

Bloom

Paediatric HIV project in 5 districts of Uganda

Baseline Assessment January 2024

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Acknowledgment

Bodmando Consulting Group would like to thank all the Bloom project implementing partners who provided great support in the design of the research framework in addition to the study's implementation. Special thanks go to Dr. David Bitira the Monitoring, Evaluation and Learning Manager at Community Health Alliance Uganda, Mr. Kuraish Mubiru the Executive Director of Uganda Young Positives and Ms. Florence the Executive Director of Joy Initiatives Uganda (JOYI). Their tireless efforts allowed the Bodmando evaluation team to seamlessly execute the field data collection exercise.

Bodmando Consulting Group is also very grateful for the efforts of the data collectors who supported the conducting of interviews and focus group discussions not forgetting the District Health Officers and District Biostatisticians who facilitated the retrieval of data from the District Health Information System 2 (DHIS2) software.

We hope that the study findings and acumens shall facilitate the Bloom project implementing partners, to implement and track the Bloom project better. We wish the successful implementation of the Bloom Project for the betterment of the lives of Young Mothers Living with HIV and their Children Living with HIV (CLWHIV) in the target districts.

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Acronyms and Abbreviations

AIDS	Acquired Immuno-Deficiency Syndrome
ART	Anti-Retroviral Therapy
AYPs	Adolescents and Young People
CHW	Community Health Worker
CLWHIV	Children Living with HIV
DSD	Differentiated Service Delivery
DHIS2	District Health Information System 2
eMTCT	Elimination of Mother-to-Child Transmission
FGD	Focus-Group Discussion
HIV	Human Immunodeficiency Virus
HIVST	HIV Self-Testing
IDI	In-Depth Interview
JOYI	Joy Initiatives Uganda
KII	Key Informant Interview
MoH	Ministry of Health
MOH/ACP	Ministry of Health, AIDS Control program
NGO	Non-Government Organization
PIASCY	Presidential Initiative on AIDS Strategy for Communication to Youth
PMTCT	Prevention Of Mother-to-Child Transmission
SIDA	Swedish International Development Agency
SBCC	Social and Behavioral Change Communication
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health and Rights
STIs	Sexually Transmitted Infections
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
UYP	Uganda Young Positives
VLS	Viral Load Suppression
VSLA	Village Savings and Loans Associations
WHO	World Health Organization
YAPS	Young People and Adolescent Peer Supporters
YMLHIV	Young Mothers Living With HIV

Glossary of terms

Lost To Follow Up (LTFU): It's defined as not taking an Anti-Retroviral Therapy (ART) refill for \geq 3 months since the last clinic appointment, this includes people whose passing away has not been registered or who shifted to another clinic without informing their previous health facility.

Viral Load Suppression: It is defined as having less than 200 copies of Human Immunodeficiency Virus (HIV) per millilitre of blood. This means that HIV medicine reduces the amount of HIV in the body (viral load) to a very low level, which keeps the immune system working and prevents illness¹.

Kids to Care Model: The Kids to Care model is an innovative community-based paediatric HIV prevention and care intervention co-created by Aidsfonds and community-based organizations. It involves the empowerment of communities to find, test, treat and retain children living with HIV and pregnant and lactating women exposed/living with HIV in care².

Prevention of Mother to Child Transmission (PMTCT): The range of services for women of reproductive age living with or at risk of contracting (HIV) to maintain their health and to protect their infants from acquiring HIV³.

Sexual And Reproductive Health: The term 'sexual and reproductive health' can be defined as a person's right to a healthy body and the autonomy, education and healthcare to freely decide who to have sex with and how to avoid sexually transmitted infections or unintended pregnancy⁴.

Adherence: This is the extent to which a person's behaviour; taking medication, attending scheduled clinic appointments, following a diet and/or changing lifestyle corresponds with care and treatment plans jointly agreed between the health worker and the person living with HIV⁵.

Retention in HIV care: This means that the person enrolled in HIV care routinely attends HIV/ Acquired Immuno-Deficiency Syndrome (AIDS) services in accordance with their needs⁶.

Paediatric HIV/AIDS: A paediatric case of AIDS is defined as a child, aged less than 13 years, with a CDC surveillance case definition of AIDS⁷⁸.

¹ Centers for Disease Control and Prevention, "HIV Treatment as Prevention | HIV Risk and Prevention | HIV/AIDS | CDC," August 9, 2023, https://www.cdc.gov/hiv/risk/art/index.html.

² Aidsfonds, "The Kids to Care Model: An Effective Community-Based Approach for Paediatric HIV Prevention and Care," n.d.

³ Qi Tang, Min Liu, and Hongzhou Lu, "Prevention of Mother-to-Child Transmission (PMTCT) Continues to Play a Vital Role in the Response to HIV/AIDS: Current Status and Future Perspectives," *Bioscience Trends* 13, no. 1 (March 14, 2019): 107–9,

https://doi.org/10.5582/bst.2019.01009.

⁴ MSI Reproductive Choices, "What Is Sexual and Reproductive Health? | MSI Reproductive Choices," accessed September 30, 2023, https://www.msichoices.org/what-we-do/learn/what-is-sexual-and-reproductive-health/.

⁵ WHO, "Service Delivery, Adherence and Retention," accessed September 30, 2023, https://www.who.int/teams/global-hiv-hepatitis-and-stisprogrammes/hiv/treatment/service-delivery-adherence-retention.

[°] WHO.

⁷ "PEDIATRIC ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS)," n.d.

⁸ "Pediatric Human Immunodeficiency Virus (HIV) - Children's Health," accessed January 25, 2024, https://www.childrens.com/specialtiesservices/conditions/human-immunodeficiency-virus-hiv.

Executive Summary

INTRODUCTION

This report presents the results of the baseline evaluation of the Bloom project in Uganda. The purpose of this project is to contribute to "a healthy life for children exposed to Human Immunodeficiency Virus (HIV) or living with HIV (aged 0-14 years) and their young mothers living with HIV (aged 10-24 years) in Uganda". The Bloom project runs from June 2023 until May 2026, and it is funded by Aidsfonds – Soa Aids Nederland; a Dutch non-profit organisation working with (3) local implementing partners namely; Community Health Alliance Uganda (CHAU), Uganda Young Positives (UYPs) and Joy Initiatives Uganda (JOYI). The evaluation was carried out over a period of 4 months from September 2023 to December 2023. Primary data was collected from all the 5 districts in which the Bloom project is implemented (Mpigi, Mityana, Butambala, Mubende and Kyenjojo). While secondary data was collected from the District Health Information System (DHIS2)⁹ to showcase the status of HIV/ Acquired Immuno-Deficiency Syndrome (AIDS) indicators across the 5 districts at baseline.

PURPOSE AND OBJECTIVES OF THE EVALUATION

The evaluation had 2 main goals and they included the following;

- To conduct and document a baseline analysis of the status of paediatric HIV prevention, treatment and support services in the target areas at the start of the project. This was focused on collecting corresponding hard data to be able to keep track of and evaluate the project's progress and impact.
- To identify the challenges of young mothers living with HIV and their children in accessing HIV information and care, and to provide guidance on how these challenges can be addressed. Specifically, insight into factors that hinder or enable the finding, testing, treatment and retention of young mothers living with HIV and their children in care.

EVALUATION APPROACH AND METHODOLOGY

The evaluation was grounded in a feminist lens to understand the lived experiences, drivers of inequality and solutions related to HIV/AIDS amongst young mothers and their children. It was also participatory and consultative in nature involving Aidsfonds and its three local implementing partners in Uganda. They provided input during the design of the research framework in addition to supporting the implementation process. The evaluation was cross-sectional, and we utilised a mixed methods approach involving a combination of data collection methods. They included a review of data from the DHIS2 system, peer reviewed and grey literature, conducting of In-depth interviews (IDIs), Key Informant Interviews (KIIs), and Focus Group Discussions (FGDs). The quantitative methods were based on a retrospective analysis of data for key HIV service delivery and utilization indicators from the DHIS2 system for the period covering April 2023 to June 2023

Data analysis

The extracted DHIS2 data was cleaned and analysed using Microsoft Excel Version 2016 to generate percentages and figures that showcased the baseline status of selected HIV/AIDS indicators. The qualitative data was cleaned, transcribed and subjected to thematic analysis using the Atlas.ti version 9 software. Both inductive and deductive coding techniques have been used to generate sub-thematic and thematic categories and to construct relationships from the narrative leading to the interpretation of findings.

⁹ DHIS2 is a tool for collection, validation, analysis, and presentation of aggregate and patient-based statistical data, tailored (but not limited) to integrated health information management activities.

Study population

Participants included Community Health Workers, Bloom project partners, young mothers exposed to or Living with HIV, pregnant and breastfeeding young mothers living with HIV, Children Living With HIV, caregivers of young mothers living with HIV, networks of young people living with HIV, health care workers, senior woman teachers, district HIV focal persons, community support groups, local religious and community leaders and church support groups.

RESULTS DHIS2 HIV/AIDS Indicators

Exposed infants tested for HIV

The proportion of female vs male infants(1-4 years) tested for HIV was 197(53%) for female and 175 (47%) for male in the district of Mityana, 220 (47%) female and 249 (53%) male in Mubende, 90 (49%) female and 93 (51%) male in Butambala, 169 (50%) female and 50% (168) male in Mpigi, 323 (53%) female and 281 (47%) male in Kyenjojo district respectively. These results indicate minor inequities in access to HIV testing services for male and female 1–4-year-olds across all the 5 districts.

The proportion of females vs males (10-14 years) tested for HIV were 220 (67%) female and 109 (33%) male in the district of Mityana, 396 (77%) female and 117 (23%) male in the district of Mubende, 77 (52%) female and 71 (48%) male in Butambala, 152 (66%) female and 77 (34%) male in Mpigi district, 387 (58%) female and 281 (42%) male in Kyenjojo district respectively. These results indicate that disproportionately more female 10–14-year-olds are carrying out HIV tests than their male counterparts in the same age bracket. This shows that caregivers/parents have a higher likelihood of supporting females (10-14 years) to seek for HIV testing services when compared to males of the same age group.

Young mothers tested for HIV

The proportion of females vs males tested for HIV in the 15-19 year age bracket included 1799 (87%) for females and 274 (13%) for males in Mityana district, 2851 (74%) females and 1000 (26%) males in Mubende district, 458 (86%) females and 75 (14%) males in Butambala district, 1392 (86%) females and 222 (14%) males in Mpigi district and 2057 (82%) females and 462 (18%) males in Kyenjojo district. These results indicate a widening disproportion in the HIV tests conducted between females and males with far more tests conducted amongst females than males. According to Melanie Paige Moore and Faye Belgrave (2018), negative testing attitudes emerged as a significant factor in HIV testing for men and not women. The authors also argued that higher testing rates among young women compared to men may be attributed to annual gynaecological screenings for women as HIV testing may be conducted during these screenings¹⁰. The low utilization of HIV services among males reflects general patterns of male health-seeking behaviour, which have been attributed to prevailing norms of masculinity, stigma, opportunity, and other costs of attending health facilities.

The proportion of females vs males tested for HIV in the 20-24 year age group included; 3975 (81%) females and 920 (19%) for males in Mityana district, 5403 (81%) females and 1278 (19%) males in Mubende district, 901 (87%) females and 129 (13%) males in Butambala district, 3003 (82%) females and 666 (18%) males in Mpigi district and 3353 (76%) females and 1054 (24%) males in Kyenjojo district.

HIV positive cases among children

Under the 1-4 year age band, Mityana district recorded 5(63%) of new HIV positive cases amongst females and 3(38%) amongst males while Mubende recorded 4(57%) females and 3(43%) males, Butambala 4(80%) females and 1(20%) males, Mpigi 2(67%) females and 1(33%) males while Kyenjojo recorded

¹⁰ Melanie Paige Moore and Faye Belgrave, "Gender Differences in Predictors of HIV Testing Among African American Young Adults," *Journal of Racial and Ethnic Health Disparities* 6, no. 1 (February 2019): 189–96, https://doi.org/10.1007/s40615-018-0513-y.

3(38%) of HIV positive cases amongst females and 5(62%) amongst males. Results indicate that except for the district of Kyenjojo, there was a higher proportion of HIV positive cases recorded amongst females than males. Taha E. Taha et al., (2005) in their study entitled "gender differences in perinatal HIV acquisition among african infants" found out that at birth, significantly more girls (12.6%) than boys (6.3%) were infected with HIV. This association remained significant after controlling for maternal viral load and other factors. Among infants who were uninfected at birth, 8.7% (135 of 1554 infants) acquired HIV by 6 to 8 weeks; of these infants, more girls acquired HIV (10.0%), compared with boys (7.4%). Robert J. Biggar et al., (2006) proposed that girls were at higher risk of early (in utero and perinatal) HIV infection than boys because minor histocompatibility reactions between maternal lymphocytes and infant Y chromosome-derived antigens reduce the risk of HIV transmission in boys¹¹.

In the 10–14-year age group, Mityana district recorded O(0%) of HIV positive cases amongst females and 3(100%) amongst males, Mubende 3(60%) amongst females and 2(40%) amongst males, Mpigi 3(100%) females and O(0%) males while Kyenjojo district recorded 28(68%) of cases amongst females and 13(32%) amongst males. This shows that except for the district of Mityana, more female children (10-14 years) acquired HIV compared to their male counterparts in the same age bracket. Butambala was excluded from the analysis because of missing data.

HIV positive cases among young mothers

In the 15-19 year age band, Mityana district recorded 25(100%) of new HIV positive cases amongst females and 0(0%) amongst males, Mubende district recorded 36(95%) amongst females and 2(5%) amongst males, Butambala 3(75%) among females and 1(25%) among males, Mpigi 15(94%) among females and 1(6%) among males while Kyenjojo district recorded 33(79%) of new HIV positive cases amongst females and 9(21%) amongst males. These findings are consistent with the narrative that adolescent girls are disproportionately affected by HIV compared to their male counterparts in the same age group. This arises from a myriad of challenges that include gender-based violence, harmful cultural and traditional practices that reinforce stigma and the dynamic of male dominance.

There were 83(87%) of new HIV positive cases amongst female 20–24-year-olds in the district of Mityana and 12(13%) among males. While in the districts of Mubende, Butambala, Mpigi and Kyenjojo, there were 87(89%) and 11(11%, 20(91%) and 2(9%), 77(89%) and 10(11%), 66(78%) and 19(22%) of new HIV positive cases amongst females and males respectively. This again showcases the disproportionate share of the HIV burden amongst females when compared to males.

HIV exposed infants given Anti-Retroviral Therapy (ART) prophylaxis

During March and June 2023, Mityana district recorded 189 (40%) of HIV exposed infants who were given ARV prophylaxis for the first time at mother baby care point followed by Kyenjojo district which recorded 119 (25%), Mubende 70 (15%), Mpigi 62 (13%) and Butambala 29 (6%). The provision of ARV prophylaxis to exposed infants is a critical component of PMTCT programmes. Young mothers living with HIV in the district of Mityana highlighted that they are provided with health education talks on Prevention of Mother to Child Transmission (PMTCT) by health care workers whenever they seek for health care services. This is a predictor and one of the explanations for the higher level of PMTCT service utilisation when compared to other districts. *".... routine health education talks or teaching of mothers on the importance of PMTCT services has helped us...."* (FGD, Young Mothers Living with HIV, Mityana district). Results call for more health education talks by Bloom partners on PMTCT targeting pregnancy and breastfeeding young mothers especially in the low performing districts.

¹¹ Robert J. Biggar et al., "Higher In Utero and Perinatal HIV Infection Risk in Girls Than Boys," *JAIDS Journal of Acquired Immune Deficiency Syndromes* 41, no. 4 (April 1, 2006): 509–13, https://doi.org/10.1097/01.qai.0000191283.85578.46.

Young mothers initiated on ART

During the quarter ending June 2023 and in the younger than 15-year age group, Kyenjojo recorded 2 cases of HIV positive pregnant women initiated on ART for Elimination of Mother-to-Child Transmission (eMTCT) at every visit irrespective of when they tested HIV positive. The rest of the districts did not record any cases. In the 15–19-year age band, Mubende recorded 14 cases followed by 12 cases for Kyenjojo, 9 for Mpigi, 7 for Mityana and 1 for Butambala. Amongst the 20–24-year-olds, Mubende recorded 34 cases followed by 32 for Mpigi, 28 for Mityana, 17 for Kyenjojo and 7 for Butambala.

Selected indicators for Children Living with HIV (from Focus Group discussions)

Children Living with HIV (younger than 10 years)

Bodmando researchers carried out focus group discussions with cohorts of children living with HIV below the age of 10 years in all the 5 districts. The proportion of Children Living With HIV (CLWHIV) who indicated that they were part of a support group for CLWHIV was 33% for males and 25% for females. These results indicate that female CLWHIV have relatively lower access to HIV social support compared to their male counterparts and they also indicate that CLWHIV have relatively lower access to social support services. This calls for more efforts by the Bloom partners in linking CLWHIV to social support services that include amongst others peer-to-peer counselling and emotional support services.

Children Living with HIV (10-14 years)

For the FGDs involving CLWHIV between 10-14 years, 50% of females and 50% of males indicated that they were part of a social support group for CLWHIV. These findings indicate that 50% of CLWHIV between 10-14 years have no access to HIV social support services that include amongst others peer-to-peer counselling and emotional support. The HIV social support network is of tremendous importance in helping CLWHIV navigate shared challenges and low access is a detriment to their overall health and emotional wellbeing.

Selected indicators for young mothers living with HIV (from FGD discussions)

Young Mothers Living with HIV (15-19 years)

Results indicate that none of the young mothers (10-19 years) had a disability, 56% are part of an HIV social support group, 56% have received training on nutritional support and 100% of them tested their child for HIV. Results also indicate that 22% of the young mothers living with HIV have a child living with HIV and 22% of the young mothers had taken their child for a viral load suppression test at least once. While 67% of them reported that they are part of income generating activities. These results show that young mothers living with HIV (15-19) years have all utilised HIV testing services for their children and hence know their HIV status, which is a promising finding. However, they also demonstrate that more trainings on nutritional support and linkage to HIV social support groups is necessary to ensure improvement in their overall quality of life.

Young Mothers Living with HIV (20-24 years)

Results indicate that none of the young mothers (20-24 years) had a disability, 42% are part of an HIV social support group, 39% have received training on nutritional support and 91% had tested their child for HIV. Results also indicate that none of young mothers has a child living with HIV. While 62% of them reported that they are part of income generating activities. These results indicate that more efforts are required by the Bloom partners in linking young mothers living with HIV to the social support networks as most of them reported not being part of any HIV social support group. Additionally, more trainings on nutritional support are required as this is a core component of HIV treatment and support.

Barriers and facilitators faced by Children Living with HIV

Themes	Social- Ecological level	Find Test		Treat		Stay			
	Leonogical lotter								
For Children living with HIV	Level	Barrier	Facilitator	Barrier	Facilitator	Barrier	Facilitator	Barrier	Facilitator
Fear and Anxiety for Needle pricks	Individual			Х					
ARV adverse sides effects and pill burden	Individual					Х		Х	
Inadequate access to food and nutrition,	Family					Х		Х	
Lack of reminders to take ARVs as per the	Family					Х		Х	
recommended schedule									
Peer abuse and social discrimination in	Community					Х		Х	
schools and/or health facilities									
Long waiting time	Health facility			Х		Х		Х	
Drug stock outs	Health facility					Х		Х	
Changes in treatment regimens due to	Health facility					Х		х	
drug stock outs,									
Abuse by health care workers due to	Health facility					Х		х	
missed drug regimens,									
Long physical distance to health facilities	Health facility	Х		Х		Х		Х	
Poor health care financing	Health facility	Х		х		Х		Х	
Financial support from parents	Family		х		х		Х		х
Social and family support and	Family						x		х
encouragement									
Social support from friends and school	Community						x		х
matrons									
House to house screening and testing	Community				х				
Community sensitisation campaigns	Community		х		X		х		х
Gifts and other rewards for treatment	Health facility						x		x
adherence									
Calls and reminders	Health facility						X		Х

Themes	Social- Ecological level	Find Test		Treat		Stay			
For Children living with HIV	Level	Barrier	Facilitator	Barrier	Facilitator	Barrier	Facilitator	Barrier	Facilitator
Free access to ARV medication	Health facility						Х		Х
Young People and Adolescent Peer	System		Х		Х		Х		Х
Supporters (YAPS) model									
Policies (test and treat policy)	System		х		х		х		х
Differentiated Service Delivery (DSD)	System		х		х		х		х
Model									
Integrated Child Health days	System		х		х		x		х

Barriers

Results from the FGDs with CLWHIV and key informant interviews revealed the following challenges and barriers in their enrolment for HIV testing, treatment and support services; **1. Individual level** (fear and anxiety associated with needle pricks, ARV adverse side effects and the pill burden), **2. Family level** (inadequate access to food and nutrition, lack of reminders to take ARVs as per the recommended schedule), **3. Community level** (peer abuse and social discrimination in schools and/or health facilities), **4. Health facility level** (long waiting time, drug stock outs, changes in treatment regimens due to drug stock outs, abuse by health care workers due to missed drug regimens, long physical distance to health facilities) and 5. System level (poor health care financing).

Facilitators

Results from the FGDs with CLWHIV and key informant interviews revealed the following facilitators in their enrolment for HIV testing, treatment and support services; **1. Individual level** (none), **2. Family level** (financial support from parents, social and family support and encouragement), **3. Community level** (social support from friends and school matrons, house to house screening and testing, community sensitisation campaigns), **4. Health facility level** (gifts and other rewards for treatment adherence, Calls and reminders, Free access to ARV medication) and 5. System level (Young People and Adolescent Peer Supporters (YAPS) model, policies (test and treat policy), Differentiated Service Delivery (DSD) Model, integrated child health days).

Barriers and facilitators faced by young mothers living with HIV

Themes	Social Ecological level	Find		Test		Treat		Stay	
For young mothers living with HIV	Level	Barrier	Facilitator	Barrier	Facilitator	Barrier	Facilitator	Barrier	Facilitator
Financial challenges	Individual			Х		Х		Х	
ARV adverse side effects	Individual					Х		Х	
Poor access to proper food and nutrition	Family					Х		Х	
Lack of reminders to take ARV medication	Family					Х		Х	
Double burden of caring for their children and themselves	Family					Х		х	
Stigma and discrimination associated with HIV/AIDS	Community			x		x		х	
Long waiting time at public health facilities	Health facility			Х		Х		Х	
Stock out of ARV drugs	Health facility					Х		Х	
Poor health care financing	System	Х		Х		Х		Х	
Positive mind-set	Individual						Х		х
Social and family support and	Family						Х		х
encouragement									
Home delivery of ARV medication	Community						х		Х
Access to saving schemes such as Village Savings and Loans Associations (VSLAs)	Community				x		x		x
Conducting of community out reaches	Community		х		х		х		х
Provision of HIV screening services during ANC visits	Health facility				x		x		х
Availability of HIV Self-testing (HIVST) kits	Health facility				Х				
Adolescent and youth friendly Sexual and	Health facility		Х		Х		Х		Х
Reproductive Health (SRH) services									
Calls and reminders	Health facility						Х		X
Long refills of 6 months duration	Health facility						Х		Х

Themes	Social Ecological level		Find	Test		Treat		Stay	
For young mothers living with HIV	Level	Barrier	Facilitator	Barrier	Facilitator	Barrier	Facilitator	Barrier	Facilitator
HIV counselling and guidance	Health facility				х		х		х
Health education talks	Health facility				х		х		х
Young People and Adolescent Peer Supporters (YAPS) model	System		x		x		x		x
Policies (test and treat policy)	System		Х		х		х		х
Differentiated Service Delivery (DSD) Model	System		Х		Х		Х		х
Integrated Child Health days	System		X		X		X		X

Barriers

Results from the FGDs with young mothers living with HIV and key informant interviews revealed the following challenges and barriers in their enrolment for HIV testing, treatment and support services; **1**. **Individual level** (financial challenges, ARV adverse side effects), **2**. **Family level** (poor access to proper food and nutrition, lack of reminders to take ARV medication, double burden of caring for their children and themselves), **3**. **Community level** (stigma and discrimination associated with HIV/AIDS), **4**. **Health facility level** (long waiting time at public health facilities, stock out of ARV drugs) and **5**. **System level** (poor health care financing).

Facilitators

Results from the FGDs with young mothers living with HIV and key informant interviews revealed the following facilitators in their enrolment for HIV testing, treatment and support services; **1. Individual level** (positive mind-set), **2. Family level** (social and family support and encouragement), **3. Community level** (home delivery of ARV medication, access to saving schemes such as Village Savings and Loans Associations (VSLAs), conducting of community out reaches**)**, **4. Health facility level** (provision of HIV screening services during ANC visits, availability of HIV Self-testing (HIVST) kits, adolescent and youth friendly Sexual and Reproductive Health (SRH) services, calls and reminders, long refills of 6 months duration, HIV counselling and guidance, health education talks) and 5. System level (YAPS model, policies (test and treat policy), DSD Model, integrated child health days).

RECOMMENDATIONS

- a. Bloom project implementing partners (CHAU, UYP and JOYI)
- Train Community Health Workers (CHWs) in sensitisation of CLWHIV and young mothers on how to deal with stigma and discrimination. Additionally, school matrons should also be trained on psychosocial counselling of CLWHIV against stigma and discrimination in the school settings which was noted to affect school going CLWHIV.
- The health and well-being of young mothers can directly impact the health of their children. The Bloom project should consider the dual health needs of both the mother and the child, recognizing that the well-being of one is closely tied to the other.
- The Bloom project partners should work with the Ministry of Health in Uganda (MoH) to ensure the availability of HIV Self testing kits across the health facilities as they were noted to be more acceptable by young mothers and their children because of their non-invasive nature. Young mothers should also be sensitised on the availability of HIVST kits.
- Conduct more community outreaches to build awareness on the availability of VSLAs for young mothers and CLWHIV and support the linkage of young mothers living with HIV and CLWHIV to these VSLAs. Additionally, it is relevant to work with local governments to institutionalise VSLAs for young mothers living with HIV and CLWHIV as part of sustainability planning.
- Strengthen the provision of nutritional and dietary counseling to pregnant young mothers living with HIV in the HIV social support groups in the 5 districts as a large proportion were found to be untrained. This can be through the development of more detailed and specific nutritional Information, Education and Communication (IEC) materials and their dissemination.
- Incorporate vocational skilling into the Bloom project to teach Young Mothers Living With HIV (YMLHIV) skills such as tailoring, making pads, and farming. This is helpful in building their income generation potential and in addressing the food insecurity and financial challenges that they face in accessing HIV/AIDS services.
- Build more knowledge and awareness on paediatric HIV in churches, schools and amongst young mothers. This can be through organisation of trainings for young mothers, church leaders and senior woman teachers who can then cascade it to other stakeholders.

c. Aidsfonds

 Advocate for increased financing of community based paediatric HIV services through the donor community networks. This can be through building of awareness on the community health inequities facing Young Mothers Living With HIV (YMLHIV) and CLWHIV including their implications and how increased financing of community paediatric HIV services can contribute to the realisation of community, national and global goals such as the SDGs.

d. District and Ministry of Health (MoH)

- Apportion more budgetary resources to support paediatric HIV prevention, treatment and support services. Increased financing of YAPs will be helpful in addressing the barriers that peers face in fulfillment of their duties to support YMLHIV and their children.
- Set up new and equip existing child/adolescent friendly spaces to enhance access and utilisation of HIV/AIDS services by CLWHIV and their young mothers.
- Provide ongoing training for healthcare workers, including community health workers and peer educators, on the use of technology for HIV care. Continuous skill development ensures that the project remains effective as technology evolves.
- Strengthen the monitoring and evaluation component of paediatric HIV/AIDS programmes to ensure that HIV/AIDS data for CLWHIV and YMLHIV is comprehensive, disaggregated and readily accessible to HIV/AIDS partners for informed decision-making. This is because we found DHIS2 data to be incomplete and non disaggregated for some HIV/AIDS indicators
- Use geospatial technology to map and analyze the distribution of HIV cases. This can help in identifying hotspots, planning interventions effectively, and optimizing resource allocation.
- Implement age-appropriate education and awareness programs in schools, communities, and youth centers to inform young individuals about HIV, its transmission, and the importance of testing.

e. Health care facilities

- Organise and carry out more community outreaches to extend HIV/AIDS services to young mothers and children in uncovered or inadequately covered communities.
- Continue with the calls and reminders which were noted to promote treatment adherence and retention of young mothers and their CLWHIV in care.
- Provide periodic professional development trainings for health care workers in child and adolescent friendly HIV/AIDS service delivery. A training at least every six months is recommended to improve health worker's attitude towards children and young mothers.
- Ensure that HIV testing services are provided in a confidential and non-judgmental manner to encourage more people, especially young mothers, to get tested.

f. Community Health Workers

- Continue with the community outreach and home visits to extend HIV testing and treatment services to YMLHIV and CLWHIV.
- Document and share experience, knowledge and best practices with Bloom partners on how to find young mothers living with HIV and children living with HIV in the targeted areas. As a result, partners can modify the activities of work plans to find, test, treat and retain young mothers living with HIV in Uganda.

g. Social support groups (community, church, HIV/AIDS networks)

- Strengthen the incorporation of income generating activities in the social support groups as a way of supporting YMLHIV and CLWHIV in accessing HIV/AIDS services. It is necessary to earmark a proportion of savings to facilitate young mothers and CLWHIV in accessing HIV/AIDS services.
- Address stigma and discrimination facing members of the social support groups through psychosocial counselling and sensitisation of communities to debunk the myths and stereotypes surrounding HIV/AIDS

1 Introduction & Programme Overview

This chapter is composed of the introduction and background, programme overview, goal and objectives of the Bloom project including its intended outcomes and the purpose and objectives of the baseline evaluation.

1.1 Introduction

For the period 2010-2020, Uganda recorded a tremendous improvement in the fight against the HIV and AIDS epidemic. It is among the (08) countries in the world that had fully achieved the 90–90 targets by the end of 2020, the others being Eswatini, Switzerland, Rwanda, Qatar, Botswana, Slovenia and Malawi. As a result of the Elimination of Mother to Child Transmission of HIV (EMTCT HIV) programs, the country achieved a reduction in the numbers and proportion of children who contract HIV from their HIV infected mothers. In Uganda, adolescent girls and young women are noted to be disproportionately affected by HIV because of their unequal social, cultural and economic status in society. These challenges include gender-based violence, harmful cultural and traditional practices that reinforce stigma and the dynamic of male dominance. It is reported that between 2010 and 2020, about 29% of all new HIV infections were amongst adolescent girls and young women, despite representing just 10% of the total population¹². And adolescents with low socioeconomic status and who live on less than a minimum wage tend to be more susceptible to vulnerabilities to Sexually Transmitted Infections (STIs) and HIV/AIDS and to have a low ability to contain associated challenges.

According to the Uganda Population Based HIV Impact Assessment Survey conducted from February 2020 through March 2021, Uganda also experiences high rates of teenage pregnancy with one in four young girls either pregnant or having given birth by age 19. This comes with its associated risks such as HIV and other STI infections in addition to pregnancy related complications and unsafe abortions¹³. Additionally, Viral Load Suppression (VLS) is distinctly lower among younger adults: 44.9% among HIV-positive females and 32.5% among HIV-positive males aged 15 to 24 when compared to older adults: 80.3% among HIV-positive females aged 55 to 64 and 70.2% among HIV-positive males aged 45 to 54. This signifies that adolescent girls and young women are at a higher risk of suffering from AIDS compared to their older counterparts¹⁴.

Good health is a prerequisite for progress on ending AIDS and the realisation of Sustainable Development Goal three (SDG 3) that seeks to ensure healthy lives and to promote the well-being for all at all ages. Ensuring healthy lives and promoting the well-being for all at all ages, including people living with or at risk of HIV, is essential to sustainable development. For example, successfully ending the AIDS epidemic will require enormous health service scale-up, with a focus on community services, targeted finding and testing strategies, ensuring treatment is offered to adolescents and children following diagnosis (including regimes appropriate for babies, children and adolescents), and regular support and monitoring for people on antiretroviral medicines. Eliminating mother-to-child transmission of HIV will depend on the provision of immediate

¹² UGANDA AIDS COMMISSION, "2021 Factsheet - Facts on HIV and AIDS in Uganda 2021 (Based on Data Ending 31st December 2020)," 2021.

¹³ UNFPA, "Technical Brief: Integrating Sexual and Reproductive Health and Rights, HIV/AIDS, Sexual and Gender Based Violence Programmes: The Case of Uganda," n.d.

¹⁴ Ministry of Health, "UGANDA POPULATION-BASED HIV IMPACT ASSESSMENT: UPHIA 2016–2017," 2017.

treatment to pregnant women living with HIV, integrating HIV and sexual and reproductive health services, and engaging male partners in prevention and treatment services.

Uganda has developed several polices and guidelines to provide an enabling environment for HIV/AIDS service delivery to young women and children. Some of them include: 1.) The National Paediatric and Adolescent HIV Advocacy Strategy and Road Map 2022-2026 whose overall objective is to provide standardized practical approaches to guide stakeholders in planning, designing, implementing and evaluating paediatric and adolescent HIV initiatives, 2.) Consolidated guidelines for the prevention and treatment of HIV/AIDS in Uganda which provide guidance on HIV prevention, diagnosis, and treatment including in children and young women, 3.) The national policy guidelines on ending HIV stigma and discrimination which seek to address HIV related stereotypes and cases of stigma and discrimination¹⁵ and 4.) The National Communication Plan for HIV Testing Services which provides a framework within which the design, implementation and evaluation of Social and Behavioural Change Communication (SBCC) interventions is undertaken.

Adolescent and youth friendly HIV/AIDS services are present in several districts, and these are partly delivered using the YAPS model. This is a community and health facility-based model related to the Kids to Care model as it seeks to identify, test, treat and promote retention of adolescents and young people in HIV care. The government of Uganda through the Ministry of Health and partners including the United Nations Children's Fund (UNICEF), the Global Fund with funding from the Swedish International Development Agency (SIDA) and the United States Agency for International Development (USAID) initiated YAPS. The programme aims at improving the quality of HIV care and to increase the retention of HIV positive young adults in HIV care¹⁶. In 2018, the Ministry of Health, AIDS Control program (MOH/ACP) developed the YAPS model as recommended by the World Health Organization (WHO) and piloted it in 9 districts. The YAPS model is a multi-sectoral intervention implemented by adolescents and young people living with HIV with the purpose of increasing identification of HIV positive Adolescents and Young People (AYP), improving their linkage into care, retention, adherence, and viral suppression to improve their health and quality of life. The YAPS program is now implemented in 136 districts country wide with over 600 health facilities including the Bloom project's 5 target districts of implementation.

Additionally, paediatric HIV prevention, treatment and support services have been set up to contribute towards positive HIV/AIDS outcomes amongst children. According to UNICEF, April and October are months dedicated to reaching every child and woman with critical health care services like catch-up vaccinations, HIV/AIDS services, deworming and vitamin A supplementation, in addition to family planning services and general health education. These special days are commonly known as Integrated Child Health Days¹⁷.

1.2 Programme overview

Aidsfonds – Soa Aids Nederland is a Dutch non-profit organisation that works with communities as equals and conducts research in addition to ensuring that HIV, AIDS and STIs remain high on the agenda worldwide. Aidsfonds strives for a world where there are no longer any deaths from AIDS and where people enjoy good sexual health. Aidsfonds accomplishes this by working together with the people who are hit hardest by HIV, STIs, discrimination and exclusion in the Netherlands and globally. It amplifies their voice and supports them with information, expertise and funding.

¹⁶ UNICEF Uganda, "Peer to Peer Support Brings Positive Outcomes among Adolescents in Northern Uganda |," accessed November 12, 2023, https://www.unicef.org/uganda/stories/peer-peer-support-brings-positive-outcomes-among-adolescents-northernuganda.

¹⁵ Uganda AIDS Commission., "NATIONAL POLICY GUIDELINES ON ENDING HIV STIGMA AND DISCRIMINATION," 2020.

¹⁷ "Health Workers Use Special Days to Reach Every Child with Life-Saving Vaccines | UNICEF Uganda," 2020, https://www.unicef.org/uganda/stories/health-workers-use-special-days-reach-every-child-life-saving-vaccines.

Aidsfonds developed the Bloom project with a goal of creating a healthy life for children exposed to HIV and their young mothers living with HIV (aged 10-24 years) in Uganda. The Bloom project runs from June 2023 until May 2026 and it is implemented in 5 districts of Uganda by 3 community-based HIV partners namely; Community Health Alliance Uganda, Uganda Young Positives and Joy Initiative Uganda.

Box 1: The Bloom project A. Districts of operation

- Central region: Butambala, Mpigi, Mubende and Mityana
- Western region: Kyenjojo

B. Implementing partners

- Community Health Alliance Uganda
- Uganda Young Positives
- Joy Initiative Uganda

1.3 Situational analysis of the Bloom project's target districts

The HIV Prevalence rate in the Bloom project's target districts ranges from Mpigi (8.4%), Kyenjojo (7.4%), Mityana 6.7%) to Mubende district (5.9%) and Butambala (6.6%) all of which are higher than the national average of 5.8%. The three districts of Mityana, Mubende and Kyenjojo are situated in higher HIV burden central (8.1%) and mid-western (5.5%) regions. They are reported to be amongst the 31 districts that contributed 60% of new annual HIV infections and 70% of undiagnosed children living with HIV (CLWHIV), with Kyenjojo registering the highest number of cases. They are in addition among the 80 districts with sub-optimal ART coverage and the HIV prevalence is eight times higher among adolescent girls 15-19 years (1.7%) than boys (0.2%). Young people are also responsible for 34% of new annual HIV infections¹⁸. By December 2022, it is noted that 21,265 people were said to be living with HIV in Kyenjojo district, 11% (2,336) of whom were young PLHIV. About three quarters (1688/2336) of the young PLHIV were young women aged 10 -24 years (DHIS2). Teenage pregnancy is also noted to be a significant problem in Kyenjojo district, with a rate of 25% of the pregnancies occurring in girls under 17 years of age. Studies in Uganda have shown that teenage pregnancy is associated with several familial and social factors. Some of them include; peer pressure, sexual abuse, lack of control over sex and lack of awareness on preventive measures for social factors and low socio-economic status, domestic violence, physical neglect, and parental divorce for familial factors. Areas with lower teenage pregnancy rates such as the central region are associated with a higher social economic status, and greater access to contraceptive information, products and services¹⁹.

1.3.1 The main outcomes of the Bloom project include ²⁰:

- Reduction of vertical transmission for children born to young (10-24 years old) mothers during pregnancy, birth, and breastfeeding/lactation period.
- Improved treatment coverage, adherence, and retention in care for young mothers (10-24 years old) living with HIV.

 $^{\scriptscriptstyle 18}$ Work plan 'A Healthy Future for Children Affected by HIV and their Young Mothers Living with HIV'

- ¹⁹ Anthony Mark Ochen, Primus Che Chi, and Stephen Lawoko, "Predictors of Teenage Pregnancy among Girls Aged 13–19 Years in Uganda: A Community Based Case-Control Study," *BMC Pregnancy and Childbirth* 19, no. 1 (December 2019): 211, https://doi.org/10.1186/s12884-019-2347-y.
- ²⁰ Aidsfonds, "Invitation for Proposals: A Healthy Future for Children and Their Young Mothers Living with or Exposed to HIV in Uganda," 2022.

 Improved treatment coverage and outcomes for children living with HIV who have a young (10-24 years old) mother.

Under the Bloom project, the 3 implementing partners aim to contribute towards the following outcomes²¹;

- Young girls and women living with or at risk of HIV who are or become pregnant are identified, tested, and supported with taking care of their child in case the infant is born HIV positive or becomes HIV positive in the period after birth and needs treatment.
- The syndemic of adolescent motherhood, HIV and the comprehensive needs of adolescent mothers are addressed through the integration of HIV prevention, treatment, care, sexual and reproductive health, and maternal and child health efforts, including PMTCT (Preventing mother to child transmission), family planning, antenatal and postnatal care, and early childhood development.
- Community structures and engagement of communities are strengthened to ensure familial and social support networks of young mothers, and to find and test children living with HIV and retain them in care.
- Strengthened community-facility collaboration to address the needs of young mothers, considering models of differentiated service delivery.
- Communities have knowledge, skills, and improved attitudes to support young mothers living with HIV and their children.
- Young mothers have knowledge, life skills and a positive attitude to treatment adherence, healthy living with HIV and maternal health.
- An enabling environment that supports the health outcomes for young mothers living with HIV and their children.
- The project contributes to the body of knowledge on healthy young mothers living with HIV and their children by documenting and disseminating best practices and lessons learned.

1.4 Main Goals and Objectives of the Baseline Evaluation

The main goals of the baseline assessment are $^{\rm 22}$

- To conduct and document a baseline analysis of the status of paediatric HIV prevention, treatment and support services in the target areas at the start of the project. This is focused on collecting corresponding hard data to be able to keep track of and evaluate the project's progress and impact.
- To identify the challenges of young mothers living with HIV and their children in accessing HIV information and care, and to provide guidance on how these challenges can be addressed.
 Specifically, insight into factors that hinder or enable to find, test, treat and retain young mothers living with HIV and their children in care.

1.4.1 Objectives of the baseline assessment

Aidsfonds set the following objectives for the baseline assessment²³:

 To determine key baseline indicators and benchmark data and to collect general benchmark information about young mothers living with HIV and their children, the demand for and access to PMTCT/HIV treatment and care services, and the indicators formulated for the Bloom project. This sets the basis for project monitoring and the end line evaluation. A control area in the targeted districts was recommended.

²¹ Aidsfonds, "Terms of Reference: Baseline Assessment 'Bloom Project' in Uganda," 2023.

²² Aidsfonds.

²³ Aidsfonds.

- To provide general benchmark information on the current situation regarding existing government policy/guidelines on young mothers, uptake of (informal) health services at community and facility level, retention rates, and PMTCT/paediatric HIV care.
- Understand the facilitators and barriers of young mothers and their children to enroll in eMTCT, HIV care, support and treatment services in the targeted areas. This includes analyzing PMTCT demand and uptake by young mothers living with HIV and creating an understanding of this process and its barriers.
- Understand the facilitators and barriers of young mothers living with HIV and their children to access, utilize and retain paediatric HIV services in the targeted areas at family, community, and health facility levels. This includes the uptake of informal health services at community and health facility level and the availability of child-friendly services for children living with HIV, the availability of paediatric HIV interventions by the government and any other Non-Government Organizations (NGOs).

2 Baseline Approach , Methodology and Management

2.1 Approach and Methodology

This section describes the approach and methodology undertaken to generate the observed findings. It includes the approach taken, evaluation design, study population, phases of the study, description of the kids to care model, methods of data collection, sampling techniques, field administration, methods of data analysis, challenges faced, study limitations and an illustration of how international evaluation quality standards were adhered to.

2.2 Approach taken

2.2.1 Participatory and Consultative Approach

Throughout the evaluation, Bodmando *employed participatory and consultative techniques*. We closely consulted Aidsfonds and the three local implementing partners (Community Health Alliance Uganda, Uganda Young Positives and Joy Initiatives Uganda). They provided input during the development of the research framework, the implementation process and provided technical insights during report writing. This allowed Bodmando evaluators to gain a better understanding of the assignment, promote local ownership and to ensure that the evaluation was utilisation-focused²⁴.

2.2.2 Feminist Evaluation Approach

Bodmando Consulting Group designed and implemented a methodology based on the feminist evaluation principles which pay attention to participatory, empowering, inclusive, and social justice agendas that seek to provide knowledge that increases social justice for women and other disadvantaged women groups. We did this by ensuring that YMLHIV and CLWHIV are given maximum opportunity to voice their perspectives during the interviews and focus group discussions. This allowed us to uncover the barriers and facilitators in accessing eMTCT, HIV care, support and treatment services in the target areas and the recommendations on how to address the challenges they face from their perspective²⁵.

2.3 Evaluation Design

The evaluation was cross-sectional in design. We utilised a mixed methods approach to the baseline evaluation involving a combination of data collection methods. They included a review of data from the District Health Information System 2 (DHIS2) software, review of both peer reviewed and grey literature from government websites including the conducting of In-depth interviews, Key Informant Interviews, and Focus Group Discussions. The quantitative methods were based on a retrospective analysis of data for key HIV/AIDS service delivery and utilization indicators from the DHIS2 system for the period April 2023 to June 2023 as this was the most current data.

²⁴ "Liberating Structures - Army After-Action-Reviews in a Fishbowl," accessed June 17, 2023, https://www.liberatingstructures.com/fs6/.
²⁵ Better Evaluation, "Feminist Evaluation," December 12, 2021, https://www.betterevaluation.org/methods-approaches/themes/feminist-evaluation.

2.4 Study population

Participants included Community Health Workers, Bloom project partners, young mothers exposed to or Living with HIV, pregnant and breastfeeding young mothers living with HIV, Children Living With HIV, caregivers of young mothers living with HIV, networks of young people living with HIV, health care workers, senior woman teachers, district HIV focal persons, community support groups, local religious and community leaders and church support groups. For the young mothers living with HIV, we focussed on the 15-19- and 20-24-year age groups and the younger than 10 and 10-14-year age groups for CLWHIV. We collected data from communities in each of the 5 districts where the Bloom project is implemented. Table 1 below shows the study participants and their contribution to FGDs, KIIs and IDIs.

Data collection methods	IDIs	Klls	FGDs
Pregnant and breastfeeding young women living with HIV			x
Young mothers to be exposed to and living with HIV			x
Caregivers and partners of young mothers living with HIV			x
Children living with HIV and/or exposed to HIV			x
Local Religious and Community leaders	x	x	
Church support groups	x	x	
Community support groups	x	x	
Community Health Workers	x	x	x
Health Care Workers	x	x	
Management of Health Centers	x	x	
Staff of Ministry of Health responsible for PMTCT and paediatric HIV care	x	x	
District HIV Focal persons	x	x	
Networks of (young) people living with HIV	x	x	x
Comprehensive HIV Implementing partners	x	x	

Table 1: Table showing the study participants

2.5 Phases of the study

The study was conducted across 4 phases as indicated in the table below. They included the Inception, data collection and analysis, reporting and validation and dissemination phase. Important to note is that high stakeholder involvement characterised the entire process.

Figure 1: Figure showing the phases of the Bloom project baseline evaluation.

2.6 Geographical coverage

- Central region: Butambala, Mpigi, Mubende and Mityana districts
- Western region: Kyenjojo district

2.7 The Kids to Care Model

Aidsfonds in collaboration with its community-based partners developed an innovative community-based intervention model for Paediatric HIV prevention, care and support. The Kids to Care model is based on experience with community based paediatric HIV programming. This model guides the design and implementation of the Bloom project by empowering communities to find, test, treat and support children, pregnant and lactating young women living with HIV and strengthen the linkages between communities and health facilities to ensure they stay in care and have access to the health services they need. This model is a response to the urgent need to improve health outcomes for children living with HIV in low resource settings and seeks to fill the gaps in existing HIV services and to provide the critical support for children and pregnant women to be identified, tested, treated, and retained in care²⁶.

Figure 2: The Kids to Care Model: Adopted from Aidsfonds, "The Kids to Care Model: An Effective Community-Based Approach for Paediatric HIV Prevention and Care."

The table below gives a description of the various dimensions of the Kids to Care model. The dimensions range from Find, Test, Start to Stay in care.

Phase	Description
Find	<i>Communities know their children</i> . Community health workers educate community members on paediatric HIV and move door-to-door to find children and pregnant women living with HIV.
Test	<i>Community health workers are trained about paediatric HIV testing and treatment, and prevention of mother-to-child transmission.</i> They test pregnant women and children in their homes or refer them for testing in the community or health facility.
Start	<i>Community health workers help caregivers gain access to HIV treatment for children.</i> Traditional and religious leaders, teachers and mentor mothers act as role models and encourage access to care. Staff at health facilities are trained to offer child friendly services and to work closely with community health workers.
Stay	<i>Community health workers support children to stay on HIV treatment</i> . They promote treatment support groups for caregivers and children, and income-generating activities and savings groups for caregivers.

Table 2: Description of the various phases of the Kids to Care model

2.8 Methods of Data Collection

Literature review: Bodmando carried out a desk review of both peer reviewed and grey literature. This included project work plans for the Bloom project partners, Bloom project description, end of term evaluation reports for previous projects (TAFU project), Aidsfonds' Theory of Change, terms of reference, Kids to Care Model description, project indicator framework amongst others. Zotero referencing software was used to support screening, selection and referencing.

Review of DHIS2 data: After Bodmando sought for permission from the district local government, the district biostatisticians provided support in the identification and retrieval of DHIS2 data related to PMTCT/HIV testing, treatment and support services for the period April 2023 to June 2023. Bodmando shared the indicator framework that was approved by the Bloom project partners to guide the district biostatisticians on the HIV/AIDS indicators of interest for the Bloom project. The biostatisticians then extracted data based on the existing DHIS2 HIV/AIDS indicators with close similarity to those in the Bloom project indicator list. This data was exported to Microsoft Excel and shared with the Bodmando evaluators. It was accordingly cleaned and subjected to analysis.

Key Informant Interviews: The Bodmando team conducted a total of 18 Key Informant Interviews with various stakeholders namely; Health Centre IV In-charges, HIV Implementing partners, district HIV focal persons, CHWs, senior woman teachers, representatives from networks of young people living with HIV and Community support groups. The identification and recruitment of key informants was supported by Bodmando's global programmes manager, the Bloom project-implementing partners and local government officials. The tools that were utilised to support data collection included an information sheet to give participants a detailed background about the study and a semi-structured key informant interview guide with probes. The key informant interviews were conducted physically with the support of five (5) field enumerators. Prior consent was obtained from the participants regarding the interviews as well as to audio record the interviews. The key informant interviews were later transcribed.

In-Depth Interviews: Bodmando also conducted 12 in-depth interviews with selected stakeholders who included; senior woman teachers, community support group representatives, local religious and community leaders, representatives from church support groups, HIV Implementing partners and CHWs.

Focus Group Discussions (FGDs): FGDs were also conducted with Pregnant and breastfeeding young women living with HIV, young mothers to be exposed to and living with HIV, caregivers and partners of young mothers living with HIV, Children living with HIV and/or exposed to HIV and CHWs. In total, 20 FGDs were conducted with each group consisting of 8-10 participants. The FGDs were participatory which enabled reflection and discussion on the facilitators and barriers that young mothers living with HIV and their children face in access and utilization of paediatric HIV/AIDS services in the targeted areas.

2.9 Sampling techniques

All five (5) Bloom project implementation districts in the Central and Western region were selected for primary data collection. We utilised purposive sampling by selecting respondents based on their knowledge and lived experiences or involvement in planning and implementation/utilisation of HIV/AIDS services in the target communities. DHIS2 data for key HIV service delivery and utilization indicators for the period; April 2023 to June 2023 was abstracted to reveal the HIV/AIDS context in each of the 5 districts and to aid in comparison.

2.10 Field Administration

Bodmando's Global programmes manager supported the recruitment of data collectors who were locally recruited from the target districts to act as a cultural intermediary because of their high understanding of the target communities. The data collectors were then provided with an intense training on ethics, safeguarding and correct interpretation of the data collection tools. The programmes manager and Bloom project partners supported the identification and recruitment of study participants in the target communities. We also used avenues such as ART clinic days at selected health facilities to allow easy

access to young mothers living with HIV and CLWHIV. During data collection, the team leader organised daily virtual debriefs to address technical and operational bottlenecks and provided feedback to data collectors on how to probe better after listening to the audio recordings as part of quality assurance protocols.

2.11 Methods of Data Analysis

The Bodmando evaluation team employed both qualitative and quantitative data analysis approaches. The data collected from various sources was triangulated to ensure reliable research findings.

Analysis of qualitative data: The qualitative data collected through the KIIs, IDIs and FGDs was transcribed, cleaned, coded and analyzed using the *Atals.ti version 9 software*. We used both inductive and deductive coding techniques, generated sub-thematic and thematic categories and constructed relationships from the narrative. The emerging patterns of thinking were revealed and some quotations from the qualitative data have been included in this report to bring out the voices of the participants in regards to the challenges and enablers of access to HIV/AIDS services.

Quantitative data: Data was downloaded from the DHIS2 system and exported to Microsoft Excel for cleaning and analysis. Univariate level analysis was conducted to generate frequencies and percentages. Trends in demand and uptake of HIV treatment and support services by YMLHIV and CLWHIV in the 5 target districts were determined. We carried out a retrospective analysis of data for the period; April 2023 to June 2023 as this was the most current data.

2.12 Challenges faced during data collection

The challenge we faced was in relation to recruitment of CLWHIV. Based on the nature of the study, it required both assent from the children and consent from their parents or guardians. We worked with health facility In-charges who advised us to schedule for FGDs during ART clinic days where CLWHIV and young mothers could be accessed more conveniently.

2.13 Limitations of the evaluation

The evaluation did not involve survey data collection but rather relied solely on the DHIS2 system for quantitative data. Our analysis of the DHIS2 system showed missing data for some Bloom project HIV/AIDS indicators. Additionally, the structure of HIV/AIDS indicators in the DHIS2 system including the indicator descriptions and level of disaggregation was different from the indicators in the Bloom project indicator framework causing a misalignment. As a result, some indicators focused on the general population rather than the target groups.

2.14 Adherence to international evaluation quality standards

The Bodmando evaluation team ensured high quality research by paying attention to both the processes and products of the evaluation work. According to Better Evaluation, the 8 evaluation standards below identify how the quality of an evaluation will be judged²⁷. The Bodmando evaluation team undertook the

²⁷ Better Evaluation, "Evaluation Standards," accessed November 1, 2023, https://www.betterevaluation.org/methodsapproaches/methods/evaluation-standards.

following measures to ensure a high-quality evaluation study that is adherent to international best practice

Evaluation standards	Description
Independent	 The Bodmando evaluation team consulted Aidsfonds and three local implementing partners throughout the evaluation process But only to the extent that it did not influence the findings and recommendations.
Intentional	 The evaluation was grounded on a research framework with explicit objectives. Its overall objective was to establish the baseline characteristics against which progress of the Bloom project can be measured.
Transparent	 The research framework was developed in close consultation with Aidsfonds, its 3 local implementing partners and research enumerators. The study findings and recommendations arose inherently and were validated by all stakeholders.
Ethical	 Informed consent: Before asking any questions during the data collection phase, the interviewers explained the purpose of the interview/FGD. Data collection only commenced after the respondents had agreed to participate and written informed consent was secured. Recording of the sessions only took place after the research participants explicitly agreed by signing on the consent forms. We explicitly informed participants of their right to voluntary participation and the right to withdraw at any time with zero consequences. Confidentiality and anonymity: We used direct quotes from the study participants but anonymised their identities in this baseline evaluation report. We implemented a private and confidential data storage process where we uploaded documents to our cloud server for easy access by the research team and then encrypted files with passwords only known to the team leader and his assistant. Respect for communities: Field enumerators were locally recruited, and we ensured respect for participants in the study.
Impartial	 The Bodmando team remained objective, ensured professional integrity, and an unbiased view throughout the evaluation process. The views and perspectives of the various stakeholders were captured in a balanced and inherent manner in this evaluation report.
Of high quality	 Training of data collectors: The Bodmando evaluation team trained the data collectors in ethics, Bodmando's Child Protection and Safeguarding Policy and correct interpretation of the data collection tools. This built their capacity for quality data collection. Putting in place a sound data collection plan: The Bodmando evaluation team leader and Global programmes manager prepared sound data collection plans which allowed us to undertake the study following the set protocols and within the stipulated time frame, which has crucial implications for producing quality deliverables. Translation and pilot testing of research tools: To fulfil the quality criteria of cultural appropriateness, Bodmando translated the research tools. After data collection, the tools and data were reverse translated into English. The pre-testing of the data collection

Table 3: Table showing how the study met the international standards of evaluation (Based on the 8 standards by Better Evaluation)

	 tools was conducted for purposes of: testing the quality of the tools, whether they are fit for the evaluation for example, whether the sequence of questions is logical, the wording of the questions is clear, translations are accurate etc. And the FGD guide for CHWs was revised for simplification of questions such as questions around Paediatric HIV interventions which were found to be less understood by the relatively under educated participants. Data quality audits: The Bodmando evaluation team leader carried out daily debriefs and real time data quality audits to ensure that the incoming data met the quality specifications set. Specifically, we listened to the FGD/KII/IDI audios and provided real-time feedback to the data collectors on how to engage and probe better. This ensured that prospective interviews/FGDs were conducted more effectively. And all the qualitative and quantitative data was cleaned before analysis. Triangulation: The data for this evaluation arose from multiple sources and mixed methods. This ensured the triangulation and validation of findings across the various data sources which has high implications for quality. Peer review and edit: The draft evaluation report was peer-reviewed by Bodmando's researchers before sharing it with Aidsfonds to collect inputs for further refinement.
Timely	 The Bodmando evaluation team was very conscious of the set timeframes by the client (Aidsfonds). Forthwith, inception planning, data collection and report writing were all conducted within the set timeframes.
Usable	 The evaluation was designed to be utilization focused. In this regard, deep and iterative consultations were carried out for input from Aidsfonds and all the three local implementing partners. They all provided comments and feedback on the research framework, and these were all addressed by Bodmando's evaluation team. The research framework was approved by Aidsfonds. The Bloom partners highlighted their information needs by identifying a set of priority indicators for which baseline data was to be collected which ensured that the study was focused on addressing their information priorities; a prerequisite for usability. The findings were also validated and disseminated to the respective actors to ensure that the recommendations can be implemented.

3 Baseline Findings and Analysis

The baseline evaluation involved the collection of quantitative data to ascertain the baseline status of indicators and benchmark data against which future performances of the Bloom project will be measured. The Bloom project developed its own set of indicators to guide the measurement of project progress and each of the 3 partners (Joy Initiatives Uganda, Uganda Young Positives and Community health Alliance Uganda) have designated indicators and their respective targets. The Bloom partners were asked to highlight priority indicators for which baseline data was to be collected from the DHIS2 system. The Bloom indicators focussed on all domains of the Kids to Care framework from number of children, pregnant and lactating women referred from the community to the facility for HIV services, number of children and young mothers tested, enrolled and retained in HIV care. This included indicators on capacity building such as training of community health workers, young male and young fathers. However, Bodmando's analysis of the DHIS2 system showed missing data and disparities between the DHIS2 indicators and most of the Bloom project indicators in the parameters of age disaggregation, indicator type and description. For that reason, the results below are an illustration of the indicators with close similarity to the Bloom project indicators and for which data was available and disaggregated to capture the Bloom project's target age groups.

3.1 Objective 1: Determine key baseline indicators and benchmark data on demand for and access to PMTCT/HIV treatment and care services by young mothers living with HIV and their children.

In line with objective one of this study, the status of indicators as per the data retrieved from the DHIS2 system is indicated below. Important to note is that this data is an average for the quarter starting on 1^{st} of April 2023 and ending on 30^{th} June 2023.

3.1.1 Pregnant young women who test HIV positive during their first ANC visit

Figure 3 below shows that Kyenjojo district recorded 2 HIV positive test results among pregnant girls younger than 15 years of age. The HIV tests were conducted when the young pregnant girls went for their first ANC visit. The rest of the districts recorded no HIV positive test results amongst pregnant girls under the age of 15.

Among young pregnant girls, in the 15-19 age group who visited ANC clinic for the first time, Mubende district recorded 14 HIV positive test results followed by 13 for Kyenjojo, 10 for Mityana, 9 for Mpigi while Butambala district reported 1 HIV positive test result in the 15–19-year age band.

In the 20–24-year age band however, Mpigi and Mubende districts reported 33 HIV positive tests which was the joint highest number of HIV positive test results among pregnant young women who went for their first ANC visit, followed by 28 for Mityana, 15 for Kyenjojo and lastly 7 for Butambala. These results indicate that Mubende district accounted for the highest number of registered HIV positive test results both in the 15-19 year and 20–24-year age groups. FGDs conducted with young mothers (15-19 year and 20-24 year age groups) in the targeted district of Mubende could not directly explain the reasons for this observation but analysis of data showed a myriad of factors ranging from stock-out of essential HIV commodities such as ARVs, economic challenges and high difficulties in accessing HIV services due to factors such as long waiting time. Results call for more efforts by CHWs in sensitising young mothers in the communities to seek for ANC which presents an opportunity to test for HIV and be initiated on PMTCT.

Figure 3: Pregnant Women tested HIV+ for 1st time this pregnancy (TRR) at any ANC Visit

3.1.2 Exposed infants tested for HIV

Figure 4 below shows that Mityana district recorded 304 HIV tests by 1st PCR for exposed infants below 18 months of age with 5 cases turning out HIV positive. Mubende district and Kyenjojo district both registered 293 HIV tests by 1st PCR for exposed infants below 18 months of age with both recording 3 positive cases. While Mpigi district and Butambala district recorded 245 tests and 60 tests with 3 and 1 positive cases respectively. A further analysis of the data to ascertain the HIV positivity rate showed that Butambala district recorded the highest at 1.67% followed by 1.64% for Mityana district, 1.22% for Mpigi district and lastly Kyenjojo district and Mubende district both recorded 1.02%.

The infant HIV positivity rate compares the number of newly diagnosed cases of HIV amongst infants to the total number of infants tested for HIV in a given period. It provides a perspective on the rate of exposure of infants to HIV and the effectiveness of PMTCT programmes. Hence, the higher the HIV positivity rate for infants tested for HIV in a district, the greater their rate of exposure to HIV which can partly arise from vertical transmission during pregnancy, unskilled childbirth or breast milk, non-compliance of the mother to ART or other incidental risks such as needle pricks. Methuselah Muhindo Kahungu et al, (2018) found out that the HIV positivity rate was associated with place of delivery and receipt of infant ARVs at birth in addition to health system challenges especially staffing and a weak community follow up system for mother-baby pairs²⁸. Reducing the HIV positivity rate requires multi-faceted efforts by CHWs, the Bloom partners, district health officials, community leaders and other HIV implementing partners in strengthening of PMTCT programmes to ensure that young mothers living with HIV are found, tested and enrolled into HIV/AIDS care and support. It also requires the provision of skilled maternal care to prevent vertical transmission of HIV either during pregnancy, at birth or the postnatal period. This is in addition to the provision of counselling and support to the young mother on how to prevent the risks of HIV transmission to their child during the breast-feeding period and thereafter.

Table 4: : Table showing Exposed Infants	Tested for HIV	below 18 months	of age by 1st PC	:R – Total
Vs HIV+				

District	Mityana	Mubende	Butambala	Mpigi	Kyenjojo	TOTAL
105-ED01a. Exposed Infants						
Tested for HIV below 18	304	293	60	245	293	1195
months of age by 1st PCR -						

²⁸ Methuselah Muhindo Kahungu et al., "Factors Associated with HIV Positive Sero-Status among Exposed Infants Attending Care at Health Facilities: A Cross Sectional Study in Rural Uganda," *BMC Public Health* 18, no. 1 (December 2018): 139, https://doi.org/10.1186/s12889-018-5024-6.

District	Mityana	Mubende	Butambala	Mpigi	Kyenjojo	TOTAL
Total						
105-ED01c. Exposed Infants Tested for HIV below 18 months of age by 1st PCR - HIV+	5	3	1	3	3	15
Infant HIV Positivity rate	1.64%	1.02%	1.67%	1.22%	1.02%	1.26%

3.1.3 HIV tests conducted (1-4-year-olds)

Figure 5 below shows that the proportion of female vs male infants(1-4 years) tested for HIV was 197(53%) for female and 175 (47%) for male in the district of Mityana, 220 (47%) female and 249 (53%) male in Mubende, 90 (49%) female and 93 (51%) male in Butambala, 169 (50%) female and 50% (168) male in Mpigi, 323 (53%) female and 281 (47%) male in Kyenjojo district respectively. These results indicate minor inequities in access to HIV testing services for male and female 1–4-year-olds across all the 5 districts. Testing of infants for HIV is of high relevance when the young mother is living with HIV or where the infant is reportedly exposed to HIV. It allows for their protection against HIV infection through enrolment for Post Exposure Prophylaxis when exposed and to monitor the effectiveness of PMTCT programmes where the young mother is living with HIV.

Figure 4: Total tested for HIV (1-4 Years)-Female vs Male

3.1.4 HIV tests conducted (10–14-year-olds)

Figure 6 below shows that the proportion of females vs males (10-14 years) tested for HIV were 220 (67%) female and 109 (33%) male in the district of Mityana, 396 (77%) female and 117 (23%) male in the district of Mubende, 77 (52%) female and 71 (48%) male in Butambala, 152 (66%) female and 77 (34%) male in Mpigi district, 387 (58%) female and 281 (42%) male in Kyenjojo district respectively. These results indicate that more female 10–14-year-olds are carrying out HIV tests than their male counterparts in the same age bracket. Studies have shown than females are indeed more likely to carry out an HIV test than males. This shows that caregivers/parents have a higher likelihood of supporting females (10-14 years) to seek for HIV testing services when compared to males of the same age group.

Figure 5: Total tested for HIV(10-14 Years)-Female vs Male

3.1.5 HIV tests conducted (15–19-year-olds)

Under figure 7 below, the proportion of females vs males tested for HIV in the 15-19 year age bracket included 1799 (87%) for females and 274 (13%) for males in Mityana district, 2851 (74%) females and 1000 (26%) males in Mubende district, 458 (86%) females and 75 (14%) males in Butambala district, 1392 (86%) female and 222 (14%) male in Mpigi district and 2057 (82%) female and 462 (18%) male in Kyenjojo district. These results indicate a widening disproportion in the HIV tests conducted between females and males with far more tests conducted by females compared to males. According to Melanie Paige Moore and Faye Belgrave (2018), negative testing attitudes emerged as a significant factor in HIV testing for men and not women. The authors also argued that higher testing rates among young women compared to men may be attributed to annual gynaecological screenings for women as HIV testing may be conducted during these screenings²⁹. The low utilization of HIV services among males reflects general patterns of male health-seeking behaviour, which have been attributed to prevailing norms of masculinity, stigma, opportunity and other costs of attending health facilities.

Figure 6: Total tested for HIV(15-19 Years)-Female vs Male

3.1.6 HIV tests conducted (20–24-year-olds)

Figure 8 below shows that the proportion of females vs males tested for HIV in the 20-24 year age group included; 3975 (81%) females and 920 (19%) for males in Mityana district, 5403 (81%) females and 1278 (19%) males in Mubende district, 901 (87%) females and 129 (13%) males in

²⁹ Moore and Belgrave, "Gender Differences in Predictors of HIV Testing Among African American Young Adults."






3.1.7 Positive cases of HIV in children (1-4 years)

Table 4 shows that under the 1-4 year age band, Mityana district recorded 5(63%) of new HIV positive cases amongst females and 3(38%) amongst males while Mubende recorded 4(57%) females and 3(43%) males, Butambala 4(80%) females and 1(20%) males, Mpigi 2(67%) females and 1(33%) males while Kyenjojo recorded 3(38%) of HIV positive cases amongst females and 5(62%) amongst males. Results indicate that except for the district of Kyenjojo, there was a higher proportion of HIV positive cases recorded amongst females than males. Taha E. Taha et al., (2005) in their study entitled "Gender differences in perinatal HIV acquisition among African infants" found out that at birth, significantly more girls (12.6%) than boys (6.3%) were infected with HIV. This association remained significant after controlling for maternal viral load and other factors. Among infants who were uninfected at birth, 8.7% (135 of 1554 infants) acquired HIV by 6 to 8 weeks; of these infants, more girls acquired HIV (10.0%), compared with boys (7.4%). Robert J. Biggar et al., (2006) proposed that girls were at higher risk of early (in utero and perinatal) HIV infection than boys because minor histocompatibility reactions between maternal lymphocytes and infant Y chromosome-derived antigens reduce the risk of HIV transmission in boys³⁰.

	Mityana	Mubende	Butambala	Mpigi	Kyenjojo
105-Total New HIV positive (1-4 Years) - Female	5 (63%)	4(57%)	4(80%)	2(67%)	3(38%)
105-Total New HIV positive (1-4 Years) - Male	3(38%)	3(43%)	1(20%)	1(33%)	5(62%)

Table 5: Table showing the total New HIV positive cases (1-4 Years) - Female vs male

3.1.8 Positive cases of HIV in children (10-14 years)

Table 5 below shows that in the 10-14 year age group, Mityana district recorded O(O%) of HIV positive cases amongst females and 3(100%) amongst males, Mubende 3(60%) amongst females and 2(40%) amongst males, Mpigi 3(100%) females and O(O%) males while Kyenjojo district recorded 28(68%) of cases amongst females and 13(32%) amongst males. This shows that except for the district of Mityana, more female children (10-14 years) acquired HIV compared to their

male counterparts in the same age bracket. Butambala was excluded from the analysis because of missing data.

	Mityana	Mubende	Butambala	Mpigi	Kyenjojo
105-Total New HIV positive (10-14 Years) - Female	0(0%)	3(60%)	xx	3(100%)	28(68%)
105-Total New HIV positive (10-14 Years) - Male	3(100%)	2(40%)	xx	0(0%)	13(32%)

Table 6: Table showing the total New HIV positive cases (10-14 Years) - Female vs male

3.1.9 Positive cases of HIV amongst young mothers (15-19 years)

In the 15-19 year age band, Mityana district recorded 25(100%) of new HIV positive cases amongst females and 0(0%) amongst males, Mubende district recorded 36(95%) amongst females and 2(5%) among males, Butambala 3(75%) among females and 1(25%) among males, Mpigi 15(94%) among females and 1(6%) among males while Kyenjojo district recorded 33(79%) of new HIV positive cases amongst among females and 9(21%) amongst males. These findings are consistent with the narrative that adolescent girls are disproportionately affected by HIV compared to their male counterparts in the same age group. These challenges include gender-based violence, harmful cultural and traditional practices that reinforce stigma and the dynamic of male dominance.

Table 7: Table showing the total New HIV positive cases (15-19 Years) – Female vs male

	Mityana	Mubende	Butambala	Mpigi	Kyenjojo
105-Total New HIV positive (15-19 Years) - Female	25(100%)	36(95%)	3(75%)	15(94%)	33(79%)
105-Total New HIV positive (15-19 Years) - Male	0(0%)	2(5%)	1(25%)	1(6%)	9(21%)

3.1.10 Positive cases of HIV amongst young mothers (20-24 years)

Table 7 below shows that there were 83(87%) of new HIV positive cases amongst 20–24-year-olds in the district of Mityana and 12(13%) among males. While in the districts of Mubende, Butambala, Mpigi and Kyenjojo, there were 87(89%) and 11(11%, 20(91%) and 2(9%), 77(89%) and 10(11%), 66(78%) and 19(22%) of new HIV positive cases amongst females and males respectively. This again showcases the disproportionate share of the HIV burden amongst females when compared to their male counterparts.

Table 8: Table showing the total New HIV positive cases (20-24 Years) – Female vs male

	Mityana	Mubende	Butambala	Mpigi	Kyenjojo
105-Total New HIV positive (20-24 Years) - Female	83(87%)	87(89%)	20(91%)	77(89%)	66(78%)
105-Total New HIV positive (20-24 Years) - Male	12(13%)	11(11%)	2(9%)	10(11%)	19(22%)

3.1.11 HIV exposed infants given ARV prophylaxis

Figure 9 below shows that during the quarter ending June 2023, Mityana district recorded the highest number of HIV exposed infants who were given ARV prophylaxis for the first time at mother baby care point 189 (40%) followed by Kyenjojo district 119 (25%), Mubende 70 (15%), Mpigi 62 (13%) and Butambala 29 (6%). The provision of ARV prophylaxis to exposed infants is a critical component of PMTCT programmes. Young mothers living with HIV in the district of Mityana highlighted that they are provided with routine health education by health care workers. This is a predictor and one of the likely explanations for the higher level of PMTCT service utilisation when compared to other districts. *"… routine health education talks or teaching of*

mothers on the importance of PMTCT services has helped us...." (FGD, Young Mothers Living with HIV, Mityana district). Results call for more health education talks by Bloom partners on PMTCT targeting pregnancy and breast-feeding young mothers especially in the low performing districts.





3.1.12 Young mothers initiated on ART

Figure 10 below shows that during the quarter ending June 2023 and in the younger than 15 year age group, Kyenjojo district recorded 2 cases of HIV positive pregnant women initiated on ART for eMTCT at any visit irrespective of when tested HIV positive. The rest of the districts recorded 0 cases. These results indicate that a high proportion of younger than 15-year-olds is not being initiated on ART. This is because despite recording 0 cases of younger than 15-year-olds initiated on ART, the district of Mityana registered at least 5 HIV positive cases amongst younger than 15-year-olds while Mubende registered 7, Butambala 4 and Mpigi registered 5 HIV positive results amongst females younger than 15 years of age. The district of Kyenjojo also had registered at least 31 HIV positive cases with only 2 initiated on ART. This calls for more efforts by the Bloom partners in working with health facilities to sensitise on the importance of ART initiation as per the HIV consolidated guidelines. The results may also point to the suggestion that the ART supply may be inadequate at public health facilities and so the young mother's resort to the private sector to fulfil their HIV treatment needs.



Figure 9: Number of HIV POSITIVE pregnant women initiated on ART for eMTCT at any visit irrespective of when tested HIV POSITIVE (younger than15 Years)

women initiated on ART (36 tested positive), followed by 12 for Kyenjojo (33 tested positive), 9 for

Mpigi (15 tested positive), 7 for Mityana (25 tested positive) and 1 for Butambala (3 tested positive). This shows that enrolment into care is significantly low across all the 5 districts which calls for more efforts by the Bloom partners in sensitising health facilities to scale up ART initiation.



Figure 10: Number of HIV POSITIVE pregnant women initiated on ART for eMTCT at any visit irrespective of when tested HIV POSITIVE (15-19Years)

Amongst the 20–24-year-olds, Mubende recorded 34 cases of young mothers 20-24 years initiated on ART (87 tested positive) followed by 32 for Mpigi (77 tested positive), 28 for Mityana (83 tested positive), 17 for Kyenjojo (66 tested positive) and 7 for Butambala (20 tested positive).



Figure 11: HIV POSITIVE pregnant women initiated on ART for eMTCT at any visit irrespective of when tested HIV POSITIVE- 20-24 Years

Table 8 below illustrates the cases of LTFU in the 5 Bloom project districts for the period; April 2023 to June 2023. Our observation of the DHIS2 system showed 40% missing data across the various Bloom age categories and in all the 5 districts making comparative analysis of LTFU particularly difficult. There is a myriad of factors responsible for LTFU amongst children and young mothers in Uganda. Among infants, Rogers Ankunda et al. (2020) found out that young maternal age, long distance to the health facility and failure to use family planning were significantly associated with LTFU. The authors added that short childbirth spacing, child wellbeing, lack of

transport, lack of partner support, client waiting time, and limited waiting space at the health facility, behaviour of health workers, and breach of confidentiality may also influence LTFU among HIV-exposed infants³¹.

While in their study entitled "Loss to Follow-Up among HIV Positive Pregnant and Lactating Mothers on Lifelong Antiretroviral Therapy for PMTCT in Rural Uganda", Matilda Kweyamba et al., (2018) reported substantial LTFU of mothers initiated on lifelong ART for PMTCT in Ntungamo district. Personal fears, wrong perceptions among patients, stigma and discrimination in the community, high transport costs, long patient waiting time, and inadequate facilitation of peer educators were some of the challenges that led to the observed high LTFU rates³².

To keep CLWHIV and young mothers living with HIV in care, it is necessary to address the observed factors responsible for causing LTFU in the first place. Our interaction with CHWs, health facility In-charges and district HIV focal persons in the 5 Bloom project districts revealed that the use of phone calls/reminders to young mothers and children, home visits for drug refills and psychosocial support, enhancement of counselling sessions to address challenges that young mothers and their CLWHIV face can contribute towards a reduction in LTFU. They also recommended that health facilities generate lists of lost patients and share them with CHWs for follow up.

".... health facilities to generate lists of lost clients and handing them over to Village Health Teams (VHTS) to follow up these clients" (FGD, CHWs, Kyenjojo district).

	Mityana	Mubende	Butambala	Mpigi	Kyenjojo
Indicator	District	District	District	District	District
106a-HC24-ART clients that were lost to					
follow-up during the quarter 1-4 years,					
Female	xx	xx	xx	2.0	3.0
106a-HC24-ART clients that were lost to					
follow-up during the quarter 1-4 years,					
Male	1.0	xx	xx	1.0	xx
106a-HC24-ART clients that were lost to					
follow-up during the quarter 10-14 years,					
Female	1.0	xx	xx	4.0	4.0
106a-HC24-ART clients that were lost to					
follow-up during the quarter 10-14 years,					
Male	2.0	xx	xx	1.0	2.0
106a-HC24-ART clients that were lost to					
follow-up during the quarter 15-19 years,					
Female	5.0	xx	2.0	11.0	3.0
106a-HC24-ART clients that were lost to					
follow-up during the quarter 15-19 years,					
Male	1.0	xx	2.0	4.0	xx
106a-HC24-ART clients that were lost to					
follow-up during the quarter 20-24 years,					
Female	8.0	4.0	3.0	23.0	13.0

Table 9: Table showing cases of Lost To Follow Up in the 5 Bloom districts (xx means missing data)

³¹ Rogers Ankunda et al., "Loss to Follow-up and Associated Maternal Factors among HIV-Exposed Infants at the Mbarara Regional Referral Hospital, Uganda: A Retrospective Study," *BMC Infectious Diseases* 20, no. 1 (December 2020): 235, https://doi.org/10.1186/s12879-020-04964-1.

³² Matilda Kweyamba et al., "Loss to Follow-Up among HIV Positive Pregnant and Lactating Mothers on Lifelong Antiretroviral Therapy for PMTCT in Rural Uganda," *Advances in Public Health* 2018 (July 2, 2018): 1–9, https://doi.org/10.1155/2018/7540587.

Indicator	Mityana District	Mubende District	Butambala District	Mpigi District	Kyenjojo District
106a-HC24-ART clients that were lost to					
follow-up during the quarter 20-24 years,					
Male	xx	xx	xx	3.0	3.0

The findings revealed the status of indicators in the project implementation districts. Overall, we observed disproportionate access to HIV testing services with females having higher access than males. This is also consistent with the number of cases of HIV recorded amongst males and females. It was also observed that enrolment into HIV care is low as a majority of young mothers and children are not being enrolled at the point of care which calls for deliberate efforts by the Bloom project on addressing this short fall.

3.2 Objective 2: Provide general benchmark information on the current situation regarding existing government policies/guidelines on young mothers, uptake of (informal) health services at community and facility level.

The study also sought to establish the current situation regarding the existing government policies/guidelines on young mothers, uptake of (informal) health services at community and facility level, retention rates, and PMTCT/paediatric HIV care. Findings from desk review, key informant interviews and in-depth interviews revealed several policies as indicated below.

3.2.1 Findings from Desk review

Adolescent Health Policy Guidelines and Service Standards

The Ugandan MoH recognises that adolescents are a special group with unique needs that must be met by the health and social service sector. It devised the adolescent health policy guidelines and service standards to mainstream adolescent health concerns in the national development process in order to improve their quality of life and standards of living³³. This policy provides a framework for the delivery of adolescent and youth friendly services, which include the following;

- Clinical Care for Sexual gender-based violence: Includes the provision of post exposure prophylaxis, emergency contraceptives, psychosocial counselling, and further referral for legal support services.
- Prenatal care and maternity care for pregnant adolescents: Includes health assessments, addressing of any pre-existing medical conditions or risk factors that may affect pregnancy, ensuring access to a range of reproductive health services, including contraception, PMTCT services, STI testing and treatment and access to skilled obstetric care.
- HPV immunization: Provision of the HPV vaccine to young girls at the ages of 11–12 years.
- HIV counseling and testing: Provision of HIV testing and counselling services in the community outreaches and youth corners.
- Information and counselling on health especially growth and development: Involves building awareness on general health and wellbeing, adolescent body changes, coping with stress, menstrual challenges.
- Information on their rights and responsibilities: Involves sensitization on Sexual and Reproductive Health and Rights (SRHR) such as the right of access to contraceptives and SRHR information.
- **Referral and follow up:** Involves the establishment of referral systems for unrestricted access to SRH information and services within the communities and health facilities.

³³ Ministry of Health, "Adolescent Health Policy Guidelines and Service Standards," 2012.

The National Sexuality Education Framework

In 2018, the Ministry of Education and Sports launched the National Sexuality Education Framework; the first ever guideline on sexuality education which seeks to create an overarching national direction for response in respect to sexuality education in the formal setting of educating young people in Uganda. The development of this national guideline is a blueprint in guiding the teaching of age appropriate, cultural and religious sensitive sexuality education in schools. The framework has however been criticized for being silent on the rights of access of adolescents to some SRHR services such as condoms which are a key preventive measure against HIV/AIDS³⁴³⁵.

Other policies include; 1. The National Paediatric and Adolescent HIV Advocacy Strategy and Road Map 2022-2026 whose overall objective is to provide standardized practical approaches to guide stakeholders in planning, designing, implementing and evaluating paediatric and adolescent HIV initiatives, 2. Consolidated guidelines for the prevention and treatment of HIV/AIDS in Uganda which provide guidance on HIV prevention, diagnosis, and treatment including in children and young women, 3. The national policy guidelines on ending HIV stigma and discrimination which seek to address HIV related stereotypes and cases of stigma and discrimination³⁶ and 4. The National Communication Plan for HIV Testing Services which provides a framework within which the design, implementation and evaluation of SBCC interventions is undertaken.

3.2.2 Findings from the key informant interviews and in-depth interviews

Test and treat policy

Findings indicate that the Ministry of Health introduced the test and treat policy to ensure that HIV positive children and young mothers get access to HIV care and support services. The "test and treat" policy involves providing lifelong ART to people living with HIV irrespective of CD4 count or WHO HIV clinical staging. This is part of the targeted approach taken to ensure that persons living with HIV get access to timely care and treatment to prevent a deterioration into AIDS. A government health care worker who serves as a Health Centre IV In-charge in Kyenjojo district stated that; "*Government has a policy of test and treat whereby in case a person tests positive for HIV, they are able to start treatment right there and then*". (Health Centre IV In-charge, Kyenjojo district)

In compliance with WHO recommendations, the Ministry of Health removed all limitations on eligibility for ART among all people living with HIV: all populations and age groups became eligible for treatment. This was a significant policy change aimed at consolidating the gains made in the past decades to reverse AIDS as a public health problem in Uganda. In addition, the 2016 guidelines do recommend HIV pre-exposure prophylaxis for HIV uninfected persons at substantial risk of HIV acquisition³⁷.

Delivery in formal health care facilities for expectant mothers living with HIV

Government requires that HIV positive expectant mothers deliver at formal health care facilities in order to reduce any possible mother to child transmission of HIV. Delivery in formal health care facilities allows access to skilled care and provision of PMTCT services if the mother is living with HIV. This was narrated by one CHW in the district of Kyenjojo who indicated that young mothers are often encouraged by the MoH and district health actors to deliver in formal health care facilities. However, delivery in informal health care facilities is still believed to take place especially

³⁴ UNFPA, "The Government of Uganda Launches the National Sexuality Education Framework," UNFPA Uganda, May 14, 2018, https://uganda.unfpa.org/en/news/government-uganda-launches-national-sexuality-education-framework.

³⁵ Pathfinder International, "A Global Landscape Assessment and Mapping Study of Private Sector QA/QI Mechanisms for

Contraceptive Services Including the New & Promising Approaches with Potential to Incentivize the Private Sector to Deliver Person Centered Contraceptive Services.," 2023.

²⁶ Uganda AIDS Commission., "NATIONAL POLICY GUIDELINES ON ENDING HIV STIGMA AND DISCRIMINATION."

³⁷ MOH, "CONSOLIDATED GUIDELINES FOR THE PREVENTION AND TREATMENT OF HIV IN UGANDA," 2018.

in the rural areas where young mothers face difficulties in accessing skilled obstetric care. Here, the Traditional Birth Attendants (TBAs) oversee the delivery process but because of their limited skills, government banned the use of TBAs in 2010 with hope of improving maternal and infant mortality rates. The CHW narrated that;

'An HIV expectant mother should deliver her baby from a health facility so that the health workers can stop HIV transmission to the child". (KII, CHW, Kyenjojo district).

Guidelines on breastfeeding for young mothers living with HIV

Additionally, it is reported that government introduced a policy for HIV positive breastfeeding mothers. This policy requires the cessation of breastfeeding at 6 months. This is narrated to be a strategy for elimination of mother to child transmission. This was reported by a local implementing partner who stated that;

"There is also another policy whereby an HIV infected mother is supposed to stop breastfeeding when the child becomes six months old in order to avoid mother to child transmission". (KII, local implementing partner, Mityana district)

The 95-95-95 policy

Another local implementing partner indicated that government introduced a policy on the proportion of people who should know their status, initiated on HIV treatment if found positive and viral load suppressed. It is called the 95-95-95 policy. He indicated that

"We have the 95 policy whereby 95% of the people should know their status, 95% of them if found to be negative should be started on HIV medicine and 95% of them should have their HIV viral load suppressed" **(**KII, representative ACORD, Kyenjojo district).

According to the Uganda Population-based HIV Impact Assessment (UPHIA 2020-2021) survey, Uganda has met the second 95-95-95 target, over 95% of adults living with HIV who were aware of their status were on ART, well in advance of the 2025 target date, and among those on ART, the country is approaching the third 95 target for the prevalence of VLS. The proportion of those with suppressed viral loads ranged from 57.8% among adolescent girls and young women (AGYW) aged 15-24 years to 97.9% among women aged 65 years and older. But the lack of paediatric data is one of the shortcomings of the survey findings³⁸.

ANC attendance for Young Women Living with HIV

Existing government guidelines for young women living with HIV prescribe that expectant mothers living with HIV regularly attend ANC to enable the monitoring of their response to HIV treatment during pregnancy. This approach allows the prevention of mother to child transmission which is a risk during pregnancy and childbirth. This was confirmed by one implementing partner who indicated that;

"There is one policy that I know, and it is required that an expectant mother attends antenatal care and services, and this helps health workers to know how the mother has been responding to the given treatment and care. And the health workers can't attend to an expectant mother since they don't know about their medical history.". (KII, Implementing partner (Joy CDC), Mityana district).

Box 2: How can the Bloom project build on these policies/guidelines to ensure sustainability?

Based on the feedback from the key informants, below are some of the recommendations.Build the capacity of CHWs and strengthen HIV/AIDS referral systems

- Support VSLAs to economically empower YWLHIV in navigating the financial barriers associated with access to HIV treatment and support services
- Support active follow up mechanisms to increase retention rates for YWLHIV and their children.
- Bloom should support profiling and segmentation of YWLHIV for more focused HIV/AIDS care and support services.
- Support routine health education and HIV testing interventions

It is necessary that the Bloom project works with partner health facilities in the targeted areas and CHWs to support the implementation of the above policies as they provide an enabling environment for the provision of HIV/AIDS services to young mothers and their children. Setting up a mechanism for policy dissemination is important in building of awareness of CHWs and other stakeholders on the guidelines for HIV/AIDS testing, treatment and support. And if properly implemented under the Bloom project, it will likely contribute to improved outcomes for young mothers and their CLWHIV.

3.3 Objective 3: Understand the facilitators and barriers of young mothers and their children in enrolment for eMTCT, HIV care and support services

As per objective three, the study sought to illustrate the enabling and impeding factors in enrolment for HIV care and support services by young mothers living with HIV and their CLWHIV in addition to understanding the process of HIV care, treatment and support in the target districts. With the aid of five (5) locally recruited field enumerators, Bodmando Consulting Group conducted 20 Focus Group discussions, 12 in-depth interviews and 18 key informant interviews. Details of the selected participants can be obtained under <u>Annex 2: The sampling distribution</u>. Primary data was collected from all the 5 districts of Butambala, Mubende, Mpigi, Mityana and Kyenjojo.

3.3.1 Social demographic characteristics of respondents

Below are the social demographic characteristics of the respondents. We also highlight results of key indicators such as the proportion of YMLHIV and CLWHIV with a disability, those part of an HIV social support group, have ever received training on nutritional support amongst others. According to figure 13, males were represented at a percentage of 65% compared to 35% for females during the key informant interviews and in-depth interviews. Children Living with HIV (younger than 10 years)



Figure 12: Figure showing the proportion of males versus female interview participants

Bodmando researchers carried out focus group discussions with cohorts of children living with HIV below the age of 10 years in all the 5 districts. Table 9 below indicates that 60% of the FGD participants younger than 10 years of age were males while 40% were females. The average age of males was 8.2 years while that of females was 8.5 years. The proportion of CLWHIV who indicated that they were part of a support group for CLWHIV was 33% for males and 25% for females.

These results indicate that female CLWHIV have relatively lower access to HIV social support compared to their male counterparts and they also indicate that CLWHIV have relatively lower access to social support services. This calls for more efforts by the Bloom partners in linking CLWHIV to social support services.

Table 10: Table showing the social demographic characteristics of FGD participants-CLWHIV
(younger than 10 years)

		Average age	Part of any su for C	upport group LHIV	Disability statu	
			Yes	No	Yes	No
				67%		
М	60%	8.2	33%		0%	100%
F	40%	8.5	25%	75%	0%	100%

Children Living with HIV (10-14 years)

For the FGDs involving CLWHIV between 10-14 years, 57% were female while 43% were males. The average age of males was 12.5 years while that of females was 12.2 years. None of the CLWHIV reported having a disability. Additionally, 50% of females and 50% of males indicated that they were part of a social support group for CLWHIV. These findings indicate that 50% of CLWHIV between 10-14 years have no access to HIV social support services. The HIV social support network is of tremendous importance in helping CLWHIV maintain good mental health due to the emotional support provided by peers and low access is a detriment to their overall health and wellbeing.

Table 11: Table showing the social demographic characteristics of FGD participants-CLWHIV (10-14 years)

		Average age	Part of any support group for CLHIV		Disability status	
			Yes	Νο	Yes	No
м	43%	12.5	50%	50%	0%	100%
F	57%	12.2	50%	50%	0%	100%

Young Mothers Living with HIV (15-19 years)

Results under table 11 below indicate that 56% of young mothers living with HIV (15-19 years) are part of an HIV social support group, 56% have ever received training on nutritional support and 100% had ever tested their child for HIV. Results also indicate that 22% of the young mothers have a child living with HIV and 22% of the young mothers had ever taken their child for a viral load suppression test. While 67% of them reported that they are part of income generating activities. These results show that young mothers living with HIV (15-19) years have all utilised HIV testing services for their children and hence do know the HIV status of their children which is a promising finding. However, they also demonstrate that more trainings on nutritional support and linkage to HIV social support groups are necessary to ensure navigation of shared challenges in their welfare.

Table 12: Table showing the showing the responses to selected indicators by young mothers living with HIV (15-19 years)

	Do you identify as a person with disability? (Yes/ No)	Are you part of a support group? (Yes/ No)	Have you ever received a training on nutritional support (Yes/ No)	Have you ever tested your child for HIV?	Do you have a child living with HIV?	Are you part of any income generating activities? Yes/ No)	Has the child ever taken a viral load suppression test? (Yes/No)
Yes	0%	56%	56%	100%	22%	67%	22%
No	100%	44%	44%	0%	78%	33%	78%

Personal income is important in promoting continued access to HIV treatment and support services by YMLHIV. It facilitates the transportation of young mothers to health facilities, access to proper nutrition, and purchase of drugs in the event of stock outs. Results indicated that 33% of them were not part of any income generating activities which can stifle their ability to access HIV care and support services. Hence, linkage to economic empowerment programmes is of high importance.

Young Mothers Living with HIV (20-24 years)

Results under table 12 below indicate that 42% of the young mothers (20-24 years) are part of an HIV social support group, 39% have ever received training on nutritional support and 91% had ever tested their child for HIV. Results also indicate that none of the young mothers has a child living with HIV and 0% of the young mothers had ever taken their child for a viral load suppression test. While 62% of them reported that they are part of income generating activities. These results indicate that more efforts are required by the Bloom partners in linking young mothers living with HIV to social support networks as most of them reported that they are not part of any HIV social support group. Additionally, more trainings on nutritional support are required as this is a core component of HIV treatment and support.

Table 13: Table s	showing the showing the responses to selected indicate	ors by young mothers living
with HIV (15-19)	years)	

	Do you identify as a person with disability? (Yes/ No)	Are you part of a support group? (Yes/ No)	Have you ever received a training on nutritional support(Yes/ No)	Have you ever tested your child for HIV?	Do you have a child living with HIV?	Are you part of any income generating activities? Yes/ No)	Has the child ever taken a viral load suppression test? (Yes/No)
Yes	0%	42%	39%	91%	0%	62%	0%
No	100%	58%	61%	9%	100%	38%	100%

3.3.2 The Life of a Ugandan young mother and child living with HIV

During the focus group discussions, Bodmando sought to establish the life of a Ugandan young mother living with HIV and their CLWHIV to better understand the context within which they live and how it could potentially affect their welfare and HIV treatment outcomes.

Young mothers living with HIV have unique challenges when compared with mothers living with HIV in general. This generally originates from age-associated factors such as economic unproductivity of young mothers especially teenage mothers which poses barriers in access to HIV/AIDS services. Additionally, adolescent mothers tend to have lower knowledge of HIV/AIDS and its risks when compared to older mothers, are more prone to peer influence and sexual exploitation because of their poorer financial status and limited peer resistance.

CLWHIV are also noted to be different from children in general because their HIV status requires unique support in the form of care and counselling, food and nutrition and psychosocial support. Because of underdevelopment, CLWHIV are more prone to the effects of stigma and discrimination, medicinal side effects and other challenges in accessing HIV/AIDS services and require the requisite social and family support. In the absence of proper care and counselling, it is likely to affect their growth and development.

3.3.3 The life of children living with HIV

In our interaction with CLWHIV, we asked them to narrate the life they go through within their communities and their responses were related to their HIV status which was inherent in the nature of the topic. In the home environment, CLWHIV acknowledged the support they receive from family members in accessing HIV services and through the reminders they receive to take ART medication. Family members are also noted to promote access to food and nutrition support and one child narrated that they are provided with milk during medication time as part of side effect management.

In the school environment, they narrated the support they receive from school matrons who are said to provide support in daily administration of ART to CLWHIV and the provision of counselling. School matrons usually work in a boarding school and are responsible for the health and well-being of the pupils. However, all is not as good as it seems for school going CLWHIV. HIV/AIDS stigma continues to negatively affect their welfare and one of them narrated of how they were cautioned by their parents against disclosure of their HIV status out of fear of inciting discrimination despite their willingness to do so. He added that at school, they are forced to take their dose of ART in hiding and sometimes hurriedly to avoid detection. This is a prime example of the existence of stigma as a barrier facing school going CLWHIV and how it shapes their interaction with society. All these factors may potentially interact and affect the mental health of the affected children which was evident in the verbal and nonverbal cues of the FGD discussant.

"For my case, I have ever been in a boarding school but I once told my parents to inform the people about my HIV status, but they refused, and they told me that the people at school will also inform our neighbours since we stay in the same area with the people at school. And they will start to discriminate me.... My medicine was always wrapped in a cloth, and I would hide it in my suitcase back in boarding school. And through that, I never missed any dose of the medicine. I was given medicine for the whole term. I started schooling in boarding in the second term. I never stayed long in boarding school". (FGD, CLWHIV, Mubende district).

In conclusion, the narratives shared by children living with HIV (CLWHIV) provide a glimpse into the multifaceted challenges they encounter within their communities and educational environments. While the crucial role of family support in accessing HIV services and managing medication is acknowledged, the pervasive issue of HIV/AIDS stigma casts a shadow over the lives of school going CLWHIV. Despite the assistance from school matrons, these children face the harsh reality of concealing their HIV status, experiencing the fear of discrimination, and resorting to clandestine administration of medication. The poignant stories underscore the urgent need for comprehensive strategies to address stigma, promote open dialogue, and foster a supportive environment for CLWHIV in both home and school settings. The intersection of these challenges highlights the potential impact on the mental health of these children, emphasizing the importance of holistic interventions to enhance their overall well-being and ensure a more inclusive and understanding society.

3.3.4 The life of a young mother living with HIV

Bodmando also explored the lived experiences of young mothers living with HIV by asking for their narration during the FGDs. As the topic was HIV related, the young mothers responded in the context of their HIV status. Most of them revealed that financial hardships characterise their life and this compounds their ability to access health facilities. And in some instances, groups of young mothers mobilise financial resources to support one of their fellow young mothers to seek for services at the health care facility. Financial challenges were narrated not to only hamper their ability to seek services but to also access adequate food and nutrition with some of them forced to take the medication on an empty stomach leading to side effects such as fatigue and dizziness. Parents and spouses have been at times helpful through personal support and encouragement, but this obstacle remains. And yet the double burden of looking after their children and themselves continues to even compound an already unfavourable situation. Young mothers living with HIV in the district of Butambala and Mubende also narrated that in addition to ensuring that their children get access to proper HIV/AIDS care, they also must take care of other expenses such as school fees and rental costs. All these create a challenging environment that negatively affects their continued access to HIV services.

"For the kind of help that I get from my parents is that I got to know in 2020 that my mother gave birth to me when I am HIV positive.so after finding this out, I told my mother that we should not keep silent about it so I told her that we should tell my brother and since then, he has been supportive in a way that he provides the transport in time and all the things that I need to sustain my everyday life. And sometimes I call him to request for transport, sugar and I don't take my medicine with water, I take my medicine with milk, and he has been supportive in anything that concerns my life". (FGD, young mothers living with HIV, Butambala district).

Finding, testing, treating and retaining young mothers living with HIV in care remains a challenge in Uganda. However, tackling the challenges of these vulnerable populations, understanding the facilitators of access to Paediatric HIV and PMTCT and emphasizing activities which first find these populations can be a good step in the achievement of desired treatment outcomes. Important to add is that addressing of the finance challenges facing young mothers is another crucial step in ensuring unhindered access to HIV services.

3.3.5 Processes in the delivery of eMTCT, HIV care, support and treatment services to young mothers and their children

The evaluation sought to establish the service delivery processes for eMTCT, HIV care, support and treatment services in the target areas. The evaluation uncovered several innovative service delivery processes which included the DSD (Differentiated Service Delivery Model) model for HIV service delivery, the use of CHWs and notification personnel, the Young Adolescent Peer Supporters (YAPS) model and the young people clinics/child clinics.

3.3.6 Differentiated Service Delivery Model (DSD)

In a discussion with one district HIV focal person, it was revealed that the district rolled out the DSD model as an initiative of the Ministry of Health in the provision of appropriate HIV services tailored to the needs of target communities including young mothers and their HIV positive children. He narrated that;

".....Here, we have the DSD model for HIV service delivery of the required services. This allows us to organise HIV services to improve efficiency and effectiveness in addressing the needs of target groups such as the children and young mothers living with HIV... For the children and the young mothers, we also have the Facility Based Groups (FBG) whereby they are 10 of them......We also conduct peer counselling". (KII, District HIV Focal person). The Uganda national consolidated HIV prevention, care and treatment guidelines of 2016, recommend DSD as a critical strategy to enable Uganda to achieve the UNAIDS 90-90-90 goals. The aim is to encourage greater use of differentiated care in increased numbers of facilities and to achieve the same or better results with the same or less resources, and without policy changes or additional resources³⁹.

According to the MoH, services should be differentiated by considering the unique needs of each specific sub-population. As models of DSD are being designed and implemented, special attention should be given to finding possible solutions addressing these unique needs rather than seeing them as barriers to implementation⁴⁰. Subpopulation groups covered include:

- Children
- Adolescents
- Pregnant women
- Lactating women
- Adult men and women
- Key populations including female sex workers, men who have sex with men i.e. MSMs, Transgender i.e. TGs, people who inject drugs i.e. PWIDs, fishing communities, truckers etc.; marginalized or minority groups such as un-documented migrants, ethnic and sexual minorities etc.

3.3.7 Working with Community Health Workers

A narration from an In-charge of a Heath Centre IV in Mityana district revealed that CHWs support the provision of HIV testing and treatment services. They support making of calls to young mothers who test HIV Positive and tracking of ART deliveries. The CHWs play a role in community mobilisation, making of referrals and home delivery of ART. They have proved to be a critical component in community linkage but are largely demotivated due to low stipends leading to high attrition rates. The In-charge stated that young mothers and children with suppressed viral loads are advised to return to the facility after 6 months while those with non-suppressed viral loads are usually advised to turn up every day.

"Now like here we have voluntary village health facilitators who look up and make follow ups.....We have VHTs that help us to conduct the testing and treatment services....We use phone calls to the people and we also track people who deliver the ART services....If someone is newly diagnosed, after seeing that they are complying we tell them to visit after 6 months if they are suppressing their viral loads and for those that are not suppressing, we tell them to visit every day. (In-Charge, Health Centre IV, Mityana district).

3.3.8 The Young Adolescents and Peer Supporters model

During interviews held with various participants such as ACCORD (Agency for Cooperation in Research and Development Uganda); an HIV implementing partner, Health Centre IV In-charges for 2 districts, a community support group representative and a representative from a network of young people living with HIV, it was revealed that the YAPS model has been deployed as an initiative of the MoH to improve on HIV service delivery to young mothers and their children. A health centre IV In-charge narrated that YAPS play a significant role in the delivery of ART drugs to the homes of young mothers rather than them visiting the health facility. This is said to solve the transport challenges associated with seeking for HIV treatment services. A community support group representative from Mityana district narrated that YAPS are involved in service delivery. They support follow up through phone calls to remind the young mothers to come for services while an In-charge indicated that the YAPS also carry out contact tracing and use bicycles to

³⁹ Ministry of Health, "Implementation Guide for Differentiated Service Delivery Models of HIV and TB Services in Uganda," 2020. ⁴⁰ Ministry of Health. deliver ART to the homes of young mothers living with HIV and their children. YAPS are also noted to promote livelihoods and economic empowerment of young mothers by providing them with technical skills in bakery and liquid soap making.

"We have YAPS who deliver treatment to the respective HIV positive mothers and other people in the community and they also offer testing services....We offered bicycles to treatment supporters (YAPs) to ease their transportation to the communities when they are going to deliver the medicine to the homes of the HIV positive mothers....They conduct contact tracing whereby we trace the patients to their homes and we deliver the medicine to them" (In charge health centre IV)

"We work with YAPs groups whereby we provide conventionery skills (soft skills) whereby we teach them bakery, liquid soap making.....We also have ECD (Early Childhood Development) sessions that we provide to these young mothers whereby we teach these young mothers about how not to infect their kids whereby we also teach them about nutrition" (KII, ACCORD, Kyenjojo district).

The YAPS Programme is an initiative of the Ministry of Health and partners including UNICEF, Global Fund with funding from SIDA and USAID. The programme aims at improving the quality of HIV care and to increase the retention of HIV positive young adults in HIV care. In 2018, MOH/ACP developed the YAPS model as recommended by WHO and piloted it in 9 districts. The YAPS model is a multi-sectoral intervention implemented by adolescents and young people living with HIV with the purpose of increasing identification of HIV positive AYPs, improving their linkage into care, retention, adherence, and viral suppression to improve their health and quality of life. The YAPS program is now implemented in 136 districts country wide in over 600 health facilities⁴¹.

3.3.9 Barriers in the service delivery processes for eMTCT, HIV care, support and treatment services for young mothers and their children

The evaluation revealed weaknesses in the financing mechanisms for the service delivery processes for eMTCT, HIV care, support and treatment services. This was revealed by a health centre IV Incharge and a representative from a network of Young People Living with HIV in Mityana district.

Poor financing of YAPS: One of such barriers is related to the lack of facilitation for the YAPs which demotivates them. This was revealed during an In-depth Interview with a health centre IV Incharge. The YAPS play a great role in finding of children and their young mothers and in linkage to the health care facility. The lack of facilitation obstructs their ability to act as the intermediary between the community and the health care facility.

"...... Unfortunately, we lost one of the YAPs in May and the available ones are not motivated since they are not usually facilitated in terms of transport costs" (IDI, Health Centre IV In-charge) (repetition of quote)

Poor integration of HIV/AIDS services with other services: The limited funds have also affected the integration of HIV care and support services for young mothers and their CLWHIV. This was narrated by a representative from a network of Young People Living with HIV in Mityana district.

".....We used to integrate other activities though we no longer do due to the funds and support that is lacking but we have a television that displays information to the youths and children whenever they come to attain the services...." (KII, Representative from a network of Young People Living with HIV, Mityana district).

⁴¹ UNICEF Uganda, "Peer to Peer Support Brings Positive Outcomes among Adolescents in Northern Uganda |."

3.3.10 Facilitators and barriers for children living with HIV

Bodmando conducted six Focus Group Discussions in all districts with Children Living with HIV. The objective was to understand the enabling factors and challenges they face in accessing HIV care and support services. Below are the findings organised based on the 2 age bands (younger than 10 years and 10-14 years).

3.3.11 Barriers in access to HIV prevention, care and support services by CLWHIV Children Living with HIV (younger than 10 years)

We conducted Focus Group discussions with children living with HIV (younger than 10 years) and below are the barriers they highlighted.

Fear and anxiety associated with needle pricks: In an interaction with CLWHIV, it was narrated that the fear and anxiety associated with needle pricks leads to the shunning of HIV services. Psychological fear and anxiety of needle pricks has been documented to be a barrier in the utilisation of HIV testing services. In a qualitative study by Bulterys et al., (2023), it was revealed that the fear of needle pricks enhanced the use of HIV self-testing kits⁴². Below is part of the narrative from the FGD discussions held with the children living with HIV.

".....we have great fear to receive the HIV services because of the pain we feel when we go to see those doctors......" (FGD, Child Living with HIV, Kyenjojo District).

Lack of reminders to take ARVs as per the recommended schedule: In an interaction with CLWHIV (younger than 10 years), they revealed that they sometimes forget to take ARV drugs and the lack of reminders from their close family members affects their treatment adherence. This challenge leads to interrupted treatment routines which can potentially affect the effectiveness of ARV treatment in addition to enhancing viral resistance. One of the CLWHIV stated that;

"Sometimes I forget to take my medicine and even the people at home forget to remind you......"(FGD, Child Living with HIV (younger than 10 years), Butambala District).

Long waiting time: The CLWHIV consistently complained about challenges to do with long waiting time at the health facilities whenever they seek for HIV/AIDS services. This was a consistently cited challenge by most of the FG discussants. One of the children narrated that on some occasions, they are prompted to resort to other health facilities to access HIV services as a coping mechanism for long waiting time at their nearest health care facility. In their study, Twimukye et al., (2017) narrated that whilst public facilities have well developed HIV services, these are often overwhelmed with long waiting times which is a significant barrier to service access and utilisation⁴³.

"Sometimes the doctors take long to work on me and yet I have come on my day they told me to come. I have to then go somewhere else." (FGD, Child Living with HIV (younger than10 years), Butambala District).

When we go there for checking the blood, you find when the line is long and so we have to wait which is not good. "(FGD, Child Living with HIV (younger than 10 years), Mubende District).

⁴² Michelle A. Bulterys et al., "Pregnant Women and Male Partner Perspectives of Secondary Distribution of HIV Self-Testing Kits in Uganda: A Qualitative Study," ed. Joel Msafiri Francis, *PLOS ONE* 18, no. 2 (February 14, 2023): e0279781, https://doi.org/10.1371/journal.pone.0279781.

⁴³ Adelline Twimukye et al., "Exploring Attitudes and Perceptions of Patients and Staff towards an After-Hours Co-Pay Clinic Supplementing Free HIV Services in Kampala, Uganda," *BMC Health Services Research* 17, no. 1 (December 2017): 580, https://doi.org/10.1186/s12913-017-2524-5.

Abuse by health care workers due to missed drug regimens: One other commonly narrated challenge facing CLWHIV (younger than 10 years) was ill treatment by health care workers in response to missed drug regimens. They complained of being subjected to abuse which often leads to unintended consequences such as personal distress and missing of pill regimens. It is narrated that health care workers mishandle reports of missed doses by CLWHIV and they subject them to abuse with the belief that this would encourage treatment adherence. Two of the CLWHIV narrated that;

".... the doctor abuses me when I forget to take my medicine and I become stressed and I even forget to take my medicine........." (FGD, Child Living with HIV (younger than 10), Butambala District).

Other barriers narrated by CLWHIV (younger than 10 years) included; changes in treatment regimens due to drug stock outs and the long physical distance to health facilities.

Children Living with HIV (10-14 years)

We conducted Focus Group discussions with cohorts of children living with HIV (10-14 years) and below are the barriers they highlighted.

Lack of reminders to take ARVs as per the recommended schedule: CLWHIV need to be reminded if compliance to treatment is to be realised. However, results of the FG discussion with cohorts of CLWHIV (10-14 years) showed that one of the commonest treatment barriers they face is the lack of reminders to take their treatment regimen. It was narrated that they sometimes forget and in the absence of family support, there is interrupted HIV treatment. One of the respondents from the cohort of CLWHIV narrated that;

Peer abuse and social discrimination: The issue of abuse and discrimination by peers was not an exception amongst the list of barriers faced by CLWHIV. They narrated stories of abuse by fellow peers and family members due to their HIV status and associated daily treatment regimens which has affected their overall quality of life. One of the CLWHIV reported that a family member disclosed their HIV status to their peers, and they got questioned why they were taking ARV medication. This cycle of unconsented HIV status disclosure by family members, coupled with peer abuse and discrimination was narrated to have a compounding effect on the quality of life and adherence to treatment recommendations.

"Someone abused me, and they asked me why I was taking HIV medicine, and I became annoyed..."..........."(FGD, Child Living with HIV (10-14 years), Mubende District).

"My older brother went and told my friends that I take medicine and they started asking me why I was taking the medicine....." (FGD, Child Living with HIV (10-14 years), Mpigi District).

"Some children in the community have a mentality whereby if they come to access HIV treatment, they fear that they will be known by other people. Not knowing that we handle such patients differently since we keep such conversations with them confidential. (KII, CHWs, Mpigi district)

In one of the most touching stories, a CLWHIV stated, that their peers avoid them because of their HIV status as they perceive HIV to be a dangerous disease. These manifestations create a

challenging environment that creates a negative impact on the mental health of the affected children. It is a demonstration of how HIV/AIDS related stereotypes within the social environment interact with the individual to lead to social isolation.

".....Some of my friends don't want me to be around them when I haven't yet taken my medicine and they always ask me when am I going to die and I leave them in peace......"(Child Living with HIV (10-14 years), Butambala District).

ARV adverse side effects and the pill burden: During the FG discussions with CLWHIV, they revealed that they are fearful of ART. When asked about the reasons for their fear, it was revealed that side effects, and the pill burden were some of the causes. These findings are consistent with similar studies conducted in Uganda such as a 2015 study entitled "*Adherence to antiretroviral therapy and retention in care for adolescents living with HIV from 10 districts in Uganda*". This study reported side effects, drug palatability and pill burden as a hindrance to adherence by adolescents from 10 districts in Uganda.⁴⁴ Some of the Children stated the following;

"------Some fear taking medicine because of its effects on the body which are not good....the tablets are many and at times cause weaknesses. "(FGD, Child Living with HIV, Mityana District).

".......Yes, I fear taking the medication.....the effects of these drugs make us to fear them because they cause a burden on our bodies......" (FGD, Child Living with HIV, Mityana District).

Inadequate access to food and nutrition: During the FG discussion, CLWHIV stated that they sometimes have challenges in accessing food during the scheduled time for taking medication which affects their adherence to treatment. Existing literature has suggested a possible link between food security and ART adherence. A study entitled "*Hunger and Adherence to Antiretroviral Therapy: Learning From HIV Positive Caregivers of Orphans and Vulnerable Children in Tanzania*", revealed declining likelihoods of ART adherence as the level of household hunger increased⁴⁵ while Negassie Berhe, Desalegn Tegabu, and Mekuriaw Alemayehu, (2013) narrated that the inability to get enough and/or quality food was about 2.1 times higher in the non-adherent group which shows a significant association with non-adherence to ART⁴⁶.

"Sometimes the time for taking the HIV medicine may come and yet the food at home is not yet cooked and this affects me when I am taking the medicine....."(FGD, Child Living with HIV (10-14), Mubende District).

Other barriers narrated by CLWHIV (10-14 years) included; drug stock outs at health care facilities and long waiting time.

3.3.12 Facilitators of access to HIV prevention, care and support services for CLWHIV CLWHIV (younger than 10 years)

Social support from friends and school matrons: In an interaction with CLWHIV, they narrated that the support provided by school matrons and friends has been helpful in promoting continued access to HIV treatment services. School matrons are noted to support the provision of food and nutrition for school going CLWHIV and they are also said to administer ARV pills to children below 10 years rather than allow self-administration. School matrons usually work in a boarding school and are generally responsible for the health and well-being of the pupils and the smooth running of the domestic side of school life. Additionally, during out-door games, CLWHIV narrated that some

⁴⁴ Nicolette Nabukeera-Barungi et al., "Adherence to Antiretroviral Therapy and Retention in Care for Adolescents Living with HIV from 10 Districts in Uganda," *BMC Infectious Diseases* 15 (November 14, 2015): 520, https://doi.org/10.1186/s12879-015-1265-5.

⁴⁵ Amon Exavery et al., "Hunger and Adherence to Antiretroviral Therapy: Learning From HIV Positive Caregivers of Orphans and Vulnerable Children in Tanzania," *Frontiers in Public Health* 9 (February 21, 2022): 719485, https://doi.org/10.3389/fpubh.2021.719485.

⁴⁶ Negassie Berhe, Desalegn Tegabu, and Mekuriaw Alemayehu, "Effect of Nutritional Factors on Adherence to Antiretroviral Therapy among HIV-Infected Adults: A Case Control Study in Northern Ethiopia," *BMC Infectious Diseases* 13, no. 1 (December 2013): 233, https://doi.org/10.1186/1471-2334-13-233.

of their fiends encourage them to take medication. All these combined factors are noted to provide a supportive environment that promotes proper drug administration, reduction in side effects, stigma and discrimination of CLWHIV ultimately leading to a better quality of life. Below are the details from the focus group discussion.

"I am in a boarding school and the school matron gives me what to eat and also the water to use when I am taking the medicine". (FGD, Child Living with HIV (younger than 10 years), Butambala District).

"I play with my friends, dodge ball or netball and they always remind me when the time for taking the medicine is almost coming" (FGD, Child Living with HIV (younger than 10 years), Mubende District).

"I have a friend of mine who I play with and he always reminds me to go and take my medicine when the time is about". (FGD, Child Living with HIV (younger than 10 years), Mubende District).

Gifts and other rewards for treatment adherence: FGD findings revealed the use of reward mechanisms as a way of encouraging treatment adherence by CLWHIV. Such gifts include clothes and sweets. This is an approach that is said to be taken by both health care workers and family members. The use of reward in promoting treatment adherence has been previously studied but with underlying scepticism on its cost effectiveness and sustainability. Anthony DeFulio and Kenneth Silverman, (2012) stated that "*Across studies that reported percent adherence comparisons, incentives increased adherence by a mean of 20 percentage points, but effects varied widely*"⁴⁷. They further concluded that incentive-based medication adherence interventions can effectively promote medication adherence under a variety of conditions. A significant challenge for research in this area is the development of sustainable and cost-effective long-term interventions⁴⁸.

"The doctors in the health facility weigh us and if we turn out to weigh more, they hug us and also give us gifts....". (FGD, Child Living with HIV (younger than 10 years), Butambala District).

"The doctors give us gifts whenever we take our medicine very well" (FGD, Child Living with HIV (younger than 10 years), Mubende District).

*"....They even buy for us clothes......" (*FGD, Child Living with HIV (younger than 10 years), Butambala District).

Free access to ARV medication from public health facilities: Results from the FGD discussion with CLWHIV revealed that ARV medication has been made available for free access in government health facilities and this is noted to promote their access to treatment services. The financing of HIV/AIDS in Uganda is largely funded by external partners. Some of the donors include; The United States government Presidents Emergency Fund for AIDS Relief (PEPFAR), the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) including Government funding⁴⁹. These have supported free access to HIV drugs⁵⁰.

"The hospital gives me medicine for free...... (FGD, Child Living with HIV (younger than 10 years), Mpigi District).

Financial support from parents: In one of the interactions with CLWHIV, they narrated the financial support that support access to health facilities for HIV testing and treatment services. Financial challenges are noted to hamper access to HIV treatment and support services for adolescent girls and young women in Uganda. This has enhanced the relevance of integrating economic empowerment and sexual and reproductive health programmes when engaging this unproductive or limitedly productive population. When young mothers are not able to access HIV/AIDS services due to financial obstacles, they often resort to alternative mechanisms some of which may pose a risk to their overall health and wellbeing. One of the CLWHIV stated that their

⁴⁷ Anthony DeFulio and Kenneth Silverman, "The Use of Incentives to Reinforce Medication Adherence," *Preventive Medicine* 55 (November 2012): S86–94, https://doi.org/10.1016/j.ypmed.2012.04.017.

⁴⁸ DeFulio and Silverman.

⁴⁹ Tom Kakaire et al., "The Future of Financing for HIV Services in Uganda and the Wider Sub-Saharan Africa Region: Should We Ask Patients to Contribute to the Cost of Their Care?," *BMC Public Health* 16, no. 1 (December 2016): 896, https://doi.org/10.1186/s12889-016-3573-0.

⁵⁰ Kakaire et al.

parents resorted to farming as a way of raising income to support access to HIV treatment and support services in the health facilities. Their narrative is highlighted below.

"....My mother has a garden in the village and she always digs... when she gets money she is able to transport so that I can be able to go to the hospital....." FGD, Child Living with HIV (younger than 10 years), Mubende District).

CLWHIV (10-14 years)

Community sensitisation campaigns: Findings from the focus group discussions with CLWHIV revealed that the strengthening of community sensitisation efforts has successfully mobilized young mothers to take their children for HIV testing. One of the children living with HIV narrated that their mother was contacted by health workers in the community and encouraged to take them for HIV testing services in the facility after which, they were confirmed positive. A church leader in Kyenjojo district also stated that they always sensitise their congregation on HIV/AIDS and further encourage them to visit health facilities for HIV services. The use of community sensitisation has proved to be a good strategy in promoting reach to communities that face access difficulties to health care facilities.

".....for example my parents were taught about HIV, picked us from the community to the health facility and we were found HIV positive.... me and my sister among the 6 children taken to the hospital". (FGD, Child Living with HIV(10-14 years), Mityana District).

"......some of us were got through a campaign to test all children.....(FGD, Child Living with HIV (10-14 years), Mityana District)

"We as the church leaders talk about HIV at the pulpit and we encourage them to attain treatment if they test positive for HIV" (IDI, local and religious community leader, Kyenjojo district).

Community-based interventions such as The YAPS model: The YAPS Programme is an initiative of the Ministry of Health and partners including UNICEF, Global Fund with funding from SIDA and USAID. The YAPS model is a multi-sectoral intervention implemented by adolescents and young people living with HIV with the purpose of increasing identification of HIV positive AYPs, improving their linkage into care, retention, adherence, and viral suppression to improve their health and quality of life ⁵¹. Results of the FGD with children in Kyenjojo district revealed that the use of YAPS has made a major contribution in promoting their access to treatment and reduction in transport barriers as ARVs are delivered to their homesteads by YAPS.

"....YAPS has increased the network to discover our problems and promote access to HIV services" (FGD, Child Living with HIV (10-14 years), Kyenjojo District).

"...the groups like YAPs have helped to support us to pick drugs and stay on it. "(Child Living with HIV (10-14 years), Kyenjojo District).

"We use YAPS whereby a health CHW delivers the HIV medicine to the homes of the patients other than the patients going to the health facility and this also reduces the transport costs that are incurred. Unfortunately, we lost one of the YAPs in may and the available ones are not motivated since they are not usually facilitated in terms of transport costs' (KII, Health Centre Incharge, Mityana district).

House to house screening and testing by VHTs: Evaluation findings from the FGD conducted with CLWHIV revealed that the conducting of house-to-house screening and testing has enhanced their access to HIV testing services. This is partly an initiative of the YAPS programme but is also supported by the CHWs.

⁵¹ UNICEF Uganda, "Peer to Peer Support Brings Positive Outcomes among Adolescents in Northern Uganda |."

"Through conducting house to house testing, they are able to find us for HIV testing and treatment...." (FGD, Child Living with HIV (10-14 years), Kyenjojo District).

Calls and reminders: The use of calls and reminders is also noted to promote access to HIV treatment, care and support services by CLWHIV. In the FGD conducted with children in Kyenjojo district, it was revealed that through the calls, they are often reminded of their medical appointments in the facilities for HIV treatment and care services. These findings are consistent with Muhindo et al., (2021) who in their study found out that text message reminders and peer education improve utilization of STI and HIV testing services⁵²

"Phone calls from health workers help to remind us in-case we forgot and missed the appointment" ... (FGD, Child Living with HIV, Kyenjojo District).

Gifts and other rewards for treatment adherence: CLWHIV between 10-14 years also indicated that reward mechanisms have been utilised and they encourage them to take medicine. One of the children indicated that when they adhere to treatment, heath care workers provide gifts in form of money and clothes. These reward mechanisms were also noted to be used even for children younger than 10 years. Although literature has documented the use of reward in promoting treatment adherence, concerns have been raised regarding the sustainability of such measures.

"....Whenever I take my medicine very well without missing, the doctor gives me a gift in form of money to appreciate me and I give the money to my grandmother to keep for me... there was a time when I was feeling unwell, they carried out tests and I had to spend a night at the hospital and I was discharged the following day..."(FGD, Child Living with HIV(10-14 years), Butambala District).

" The people at the facility gave me a gift inform of a shirt because I was taking my medicine well without missing any tablet and I thanked them...."FGD, Child Living with HIV(10-14 years), Mubende District).

Social and family support and encouragement: CLWHIV need encouragement to adhere to treatment but to also navigate the complex social and individual challenges associated with living with HIV. In their feedback, the CLWHIV stated that family members have played a major role in reminding them to take medication in addition to provision of food to cushion against side effects. They are noted to provide encouragement to adhere to treatment and health care workers were also noted to play a significant role in doing the same. The implications of this is that when the various social ecological domains of family, community and facility combine to foster a supportive environment for CLWHIV, better ARV treatment outcomes are likely to be realised. This was revealed by Jerry John Nutor et al., (2023) who in their study found out that having high interpersonal support is associated with higher adherence⁵³.

"When I am asleep sometimes, my grandmother wakes me up or when I am playing she reminds me by using a sign language to mean that it is time to take the medicine and I am always given food before the others and I am also given tea so that I can be able to take the medicine on time. ..."(FGD, Child Living with HIV (10-14 years), Butambala District).

⁵² Richard Muhindo et al., "Text Message Reminders and Peer Education Increase HIV and Syphilis Testing among Female Sex Workers: A Pilot Quasi-Experimental Study in Uganda," *BMC Health Services Research* 21, no. 1 (December 2021): 436, https://doi.org/10.1186/s12913-021-06461-w.

⁵³ Jerry John Nutor et al., "Influence of Depression and Interpersonal Support on Adherence to Antiretroviral Therapy among People Living with HIV," AIDS Research and Therapy 20, no. 1 (June 29, 2023): 42, https://doi.org/10.1186/s12981-023-00538-8.

"People at the health facility encourage us to take our HIV medicine...."FGD, Child Living with HIV(10-14 years), Mubende District).

Financial support from parents: Access to HIV services is often a challenge for young mothers and their children from a financial perspective. Therefore, solutions lie in venturing into income generating activities to support both transportation to health facilities for treatment and to support access to food and nutrition in addition to purchase of ARV medication in the event of stock outs. The CLWHIV indicated that their parents have ventured into income generating activities such as running of saloon businesses as a coping mechanism. Many SRH programmes have been noted to support the provision of vocational training to young mothers such as making of pads, artefacts, tailoring and running of saloon businesses. One of the CLWHIV stated the following;

My mother gives me some transport so that I can be able to go to the health facility after selling some of her things at home because she works in a salon." FGD, Child Living with HIV (10-14 years), Mubende District).

Other facilitating factors in access to HIV prevention, care and support services in the target area for CLWHIV (10-14) years included home visits by health care workers.

3.3.13 Facilitators and barriers for young mothers living with HIV

Below is a description of the barriers that young mothers living with HIV face in access to HIV prevention, care and support services in the target areas.

3.3.14 Barriers in access to HIV prevention, care and support services by young mothers living with HIV (15-19 years)

Stigma and discrimination associated with HIV/AIDS: The findings of the evaluation revealed that stigma and discrimination remain a challenge in promoting access to HIV treatment and support services for young mothers. In one FGD conducted with young mothers in Kyenjojo district, it was revealed that some young mothers fear exposure of their HIV status to their in-laws and this has negative knock-on effects in enrollment for HIV care and support services. While another mother indicated that they got isolated by fellow family members once their HIV status was revealed. All these circumstances create a negative environment for young mothers living with HIV with negative impacts on their mental health and social belonging which hinder their access to HIV treatment and support services.

*"Some mothers still have stigma about HIV especially fearing their husbands' families to know that she has HIV" (*FGD, Young Mothers Living with HIV (15-19 years), Kyenjojo*).*

*Stigma among mothers and therefore we requested for special clinics and enhanced peer education for young mothers (*FGD, CHWs, Kyenjojo district)

"Ever since the people at home got to know about my HIV status, they started isolating from me since they were no longer associating with me...." (FGD, Young Mothers Living with HIV (15-19 years), Mubende district).

Financial challenges: It is well known that adolescents and young people face a number of social economic barriers in accessing health services. Being a largely unproductive age group, adolescents and young mothers are caught up in a scenario where they need to navigate financial challenges associated with access to health services. One of the young mothers elaborated that they sometimes fail to meet the transport costs associated with travelling to the health care facility for HIV services. In the presence of financial difficulties, young mothers' resort to alternatives to ensure they sustain their livelihoods in addition to accessing HIV treatment and support services. One young mother narrated that they sometimes request for financial support from their spouse

or request health care workers to make home deliveries. Another narrated that they at times access credit from Savings and Credit Cooperative Societies (SACCOS)/VSLAs whenever they face financial challenges in accessing the health facility for ARV refills. All this demonstrates the alternative decisions taken by young mothers to navigate financial barriers to HIV care and support. In the event that they cannot access alternative sources of finance, one mother narrated that they postpone their appointment until when they get financial support for transport which in effect has a negative impact on treatment outcomes.

"I sometimes face a problem of transport since I sometimes ask for transport money from my husband and he sometimes borrows from his friends and if they don't lend him money, we always contact one of the medical people and they deliver the medicine home from the health facility. (FGD, Young Mothers Living with HIV (15-19 years), Mubende district).

"Lack of transport since some young mothers come from far and to some, their sub counties have no health centres and end up travelling long distances seeking for health services" (FGD, Young Mothers Living with HIV (15-19 years), Kyenjojo district).

"I face a challenge of lack of transport to the facility let's say when your day for the refill is 30th, then you find yourself with no money to cater for transport for that day and you end up postponing the appointment for like 3 or 4 days ahead so that you can get time to look for the transport. (FGD, Young Mothers Living with HIV (15-19 years), Butambala district).

Poor access to proper food and nutrition: The association between food and nutrition and ARV treatment adherence is well referenced in literature. According to Sera Young et al., (2014), food insecurity is emerging as one such prominent barrier to ART adherence and to care and treatment recommendations in both resource-rich and poor settings, and among adult and pediatric populations⁵⁴. Fears or actual negative experiences of taking ART on an empty stomach makes food and nutrition an integral element of ARV treatment. In a discussion with young mothers (15-19 years), they narrated that they sometimes find it hard to access food to allow them to take their ARV medication and this culminates into treatment interruption.

"The challenges that I usually get is that since I am the only one who knows about my HIV status so sometimes I am unable to find food so that I can be able to take the medicine .so I find it hard to borrow money from someone so that I can buy food since you have to give the reason as to why you are borrowing the money...." (FGD, Young Mothers Living with HIV (15-19 years), Butambala district).

Long waiting time at public health facilities: The problem of waiting time is consistently referenced across the entire scope of health services delivered at public health faculties. This is especially a problem in the low- and middle-income countries where health worker to patient ratios falls short of local and international standards. Long waiting times do not only discourage clients from seeking for treatment but also cause frustration with the entire health care system with potential unintended consequences such as poor future treatment seeking behaviour. This is not alien to young women who seek HIV/AIDS services especially in the rural districts of Uganda such as Mubende district where the Bloom project is being implemented. During an interaction with the young mothers, they narrated long waiting times at public health facilities with one indicating that they once turned up for a refill in the morning and got their medicine in the evening. These revelations are a clear testimony of a huge barrier that young mothers face at the social ecological level of the health care facility.

⁵⁴ Sera Young et al., "A Review of the Role of Food Insecurity in Adherence to Care and Treatment Among Adult and Pediatric Populations Living with HIV and AIDS," *AIDS and Behavior* 18, no. S5 (October 2014): 505–15, https://doi.org/10.1007/s10461-013-0547-4.

"There is always a long queue at the hospital, and we sometimes get the medicine very late for example, there was a time when I came for the refill in the morning and they gave me the medicine in the evening..." (FGD, Young Mothers Living with HIV (15-19 years), Mubende district).

"They sometimes delay when we are receiving treatment from the hospital...."(FGD, Young Mothers Living with HIV (15-19 years), Butambala district*).*

Some of the other barriers facing young mothers (10-19 years) include lack of reminders to take ARV medication.

Young Mothers (20-24 years)

Inadequate access to food and nutrition: Results of the FGD discussion conducted with young mothers (20-24) years revealed challenges in access to food and nutrition which are paramount in ARV treatment adherence. One of the mothers narrated that they at times are forced to have one meal a day and this may not coincide with treatment schedules. This revelation was consistently cited by a number of discussants. Reports indicate that they are at times forced to take the medication on an empty stomach leading to adverse side effects. All these circumstances combine to negatively affect the quality of life of young mothers who would have otherwise wanted to adhere to their treatment regimens⁵⁵.

"Since there is a lot of hunger, and we may take breakfast (tea) in the morning and we have to wait for supper or even having a meal once in a day, yet you are supposed to take your medicine daily. (FGD, Young Mothers Living with HIV (20-24 years), Butambala district).

Whenever I take the medicine without eating anything, my vision becomes cloudy, and I am unable to see very clearly. (FGD, Young Mothers Living with HIV (20-24 years), Mpigi district).

Double burden of caring for their children and themselves: In a study by Ibrahim Mujjuzi et al., (2021) entitled "*Care Burden and Coping Strategies among Caregivers of Paediatric HIV/AIDS in Northern Uganda: A Cross-Sectional Mixed-Method Study*", it was revealed that the care burden is common among the caregivers of children living with HIV ⁵⁶. These findings are consistent with the narration from the young mothers living with HIV in the district of Butambala and Mubende only. The young mothers narrated that in addition to ensuring that their children get access to proper HIV/AIDS care, they also have to take care of other expenses such as school fees and rental costs. All these create a challenging environment that negatively affects continued access to HIV services.

"There is also an issue of worrying about the school fees of the children since I am the one who is taking care of myself, and my children and I end up being stressed and this may lead to my irregular taking of the medicine. (FGD, Young Mothers Living with HIV (20-24 years), Butambala district).

"I also get worried about the rent dues and the landlord or landlady may chase me out of their house when the rent fees are due, and you find out that you have nowhere to go to incase that happens...." (FGD, Young Mothers Living with HIV (20-24 years), Mubende district).

Long waiting time at public health facilities: Complaints about long queues at public health facilities are akin to the Uganda context. Some authors have even linked long waiting times to

⁵⁵ Young et al.

⁵⁶ Ibrahim Mujjuzi et al., "Care Burden and Coping Strategies among Caregivers of Paediatric HIV/AIDS in Northern Uganda: A Cross-Sectional Mixed-Method Study," ed. Jim Tartaglia, *AIDS Research and Treatment* 2021 (September 13, 2021): 1–14, https://doi.org/10.1155/2021/6660337.

missed appointments. This was re-echoed by Rogers Isabirye et al., (2023) who reported that congestion and long waiting times at points of care can lead to missed appointments and poor follow-up care, further exacerbating the negative impact on patient outcomes⁵⁷. The young mothers interviewed during the focus group discussions complained of challenges they face in accessing HIV treatment services citing waiting time and how it further interferes with their work routines. Some even complained of exhaustion at the health care facility as they are made to wait for prolonged periods of time due to the congestion at points of care. All these factors predict negative effects on future health seeking behavior and on continued and uninterrupted access to HIV services.

"Some time I rush to the hospital, and I have to also go to work, but I unfortunately find a very long queue of the patients and I have to sit and wait in order to access the services and treatment that I need, and this may affect my working hours at the job". (FGD, Young Mothers Living with HIV (20-24 years), Butambala district).

"Doctor, we take long while waiting for medical personnel to work on us and you end up leaving the health facility felling more unwell than when you came to the health facility...." FGD, Young Mothers Living with HIV (20-24 years), Mityana district).

Stock out of ARV drugs: Stock out of ARV drugs was revealed by the young mothers as an impeding factor in access to HIV treatment services at public health facilities. This often leads to the lack of medicine refills which unintentionally causes HIV treatment interruption. Coupled with transport challenges and long physical distance to health facilities, when young mothers face challenges of drug stock outs at the public health facilities, it has a compounding effect on their finances and treatment outcomes. Drug stock outs and procurement bottlenecks remain a thorny issue in the context of Uganda despite interventions by development partners and civil society organizations. More advocacy needs to be done to solve this problem and ensure that young mothers have access to an uninterrupted supply of essential HIV/AIDS commodities.

"We sometimes reach the health facility when the medicine is not enough for us, and they tell us to go to other facilities and you may sometimes miss out on the medicine refills since they are always far from us." (FGD, Young Mothers Living with HIV (20-24 years), Butambala district).

Other barriers highlighted by young mothers (20-24) included adverse side effects, financial challenges, stigma and discrimination.

3.3.15 Facilitators of access to HIV prevention, care and support services by young mothers living with HIV

Young mothers (15-19) years old

Provision of HIV screening services during ANC visits: In Uganda, the Ministry of Health introduced a policy requiring the testing of pregnant women for HIV during ANC visits. Current guidelines recommend inclusion of HIV testing in routine screening tests for all pregnant women. For this reason, antenatal care (ANC) represents a vital component of efforts to prevent mother-to-child transmission (PMTCT) of HIV. One young mother narrated that this promotes access to HIV testing and treatment services having used the same during her pregnancy⁵⁸.

⁵⁷ Rogers Isabirye et al., "Factors Influencing ART Adherence Among Persons Living with HIV Enrolled in Community Client-Led Art Delivery Groups in Lira District, Uganda: A Qualitative Study," *HIV/AIDS - Research and Palliative Care* Volume 15 (June 2023): 339–47, https://doi.org/10.2147/HIV.S414971.

⁵⁸ E. C. Larsson et al., "Opt-out HIV Testing during Antenatal Care: Experiences of Pregnant Women in Rural Uganda," *Health Policy and Planning* 27, no. 1 (January 1, 2012): 69–75, https://doi.org/10.1093/heapol/czr009.

"Screening and testing for HIV among all pregnant women coming to health centres for antenatal check-ups promotes access to services (FGD, Young Mothers Living with HIV, Kyenjojo district).

Availability of HIV Self-testing (HIVST) kits: In an FGD with young mothers, a participant narrated that she received an HIVST kit that she conveniently used to test her husband and when he returned a positive result, he started on treatment at the health facility. HIV self -testing services have been a major innovation in the HIV/AIDS sector in Uganda in the promotion of access to HIV testing services which are seen as non-invasive and acceptable to most patients. These results are consistent with a 2023 study on the feasibility and acceptability of peer-delivered HIV self-testing and PrEP for young women living with HIV in Kampala, Uganda, where it was reported that HIVST was seen as an acceptable method that young women used to protect themselves from HIV⁵⁹.

".... availability of HIV self-testing kits for example I was given one to take to my husband and when he tested positive, he came and started treatment (FGD, Young Mothers Living with HIV, Kyenjojo district).

"HIV self -testing oral kits given to us mothers to take to our husbands has helped us to get a way of opening up to our husbands" (FGD, Young Mothers Living with HIV, Mityana district).

Social and family support: Evaluation findings reveal that social and family support has been influential in promoting access to HIV treatment and support services by young mothers living with HIV. This was revealed by a young mother who narrated that their parents provided counselling and compelled them to seek and be retained in treatment.

"Family support is critical for example my parents counselled me which motivated me to start, and I have found no problem staying on treatment" (FGD, Young Mothers Living with HIV, Mityana district).

"Some of our families especially our mothers have stood with us and have greatly supported us" (FGD, Young Mothers Living with HIV, Mityana district).

Adolescent and youth friendly SRH services: The establishment of youth spaces was noted to be an enabling factor in access to youth friendly HIV/AIDS services by young mothers. They stated that separation of services has allowed them to be served in an age-appropriate manner which promotes HIV service access and utilisation. Adolescent and youth friendly reproductive health services have distinctive features to attract, meet the needs of, and retain young people as clients. They are built to be accessible and acceptable by young people.

"The health facility has a good policy of separating us from the other people who have come to access different services from the health facility, and this has also led to us being in our different groups according to our age categories." (FGD, Young Mothers Living with HIV (20-24 years), Mubende district).

Other enabling factors include social support and encouragement from parents and health workers, calls and reminders from health care workers for medicine refills, long refills of 6 months duration, HIV counselling and guidance, and home delivery of ARV medication.

⁵⁹ Rita Nakalega et al., "Feasibility and Acceptability of Peer-Delivered HIV Self-Testing and PrEP for Young Women in Kampala, Uganda," *BMC Public Health* 23, no. 1 (June 16, 2023): 1163, https://doi.org/10.1186/s12889-023-16081-0.

Young mothers (20-24) years

Home delivery of ARV drugs: The home delivery of ARV drugs is a good innovation that promotes continued and uninterrupted supply of HIV/AIDS drugs and hence is an enabling factor for access to treatment as narrated by young mothers. It is noted that YAPS support the role of delivering ARVs to homesteads of young mothers allowing them to access treatment in a more convenient manner. Additionally, the YAPS also carry out blood tests hence promoting extension of HIV testing and treatment services to families that could have otherwise been unable to access them.

*"The doctors deliver medicine to our homes, and they also take blood samples for testing from my children...". (*FGD, Young Mothers Living with HIV (20-24 years), Mubende district*)*

Access to saving schemes such as SACCOS (VSLAs): Savings and Credit Cooperative Societies were narrated by young mothers to provide an alternative source of finance that allows them to navigate the financial challenges associated with access to HIV care and treatment services. They noted that some of the challenges are related to transportation to health facilities. When young mothers do not have money, they indicated that they borrow from their SACCOS (VSLAs), and this has been one of the coping mechanisms in an economically turbulent social environment. Lynda Namukwaya, (2019) recommended that HIV/AIDS care programs should integrate financial education and empower women to establish small savings groups whose goal is geared towards socio-economic transformation for health care access⁶⁰.

We sometimes borrow money from our SACCOs (VSLAs), and we use such money to pay for the transport fares. (FGD, Young Mothers Living with HIV (20-24 years), Mubende district)

Calls and reminders: The use of calls and reminders was narrated by young women to promote their utilisation of HIV care and support services. An HIV focal person in one district narrated that they have HIV registers that capture the names of all clients who enrolled for ART. And by tracking them through follow ups, they are able to be reminded to make clinic visits. This mechanism is noted to facilitate retention of young mothers in care. A senior woman teacher also echoed the same narrative by highlighting that health workers make follow ups through calls and reminders which has promoted the utilisation of HIV care and treatment services. A randomised controlled trial titled "*Mobile phone reminders and peer counseling improve adherence and treatment outcomes of patients on ART in Malaysia*", reported a 15.5 percentage points increase (small effect size) in mean adherence at six months follow up and was revealed to be one of the highest intervention effects reported by any similar study in a developing country or resource-limited setting⁶¹. All these findings point to the positive effects of calls and reminders as an enabling factor for retention in care.

"*For the refills, the doctors always make calls to us when the date of appointment is near. (*FGD, Young Mothers Living with HIV (20-24 years), Mubende district*)*

"The health workers make follow ups on the people that take the medicine" **(**KII, Senior woman teacher, Kyenjojo district)

"We also use books to track down those that attended the services, and this helps us to know those that never attended them, and we make follow ups (KII, HIV focal person, Mityana district)

⁶⁰ Lynda Namukwaya, "Female Retention in HIV/AIDS Care: The Role of SACCOs in Kampala," 2019.

⁶¹ Surajudeen Abiola Abdulrahman et al., "Mobile Phone Reminders and Peer Counseling Improve Adherence and Treatment Outcomes of Patients on ART in Malaysia: A Randomized Clinical Trial," ed. Larry Chang, *PLOS ONE* 12, no. 5 (May 16, 2017): e0177698, https://doi.org/10.1371/journal.pone.0177698.

Conducting of community out reaches: The conducting of community outreaches has enabled the extension of HIV care and support services to young mothers and their HIV positive children. This was elaborated in a number of interviews and FGDs that were conducted. A senior woman teacher narrated that health workers periodically travel to villages to extend treatment services which has promoted access. And in addition, a representative from a network of young people living with HIV also narrated that testing services have also been made accessible through the outreaches conducted. In their study, Adwar et al., (2022), also found out that carrying drugs and registers to outreaches ensured immediate and early initiation of care⁶².

*"Health workers have tried to move to the villages and provide the treatment to the community members (*IDI, Senior woman teacher, Kyenjojo district)

"Outreaches by the health workers through visiting the villages has enabled the testing services to be accessible to the people" (KII, Representative from a network of Young People Living with HIV, Mityana district)

Health education talks: Health education talks were revealed to play a great role in sensitising young mothers on proper food and nutrition, creating awareness of PMTCT, HIV and other diseases. These are delivered not only by health care workers but also by CSOs. One of the young mothers involved in an FGD indicated that health education talks conducted by peer mothers have been helpful in creating awareness that promotes enrollment for HIV treatment, care and support services by the young mothers. Health education as a public health approach encourages voluntary behavioral changes.

There was an organization that was teaching us about nutrition, and they used to encourage us to eat health and we would eat food items like cabbage, vegetables and many others. (FGD, Young Mothers Living with HIV(20-24 years), Mubende district).

"....We receive several education-talks from health workers and at times peer mothers about HIV and other diseases which is good in allowing us to use the services...." (FGD, Young Mothers Living with HIV, Kyenjojo district).

".... routine health education talks or teaching of mothers on the importance of PMTCT services has helped us...." (FGD, Young Mothers Living with HIV, Mityana district).

Other facilitators include HIV counselling and guidance, social support and encouragement from parents and health workers.

3.3.16 Distinctions between young mothers living with HIV and older mothers living with HIV

The experiences of finding, testing, treating, and keeping young mothers living with HIV in Uganda can differ from those of older mothers with HIV due to various factors. Here are some key distinctions:

Age-Specific Challenges:

Young mothers may face unique challenges related to their age, such as limited decision-making power, lack of experience, and dependence on family or partners. These factors can impact their ability to access and adhere to HIV services.

"I sometimes face a problem of transport since I sometimes ask for transport money from my husband and he sometimes borrows from his friends and if they don't lend him money, we always

⁶² Claire Adwar et al., "Factors Associated with Linkage to Care Following Community-Level Identification of HIV-Positive Clients in Lira District," ed. Bayu Begashaw Bekele, *Advances in Public Health* 2022 (February 4, 2022): 1–9, https://doi.org/10.1155/2022/4731006.

contact one of the medical people and they deliver the medicine home from the health facility. (FGD, Young Mothers Living with HIV (15-19 years), Mubende district).

Stigma and Discrimination:

Young mothers might experience heightened levels of stigma and discrimination due to societal norms and expectations surrounding age, sexuality, and motherhood. This stigma can act as a barrier to seeking and continuing HIV care.

"Ever since the people at home got to know about my HIV status, they started isolating from me since they were no longer associating with me...." (FGD, Young Mothers Living with HIV (15-19 years), Mubende district).

Reproductive Health and Family Planning:

Young mothers may have distinct reproductive health needs and family planning considerations. Integrating HIV services with reproductive health care is essential to address the dual challenges of preventing mother-to-child transmission and supporting family planning decisions. For example, research shows that the younger a girl is when she becomes pregnant, whether she is married or not, the greater the risk to her health. It is estimated that girls under the age of 15 are at greater risk of dying in childbirth than women in their 20s⁶³

Double burden of care:

Young mothers are faced with the double burden of balancing childcare responsibilities with their own needs. Ensuring that adequate social economic opportunities are provided to them is important in promoting the overall health of both the mother and child.

"I also get worried about the rent dues and the landlord or landlady may chase me out of their house when the rent fees are due, and you find out that you have nowhere to go to incase that happens...." (FGD, Young Mothers Living with HIV (20-24 years), Mubende district).

Mental Health Considerations:

Young mothers may be more susceptible to mental health challenges, given the potential stressors related to HIV, stigma, and the demands of motherhood at a young age. Integrating mental health support into HIV care is important for holistic well-being.

...It is challenging for us, and we suffer from stigma and stress because of the problems we get due to our HIV status (FGD, Young Mothers Living with HIV (15-19 years), Kyenjojo district). Addressing these age-specific considerations is crucial for the success of HIV programs targeting young mothers in Uganda. Tailoring interventions to the unique needs and circumstances of this demographic can contribute to improved testing, treatment, and retention outcomes which the Bloom project aims to achieve.

3.3.17 Distinctions between children living with HIV of young mothers and children in general.

Finding, testing, treating, and keeping children of young mothers living with HIV in Uganda may present unique challenges and considerations compared to other children living with HIV. Here are some key distinctions:

Mother-to-Child Transmission (MTCT) Risk:

Children born to young mothers living with HIV may face a higher risk of mother-to-child transmission due to factors such as limited access to prenatal care, lack of knowledge about prevention measures, and socioeconomic challenges. According to USAID, (2022), Infants born to younger mothers had higher rates of HIV infection, with 3.7 percent of infants of mothers aged 15–24 having HIV compared to 1.4 percent among those born to mothers 25 years and older ⁶⁴.

Adherence to Paediatric Treatment:

Children of young mothers may face challenges related to treatment adherence, as the mothers

⁶³ UNFPA, "FROM CHILDHOOD TO WOMANHOOD: MEETING THE SEXUAL AND REPRODUCTIVE HEALTH NEEDS OF ADOLESCENT GIRLS," 2012.

⁶⁴ USAID, "Uganda Significantly Reduces Rates of Mother-to-Child Transmission of HIV With CDC Support," September 26, 2022, https://www.cdc.gov/globalhivtb/who-we-are/success-stories/success-story-pages/uganda-pmtct.html.

themselves may encounter obstacles in adhering to their own HIV treatment regimens. Interventions should consider the family unit and provide support to both mothers and children to improve overall adherence.

"........Yes, I fear taking the medication.....the effects of these drugs make us to fear them because they cause a burden on our bodies......" (FGD, Child Living with HIV, Mityana District).

Sociodemographic Factors:

Children living with HIV of working mothers are most likely able to afford clinic visits for their children in comparison to unemployed mothers. This can be due to many reasons including the high awareness of working mothers about Paediatric HIV and the ability to afford their children's treatment. The Bloom project should address social economic challenges facing young mothers to improve overall outcomes for these children.

My mother gives me some transport so that I can be able to go to the health facility after selling some of her things at home because she works in a salon." FGD, Child Living with HIV (10-14 years), Mubende District).

Tailoring interventions to address the specific challenges faced by children of young mothers living with HIV is essential for improving outcomes and breaking the cycle of transmission and disadvantage within this vulnerable population. This is because as dependants, children of young mothers bear the consequences of the social economic and gender-related barriers that their young mothers face. Identifying their unique needs and co-creating targeted solutions at all social ecological levels is paramount in improving their HIV/AIDS outcomes. Projects like Bloom through the Kids to Care model have the edge and opportunity of working with district and community level actors like CHWs to address the barriers and challenges as raised by CLWHIV and their young mothers to identify these groups, test them, link them to care and retain them in care.

3.4 Objective 4: Facilitators and barriers of YMLHIV and their children in access, utilization and retention in paediatric HIV services at family, community, and health facility levels.

The study also sought to unravel the barriers and facilitators in access, utilization and retention in paediatric HIV services in the targeted areas at individual, family, community, health facility and system levels considering young mothers living with HIV and their children. Below are social ecological frameworks illustrating the findings from the study.

3.4.1 Social ecological framework showing facilitators and barriers faced by CLWHIV in access, utilisation and retention in paediatric HIV care.

Social ecological framework (CLWHIV)

Individual level

Barriers (Fear and anxiety associated with needle pricks, ARV adverse side effects and the pill burden)

Family level

Barriers (Inadequate access to food and nutrition, Lack of reminders to take ARVs as per the recommended schedule) acilitators (Financial support from parents, Social and family support and encouragement)

Community level

Barriers (Peer abuse and social discrimination)
Facilitators (Social support from friends and school matrons, House to house screening and testing,

Community sensitisation campaigns)

Facility level

Barriers (Long waiting time, drug stock outs, Changes in treatment regimens due to drug stock outs, Abuse by Health care workers due to missed drug regimens, Long physical distance to health facilities) Facilitators (Gifts and other rewards for treatment adherence, Calls and reminders, Free access to ARV medication)

System level

Facilitators (YAPS model, Policies (Test and treat policy), DSD Model, Integrated Child Health days) Barriers (poor health care financing)

Figure 13: A social ecological framework illustrating barriers and facilitators faced by CLWHIV in access, utilization and retention in paediatric HIV care in the target areas.

3.4.2 Availability of child friendly services

The study sought to establish the availability of child-friendly services for children living with s, the availability of Paediatric HIV interventions by the government and any other NGOs. Results from interviews involving HIV focal persons, HIV implementing partners, networks of young people living with HIV, CHWs, government stakeholders and a senior woman teacher indicated that indeed child friendly services have been established by government and several NGOs. Some of them include the PIASCY club (Presidential Initiative for Aids Support for the Youth), adolescent health clinics in Kyenjojo district, paediatric clinics in Mpigi district and child health days in Mpigi district.

PIASCY clubs across the country

In Kyenjojo district, a senior woman teacher

Box 3: Child Friendly services and paediatric HIV a. Definition of Child friendly services

Child Friendly services were well understood. A group of Caregivers and partners of Young Mothers Living with HIV defined Child friendly services as "*This refers to good and appropriate services to the child which motivate them to take and continue with their treatment*".

b. Understanding of paediatric HIV

Paediatric HIV was a relatively understood term especially by health workers and HIV programme implementers. A Community support group representative from Kyenjojo district described it as "To me, paediatric HIV means that a child between the age of 0 to 17 years is living with HIV".

indicated that a support group was established as an initiative of the president to support child friendly HIV/AIDS services.

""We have cocurricular activities that get the children to work and play together. We have the PIASCY club (Presidential Initiative for Aids Support for the Youth), and it teaches us on what to do in terms of preventing HIV among the young children. We lack refreshments in the club because we lack facilitation" (IDI, senior woman teacher, Kyenjojo district).

In 2002, the President of Uganda, proposed a way to improve communication on HIV and AIDS among adolescents and young people to sustain declining trends in HIV prevalence rates. The President's vision was for head teachers to address assemblies on HIV and AIDS every two weeks, after which other teachers could continue the discussion in classrooms and clubs. The Uganda AIDS Commission responded to the President's call and brought together line ministries, civil society organizations, the private sector, and individuals working in HIV to forge a way forward, which led to the inception of the Presidential Initiative on AIDS Strategy for Communication to Youth (PIASCY). Targeting parents and communities reinforces activities delivered in the school. PIASCY expanded to cover post primary institutions under the Uganda Initiative for Teacher Development Management System and PIASCY. A formative evaluation of the PIASCY programme showed that it successfully contributed to a stigma-free school environment, but inadequately addressed the needs of the HIV-infected. The lack of monetary compensation was regarded by most teachers as a major weakness⁶⁵.

Adolescent health clinics in Kyenjojo district

A CHW in Kyenjojo district highlighted that in their district, adolescent health clinics have been set up to support the delivery of adolescent friendly services. These adolescent health clinics provide an appropriate environment that is appealing to young mothers living with HIV because they are run by their peers. They hence seek HIV treatment services within the adolescent clinics. *"There are adolescent clinics like ngoma, idongo, mpirira clinic and this creates a friendship among them and the health workers thus they are able to attain HIV treatment in a friendly environment"* (KII, CHW, Kyenjojo district)

⁶⁵ African Population and Health Research Center, "Formative Evaluation: Presidential Initiative on AIDS Strategy for Communication to Youth," 2009.

Paediatric clinics in Mpigi district

A government health worker in Mpigi district narrated that paediatric clinics have been set up by the local government to support the delivery of child friendly services. Additionally, it is reported that Family support groups have also been established to provide social support to young mothers. Organisations such as Masaka Diocesan Medical Services – MDMS provide child friendly services. He narrated that

"We have the paediatric clinic where children come to access HIV treatment and services. And we also have the FSG (Family Support Group) where the pregnant young mothers come to access such services.....Such services are available and we also have non-governmental organizations such as MDMS......and they offer such services" (IDI, government stakeholder, Mpigi district).

In their study entitled "*Child-Centred Care in HIV Service Provision for Children in Resource Constrained Settings: A Narrative Review of Literature*", Chipo Mutambo, Kemist Shumba, and Khumbulani W. Hlongwana, (2019) stated that child-centred care approaches are important in healthcare provision as they potentially increase children's participation, improve health outcomes, and promote resilience among children living with HIV, which is a communicable, highly stigmatised, and chronic condition⁶⁶.

Integrated Child health days in Mpigi district

Integrated Child health days have been set up in Mpigi district in central Uganda and on such special days, children undergo viral load testing, get medicine refills amongst others. However, this is reported to be a nationwide rather than district specific innovation that focusses on the provision of integrated and focused health services to children. The government health worker reported that;

"We have an ART clinic whereby different children are given health days and time according to the viral load, their health conditions ie those that have not been getting HIV medicine refills and those that have been consistent with their dosage intake, location. Even the mothers are given appointment dates like once in every month...... We also dedicate the first Wednesday of every month to offer such services for children living with HIV". (KII, Government Stakeholder, Mpigi district)

According to UNICEF, April and October are dedicated to reaching every child and woman with critical health care services like catch-up vaccinations, deworming and vitamin A supplementation, in addition to FP services and general health education in Uganda. These special days are commonly known as Integrated Child Health Days⁶⁷.

The study demonstrated that child friendly services do exist in Uganda and in the target districts. This ranges from PIASCY clubs across the country, adolescent health clinics in Kyenjojo district, paediatric clinics in Mpigi district to integrated child health days. This is known to promote access to age-appropriate HIV/AIDS services for children which has implications on service access and utility. Leveraging of such innovative service delivery models by Bloom partners and CHWs has the potential to contribute towards the achievement of project goals of creating a healthy life for children living with HIV and their young mothers

⁶⁶ Chipo Mutambo, Kemist Shumba, and Khumbulani W. Hlongwana, "Child-Centred Care in HIV Service Provision for Children in Resource Constrained Settings: A Narrative Review of Literature," *AIDS Research and Treatment* 2019 (November 26, 2019): 1–10, https://doi.org/10.1155/2019/5139486.

⁶⁷ "Health Workers Use Special Days to Reach Every Child with Life-Saving Vaccines | UNICEF Uganda."

4 Conclusions and Recommendations

This section describes the conclusions and recommendations including how to reduce stigma and discrimination against young mothers living with HIV, deal with lost to follow up, promote project sustainability and the recommended trainings for CHWs and other health workers.

4.1 Conclusions

- The YAPS model is a highly effective and innovative facilitator in the delivery of HIV services to young mothers living with HIV and their children. Based on this, the Bloom project, which is a community-based project, will have a positive impact on the finding, testing, treating and retention of young mothers living with HIV and their children in care, in the targeted areas. However, it is recommended to explore the specific impact of YAPS on CLWHIV, assess how the model contributes to the overall wellbeing, education, and healthcare of children born to mothers living with HIV. After that, these findings can be integrated into the Bloom project.
- Stigma and discrimination are strongly embedded barriers in access and utilization of HIV/AIDS testing, treatment and support services by both young mothers and their children. It was a consistently highlighted challenge faced by the young mothers living with HIV and their CLWHIV. This barrier continues to have a negative impact on HIV service access and utilization. This calls for cross cutting interventions by Bloom partners at all levels to address stigma and discrimination of young mothers and CLWHIV by working with all community members.
- HIV Self-testing kits are a strong facilitator for access to HIV testing services by young mothers and their children. They also allow for the navigation of financial barriers associated with transport to medical facilities for HIV testing services in addition to the stigma associated with it. The young mothers living with HIV and children interviewed preferred the self-testing kits as they promote more privacy and address the fear and anxiety associated with needle pricks which children complained about during the FGDs. Since their use is non-invasive, the children find them unpainful and hence more acceptable compared to the traditional blood tests. The Bloom project should work with the districts and facilities to ensure the availability of adequate supplies of HIV-ST kits as this will promote HIV testing by CLWHIV.
- The use of calls and reminders by YAPS and other health care workers is an effective facilitator for retention in care. It allows young mothers living with HIV and their CLWHIV to receive counselling, adhere to their treatment regimens and to turn up for medical appointments for ARV refills. Most of the children indicated that they sometimes forget to take their ARVs, and hence continuous calls and reminders were reported to be a good innovation in promoting ARV treatment adherence and ultimately the quality of treatment outcomes. It is hence of profound importance that Bloom works with partner health facilities and CHWs to strengthen call and reminder mechanisms as this promotes retention of young mothers and CLWHIV in care.
- Results insinuate that the integration of economic empowerment and HIV programmes for young mothers living with HIV and their CLWHIV has the potential to enhance access and utilization of HIV/AIDS services. In the event of financial challenges, some mothers narrated that they borrow money from their VSLA groups to facilitate transport to health facilities for HIV care. When young mothers have access to economic opportunities, they are likely to access or support their children to access HIV services.
- Poor access to food and nutrition was one of the prominent challenges facing YMLHIV and CLWHIV.
 Some narrated that they have one meal a day which may not coincide with treatment schedules. And in the face of inadequate access to food and nutrition, they are forced to take ARVs on an empty stomach

causing adverse side effects in the process. All this has negative implications regarding the quality of life and continued compliance with treatment regimens. Interventions targeting improved food security through income generation or farming are of high importance.

- The problem of long waiting time is a significantly noted challenge in access to HIV/AIDS services by all cohorts of CLWHIV and young mothers. They complained about waiting at health facilities for prolonged periods for the medicine refills. One of the CLWHIV narrated that on some occasions, they are prompted to resort to other health facilities to access HIV services to overcome long waiting time at their nearest health care facility. This calls for more investment in CHWs to conduct community outreaches and promote convenient access to HIV/AIDS services beyond the domain of the health care facility.
- Results from FGDs indicated low coverage of the social support network for both CLWHIV and young mothers living with HIV. The proportion of CLWHIV (younger than 10 years) who indicated that they were part of a social support group for CLWHIV was 33% for males and 25% for females. In the 10–14-year age group, it was 50% of females and 50% of males. While for young mothers living with HIV (15-19 years), 56% indicated that they are part of an HIV social support group while in the (20-24) year age group, it was reported to be 42%. The HIV social support network is of tremendous importance in helping CLWHIV and young mothers living with HIV in navigating shared challenges due to the emotional support provided by peers and low access is a detriment to their overall health and wellbeing.

4.2 Recommendations

The recommendations below have been enacted considering the findings from the study. They are directed to each of the stakeholders responsible for acting.

a. Bloom project implementing partners (CHAU, UYP and JOYI)

- Train Community Health Workers (CHWs) in sensitisation of CLWHIV and young mothers on how to deal with stigma and discrimination. Additionally, school matrons should also be trained on psychosocial counselling of CLWHIV against stigma and discrimination in the school settings which was noted to affect school going CLWHIV.
- The health and well-being of young mothers can directly impact the health of their children. The Bloom project should consider the dual health needs of both the mother and the child, recognizing that the well-being of one is closely tied to the other.
- The Bloom project partners should work with the Ministry of Health in Uganda (MoH) to ensure the availability of HIV Self testing kits across the health facilities as they were noted to be more acceptable by young mothers and their children because of their non-invasive nature. Young mothers should also be sensitised on the availability of HIVST kits.
- Conduct more community outreaches to build awareness on the availability of VSLAs for young mothers and CLWHIV and support the linkage of young mothers living with HIV and CLWHIV to these VSLAs. Additionally, it is relevant to work with local governments to institutionalise VSLAs for young mothers living with HIV and CLWHIV as part of sustainability planning.
- Strengthen the provision of nutritional and dietary counseling to pregnant young mothers living with HIV in the HIV social support groups in the 5 districts as a large proportion were found to be untrained. This can be through the development of more detailed and specific nutritional Information, Education and Communication (IEC) materials and their dissemination.
- Incorporate vocational skilling into the Bloom project to teach Young Mothers Living with HIV (YMLHIV) skills such as tailoring, making pads, and farming. This is helpful in building their income

generation potential and in addressing the food insecurity and financial challenges that they face in accessing HIV/AIDS services.

 Build more knowledge and awareness on paediatric HIV in churches, schools and amongst young mothers. This can be through organisation of trainings for young mothers, church leaders and senior woman teachers who can then cascade it to other stakeholders.

h. Aidsfonds

 Advocate for increased financing of community based paediatric HIV services through the donor community networks. This can be through building of awareness on the community health inequities facing Young Mothers Living With HIV (YMLHIV) and CLWHIV including their implications and how increased financing of community paediatric HIV services can contribute to the realisation of community, national and global goals such as the SDGs.

i. District and Ministry of Health (MoH)

- Apportion more budgetary resources to support paediatric HIV prevention, treatment and support services. Increased financing of YAPs will be helpful in addressing the barriers that peers face in fulfillment of their duties to support YMLHIV and their children.
- Set up new and equip existing child/adolescent friendly spaces to enhance access and utilisation of HIV/AIDS services by CLWHIV and their young mothers.
- Provide ongoing training for healthcare workers, including community health workers and peer educators, on the use of technology for HIV care. Continuous skill development ensures that the project remains effective as technology evolves.
- Strengthen the monitoring and evaluation component of paediatric HIV/AIDS programmes to ensure that HIV/AIDS data for CLWHIV and YMLHIV is comprehensive, disaggregated and readily accessible to HIV/AIDS partners for informed decision-making. This is because we found DHIS2 data to be incomplete and non-disaggregated for some indicators
- Use geospatial technology to map and analyze the distribution of HIV cases. This can help in identifying hotspots, planning interventions effectively, and optimizing resource allocation.
- Implement age-appropriate education and awareness programs in schools, communities, and youth centers to inform young individuals about HIV, its transmission, and the importance of testing.

j. Health care facilities

- Organise and carry out more community outreaches to extend HIV/AIDS services to young mothers and children in uncovered or inadequately covered communities.
- Continue with the calls and reminders which were noted to promote treatment adherence and retention of young mothers and their CLWHIV in care.
- Provide periodic professional development trainings for health care workers in child and adolescent friendly HIV/AIDS service delivery. A training at least every six months is recommended to improve health worker's attitude towards children and young mothers.
- Ensure that HIV testing services are provided in a confidential and non-judgmental manner to encourage more people, especially young mothers, to get tested.

k. Community Health Workers

• Continue with the community outreach and home visits to extend HIV testing and treatment services to YMLHIV and CLWHIV.
- Document and share experience, knowledge and best practices with Bloom partners on how to find young mothers living with HIV and children living with HIV in the targeted areas. As a result, partners can modify the activities of work plans to achieve this goal.
 - I. Social support groups (community, church, HIV/AIDS networks)
- Strengthen the incorporation of income generating activities in the social support groups as a way of supporting YMLHIV and CLWHIV in accessing HIV/AIDS services. It is necessary to earmark a proportion of savings to facilitate young mothers and CLWHIV in accessing HIV/AIDS services.
- Address stigma and discrimination facing members of the social support groups through psychosocial counselling and sensitisation of communities to debunk the myths and stereotypes surrounding HIV/AIDS.

Based on the feedback from the key informants and focus group discussants, below are the measures to reduce stigma and discrimination facing YMLHIV, dealing with Loss to Follow Up in addition to the recommended trainings for CHWs and other health workers.

Box 4

Reducing stigma and discrimination against young mothers living with HIV

- Train health care workers on how to best address stigma and discrimination.
- Support referral of YWLHIV to peer support groups or networks of young people living with HIV for social support against stigma.
- Relatives, spouses and family members of YWLHIV should be sensitized to play an increasingly supportive role.
- Strengthen psychosocial support/counselling for YWLHIV on how to recognize and overcome stigma
- Capacitate CHWs in conducting community sensitization against stigma and discrimination.

How do we deal with Loss To Follow Up?

- Phone calls/reminders to YWLHIV and children
- Home visits for drug refills and continued psychosocial support
- Enhance counselling sessions to address challenges that young mothers and their CLWHIV face
- Health facilities need to generate lists of lost patients and share them with CHWs for follow up

Recommended trainings for CHWs and other health workers

- Youth and child friendly HIV/AIDS services delivery
- Refresher trainings on facts about HIV/AIDS
- Capacitation of CHWs in community mobilization for HIV services
- HIV/AIDS counselling

4.3 Promoting sustainability of the Bloom project

Results from the KIIs and the IDIs revealed the following measures as key in promoting sustainability of the Bloom project.

• Economic empowerment of young women living with HIV is key for continued access to HIV care and support services. This can be done through supporting the establishment of VSLAs for YMLHIV or linking them to existing groups. Enhancing the skills for young girls living with HIV to participate in

income generating activities such as shoe making, tailoring, and other entrepreneurial skills is paramount as it financially empowers them promoting access to HIV services.

- Foster strong community engagement by involving local community members in the planning and implementation process. Empower local community structures to take ownership of the project. This can be achieved by involving them in decision-making processes and allowing them to tailor interventions to their specific context.
- Health facilities should expand holding of child health days for provision of targeted HIV/AIDS services to children.
- The Bloom project should start collaborations and partnerships with comprehensive HIV implementing partners such as IDI, Baylor Uganda especially in the implementing districts. Partnerships and collaborations will be key in promoting project sustainability as these partners have a permanent presence in Uganda and implement diverse HIV/AIDS programmes. They can likely take up some of the Bloom project activities at end of term.
- Train community gatekeepers such as church leaders, local Council officials in addressing stigma and discrimination and in advocating for the rights of access to HIV/AIDS services by young mothers living with HIV and their children.
- Strengthen peer support groups or networks of young people living with HIV and linkage of young mothers and CLWHIV to these groups to ensure continued peer support.
- Develop a comprehensive knowledge-sharing system that includes manuals, guides, and documentation of successful strategies. This will facilitate the transfer of knowledge to new community members and health workers, ensuring continuity.

4.4 Advocacy priorities for PMTCT /Paediatric HIV prevention, treatment, and support services for young mothers.

• According to a CHW in Kyenjojo district, there is need to advocate for adequate and uninterrupted supply of HIV/AIDS commodities such as ARVs as stock outs are some of the most prevalent challenges they face. Despite numerous efforts by HIV/AIDS partners and donors, multiple complaints of drug stock outs arose during the FGDs for both children and young mothers. Some children revealed that sometimes they are forced to take alternative ARV drugs when their prescribed drugs are unavailable which has possible negative implications on treatment outcomes. Below is the feedback from the CHW. *"Advocate for enough supply of the HIV treatment and drugs such as the prophylaxis in health facilities so as to prevent early transmission of the HIV virus."* (KII, CHW, Kyenjojo district)

• Integration of HIV/AIDS services with other health care services to enhance their access and utilization. This can be done through ensuring that community outreaches for other health services such as immunization and family planning also involve the provision of HIV/AIDS information, testing, counselling and treatment services.

"I think we need to combine HIV services amongst other services in the outreaches to increase the access..." (FGD, YMLHIV, Kyenjojo district).

• The establishment or equipping of adolescent and child health spaces at health facilities was noted to be a necessary advocacy priority to promote access to adolescent and child friendly services. Many youth spaces are noted to be inadequately equipped and yet they play a major role in enhancing access to child and adolescent appropriate HIV/AIDS services. According to a CHW in Mpigi district;

"We should have edutainment movies, films that communicate to the young mothers exposed to HIV and positive children about HIV so that people can get to understand everything related to it such as how to prevent and treat HIV. Such as bringing people from Naguru Teenage Centre to come and also talk to the young mothers to be exposed and positive children" (KII, CHW, Mpigi district).

• Revive the YAPS programme in the other parts of Uganda which the Bloom project is currently not working to enhance home visits for ART refills, counselling sessions, testing and linkage to care. YAPS is both a community and health facility-based model related to the Kids to Care model as it seeks to identify, test, treat and promote retention of adolescents and young people in HIV care. The YAPs play a great role in promoting convenient access to HIV testing and treatment services by young mothers and CLWHIV and they make home visits for follow up and support. They are a key component in adolescent and child friendly service delivery. According to an In-charge, Health Centre IV in Kyenjojo district, there is need to train the YAPS on how to find and conduct tests for different groups of people.

".....for advocacy, YAPs should be equipped with more skills on how to find the infected young people and children. And also, how to conduct different tests to the different categories of people". (In-charge, Health Centre IV, Kyenjojo district)

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Annex 1: The Baseline Indicator Framework-DHIS2 DATA

Considered DHIS2 data from April 2023 to June 2023

Note: xx means missing data

		DISTRICT					
No.	INDICATOR	Mityana	Mubende	Butambala	Mpigi	Kyenjojo	TOTAL
		n	n	n	n	n	n
TEST							
1	105-AN30a. Pregnant Women tested HIV POSITIVE for 1st time this pregnancy (TRR) at any ANC Visit - Total younger than 15 Years	0	0	0	0	2	2
2	105-AN30a. Pregnant Women tested HIV POSITIVE for 1st time this pregnancy (TRR) at any ANC Visit - Total 15-19Years	10	14	1	9	13	47
3	105-AN30a. Pregnant Women tested HIV POSITIVE for 1st time this pregnancy (TRR) at any ANC Visit - Total 20-24Years	28	33	7	33	15	116
	TOTAL	38	47	8	42	30	165
4	105-AN02. ANC 4th Visit for women 15-19Years	334	599	100	316	584	1933
5	105-AN02. ANC 4th Visit for women 20-24Years	755	1065	227	728	1000	3775
6	105-AN02. ANC 4th Visit for women younger than 15Years	3	3	xx	6	10	22
	TOTAL	1092	1667	327	1050	1594	5730
7	105-ANO3. ANC 4+ visits for Women 15-19Years	339	417	89	175	372	1392
8	105-AN03. ANC 4+ visits for Women 20-24Years	770	700	175	438	595	2678
9	105-AN03. ANC 4+ visits for Women younger than 15Years	0	2	xx	0	0	2
	TOTAL	1109	1119	264	613	967	4072
10	105-AN04. ANC 8 contacts/visits for women 15-19Years	24	38	4	3	237	306
11	105-AN04. ANC 8 contacts/visits for women 20-24Years	40	57	4	22	336	459
12	105-AN04. ANC 8 contacts/visits for women younger than 15Years	0	1	xx	0	1	2

	TOTAL	64	96	8	25	574	767
13	105-Total tested for HIV(1-4 Years)- Female	197	220	90	169	323	999
14	105-Total tested for HIV(1-4 Years)- Male	175	249	93	168	281	966
	TOTAL	372	469	183	337	604	1965
15	105-Total tested for HIV(10-14Years)- Female	220	396	77	152	387	1232
16	105-Total tested for HIV(10-14Years)- Male	109	117	71	77	281	655
	TOTAL	329	513	148	229	668	1887
17	105-Total tested for HIV(15-19Years)- Female	1799	2851	458	1392	2057	8557
18	105-Total tested for HIV(15-19Years)- Male	274	1000	75	222	462	2033
	TOTAL	2073	3851	533	1614	2519	10590
19	105-Total tested for HIV(20-24Years)- Female	3975	5403	901	3003	3353	16635
20	105-Total tested for HIV(20-24Years)- Male	920	1278	129	666	1054	4047
	TOTAL	4895	6681	1030	3669	4407	20682
21	105-ED01a. Exposed Infants Tested for HIV below 18 months of age by 1st PCR - Total	304	293	60	245	293	1195
22	105-ED01c. Exposed Infants Tested for HIV below 18 months of age by 1st PCR - HIV+	5	3	1	3	3	15
	TOTAL	309	296	61	248	296	1210
23	105-Total New HIV positive (1-4 Years) - Female	5	4	4	2	3	18
24	105-Total New HIV positive (1-4 Years) - Male	3	3	1	1	5	13
	TOTAL	8	7	5	3	8	31
25	105-Total New HIV positive (10-14 Years) - Female	0	3	2	3	28	36
26	105-Total New HIV positive (10-14 Years) - Male	3	2		0	13	18
	TOTAL	3	5	2	3	41	54
27	105-Total New HIV positive (15-19 Years) - Female	25	36	3	15	33	112
28	105-Total New HIV positive (15-19 Years) - Male	0	2	1	1	9	13
	TOTAL	25	38	4	16	42	125
29	105-Total New HIV positive (20-24 Years) - Female	83	87	20	77	66	333

30	105-Total New HIV positive (20-24 Years) - Male	12	11	2	10	19	54
	TOTAL	95	98	22	87	85	387
START							
31	105-AN32. HIV POSITIVE pregnant women initiated on ART for eMTCT at any visit irrespective of when tested HIV POSITIVE(TRR,TRR+,TRR,TRRK) younger than 15Years	Ο	0	0	0	2	2
32	105-AN32. HIV POSITIVE pregnant women initiated on ART for eMTCT at any visit irrespective of when tested HIV POSITIVE (TRR,TRR+,TRR,TRRK) 15-19Years	7	14	1	9	12	43
33	105-AN32. HIV POSITIVE pregnant women initiated on ART for eMTCT at any visit irrespective of when tested HIV POSITIVE (TRR,TRR+,TRR,TRRK) 20-24Years	28	34	7	32	17	118
	TOTAL	35	48	8	41	31	163
34	105-ED07. HIV exposed infants given ARV prophylaxis for the first time at mother baby care point	189	70	29	62	119	469
35	106a-HC24-ART clients that were lost to follow-up during the quarter 1- 4Yrs, Female	xx	xx	xx	2.0	3.0	
36	106a-HC24-ART clients that were lost to follow-up during the quarter 1- 4Yrs, Male	1.0	xx	xx	1.0	xx	
37	106a-HC24-ART clients that were lost to follow-up during the quarter 10-14Yrs, Female	1.0	xx	xx	4.0	4.0	
38	106a-HC24-ART clients that were lost to follow-up during the quarter 10-14Yrs, Male	2.0	xx	xx	1.0	2.0	
39	106a-HC24-ART clients that were lost to follow-up during the quarter 15-19Yrs, Female	5.0	xx	2.0	11.0	3.0	
40	106a-HC24-ART clients that were lost to follow-up during the quarter 15-19Yrs, Male	1.0	xx	2.0	4.0	xx	
41	106a-HC24-ART clients that were lost to follow-up during the quarter 20-24Yrs, Female	8.0	4.0	3.0	23.0	13.0	
42	106a-HC24-ART clients that were lost to follow-up during the quarter 20-24Yrs, Male	xx	xx	xx	3.0	3.0	

Annex 2: THE BASELINE INDICATOR FRAMEWORK-PARTNER DATA

			Baseline value (Oct 2023)
No.	Indicators	Indicators Definition	
1	# Children (0-14) living with HIV engaged supported via support groups	Number of children (0 - 14) years old who are reached and supported via the support group(s) for young mothers (10 - 24) years old living with HIV	0
2	# Young mothers / caregivers participate in VSLAs	Number of young mothers (10-24) living with HIV and caregivers of children (0 - 14) affected by/living with HIV who are part of a VSLA(s)	0
3	# Households supported with nutritional support (e.g. kitchen gardens, seeds etc)	Number of households with a young mother (10 -24) living with HIV and a child (0 -14) affected by HIV supported with kitchen garden seeds	0
4	# Young mothers supported via active safe spaces	Number of young mothers (10 - 24) living with HIV who are part of the active safe spaces	0
5	# Community health workers / mentor mothers trained	Number of community members who received training to become community health worker and/or mentor mother under the Bloom project	0
6	# Health care workers trained (facility level)	Number of health care workers who received training at the facility level under the Bloom project	0
7	# of young male and young fathers reached and trained in the project	Number of young males (10-24), young fathers living with HIV or partners of young mothers (10 - 24) who were reached and trained under the Bloom project	0
8	# Community resource persons, community leaders, gate keepers trained	Number of community resource person, community leaders and/or gate keepers who received training under the Bloom project (expert clients)	0

Annex 3: The sampling distribution

Categories of Stakeholders	In-Depth Interviews	Key Informant Interviews	Focus Group Discussions
Pregnant and breastfeeding young women living with HIV	-	-	2
Young mothers to be exposed to and living with HIV	-	-	6
Caregivers and partners of young mothers living with HIV	-	-	2
Children living with HIV and/or exposed to HIV	-	-	6
Local Religious and Community leaders	1	1	-
Church support groups	1	1	-
Community support groups	1	2	-
Community Health Workers	1	2	
Health Care Workers	1	2	-
Management of Health Centers	1	2	-
Staff of Ministry of Health responsible for PMTCT and paediatric HIV care	1	2	-
District officials, District Health Teams, and other relevant departments	2	2	-
Networks of (young) people living with HIV	1	2	2
Comprehensive HIV Implementing partners such as Mildmay, TASO, IDI and Baylor Uganda. And OVC partners or any other involved partner which is not listed here but will be finalised with Aidsfonds team.	2	2	-
Total	12 In-Depth Interviews	18 Key Informant Interviews	20 Focus Group Discussion s

Annex 4: Treatment and control groups

	Butambala district sub counties	Mpigi district sub counties	Mubende District sub counties	Mityana district sub counties	Kyenjojo District sub counties
Treatmen sites	 Budde Bulo Nganda Gombe Town Council 	 Mpigi Town Council Kammengo sub-county Buwama Town council. 	 Bagezza Butoloogo Kasambya Kasambya T/C Kigando Kiyuni Kyenda TC Lubimbiri Nabingoola TC West division 	 Bulera, Kalangalo, Butayunja, Zigoti Town Council, Maanyi, Kakindu, Malangala, Busimbi Division, Mityana Central Division Tamu Division 	 Nyabuhaburw Nyatungo Kyenjonjo TC Kigarale Butiti Katooke Bufunjo Kanyegaramir
Control sites	 Kibibi Town Council Kalamba sub- county Kalamba Town council. 	 Kituntu sub- county Nkozi sub- county Buwama sub-county Kiringente sub-county Muduuma sub-county 	 Kayebe Kiruma, East division, South division 	 All the 17 sub counties/ town councils in Mityana are project supported. Proposed control facilities: Kyamusisi Health Centre III in Kyatungo subcounty Kambala HCIII in Maanyi subcounty 	 Batalika Kitega Kyamutunzi Town Council Kyarusozi S/C Mbale Town Council Nyabirongo





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