insufficient knowledge about treatment, care and treatment, social support and Home based Care needs of Older persons. NSP operational documents such as the PMMP, NPAP Operational Handbook and the NPAP are not explicit on HIV/AIDS services targeting older persons. There's no specific guideline on HIV/AIDS services for Older Persons, there are generally community HIV/AIDS services, yet the older persons have their unique challenges that require special attention (cancers, paralysis, arthritis, stigma, etc in addition to HIV/AIDS). The available guidelines are related to management of fever, opportunistic infections and social support to the vulnerable groups and this is not specific to older persons but to orphans and vulnerable children, people with disabilities and pregnant women.

Furthermore, although the NSP provides a detailed monitoring and evaluation framework with indicators for tracking progress, none of the indicators is specific to the older persons.

The gaps identified are major but can be addressed especially as we look forward to annual partnership at district and national levels that set out priorities and as UAC continues to review its performance with regard to the NSP. The assessment highly recommends universal access to HIV/AIDS services including prevention, HBC, social support, care and treatment for older persons as they face unique life challenges as part of the most at Risk population and as carers of OVCs and other persons infected and affected by HIV/AIDS

2.5 The National Priority Action Plan for the National Response to HIV and AIDS

The National Priority Action Plan (NPAP) 2008/09—2009/10 is intended to operationalise the NSP.

Gap

Unfortunately, the NPAP has a limited focus on older person populations, only targeting them for income generating activities and provision of basic needs (for those in HIV affected households). The NPAP therefore misses out the opportunity to target older person populations with preventive and treatment services. It is not surprising therefore to note that the resultant NPAP interventions have no specific initiatives targeting older persons with HIV/AIDS prevention and treatment services.

2.6 Uganda Sero-Behavioural Survey

The Uganda National Sero-Behavioural Survey (USBS) 2005¹⁸ results showed that the overall HIV prevalence among the 15-49 and 15-59 age groups was 6.4 and 6.3 percent respectively. In the USBS, 77 percent of the HIV infections occurring in adult men and 58 percent of those in adult women happened among persons older than 30 years of age¹⁹. Furthermore, 65 percent of all new infections occurred among married people, and 77 percent occurred among persons older than 25 years of age²⁰.

Gaps

A review of the USBS reports shows that there is a dearth of information on categories of the population which are 55 years and above. The HIV/AIDS prevalence rate, patterns of infection and awareness levels for such categories of the population are not known. Absence of this information negatively affects the level of response for older persons. The limited appreciation of HIV/AIDS issues affecting older persons among policy makers can be partially attributed to this information gap.

Evidence from consultations with stakeholders at district level showed that there are HIV positive older persons in the community where mobile clinics have been extended. This implies that inclusion of older persons in the USBS sample would yield concrete information on the extent to which the HIV/AIDS pandemic is affecting older persons in Uganda and the extent to which they have access to different HIV/AIDS services.

Opportunities

The gaps identified are major but can be addressed especially now when MoH is currently conducting the National Sero-Behavioural Survey to include age groups above 60 years. Indicators of health and wellbeing, and measures of income and support, are vital to enable government and NGOs to respond more effectively to the impact of HIV and AIDS. If we are to gain a comprehensive picture of the impact of the epidemic at the national and international level, data must be collected for all people and disaggregated by age, sex and socio-economic status – particularly in high-prevalence areas.

2.7 Home Based Care Policy in Uganda

Home Based Care (HBC) refers to the care given to individuals in their own environment (home) by their family members and supported by skilled welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs [Gaborone Declaration on CHBC, 2001]. The HBC policy guidelines specify elderly persons (60 years and above) as a population category which is eligible for HBC services.

Opportunity

An HBC training and development manual is in place to guide the recruitment and training of home based caregivers who are culturally and gender sensitive willing, committed, dedicated, reliable, locatable, honest, literate, and confidential. Such training would include holistic palliative care and rehabilitation using the community-centered approach. The training should take place at all levels, following approved guidelines; standards of practice and language of choice and content of training will be determined by the needs, role and responsibility of caregivers.

¹⁸ MoH and ORC Macro (2006) Uganda HIV/AIDS Sero-Behavioural Survey 2004/2005. March. MoH and ORC Macro

¹⁹ MoH and ORC Macro (2006) Uganda HIV/AIDS Sero-Behavioural Survey 2004/2005. March. MoH and ORC Macro

²⁰ Mermin, J., et al (2006)

It was realised that the HBC draft policy was silent on specification on HBC provisions for older persons until consultative review and discussions initiated by the Manager of Allied Health services in The Mildmay Centre which influenced articulation and inclusion of clauses on older persons.

Gaps

However, the knowledge gap about the HBC needs of older persons still remains valid. HBC Training manuals for the Community Based Volunteers are silent on offering such care to older persons and there are no specific guidelines on HBC for older persons. The available guidelines are related to management of fever, cancers, arthritis, paralysis, backache, nutrition, diarrhoea, and other opportunistic infections as well as social support to the vulnerable groups and this is not specific to older persons but to orphans and vulnerable children, people with disabilities and pregnant women.

The monitoring and evaluation tools examine availability of the HBC policies and guidelines at the levels of response, but like other policies and guidelines, they do not spell out HBC services offered to older persons.

Anecdotal evidence from Kasese reveals that some older persons are providing home-based care to their counterparts living with HIV/AIDS. However, such volunteers reported to be very ill-equipped. Key challenges included lack of HBC kits and excessive demands from older persons on HBC volunteers. A Peer educator at Bughoye sub-county involved in providing HBC said,

“Most of the older persons on ARVs do not have food. The HIV infected older persons request for support such as food, sugar from us which we unfortunately do not have. This makes them not to adhere to swallowing ARV drugs”.

In another focus group discussion with older persons, one peer educator further lamented that:

“We do not have protective items such as gloves and gumboots as we seek to provide care to people living with HIV/AIDS”.

Although some of these needs may not be so unique to older persons, they demonstrate lack of appropriate interventions in working with older persons to provide care to PLHIVs or providing care to older persons infected with or affected by HIV/AIDS.

Recommendations

- HBC guidelines should be revised to include specific references and protocols for providing HBC to older persons infected with HIV and living with AIDS.
- The HBC evaluation strategy and its M&E tools should capture and report information on older persons' access to such support as well as their contribution to HBC in Uganda.
- Provide HBC kits to older persons providing care PLWHA or living with HIV/AIDS. Older persons should be targeted in interventions providing HBC and where possible support interventions targeting older persons.

2.8 Accelerating HIV Prevention: The Road Map towards Universal Access to HIV Prevention in Uganda (April 2007)

The Road Map identifies ten intervention areas that constitute the comprehensive package for prevention but none of these has specific targets for the older persons' population.

2.9 Communication strategy

This strategy describes the communication strategies that support the Ministry of Health Strategy for Home-Based Management of Fever/Malaria in Uganda. The strategy is presented in two parts: the first part describes the communication approaches for improving home management of fever/malaria among the under-fives while the second describes the approaches for controlling malaria more effectively during pregnancy.

Opportunity

There are three audiences common to both parts of the communication approaches: men and opinion leaders, young and expectant mothers, and service providers. If older persons are included among opinion leaders, they are likely to access information on management of fever and malaria in their homes.

Gaps

The strategy is silent on Home-Based Management of Fever/Malaria among the older persons and yet this is one of the opportunistic infections that characterise HIV/AIDS across all age groups.

2.10 Uganda National Guidelines for HIV VCT (2005)

The Uganda national policy on HIV counselling and testing (HCT) provides a framework for service provision. It also provides service guidelines, approaches and protocols for service provision; a broad framework for human resources requirements and specifies the nature of training and certification for HCT providers. VCT is a major lynchpin in HIV and AIDS prevention and care strategies. People and their sexual partners are better equipped to make appropriate and informed decisions if they know their HIV status. Couples about to be married can use VCT to know their status before deciding on marriage. VCT enables pregnant women to learn about their HIV status and if positive to seek PMTCT prevention services. VCT helps in seeking early HIV care and support services, which in the end help improve quality of life.

Opportunity

The policy provides for a monitoring and evaluation framework; identifies demographic variables to be included in site registers and provides an optional opportunity to record the age of those seeking for services. The policy offers a basis for analyzing HIV cases among all population age groups including older persons. It also identifies and outlines unique guidelines for special population groups including children, couples and persons with disability.

Gaps

The final Draft of the Uganda National Guidelines for HIV/VCT does not specifically address issues of access to VCT for older persons despite the stigma associated with HIV and more so among the older persons. It simply generalises HIV VCT. The guidelines also indicate that PEP should be given to those exposed to HIV. However, it does not mention that older persons should also get PEP yet it is known that they sometimes get exposed to HIV through caring for OVC and other relatives living with HIV/AIDS. The older persons are however, sidestepped by the policy.

Grassroots Evidence

Consultation with older persons, older carers, peer educators and key district personnel on the subject of access to VCT services noted some of the different dilemmas faced by older persons in accessing HIV VCT services. In an FGD of older persons, one participant said,

"In my village, there are older people living positively but have not disclosed their status to the rest of the community."

In response to constraints faced in accessing VCT services, it was echoed that, *"While those near the roads get easy access to VCT, those from remote and mountainous areas find it hard due to mobility problems."* Another fear expressed by the older persons was that, *"Most workers at the Health Centre or VCT outreaches are young people, so the older persons fear to proceed from counselling to testing as well as approaching them for condoms for fear that they will be regarded promiscuous and yet they are already old and should have retired from sexual activity"* (Peer Educator, Bughoye Sub-county).

These testimonies show that despite the sustained campaign for access to VCTs, older persons still remain in the shadow of access to such services. Inadequate access to VCT services by older persons is embedded within the existing biases among service providers. While reflecting on exclusion of older persons from HIV/AIDS prevention and treatment programmes, one stakeholder had this to say:

"The bias was that older persons were considered not [to be] sexually active. We have now realised that we had wrong perceptions about sexuality of older persons. Older persons are still sexually active. Whenever we undertook research and designed interventions we could stop at 54 years. But now we have started seeing people who are 60 years and above that are positive. This calls for design of interventions for their inclusion in the continuum of care, treatment and support"(Anonymous).

The feedback and reflection points presented above demonstrate existing inadequacies in access to HIV VCT services by older persons. This problem is attributed to inaccessible services due to distance to service points, unfriendly services, stigmatisation and biases of service providers.

2.11 Antiretroviral Treatment Guidelines for Uganda (July 2008)

Antiretroviral treatment (ART) Guidelines are intended for all health providers who work with HIV positive patients. The guidelines however do not recognise that older persons with HIV may have their unique medical, social and emotional tensions, which should be addressed to aid decision making in ART. The development of ART policy and guidelines included public and private sectors led by the MOH, through the AIDS Control Programme (ACP). The policy spells out the recommended use of Anti Retroviral Drugs. In Uganda, ARVs are recommended for treatment of HIV-infected patients and prevention of HIV transmission as below:

- Treatment of HIV infected people who meet clinical eligibility criteria.
- PMTCT.
- Post-exposure prophylaxis (PEP), in case of accidental exposure for health workers or for rape victims.
- Treatment of HIV-infected mothers identified in PMTCT programs and to their HIV infected family members (PMTCT-Plus).
- Treatment of children and infants infected by HIV through mother-to-child transmission, blood transfusion, sexual abuse and infected needles.
- Treatment of HIV-infected people already enrolled in care and support activities.
- Treatment of the HIV-infected participants involved in health research projects for HIV/AIDS, after completion of the research protocol.

Gap

The guideline recommends adoption of a family based care approach as the best strategy for addressing issues of disclosure and partner testing; this can be particularly difficult for older persons, because

society considers them sexually inactive, and does not expect them to contract HIV. The ART guidelines do not specifically describe treatment for the older persons. Many older persons living with HIV/AIDS consulted reported having challenges with ARV medications more specifically the drug interactions with treatment for other age related ailments.

2.12 Uganda HIV Modes of Transmission and Prevention Response Analysis

A review of distribution of the resources among the prevention interventions in the Uganda HIV Modes of Transmission and Prevention response analysis indicated that the greatest proportion of the resources are spent on HIV Counselling and Testing (HCT). This proportion accounts for 25%, followed by BCC/Mass Media/ IEC (20%), condom promotion (18%) and PMTCT (16%). The main focus is on HIV prevention services for the general population.²¹ The greatest effort in prevention is focused on delivery of HIV prevention services which benefit the general population, with biomedical interventions accounting for 48 percent of the expenditure and 52 percent being spent on community and behavioural interventions

Gaps

Much of the prevention effort is focused on delivery of HIV prevention services which benefit the general population, with no specific preventive strategy for the older persons. Moreover older persons have unique challenges in accessing generic HIV/AIDS prevention services. Such challenges include fear to approach health service providers for condoms, long distances to service points, lack of confidence in young health workers and inadequate information on HIV.

Recommendation

The spending allocations on HIV /AIDS require to be reviewed because behavioural and community interventions are likely to have the greatest impact on prevention of new HIV infections across all population segments. New and innovative strategies are required to improve uptake of HIV/AIDS prevention services. Special prevention messages and approaches ought to be tailor made to the challenges and needs of older persons in accessing HIV/AIDS prevention and treatment services. The current approaches targeting mostly young people are not appropriate for older persons.

2.13 National Policy on Mainstreaming HIV and AIDS in Uganda

This policy sets out to operationalise the national overarching HIV and AIDS policy (NAP). It identifies specific roles of various ministries.

Opportunity

Specific to older persons, the policy identifies two roles for the ministry responsible for community mobilization and empowerment, promotion of rights and social protection. It prescribes that the ministry shall:

- (a) provide supportive supervision to all ministries, FBOs, PHA, Private sector and civil society in adoption and implementation of internal mainstreaming of HIV and AIDS and;
- (b) develop and implement HIV and AIDS programmes for special population groups/highly vulnerable groups to HIV infection within their mandate.

²¹ Uganda HIV Modes of Transmission and Response

This policy therefore provides URAA and other organisations working for the interests of older person populations the opportunity to direct their advocacy activities, to ensure that the Ministry mainstreams issues related to old age and HIV/AIDS.

2.15 The National Policy Guidelines on Post Exposure Prophylaxis

The National Policy Guidelines on Post Exposure Prophylaxis (PEP) focuses on HIV, Hepatitis B and Hepatitis C.

Gap

Overall, the PEP Guideline focuses primarily on PEP for health workers and does not address the need for PEP for older persons yet the latter are exposed to risks of HIV infection in their role as carers of orphans and their relatives infected with HIV as well as HIV infected mothers delivering under the support of traditional birth attendants (TBAs).

2.16 The HIV/AIDS Peer Education Training Curricular and Guidelines

Peer education typically involves the use of members of a given group to effect change among other members of the same group. Peer education is often used to effect change at individual level by attempting to modify a person's knowledge, attitudes, beliefs, or behaviours. However, peer education may also effect change at the group or societal level by modifying norms and stimulating collective action that leads to changes in programmes and policies (UNAIDS 1999).

Overview of the Positive Prevention Peer Educators Trainers' Manual

The training manual was intended to contribute to the reduction of HIV transmission by building the capacity of peer educators in positive prevention. The training content contained in the manual is divided into three sequential modules; modules 1, 2 and 3, which are referred to as Elements in Positive Prevention; Skills For Peer Educators to Implement Positive Prevention; and Community Mobilization Skills. The manual has content that is critically relevant for older persons namely; disclosure, HIV discordance, sex and sexuality.

Gaps in the Peer Education Manual

The training manual recognizes the need to provide an exclusive component for the adolescent group. Like adolescence, old age is but a transition stage as one progresses to advanced stages of adulthood. The aged also metamorphose although contrary to those that adolescents experience. Therefore, while the general approaches to positive prevention could be applied to the aged, specific targeted approaches for the older persons would be more effective. Such approaches would breed a critical mass of specialized educators for the older persons.

The manual focuses on stigma and discrimination under: gender, social and racial discrimination. The manual does not recognise that age is a basis for discrimination in many societies because people tend to stereotype older persons as 'incapable', 'archaic', 'backward' and generally out of touch with current lifestyles. This makes them soft landing targets for unwitting discrimination in HIV/AIDS care and prevention services provision.

In its definition of discrimination and human rights violations the manual does not recognise the vulnerability of older persons to discrimination. The older persons are almost as equally susceptible to discrimination as are women and children in the current social environment because they are not effectively provided for by the social safety net. Lack of lucrative economic ventures makes them

dependent on family and relatives for support, making them reliant on their benefactors for livelihood and survival; a feature that is characteristic with most women and children in the developing world. The section on sex and sexuality is rather broad, focusing on definitions, sexual and reproductive rights and responsibilities. The manual does not consider sexuality from a perspective of age, and therefore does not satisfactorily address sexuality issues for the older persons. The component on safer sex in the manual specifically targets younger population groups. This is evident in the role plays, which present scenarios for younger persons.

Mainstreaming Opportunities at community level

As URAA seeks to improve the quality of peer education programmes and their contribution to HIV/AIDS/STI prevention, care, and support for the older persons in Uganda the opportunities highlighted hereunder can provide feasible entry points:

Opportunities in Planning Frameworks

Within the broader planning frameworks, the NDP and NSP provide opportunities for developing interventions and allocating resources to address older persons' HIV and AIDS concerns. They acknowledge the role of older persons in caring for orphans and family members infected and affected by HIV and AIDS. The planning frameworks also recognize the diminished capacity to sustainably rely on older persons to provide care for the large number of orphans. The NSP identifies older persons as a target for social support interventions which include addressing the legal and political environment; provision of social rights including education; counselling and psychosocial support; food security and social protection initiatives for key populations at higher risk. These two national level plans are therefore opportunities for the line ministry and its partners to meaningfully plan and design interventions for older persons.

Networking Opportunities

The availability of peer education programmes among a range of actors presents URAA with the opportunity for communication and interaction with other peer programmes in order to learn from their experiences. URAA can learn from best practices or success stories related to peer education methodologies used by other programmes so as to design and implement their appropriate programmes. Programmes like TASO/SCOT, RHU have peer education programmes from which URAA's intervention can borrow valuable lessons. Networking for peer educators is important for facilitating the exchange of ideas and techniques, for building motivation, solidarity, consensus building, and social support, and for ensuring mobilization and collective action among peer educators.

Use of Research Findings from Existing Programmes on HIV/AIDS and Peer Education

Studies on peer education and HIV and AIDS have been conducted (UNAIDS 1999; Hooks 1998; Flanagan 1996). These studies are a source of valuable information from experiences of programmes that have integrated peer education strategies in HIV/AIDS service provision. Some key issues from the UNAIDS study are highlighted below. The study findings showed that development and implementation of peer education programmes could be guided by a series of programmatic considerations, including:

- Enhancement of community involvement and ownership to facilitate programme continuity and sustainability;
- Ongoing capacity-building, such as continuing supervision and follow-up with peer educators to ensure programme quality;
- Capitalizing on and using the knowledge, creativity, and energy of peer educators in programme planning;

- Provision of both non-monetary (e.g. bicycles, T-shirts, materials) and financial incentives (e.g. access to credit and compensation for expenses) to motivate peer educators; and
- Integration of reproductive health and other topical areas, as identified by communities, into the scope of peer educators.

Evidence from available studies can provide information that URAA will use to develop and implement its peer education programme.

2.17 URAA National Advocacy Efforts

As we approach the fourth decade of the HIV epidemic, more of all people living with HIV/AIDS in Uganda are becoming older. In some ways this is a welcome development, because it means that people are living longer with HIV, however older people continue to be newly infected and ageing with HIV brings another set of issues to the table.

Increased life expectancies bring a suite of new health problems that involve complex interactions between the virus, antiretroviral therapies, the natural aging process, and in some cases, other behavioral risk factors. Some evidence suggests that HIV accelerates the ageing process, and both ageing and HIV infection dramatically influence the immune system. It is well-known that older people in general have more chronic diseases, limited knowledge about the effects of long-term exposure to ART, drug toxicity, and drug-drug interactions. Although much has been documented in research, there is still much to learn. Consequently, service providers need to manage HIV in the context of a host of other conditions.

To increase awareness about this vital issue, URAA and her partners have taken a number of steps including setting up of advocacy teams, with focal point persons in HIV prevention, care and treatment, general health, data desegregation and social development. Besides, URAA has convened meetings with various service providers, advocacy organizations, and policy makers in Uganda.

Achievements of URAA Advocacy team

As for the Prevention, care and treatment the advocacy team had registered the following:

- Advocated for prevention, care and treatment for the older persons and those under their care through advocating for HCT, drug adherence as well as access to HIV/AIDS drugs and holistic treatment.
- Inclusion of older persons in the MOH Five (5) year HSSP (2010-16)

General Health

- Advocated for drugs of older persons as part of the essential drugs list (diabetes, hypertension, arthritis, dementia, bone diseases, etc)
- Advocated to ensure older persons access physiotherapy and rehabilitation where they may be disabled.

Social Development

- Advocated for older persons' access to services which can help them improve their health status as well as food security for improved nutritional plane, IGAs for earning a living

Data Desegregation

- Advocated for inclusion older persons in all MOH programmes and surveys for establishment of age and gender desegregated data to keep pace with the changing face and trend of the epidemic and how it impacts on older persons.
- Advocated for CSOs that have information on HIV/AIDS to bring out such desegregated data
- Advocate for investment in analysis of available data on older persons

Challenges

- The engagement of the advocacy team for older persons does not necessarily translate into reality as access to utilities, policies, actions and impacts are still difficult to realize amidst limited resources.
- Dealing with illnesses can be difficult, but the stigma associated with HIV/AIDS can create additional hardship in the form of judgment and social exclusion. HIV/AIDS has been particularly stigmatized among the older persons since the beginning of the epidemic. Sex education is not just for kids and condoms are not just birth controls.
"We made tremendous progress, but we still have ways to go, and since we're dealing with such bedrock values and issues around sexuality, sexual activity, drug use, it's going to be slow to change some of the remaining amounts of the value issues that lead to stigma." (KII, Advocate team member)
- Additionally, inadequate knowledge on how HIV is spread can lead friends, family, and community members to avoid physical and social contact with HIV-positive people. Despite fears to the contrary, HIV is not transmitted through casual contact like hugging, shaking hands, or sharing a meal with a person with HIV. One member on the advocacy team working with a service provision institution said:
"When I went to my support clients, some people would talk about how their families rejected them, or when they go to their houses they give them plastic plates and knives and forks, and I said to myself, if we have to reverse the trend, there must be increased awareness creation."
- At times, the negative IEC messages can be internalized by people who are living with the virus, resulting in feelings of shame, a decreased sense of self worth, and difficulty reaching out to others for the much needed social support. Fear of rejection can lead some to keep their diagnosis to themselves, thereby increasing self isolation.
"A lot of people don't tell you. I guess they're ashamed. You know, maybe embarrassed that they succumbed to this. Because it has a lot to do with sex, multiple relationships, promiscuity, drugs, so they would be associated with both those things."
- Social stigmatization can take many forms. While people of all ages living with HIV may experience HIV-related stigma, older adults living with the virus may also feel marginalized by ageism in Ugandan cultures in general and by youth-obsessed segments in particular. "Ageism" describes a cluster of negative attitudes about older people, including that they are less sexually active, less appealing, and less capable and with low sexual urge.
- Health care and social service providers—like everyone else—sometimes make assumptions about people based on personal prejudices that they may not be aware of. Ageism and HIV-related stigma—as well as racism, sexism, and homophobia—can impact relationships between older people and their care providers. Problematic behaviors can include overt discrimination, "infantilizing elderspeak," violation of patient confidentiality, and exclusion of patients from provider/family discussions of patient care, regardless of a patient's cognitive abilities.
- Funding for health related studies/surveys is not inclusive of data capture for older persons at national level

2.18 Synthesis of Gaps in National Policies and Plans

The policy review reveals that there are several policies, strategies and programme that have been formulated within the framework of the National HIV/AIDS policy. Many of these policies make reference to older persons as a special category of the population affected by the AIDS scourge. Their references to older persons provide opportunity for access to different services and also advocacy for improving access to HIV/AIDS services by older persons in Uganda. However, most of these interventions fall short in specifying specific entitlements and defining specific strategies for addressing the AIDS pandemic and its effects on older peoples. A synthesis of the review of different policies reveals gaps in access to HIV/AIDS prevention, treatment and information services. Below is a synthesis of observed gaps in these documents and older persons' experiences from the community level.

Prevention of transmission

The review covered prevention policies related to HCT, ABC strategy and PEP. While these policies make some references to older persons, the analysis reveals that these policies make no acknowledgement of older persons' specific needs. The policies and plans raise issues that have elderly related dimensions but do not relate them to older persons' realities. For example:

- The National HIV/AIDS policy does not specify older people as a risk and special group which require special attention in the fight against HIV/AIDS
- The NSP does not specifically spell out prevention, care and treatment, social support and HBC services for older persons.
- The HCT policy for instance discusses PEP but does not discuss it in the context of the elderly, who may be exposed to the risk of infection in the process of care giving. Similarly, the HCT Policy is silent on this population group, failing to acknowledge that they are at risk, like all the others.
- Overall, the PEP Guideline focuses primarily on PEP for health workers and does not address the need for PEP for older persons yet the latter are exposed to risks of HIV infection in their role as carers of orphans and their relatives infected with HIV as well as HIV infected mothers who deliver under the support of traditional birth attendants (TBAs).

Furthermore, evidence from consultations at community level reveal that HIV/AIDS services are not friendly to needs of older persons. For example, access to generic services is constrained by lack of confidence in health workers, long distances to service points, shying away from getting condoms from health units and lack of understanding of unique challenges faced by older person in accessing HIV/AIDS services.

Mitigation of adverse health impact of HIV and AIDS

Some of the policies and strategies reviewed provide room for access to HIV/AIDS prevention, care and treatment services albeit with no specific mechanism for facilitating older persons' access to such services. Key gaps in line with mitigating adverse health effects of HIV/AIDS in reference to older persons include:

- ü ART guidelines do not provide directions to health workers on how to respond to older persons, provide counselling and follow up.
- ü ART guideline recommends adoption of a family based care approach as the best strategy for addressing issues of disclosure and partner testing; this can be particularly difficult for older persons, because society considers them sexually inactive, and does not expect them to contract

- HIV. The ART guidelines do not specifically describe treatment for the older persons. Many older persons living with HIV/AIDS consulted reported having challenges with ARV medications.
- ü HBC Training manuals for the Community Based Volunteers are silent about offering such care to older persons and there are no specific guidelines on HBC for older persons.
 - ü NSP operational documents such as the PMMP, NPAP Operational Handbook and the NPAP are not explicit about HIV/AIDS services targeting older persons. There's no specific guideline on HIV/AIDS services for Older Persons, there are generally community HIV/AIDS services, yet the older persons have their unique challenges that require special attention (cancers, paralysis, arthritis, stigma, etc in addition to HIV/AIDS).

In addition to these gaps, there is the emerging evidence that older persons are equally affected by HIV/AIDS. Furthermore, with increased life expectancy for PLWHA, older people will constitute a large proportion of ART clients. Therefore, ART guidelines which do not address age related conditions of some the clients lag behind in ensuring that there is access to appropriate services.

Impact mitigation at individual and community levels

The different policy guidelines acknowledge the impact of HIV/AIDS on older persons. Older persons are explicitly specified as a special category for different income generating activities as part of the support to infected and affected households. Older persons are identified as a target for social support interventions. The NSP further proposes income generating activities for elderly caregivers. However, the evidence from Kasese shows that older persons have limited access to such support. Many of them (older persons) have no access to appropriate counselling services while others are struggling to support infected and affected persons with basic necessities such as food, soap and clothing.

Address key populations at higher risk

There is an apparent lack of discussion of elderly persons' specific risks and vulnerabilities within policies under the scope of the study. The HIV-specific policies and guidelines reviewed and highlighted herein do not include any discussion of elderly persons' specific HIV risks and vulnerabilities and don't recognize that older persons are susceptible to the risk of HIV transmission like other age groups.

Gender, HIV and AIDS

Inadequate focus on prevention for older persons' needs: The policies and guidelines reviewed pay inadequate attention to elderly persons' gender-specific prevention needs. Although there is wide spread evidence that make older persons, especially elderly women susceptible to HIV infections due to age related changes, no policies have explicit reference to this aspect.

Research and Utilization of Research Products

There is a dearth of information on ageing and HIV/AIDS in Uganda. This absence of information is attributed to lack of inclusion of age specific performance indicators for HIV/AIDS and lack of HIV/AIDS and gerontology research agenda. Although the NAP outlines research needs and lays out a national research agenda on HIV/AIDS, it does not include gerontology and HIV as a research priority. It can be deduced absence on age group of 60 years and above in the USBS report that could be attributed to lack of research agenda on HIV/AIDS and ageing in Uganda.

Chapter 3: Conclusion and Policy Implications

3.1 Conclusions

The link between the high proportion of older persons living without prime age adults and AIDS mortality could have important policy implications for Uganda. This phenomenon coincides with demographic changes that are projected to increase the size of the older persons. The number of older persons who may require substantial support but have no prime age family members to care for them could pose significant challenges to communities and government. Given that Uganda does not have “safety net” programmes for the elderly and government is not likely to enact broad new support programmes for older persons in the immediate future, prime age adults will be increasingly important in caring for the elderly persons. Thus, policies that reduce morbidity and mortality from HIV/AIDS in the adult population may have considerable “spillover” benefits for older persons.

The HIV/AIDS epidemic is changing the demographic landscape. The existence of a new population of older persons who lack support from adults and who may need to provide for their grandchildren has emerged. Future work is needed to examine more closely the health and overall welfare of this population; although there are indicators that reducing AIDS deaths in Uganda may provide substantial benefits to this under-recognized population. Furthermore, with increased efficiency of ARVs and increased longevity of people that are currently living with AIDS, the proportion of older persons in need of different HIV/AIDS services is definitely going to increase. Therefore, passiveness in approaches for promoting access to HIV/AIDS services will not aid serious efforts aimed at addressing the AIDS pandemic in Uganda among the older persons.

3.2 Recommendations

Like adolescence, old age is but a transition stage to advanced stages of adulthood. The changes are therefore differently experienced at every stage. Older persons are sexually active and many are exposed to HIV through caring for AIDS patients.

In order to be effective, URAA should call for a major shift in HIV/AIDS responses to support older persons by actively involving them. This can be done by including people aged 50 and above in prevention, treatment, care and support programmes, and by setting up social protection schemes. There must also be greater inclusion of older persons at all stages of HIV responses, from design to evaluation, at the international, national and local levels.

3.2.1 National Advocacy Efforts

- 1) The Ministry of Health and medical research institutions should expand clinical research to learn how medications used to treat HIV are, or are not compatible with medications used to treat age-related illnesses and understand what the long-term effects of HIV medications (both on their own and in combination with other medications) might be.
- 2) URAA and CSOs should raise consciousness of providers of HIV/AIDS services such as medical and social service institutions and gerontologists on issue of older persons and their access to different HIV/AIDS services.

- 3) URAA should build inter-disciplinary collaborations and expand approaches to coordinating care for older persons living with HIV/AIDS and engage the Ministry of Health to include ageing related issues in all medical trainings.
- 4) The makers of HIV/AIDS policies and providers of resultant services should constantly engage older PLHIVs, their families, and their communities as we tackle these new challenges.
- 5) Government (MGLSD, MoH, UAC) and civil society (URAA) should replicate good practices exhibited in districts such as Mukono to enable older persons have improved access to HIV/AIDS services.
- 6) URAA and her partners should strengthen advocacy through media, follow-up, publicity and networking.
- 7) URAA should mobilise older persons living with HIV for services uptake and participation in policy advocacy on universal access to HIV/AIDS services.
- 8) URAA should expand its district advocacy efforts so as to realise integration of older persons' HIV/AIDS issues in local government and civil society programmes in sub-county and district plans to provide sustainable mechanism current advocacy efforts.
- 9) URAA and the Department for Disability and Elderly in the MGLSD should work together to strengthen collaboration and networking for collective utilization of resources for provision of quality services for older persons should be explored.

3.2.2 Government and other Stakeholders

- 1) Concerned Government ministries (MoH, MGLSD, MoPS) should develop action plans for Uganda that recognize the pivotal role that elderly people play in the HIV and AIDS response, and provide the support they need.
- 2) Uganda government (UAC, MoH, MGLSD) and civil society (URAA, HAI) should work in partnership to develop national HIV and AIDS strategies that are inclusive of older persons, and to increase practical support to older persons, including those with caring roles.
- 3) Review and harmonize the national HIV and AIDS policies, plans, and strategies to integrate and systematically mainstream HIV/AIDS issues concerning older persons. Ugandan government and its institutions (UBOS) should increase their understanding on how HIV impacts on older persons and their role in responses, and to focus greater attention on this issue in country strategies.
- 4) Government departments should ensure that the existing HIV/AIDS M&E systems, HMIS and other relevant HIV/AIDS data bases capture and produce age disaggregated data.
- 5) Secure funding for funding Ageing and HIV/AIDS agenda at national and local levels
 - ü Government should commit resources to addressing financing gaps in addressing HIV/AIDS and ageing agenda since some of the areas seem not to big donor agencies.
 - ü Government should invest in social protection systems that support older persons affected by HIV and AIDS and their dependants.

ü Civil society should forge partnership with corporate bodies in generating valuable financial contributions towards enabling older persons access HIV/AIDS services.

- 6) The National HIV/AIDS Advocacy Team in partnership with the MoH and UAC should use influence within UNAIDS and the UN General Assembly to press for a greater focus on the impact of HIV and AIDS on older persons, and on their crucial role in the response to the pandemic

2.2.3 URAA and her Partners

- 1) Develop specific programmes targeting older persons and the wider community for behaviour change. Specifically, URAA and her partners should:

- a. Promote public recognition of the value, contribution and rights of older carers.
- b. Collect more comprehensive data about older carers, and ensure a more sophisticated analysis and understanding of their role, so that they can be better supported.
- c. Improve access to existing services and rights.
- d. Set up home-based care policies and programmes, including standards-of-care guidelines to address the specific economic, health and psychosocial needs of older carers.
- e. Support establishment of older persons post-test clubs
- f. Evidence from studies conducted can provide learning experiences that can be reflection platforms for URAA to feed into its programmes e.g. the peer education programme
- g. Mainstream HIV/AIDS in its programmes
- h. Work with her district based partners to establish day care centres for older persons following the models of Reach One Touch One Ministries in Mukono.

- 2) Advocate for:

- Age-sensitive HIV prevention messages, developed with and provided by older persons themselves.
- Access to HIV testing and treatment for older persons and trained health workers that understand their specific needs.
- Increased recognition of the vital contribution of older carers are making and support in this role with income security, access to healthcare and protection of inheritance rights.
- Indicators that include older persons and national surveys and economic monitoring extended beyond the age of 49 years
- Develop customized training and other IEC materials targeting unique challenges of older persons. Available materials such as the peer education manual exist for specific programmes and for particular population categories. Although it provides a benchmark for URAA's peer education programme, it does not address HIV/AIDS concerns for older persons.

List of Reviewed Documents

1. Constitution of the Republic of Uganda
2. The National Development Plan (NDP 2010/11-2014/15)
3. The Uganda National AIDS Policy 2008
4. The National HIV/AIDS Strategic Plan (2007/8-2011/12)
5. The National Priority Action Plan for the National Response to HIV and AIDS 2008/09—2009/10
6. Uganda Sero-Behavioural Survey (USBS)
7. Home Based Care Policy (HBC) in Uganda
8. Accelerating HIV Prevention: The Road Map towards Universal Access to HIV Prevention in Uganda (April 2007)
9. Communication strategy
10. Uganda National Guidelines for HIV VCT (2005)
11. Antiretroviral Treatment Guidelines for Uganda (July 2008)
12. Uganda HIV Modes of Transmission and Prevention Response Analysis
13. National Policy on Mainstreaming HIV and AIDS in Uganda
14. The National Policy Guidelines on Post Exposure Prophylaxis for HIV B and Hepatitis C (PEP Guidelines) November 2007
15. The HIV/AIDS Peer Education Training Curricular and Guidelines