THE MINISTRY OF HEALTH

Paediatric HIV Communication Campaign Strategy

November 2010

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARVs	Anti Retrovirals
CDFU	Communication For Development Foundation Uganda
HCP	Health Communication Partnership
HIV	Human Immunodeficiency Virus
IRCU	Inter-Religious Council of Uganda
JCRC	Joint Clinical Research Centre
MJAP	Mulago Mbarara Teaching Hospital's Joint Program
MoH	Ministry of Health
MTCT	Mother to Child Transmission
MUJHU	Makerere University- John Hopkins University
NACWOLA	National Community Of Women Living With AIDS
NGO	Non Governmental Organization
NUMAT	Northern Uganda Malaria AIDS & Tuberculosis Program
PEPFAR	Presidential Emergency Plan for AIDS Relief in Africa
PIDC	Paediatric Infectious Disease Clinic
PMTCT	Prevention of Mother to Child Transmission of HIV
RCQHC	Regional Centre for Quality of Health Care
RM&E	Research Monitoring and Evaluation
STI	Sexually Transmitted Infections
STAR EC	Strengthening TB and HIV| AIDS Response in East Central Uganda
TASO	The AIDS Support Organisation
TFL	Treat for Life
TB	Tuberculosis
UAC	Uganda AIDS Commission
USAID	United States Agency for International Development
VHT	Village Health Team

Acknowledgements

The development of the Paediatric HIV Communication Campaign -Strategy has been a truly collaborative effort. We would like to whole heartedly thank the organizations and individuals who contributed to this strategy for their invaluable support. They willingly shared their time and ideas despite their busy schedules and this is warmly appreciated.

We would like to thank the United States Agency for International Development (USAID), without whose technical and financial support, this strategy would not have been possible.

We would also like to credit Joint Clinical Research Centre (JCRC) for their contribution; and Health Communication Partnership (HCP), for their technical support towards the development of this strategy.

All your efforts are greatly appreciated.

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Background and Rationale

ART uptake in Uganda

According to the Uganda HIV and AIDS Sero-Behavioral Survey - UHSBS (2004/05), HIV prevalence in adults is 6.4% and 0.7% in children[1]. Approximately 1.1 million people in Uganda are HIV-infected[2] in a total country population of 30 million. Currently, estimates indicate that there are over 100,000 new HIV infections annually, 25,000 of which are among children. Of those infected, 200,000 people are eligible for ARVs, but only 90,000 are accessing them.[3]

While adult uptake is beginning to increase due to greater awareness about testing, available medication and increased belief in its efficacy, the number of children on ARVs has lagged far behind. Of the estimated 42,000 children eligible to be on ARVs, only 41% had actually started as of September 2009[4]. Whereas 89 % of eligible adults over 15 years of age are currently accessing ART, only 8% of eligible children 0-14years are on the life-prolonging treatment.[5] If they do not get treatment, 66% of children eligible for ARVs will die before they are three, 75% will die before they turn five.[6]

Factors at service delivery and community levels contribute to this situation. Paediatric HIV/AIDS services are not widely available and this presents a major barrier to testing at-risk children and enrolling HIV-positive children in ART programmes. Most health care workers lack the skills to identify, treat and care for children at risk of HIV and to counsel and provide psycho-social support for HIV-positive children and their caretakers.[7]

At the community level, most caretakers are not aware that children born with HIV can, and should be urgently tested and treated and do not know where to go for services. Some caretakers as well as health care providers do not recognise the importance of treating HIV-positive children and assume that all children infected with HIV will die early.

In a survey conducted by HCP in 2008, increased exposure to ART messages was associated with a 57% increase in the likelihood of knowing about a place where children can obtain HIV treatment and a 30% increase in the likelihood of expressing a positive attitude about the effectiveness of ARVs.

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[1] Republic of Uganda, National HIV&AIDS Stakeholders & Services Mapping Report Uganda AIDS Commission, 2009

[2] Republic of Uganda, Uganda HIV&AIDS Sero-Behavioral Survey 2004-5, Ministry of Health,

[3] WHO/UNAIDS/UNICEF (2010)

[4] Ibid; Republic of Uganda (2009)

[5] Ministry of Health, Annual Health Sector Performance report, Financial year 2009-2010

[6] Newell ML, Coovadia H, Cortina-Borja M, et al. Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis. Lancet. 2004 Oct 2-8;364(9441):1236-43

[7] Nabukeera-Barungi, Factors Affecting ART Uptake, Adherence and Prevention of Transmission Among HIV Positive Children and Adolescents in Uganda" Literature Review, February 2007

Paediatric HIV Services

Paediatric HIV services (testing, care and treatment) are available at several public and private health facilities throughout the country. According to MoH, 258 facilities were providing Paediatric HIV services by September 2009, though 87 of these facilities have 10 or fewer children as clients and another 95 have between 11-50 children on ART. While diagnostic tests and drugs are free for children, the DNA PCR – the test which confirms HIV status in children under 18 months is only available at regional referral centers and HC IVs.

The MoH is currently working to expand the availability of paediatric HIV services. The HIV testing and counseling policy was revised in 2010 to include paediatric testing and counseling,[8] and training is on-going for health workers and supervisors. But many providers still lack knowledge about specific paediatric HIV/AIDS issues, and do not have the skills to communicate with caretakers and clients around complex and sensitive issues such as disclosure, dealing with stigma, and the challenges of adherence. In addition, there are few "child/adolescent" friendly services where children and adolescents can feel at ease and receive services and information tailored to their age. Linkages with Prevention of Mother to Child Transmission of HIV (PMTCT) services are still limited, leading to missed opportunities for follow-up and getting children on treatment.

Communication Strategy Development Process

MoH in partnership with the Joint Clinical Research Center (JCRC) initially implemented a "Treat for Life" three phase campaign aimed at promoting adult ART literacy, increasing uptake of care and treatment services among children at risk of HIV, and minimizing HIV/AIDS stigma and discrimination.

In 2010, the MoH invited a wider group of stakeholders to update the communication strategy for paediatric HIV developed as part of the Treat for Life Campaign. A literature review on factors affecting ART uptake and adherence and the prevention of transmission among HIV positive children and adolescents in Uganda and East Africa was conducted in August 2010. This was followed by a workshop of paediatric HIV/AIDS partners who reviewed and refined the existing strategy based on the literature review. The resulting strategy draft was reviewed by paediatric HIV/AIDS partners and their comments incorporated. The strategy is in line with provisions of the Ministry of Health HIV policy and frameworks.

[8] Dr. Elizabeth Namagala, STD/AIDS Control Program, Ministry of Health, Uganda; Presentation to Pediatric ART Communication Strategy Workshop

Theoretical Framework

This strategy adopts the theory of Reasoned Action which stresses that individuals who have positive attitudes toward performing a behaviour and who believe that others will react positively to their decision to adopt a behaviour will be more likely to adopt the practice. The theory considers three aspects:

Personal attitudes- Does person think getting their child tested and started on treatment is worthwhile and useful? If a caretaker feels that testing and treating a child if found HIV positive, will make a difference to the child's health, then the caretaker will seek for paediatric HIV services. A positive attitude towards HIV testing and treatment for the child, enhances health seeking behaviour. Adherence to ART among children is achieved if the caretakers consider this worthwhile for instance when the child falls sick less often.

Perceived social pressure xxx

A person's belief about how their family, friends, peers will react if they get their child tested; and if the child tests positive. A caretaker is more likely to take appropriate action if she or he believes that the family and other close contacts will be supportive and will not unleash stigma if the child tests positive.

Perceived behavioural control:

Beliefs the person has about the availability of resources and obstacles to adopting the behaviour. Most caretakers do not believe that free HIV services are available for babies and older children. A caretaker is likely to seek HIV testing and treatment for the child if they believe these services are available, accessible and free or affordable.

Barriers and Facilitators to Paediatric HIV

Barriers and Facilitators to the Uptake of ART among children:

Uptake refers to the number of children who are tested for HIV, and, among those who are positive, the number who initiate ART.

Barriers

Caretakers of children who may need ARVs face many barriers to accessing services and getting their children tested. These include: financial (cost of transport to get the drugs, competing demands like food expenses), lack of awareness that Paediatric HIV services exist and are free, or where they can access services, frustration with services where there are long lines, delays in receiving test results and negative attitudes among health providers towards PLHIV;fear of stigma and discrimination.

Facilitator

Uptake has been shown to increase when caretakers are aware of HIV testing, care and treatment services; believe accessing them will make a difference in the children's lives and their own lives; believe that their peers, family and friends will think well of them for availing their children of services; and believe that the services are not difficult or costly to use.

Barriers and Facilitators to the Adherence to ART among children:

Adherence refers to taking medication everyday at the appointed time and following the instructions as given by the health care provider. One is said to be"adhering" if the drug regimen is followed 95% of the time.

Barriers to adherence among children usually have to do with their caretakers, who act as the gatekeepers to treatment. According to the literature, the most common barriers include: drug fatigue; the caretaker gets out of the habit of administering the drugs on a daily basis; feeling it is too difficult, not worth it, or don't care;; being too busy; not involving others alternative caretakers and health workers; and concerns about disclosure and stigma. For adolescents on ART, these issues are compounded by wanting to fit in and "be normal", not wanting others to see them take their drugs (especially in boarding schools), and forgetting them if/when they travel from one location to another.

Facilitators

Factors that have been shown to increase adherence include disclosing to the child or adolescent and including them in maintaining the drug regimen; seeing the results of what happens when one stops taking the drugs (falling sick); a good relationship between the caretaker and the child; and, social support from other caretakers/family members, the health worker, and/or treatment supporters.

Barriers and Facilitators to Prevention of Transmission among Adolescents:

Sexually active HIV positive adolescents are a diverse group. They include young people in and out of school, living on their own or with caretakers, taking ARTs or not yet eligible, and those who became infected at birth or because they had unprotected sex with an infected partner. The approaches to prevent transmission and re-infection among adolescents are to remain abstinent for as long as possible or to use condoms correctly and consistently every time they have sex. Disclosing one's status to intimate partners is also an essential step to ensure that a person's rights are respected and that they have made an informed decision about whether to engage in sex or not.

The literature review of 2007, shows that young people are more likely to abstain if they are under 16, have strong religious beliefs, are fearful of getting pregnant or an STI, think they may be taken off ARVs if anyone finds out, believe sex is strenuous and they will become weaker if they engage in it, and are concerned

about infecting others, so they do not suffer as they did.[9] They are more likely to use a condom if they are accessible.

Barriers to practicing safer sex among adolescents include misconceptions around HIV (belief that HIV is only in blood, not sperm); desire to have children; peer and partner pressure; anger and bitterness about being infected; thinking other young people are all infected but just don't know it; desire to have children; and the financial gains of transactional sex.

Resistance to using condoms is further intensified by fear of rejection as one's partner may think one is positive just by mentioning condoms, or when someone actually discloses. Young people can also feel discouraged about abstaining because they wonder if they will have to abstain forever – "abstain until when?" is a common question asked of counselors.[10]

Campaign Goal:

Improve the quality of life of HIV positive children and adolescents by increasing uptake and adherence to ARVs and prevention of transmission and re-infection.

Audiences and Phasing:

Phase I Audiences:

I. Caretakers of children who are at risk of being HIV+ (focus on uptake)
II. Caretakers of children and adolescents on ARVs (focus on adherence)

Proposed Phase II Audiences:

III. Adolescents on ARVs (focus on adherence)
IV. Sexually active HIV+ adolescents (focus on prevention)

Phasing Rationale

HIV positive children are a unique group that has been identified as requiring special attention by the Ministry of Health. The Ministry and their partners are committed to seeing a significant increase in the number of HIV-positive children accessing ART and adhering to the medication. While uptake for adults has improved considerably and adherence is beginning to rise, children are lagging far behind. Yet taking ARVs properly and consistently can make the difference between an HIV positive child dying by age three, and growing up to be a productive member of society.

In view of this, the campaign will initially focus on caretakers of children who are at risk of being HIV positive and may need ARVs, and caretakers who are looking after children and adolescents already on ARVs to improve adherence.

[9] Nabukeera-Barungi
[10] Counselors at the Pediatric Communication Strategy Workshop, February 2007 Kampala, PAEDIATRIC ART COMMUNICATION STRATEGY _DRAFT February 2007

Phase I: Message Briefs by Audience:

Audience I: Caretakers of children and adolescents at risk of HIV

(Includes HIV positive parents and caretakers of children who were orphaned by AIDS)

Portrait of the Audience:

- Gender: Mostly female
- Economic status: majority are poor.
- Education background: low levels of education. (19 % & 48.7% of women; no formal schooling and primary education level respectively).[11]
- Media habits and sources of information: Radio and peers.
- This includes both biological parents and foster parents
- Some may also be HIV- positive

Influencers:

- Religious leaders
- Partners
- Peers
- Women's groups
- Clan leaders
- Local councils
- Immediate family members

Desired Behaviors:

- Get children in their care tested for HIV
- If HIV positive, get the child enrolled in ART clinic care (e.g. find out if eligible for ARVs, get started on medication if eligible, and get counseling)

Current behaviour:

- Care givers do not test children for HIV and do not enroll eligible children for ART and care.

Reasons why they are not currently taking children for testing and ART services:

1. Living in denial: Many caretakers are in denial about their own status and do not want to confirm it by having the child(ren) tested.

[11] Uganda Demographic and Health Survey, 2006.

2. Stigma/rejection: Stigma is still prevalent in many families and communities and a positive diagnosis could subject them to stigma and discrimination, rejection and gossip that follows. The stigma may stem from the child's or their own status being revealed.
3. Lack of awareness that HIV tests and treatment are available for children: There has been relatively little communication around the services that are available for children and many caretakers do not know they exist and are free. Additionally with few linkages between PMTCT and testing, care and treatment for children, many families have "gotten lost in the system."
4. Perception/belief that the trreatment won't make a difference: Many do not believe getting children on ARVs will make a difference in their lives (the child's and the caretaker). Others do not care, as they are overburdened by too many children to look after, or may be elderly and not have the energy to invest in taking the child to the clinic.
5. Health Workers not adequately trained in pediatric ART: Even if they go for services, providers may give them misinformation or treat them in a manner that does not encourage follow-up.
6. Lack of Finances: Although HIV testing and ART services are free for children, many are not aware of this. Even so, the additional costs for transport may be perceived as too great a burden.
7. Myths and misconceptions: There are myths that the drugs will make children infertile or make them worse. This has led to caretakers' unwillingness to take children for HIV services.

Key Barrier/Constraint to adopting the behavior:

- Ignorance (about available services)

Communication Objective

By the end of the campaign, all care givers of children and adolescents at risk of HIV will know about HIV testing, care and treatment services for children and adolescents and where they can be accessed.

Benefit of adopting the desired behaviour

- You will feel a sense of relief when you have knowledge about the child's status and will be able to act from an informed point of view.
- If a child is on ARVs, they will fall sick less frequently, they will require less hospital visits, will be less likely to be hospitalized; you will therefore be able to save money and you will have more time to do your work.

Support points

- HIV testing services are available at government facilities from Health center IV level upwards.
- Children can be tested for HIV and it is free.
- Children can take ARVs and they are free at public health facilities.
- Advice on who should be tested – includes: children of parents who tested HIV positive or where one or both parents died of AIDS; children who are orphaned and vulnerable; children who are falling sick often.
- Testimonials from parents/caretakers about how helpful ARVs have been.
- Facts: At least 1000 out of the 12,000 new patients initiated on ART in 2009/10 were children.12
- Without ART, most HIV positive children (66%) will die by the time they are 3 years old; 75% will die before they are 5.13
- With ARVs, HIV+ children can live into adulthood and lead productive lives; a child can live longer and realize his or her dreams.
- ART side-effects are manageable.

Communication Channels and Approaches:

This audience can potentially be reached by mass media given their numbers and through community sensitization, community outreaches, social networks. Radio Diaries can be an option to follow a caretaker and child as they navigate uptake. Radio talk shows, print materials may be explored. Interpersonal communication will play a key role – tools for providers to help counsel caretakers and that help caretakers talk to the infected children can be produced. Caretakers should be reached where they will most likely be found, through PMTCT clinics, HIV testing sites, OVC programs, Adult ART programs, Home Based Care programs and PLHIV groups. In addition, signage that indicates services are available to children should be clearly displayed.

[12] Ibid MoH 2009/10

[13] See: Draft Report: Review of Early Infant Diagnosis Services in Uganda, 2009; National Scale-up Plan for Paediatric HIV/AIDS Care

Audience II: Caretakers of children and adolescents on ART

Portrait of the Audience:

Gender: Mostly female
Economic Status: Ranges from low to high; majority is poor.
Educational level: low level; but in some cases up to secondary school.
Media habits: listening to radio in local language; newspapers
Sources of Information: Community churches

Influencers:

- Religious leaders
- Peers
- Women's groups/clubs
- Clan leaders
- Local councils
- Immediate family members

Desired Behaviors:

- To discuss adherence challenges with the health workers, caretakers, children and adolescents and make plans to overcome them.

Reasons why they are currently not doing this:

- Attitudes concerning Health Worker: Many caretakers do not see the Health Worker as an ally and are fearful to discuss adherence challenges with them. They may want to maintain their reputation as a good caretaker and not be seen as doing a bad job looking after the children. Many counselors are not trained in pediatric counseling and may not be sensitive to the need of the caretaker or respond appropriately to their challenges. They may scold them for not taking better care of the child, which may result in the caretaker being even less open.
- Relationship with other caretakers: in many cases there is more than one caretaker looking after the child. But it may be that no one person wants to take responsibility for the child, and so there is no consistency of care. All of the caretakers may not be aware of the child's status or know about the ART regimen they need to follow and why. Caretakers may not wish to reveal to others that the child is HIV positive, because of disclosure issues and fear of stigma. Often the person who goes to the health care worker does not communicate to the other caretakers. Other times, the main caretaker may not know how to approach the others nor how to improve their adherence behavior. In some cases,

cultural barriers may make it difficult for one member of the family to discuss the issue openly with other family members. (Example: among the Baganda, daughter-in-law cannot openly raise issues with their father-in-law.)

- Disclosure to the Child: Although disclosure has been shown to help increase adherence, many caretakers are reluctant to disclose for fear of the child's reaction and because they are not sure how to approach it. They may also be concerned that the child will disclose to others, and in doing so, reveal their status as well, subjecting them both to stigma and its negative impact. The caretaker needs to consider a child's maturity, cognitive capacity, personal and individual situation and benefits of disclosure when disclosing the child's HIV status to them. (Note: the preference is usually to have the health worker disclose to the child.)
- Disclosure to partners: Many HIV-positive caretakers do not disclose their status to their partners for fear of rejection. Because they are not open about their own status, they do not want their partners to know that their child is infected. Thus, they hide the child's ARVs or take long to return to health facilities for refills.
- Burden of care and social responsibilities of the Caretakers: Many caretakers are looking after several children and do not feel they have the energy, time and resources to continue with the ARV regimen and continued visits to the clinic and are overwhelmed with ARV regimen and responsibilities.
- Lack of belief in ARVs: Many caretakers do not believe that ARVs will make a difference/are effective and have given up hope for the child's future, leading to lack of commitment.
- Lack of understanding of the rights of children. Most care givers are not aware that as children grow older, they have a right to know their HIV status, voice their concerns, and thus caretakers disregard the rights of children as set out in the UN conventions.
- Limited knowledge on adherence benefits. Caretakers are not aware that with adherence; the child's immunity and health will improve, and this will lessen visits to the health center, reduce the expenditure on health and reduce the stress related to the child's frequent sickness.
- Spiritual misguidance: some religious leaders discourage clients from taking their medication and claim healing powers.

Key Constraint to desired behaviour:

- Caretakers lack hope for the child and thus lack commitment to treatment.
- Lack of ample knowledge on the benefits of adherence.

Communication Objective:

By the end of this campaign caretakers of children on ART will know and believe that children taking ART correctly can live longer and productive lives.

Benefit:

- Trust in ARVs and ensure that the child adheres to them (correctly takes doses every time they are supposed to) and your child will grow to become a productive family member and you will be appreciated by them and by others.

Support points

- The child will not be sick as often if they take their ARVs as directed
- You will save money by adhering to the free ARVs, vs. having to go to the clinic when they are sick
- Disclosing to the child helps relieve some of the burden as they can be involved in adhering – provide advice on when to disclose and skills on how to do it.
- The consequences of not adhering can be very severe and far outweigh adhering
- If you are open and honest with the health worker, they can do a better job of helping you and be your partner in caretaking
- Provide information/model how to talk to alternative/other caretakers and tips for reminding them on how to help the child adhere
- The person who is responsible for caretaking needs to come to the clinic to get the medication and all the information; this will make adhering easier
- Testimonials from caretakers who can talk about how the quality of life for the child and for them has improved with adherence
- Adherence can prolong the child's life.

Communication Channels and Approaches:

This approach will be primarily through inter-personal channels. Tools for health workers to assist them in counseling caretakers, as well as tools to help caretakers talk to others and disclose to the child should be developed. They may include"Lukia's Story" book, or other interactive, highly visual materials. Tips or aids to help the caretaker and the child adhere are also important; these include mobile health which involves using mobile technologies such as text messaging. The audience should be reached at ART centers and their catchment areas, OVC programs, Home Based Care. Radio Diaries may be an option to highlight the challenges of adherence and the strategies caretakers have found to overcome them.

Phase II: Message Brief by Audience

Audience III: Adolescents on ART

Portrait of Audience

Age: 10-19 years (UN definition)
Gender: male and female
Economic status: low, middle and upper income
Location: rural and urban; majority are rural based.
Education level: both at primary and secondary level

Media habits/Source of information:

- Electronic media including TV, radio
- Internet
- Print media
- School notice boards
- School clubs
- Peers
- Magazines
- Books/Novels

Influencers:

- Peers
- School leaders/prefects
- Artists/musicians
- Sports men/women
- Guardians
- Parents
- Teachers
- Community leaders
- Celebrities
- Professionals i.e. doctors, engineers, lawyers

Desired Behavior:

- Follow their ARV medication regimen (time, dosage, etc.)
- Accept that they have to take their drugs each day to maintain good health
- Seek support whenever they experience challenges resulting from ARVs

Current or actual behavior

- Do not take drugs everyday as prescribed.

Benefits of the current or actual behavior

- A sense of freedom from the encumbrance of taking drugs every day.
- Makes them feel that they are like any other adolescent.

Constraints to desired behavior/ reasons why they are currently not doing this:

- Feel better and stop: Adolescents (and adults) whose health improves because of ARVs often stop taking the drugs. They may continue taking them again when their health declines without being aware of the risks of developing resistance to the drugs and the negative consequences such as needing to change drugs, or eventually not having a combination of drugs to deal with their resistant strain.
- Do not want others to see them taking drugs: This issue is particularly relevant in boarding schools, where young people do not want others to see them taking the drugs because of stigma.
- Drug fatigue: Knowing they have to take the drugs their entire lives, some adolescents may get tired of the regimen and begin to slip, or react against it and stop taking the drugs.
- Not disclosed to or delay in disclosure: Telling your child they are HIV positive is a difficult task for many parents and caretakers and some opt not to tell the child or tell them after an incident requires that they do. Adolescents who are not aware of why they are taking the drugs are more likely to stop taking them, because they do not understand the full implications of why they need to take them or may feel they are "cured" of whatever illness the parent said they had.
- Not accepting they are HIV positive: Coming to terms with the reality that one is HIV positive involves many stages similar to those in grieving including denial, anger, and finally acceptance. Without counseling or some kind of assistance to move through the phases, an adolescent may get stuck in one and act out. They may refuse to take the drugs because it is a reminder they are positive, or because they feel resentment that they got infected through "no fault of their own".
- Forget to take the drugs when they travel: Adolescents who travel between school and home or who stay with more than one caretaker may forget to take their drugs with them when they leave their primary residence. Or they may conveniently forget them because they do not want others to see them taking the drugs, again as a result of perceived and real stigma.

- Desire to be independent and in charge: Adolescents should therefore be empowered to be in-charge of their health and medicine to enhance adherence.
- Curious and adventurous: The adolescent phase has numerous psychological manifestations. Adolescence involves experimenting and taking risks without considering the implications. Some adolescents take drug holidays to establish what the implications are.
- Inadequate food; clients on ARVs have to follow the nutritional and dietary recommendations.
- Drug Stock outs; The Paediatric HIV Assessment (2010) and other studies show that facilities sometimes run out of ARVs, so clients may not access the drugs when they need to.
- Lack of psychosocial support: The Caretakers may not have the skills or even the time to offer this support; and the entire social support system is inadequate; yet adolescent friendly health services are limited.

Key Constraint(s):

- Feeling better when taking the drugs so stopping (related to drug fatigue)
- Not being able to accept status
- Not wanting others to see them taking the drugs

Communication objectives

- By the end of this campaign adolescents on ART will believe / have an attitude that they can achieve their dreams by adhering to ART

Benefit(s)

- You can live to achieve your dreams
- You can enjoy youth while on ARVs
- You can have hope for tomorrow
- Other adolescents on ART have maintained good health.

Support points

- Testimonies from youth who are adhering and fulfilling their ambitions
- Testimonies or stories from young people who have accepted their status and how they got through it
- Counseling on what to expect from certain stages of adolescence and how to cope with them

Messages:

- Take your medication/ARVs according to the health worker's instructions.
- Taking ARVs correctly leads to good health.
- With good health, you can go to school, acquire skills and achieve your dreams.
- With ARVs you can still be useful members of the community.
- Seek support from health workers, peers, and guardians in regard to challenges that may prevent you from taking ARVs.

Communication Channels and Approaches:

- This audience will be reached primarily through interpersonal approaches, including counseling and at ARV centers where they are already accessing care. Mass media can be taken advantage of by having the topic raised on already existing youth programming on electronic media- radio, television, drama, print media – pull outs, supplements.
- School debates.
- Facilitated interactive sessions during adolescent club activities.
- Peer educators to positively influence behavior.
- Youth camps
- Influencers such as religious leaders and Faith Based Institutions
- Internet
- Text messaging
- Magazines

Audience IV: HIV Positive Sexually Active Adolescents

Portrait:

Age: 15-19 year olds.

Gender: male and female

Economic status: low, middle and upper income

Education levels: all levels within the age brackets that has to be defined (in and out of school)

Media habits/Sources of information:

- Electronic media including radio and television.
- Internet
- Print media- newspapers, magazines, books, novels.
- Mobile health
- School notice boards
- School clubs
- Peers

Influencers:

- Peers
- School leaders/prefects
- Artists/musicians
- Sports men/women
- Guardians
- Parents
- Teachers
- Community leaders
- Celebrities
- Professionals i.e. doctors, engineers, lawyers

Desired Behavior

- HIV+ sexually active adolescents practicing safer sex and disclosing to potential sexual partners

Current or actual behavior

- HIV+ sexually active adolescents in some instances do not practice safer sex.
- Most HIV + adolescents rarely disclose their status to sexual partners.

Benefits of the actual behavior:

- Avoid possible rejection.
- Retain partner.

Reasons why they are currently not doing this:

- Misconceptions: Some young people believe that the virus only lives in blood and not in sperm, so they don't need to protect themselves. They also are not always clear about the distinction between ARVs being a treatment and not a cure. Still others believe that all young people are infected but they don't know it yet. However this could be how they rationalize not using condoms and/or disclosing.
- Fear of disclosure/partial disclosure: Young people may be unwilling or fearful of facing the potential consequences of disclosure, primarily rejection. So they may not bring up the subject of condoms, as their partner may take this as a sign they are HIV positive, or they may not disclose that they are HIV positive. They may have also been encouraged by their caretakers not to disclose, based on their own experiences when they did. Others may "partially disclose" where they try to get their partners to use condoms, but do not tell them why they want to. If the partner refuses to use them, they will not disclose.
- Peer and Partner pressure: Abstinence is difficult to maintain when one is facing outside pressure to conform. For boys, they may feel a push to have sex to "prove their manhood"; girls may be teased for still being a virgin. They are likely to feel additional pressure from their partners to have sex to "show their love."
- Inconsistent condom use as relationship grows: Many young people begin using condoms when they are first in a relationship, but as the trust develops, they stop using them. They may also have a problem consistently accessing condoms.
- Non -acceptance of status: See above for Adolescents on ARVs. With this audience, it may get acted out as having unprotected sex and desiring or not caring if they infect others.
- Material Gain: Young people in transactional sexual relationship benefit by receiving "goods" in various forms – money, school fees paid, clothes, cell phones etc. They usually have little or no power to negotiate condom use in these relationships.
- Desire for pregnancy: While for some young people the fear of getting pregnant is a deterrent to engaging in sex, for others it is a desired outcome. Girls may wish to demonstrate their fertility; both sexes may wish to have a child to carry on their name believing they will die young.

- Adolescent developmental stage: Adolescence is a natural time of experimentation and risk taking. Unfortunately many young people who are HIV positive do not fully understand the risks they are taking and how it will impact others. They may also take HIV lightly.
- Desire to be just like everyone else: Young people want to fit in and not be different from their peers (even though they also want to be "unique".)
- Lack of youth friendly services: Many counselors do not have the skills to talk to young people. They may not create an environment where young people can openly discuss the challenges they are facing, may criticize the young people for having sex, or may not even raise the issue because they don't believe the young people could be/should be having sex.
- Condom access and acceptance: Many health care providers do not offer condoms to young people for reasons mentioned above, and youth often do not have the finances to purchase them. They may also be fearful of buying them if they live at home should their parents find them.

Key constraint:

- Fear of disclosing their status to sexual partners because of rejection/ stigma.
- Desire to be like everyone else.

Communication Objective

- As a result of our communication the audience will feel responsible for protecting themselves and the lives of their sexual partners by disclosing their status and using condoms.

Key promise(s)

- Avoid re-infection.
- Not feel guilty they have infected others/feel good about themselves.
- More likely to have a long term relationship if they are honest from the start about their status.

Support Points

- If you have unprotected sex with someone who is HIV positive, you run the risk of getting re-infected with a different strain of the virus. This will make it harder to get the right combination of ARVs for your treatment. In addition, your viral load will increase, and you may fall sick.
- In order to avoid infecting your sexual partner and re-infecting yourself, you should use condoms correctly and consistently every time you have sex, or you should abstain.

- Although disclosing can be very difficult and you may face rejection, you will feel good knowing that you did not knowingly infect another person. You will also not have to feel guilty or bad knowing that you did.
- Demonstrate the consequences of not using a condom and not disclosing
- You can have a tremendous role in history – you can make a difference between HIV spreading or stopping with your generation
- Search for the hero inside yourself and stop the spread of HIV and the epidemic
- Testimonies or modeling of disclosing and the various reactions
- Testimonies of couples who are in long term relationships and disclosed early on
- You can practice disclosing with your counselor

Communication Channels and Approaches:

- This audience will be reached primarily through interpersonal approaches. Counselors who interact with young people at HIV testing sites, and ARV centers should have training and tools to appropriately interact with young people and address their needs. Mass media can be taken advantage of by having the topic raised on already existing youth programming and modeling; condom negotiation and disclosure.
- Electronic media- radio, television; print media such as pull outs, supplements.
- School debates.
- Peer educators to positively influence behavior.
- Youth camps
- Influencers such as religious leaders and Faith Based Institutions
- Internet
- Text messaging
- Magazines

Implementation Arrangements

The success of this campaign hinges on the expertise and participation of Paediatric HIV stakeholders throughout the country. The Ministry of Health (MOH) will serve as the major co-ordinating body for this campaign. The Health Communication Partnership (HCP) will provide technical assistance to the design, implementation, monitoring and evaluation of the communication campaign through funding from USAID/Uganda and will share available communication resources with Paediatric HIV partners.

The MoH will actively co-ordinate the communication campaign. The progress and implementation of the strategy will be discussed at quarterly ART Partner

meetings, at Paediatric ART Sub –committee meetings and at the national HIV coordination meetings. The coordination function will ensure timely execution of activities, sharing of information among partners, and addressing any issues pertaining to the campaign.

HCP will engage the services of an advertising agency for design and adaptation of campaign concepts and materials, as well as media placement. The MoH Promotion and Education Division will approve all materials prior to production.

HCP will provide technical assistance to the Paediatric HIV communication campaign. HCP will work closely with staff of partner organizations to transfer skills, and strengthen their capacity to manage the campaign on behalf of MOH and its partners.

Research, Monitoring and Evaluation (RM&E)

A RM & E plan for the Paediatric HIV communication campaign will be developed by the RM&E component of the Paediatric HIV Training & Communication program and supported by the HCP Monitoring and Evaluation department. Partners will be involved in developing and implementing this RM &E plan. It is anticipated that the RM&E Plan will include three major components; formative assessments, monitoring of implementation process and impact evaluation. Illustrative activities in these categories are outlined below:-

Formative Assessment

- Pre-testing of the campaign and provider materials, to determine their appropriateness and acceptability.

Monitoring of the Implementation Process

- Uptake of Paediatric HIV services before, after and during the campaign
- Regular support supervision visits
- Reports of Champions, Community Health Workers and VHT activities
- Assessment of client satisfaction
- Identification of success and challenges in the Implementation of Provider Tools and Community Mobilization Approaches
- Exposure to campaign media/messages
- Media Monitoring

Impact evaluation

- Household survey in 2012 to determine exposure to campaign and changes in knowledge, attitudes and practices surrounding Paediatric HIV.

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Appendix I:

Stakeholders workshop for the paediatric HIV communication campaign strategy design - List of participants:

Date: 29th October 2010 Venue: Imperial Royale Hotel

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