SYSTEMS FOR BETTER HEALTH
HIV LINKAGES ACTIVITY

End-of-Project Documentation
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<td>AIDS</td>
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<td>ART</td>
<td>Antiretroviral Therapy</td>
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<td>Community Adherence Club</td>
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<td>CBO</td>
<td>Community-Based Organization</td>
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<td>CBV</td>
<td>Community-Based Volunteer</td>
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<td>CIDRZ</td>
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<td>Determined, Resilient, Empowered, AIDS-free, Mentored and Safe</td>
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<td>Girls Empowerment and Women's Livelihood</td>
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<td>Growth Monitoring and Promotion</td>
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<td>GRZ</td>
<td>Government of the Republic of Zambia</td>
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<td>HEI</td>
<td>HIV Exposed Infant</td>
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<td>John Snow Inc.</td>
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<td>LTFU</td>
<td>Lost to Follow-Up</td>
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<td>UNAIDS</td>
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<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<tr>
<td>U.S.</td>
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<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
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<td>Abbreviation</td>
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<td>USG</td>
<td>United States Government</td>
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<tr>
<td>VL</td>
<td>Viral Load</td>
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<td>VSU</td>
<td>Victim Support Unit</td>
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<td>ZAMFAM</td>
<td>Zambia Family Activity</td>
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<td>ZAMPHIA</td>
<td>Zambia Population-Based HIV Impact Assessment</td>
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<td>ZICTA</td>
<td>Zambia Information and Communications Technology Authority</td>
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We wish to extend our gratitude to the United States Agency for International Development and the President’s Emergency Plan for AIDS Relief for funding the Systems for Better Health HIV Linkages Activity. We greatly appreciate the support from the Government of the Republic of Zambia, specifically the Ministry of Health and its staff at the District Health Office and the five health facilities in Kitwe District for their leadership in the implementation of the Systems for Better Health HIV Linkages Activity. We are grateful to the Government of the Republic of Zambia line ministries (i.e., the Ministry of General Education, the Ministry of Community Development and Social Services, the police, and the Ministry of Youth, Sport, and Child Development), health facility staff and community-based volunteers, numerous civil society organizations, the Area Coordinating Committee members, the Community Welfare Assistance Committee members, the schools, and other key stakeholders for their valuable contributions to this project.

The End-of-Project Documentation for the Systems for Better Health HIV Linkages Activity was comprised of two components—qualitative and quantitative—and conducted in close collaboration with the project team. The qualitative data collection and analysis was led by Cornelia van Zyl and the data collection team included Bernard Kasawa, Bryan N’gambi, Champo Mwelwa, Janet Mwambi, Nathan Chileya, and Roderick Bwalya. The compilation of the quantitative project data was conducted by the project monitoring and evaluation team and included Benson Bwalya, Ekpenyong Ekanem, Kennedy Makulika, Paul Bouey, and Paul Chirwa. Data from both components were triangulated and culminated into this report.

The Systems for Better Health HIV Linkages Activity team wishes to thank the following focus group participants for their candid and insightful feedback during the discussions: Ministry of Health and its staff at the District Health Office and the five health facilities, the Government of the Republic of Zambia line ministry representatives, community-based volunteers, community-based social services providers, and Systems for Better Health project staff.
EXECUTIVE SUMMARY

The Government of the Republic of Zambia (GRZ) has adopted the Joint United Nations Programme on HIV and AIDS (UNAIDS) 90-90-90 targets and continues to make significant gains in the fight against HIV. The United States Agency for International Development (USAID)’s Systems for Better Health Project (SBH) has contributed to this fight through programming targeted at children and adolescents most at-risk through innovative programs spanning mobile health, capacity building, and technical assistance to the Ministry of Health (MOH), civil society partners, and community-based volunteers (CBVs).

As Zambia’s HIV epidemic continues to reduce, it remains vital that HIV positive clients are identified, initiated, and retained on treatment and are virally suppressed. Evidence has shown that half of the Zambian children aged 0-14 living with HIV know their HIV status, 92% of those children are on antiretroviral therapy (ART), while over half are virally suppressed (25). The innovative strategies implemented by SBH responded to the need for targeted HIV identification, ART initiation, and retention for HIV positive infants, children, and adolescents as well as case management to ensure their psychosocial and socio-economic needs are met. Implemented in five health facilities in the Kitwe District of the Copperbelt Province, the interventions included: placement of a “case worker” at health facilities, capacity building of—and close collaboration with—CBVs, use of a short message service (SMS) patient reminder system (i.e., PedTrack), and comprehensive case management including referrals to social support services.

The End-of-Project Documentation for the SBH HIV Linkages Activity was conducted to gather quantitative data which monitored program performance from March 2017 to September 2018 and qualitative data to determine what did and did not work well with implementation strategies. Quantitative and qualitative data was collected, analyzed, and used to generate lessons learned and recommendations for USAID, GRZ, donors, implementing partners, and civil society stakeholders including community members.

Overall, the results of the review found that SBH had a positive effect on HIV care and treatment services for HIV positive infants, children, and adolescents in the five intervention sites.

HIV CARE AND TREATMENT

The Activity placed full-time case workers at five high-volume health facilities to identify and follow-up on HIV-exposed infants (HEIs) and HIV positive children and adolescents to ensure they received the needed HIV services. Respondents reported feeling that they had made a positive impact on HIV services provided to clients. Project data associated with the Activity indicated an average 12-month retention rate of HIV positive children and adolescents on ART was 84%, with a corresponding lost to follow-up (LTFU) average rate of 16%. Adherence to appointments showed that 80% of clients returned for first appointments, while 91% of those who missed the first appointment, came back after rescheduling.

Through respondent feedback, several enabling factors were identified as contributing to these results. The case workers—filling an important gap at understaffed health facilities—had an exclusive focus on children and adolescents. In some health facilities, they were assigned the responsibility to administer dried blood spot (DBS) tests and provide prophylaxis to HEIs and/or oversee the CBVs who were trained to do so. The case workers were empathetic, respectful, compassionate, created relationships of trust with clients, and helped them through their trajectory of HIV care. They implemented their work through a case management lens and helped facilities to identify clients due for services (HIV testing, ART initiation, medical reviews, refills, and viral load [VL] testing).
Together with the CBVs, they also helped trace clients who missed appointments. Due to their permanent presence at health facilities, they were able to provide integrated services which improved HIV care provided to the target groups. In summary, the case workers provided mothers and guardians, and HIV positive children and adolescents, with counseling and access to services which they might otherwise not have received at the health facilities.

The use of PedTrack was considered a helpful tool in ensuring that facility providers, CBVs, and clients were reminded of follow-up appointments. Respondents felt that the system was effective because most clients with phones, who received the messages, adhered to appointments. The placement of case workers at health facilities, coupled with the SMS reminder system, and follow-up and counseling through CBVs, contributed to client appointment adherence (80% of first appointments were fulfilled).

The HIV care and treatment component the Activity encountered some challenges. Some clients provided incorrect contact details (i.e., phone numbers or addresses) which made follow-up challenging. Non-disclosure of HIV status to children and adolescents, inadequate food and nutrition, and orphanhood challenged client adherence to ART and their ability to stay in HIV care and treatment services. The effectiveness of the PedTrack system was jeopardized by its late introduction, power outages, and unreliable internet services. Some case workers also experienced difficulty managing the system. Inadequacies were noted in the monitoring of the quality of data generated through the PedTrack system. These challenges precluded it from being a quantitative data source, thus its contribution to the outcomes is unclear.

**COMPREHENSIVE CASE MANAGEMENT AND SOCIAL SUPPORT SERVICE REFERRALS**

Through the comprehensive case management approach, a number of HIV positive children and adolescents were effectively referred to, and received, social support services. The referral network helped stakeholders better understand the services available, fostered relationships, and increased referrals and feedback. However, despite these efforts, program data showed that all clients identified as eligible were referred for social support services but approximately only one in three (28%) clients received a service. This was due to, among others, the demand for services (especially education and nutrition) outnumbering the supply, limited donor funding, organizational policies and inclusion criteria, the centralization of decision-making at the District Social Welfare Office (DSWOO), and the lack of decision-making by representatives of the Department of Social Welfare at the community level.

**RECOMMENDATIONS**

Respondents indicated that SBH contributed to an increase in retention and patient appointment adherence, and a decrease in LTFU. This, they felt, was mostly due to the placement of the case workers, allowing for increased capacity and skillsets to fill vital gaps at health facilities, as well as their close collaboration with the CBVs. Overwhelmingly, the recommendation was for GRZ, USAID, and partners to continue funding such a position as part of the implementation strategy—to reach and exceed the 90-90-90 targets—while an evidence-informed case is made to the MOH for this position to be included in the GRZ payroll.

PedTrack is a user-friendly tool which relies on a person to assume the case management function (e.g., identify clients, follow-up on clients, trigger SMS reminders, determine if clients came, update the system, and synchronize the system with SmartCare). In addition to the position being funded, recommendations for PedTrack and its data management component included: developing national
standards and procedures for data quality assessments which require implementation at all ART sites, funding PedTrack as part of a more inclusive data system at a relatively low cost, expanding PedTrack to all ART sites, and ensuring it supports children, youth, and adults. Support for sustaining PedTrack should also be considered in the context of a wider initiative to strengthen overall approaches and planning as part of the health information system to improve data use and decision-making.

Non-disclosure, stigma, poverty, and orphanhood were prevalent and persistent barriers to HIV care and treatment. To counter these, recommendations for differentiated strategies to increase HIV testing, care, and treatment services, and for effective referrals to social support services, included, but were not limited to:

- Funding a case worker position at the health facility, as they contributed to the increase in number of clients returning for visits, being tested for HIV, and initiated and retained in ART;
- Establishing different days for children and adolescents to receive HIV services, and adolescent support groups to increase peer support, adherence, and retention;
- Increasing the number of health providers, CBVs, lay counselors, and child counselors who are trained and experienced in adherence and disclosure counseling and psychosocial support;
- Expanding community adherence clubs (CACs) for stable patients, including children and adolescents (following the Centre for Infectious Disease Research in Zambia [CIDRZ] model) with a CBV participating in the CAC and overseen by a case worker and ART clinician;
- Recognizing the value of CBVs and the expanded role they could play to reach epidemic control, and designing an incentive package commensurate with their work;
- Investing in age-appropriate sexual and reproductive health education at all levels of schooling to combat false beliefs and HIV stigma, and investing in community interventions to decrease stigma and improve the lives of people living with HIV and AIDS (PLHIV);
- Investing in coordination mechanisms at the community level to enhance local ownership;
- Increasing investment in social service programs to reach more children and adolescents with education, nutrition, child protection, and economic strengthening programs;
- Establishing social protection programs to intensify efforts to create efficient pathways out of poverty.

Implementing these recommendations will contribute to *Accelerate Development Efforts in Zambia without Leaving Anyone Behind* (23).
I. INTRODUCTION

1.1 CONTEXT

Zambia has one of the highest burdens of HIV in Sub-Saharan Africa with a generalized epidemic of 13.3% among adults aged 15-49 with more women (15.1%) than men (11.3%) living with the virus (2). The Zambian population is predominately young, with approximately 23% aged 10-19, according to the 2014 Central Statistics Office. The estimated HIV prevalence rates among adolescent girls and boys aged 15-19 is 3.5% for girls and 1.8% for boys (3). According to the Zambia Population-based HIV Impact Assessment (ZAMPHIA) study conducted in Zambia in 2016, the disparity in HIV prevalence by sex is most pronounced among young adults: HIV prevalence among those aged 20-24 is four times higher among females (8.3%) than among males (2.0%). HIV prevalence among children aged 0-14 is estimated to be 1.1% (21).

ZAMPHIA measured the country’s progress toward attainment of the 90-90-90 targets. The study estimated that among all HIV positive people aged 15-59, 66% knew they were HIV positive (below the intended 2020 target), 85% self-reported receiving ART, and 89.3% of adults receiving ART were virally suppressed. The prevalence of VL suppression increased with age, from 30.7% among HIV positive people aged 15-19 to 79% among those aged 55-59. Overall, ZAMPHIA estimated that the combined parent-reported and ARV-adjusted data shows that 50.6% of HIV positive Zambian children aged 0-14 knew their status. Of children aged 0-14, who were previously diagnosed, 92.3% were on ART. Of those on ART, only 54.3% had suppressed VLs (25). The GRZ and its partners recognized that children and adolescents are distinct vulnerable populations, and require a mix of targeted but differentiated programs in order to achieve the Fast-Track targets (3; 18).

Addressing HIV positive children and adolescent vulnerabilities requires a coordinated approach across government, civil society, and private sector actors. Evidence has shown that several determinants of HIV—household poverty, lack of access to education, lack of adequate food and nutrition, orphanhood, violence, and abuse and neglect—affect children and adolescents’ development and ability to adhere to and stay on to ART (1). Evidence in Zambia has also shown that children in urban areas are most at risk of increased vulnerability due to poverty. In the Copperbelt and Lusaka provinces, 88% of all children are deprived according to at least one dimension of poverty (96% in Copperbelt and 81% in Lusaka) and 54% of children and adolescents are considered deprived according to all dimensions of poverty (19; 25). It is estimated that more than one quarter (28%) of families live below the poverty line and an even larger share of children live in those poor families (20). It is estimated that 42% of children aged 0-4 in the two provinces are deprived of adequate nutrition and one in five children aged 5-17 are deprived of an education (19). The HIV pandemic further exacerbates these effects on children, adolescents, and their families with urban areas more affected than rural areas (18.2% of urban residents are HIV positive, compared to 9.1% in rural areas) (2).

1.2 USAID’S SYSTEMS FOR BETTER HEALTH HIV LINKAGES ACTIVITY

USAID’s 5-year SBH project aimed to improve health outcomes for Zambians by strengthening systems that underpin the delivery of high-quality health services. The project also sought to increase the utilization of high-impact health interventions including strengthening linkages between communities and facilities for key health interventions. SBH implemented the HIV Linkages Activity: a package of interventions in Kitwe District, Copperbelt Province, to improve health outcomes of HEIs and HIV positive infants, children, and adolescents, by improving access to HIV clinical care and
social support services through strong linkages between health facilities and communities. The specific objectives of the HIV Linkages Activity were to:

- Enhance HIV testing for children aged 0-10 of HIV positive index cases;
- Ensure HEIs received diagnostic tests and results at 12 and 18 months of age;
- Ensure HEIs, children, and adolescents who tested HIV positive initiated ART;
- Improve retention in treatment for HIV positive infants, children, and adolescents;
- Ensure HIV positive infants, children, and adolescents on ART received bi-annual VL tests;
- Mitigate social factors which adversely affected HIV health outcomes by linking infants, children, adolescents, and their guardians to social support services.

The Activity established a functional referral system between health facilities and community structures for comprehensive case management. This was done through:

- Placing a special cadre of case workers at five selected health facilities in Kitwe District;
- Implementing PedTrack, a patient appointment scheduler and SMS reminder system;
- Strengthening coordination and linkages of health facility-community stakeholders in HIV care;
- Strengthening linkages to social support services.

The HIV Linkages Activity started in March 2017. Based on discussions with USAID in early 2018, the Activity refocused its interventions to strengthen HIV testing and ART linkage and retention among HIV positive children and adolescents, as well as referrals to social support services. The Activity developed a revised conceptual framework, a theory of change, and a monitoring and evaluation (M&E) framework with clear indicators to reach results. Initially the Activity was implemented in five high-volume health facilities (i.e., Kawama, Twatasha, Ipusukio, Wusakile, and Mulenga) in Kitwe District, Copperbelt Province. It expanded to six additional health facilities in August 2018. To accommodate these changes, the management team and structure was modified, including redistribution of case workers so that each of the 11 facilities had one case worker, instead of three case workers at each of the initial five health facilities.

1.2.1. HIV LINKAGES ACTIVITY – IMPLEMENTATION APPROACHES

The HIV Linkages Activity included the following interventions (also indicated above): placement of a case worker at the health facility, collaboration with CBVs, PedTrack SMS reminder system, case management and referrals to health and social support services, and collaboration and coordination between the health facility and community-based social service providers and between the district health office (DHO) and partners. These interventions were all linked together to form a holistic case management approach to reach the Activity’s objectives. The case worker was the central figure around which the other interventions pivoted.

Graphic 1.1 depicts the HIV testing, care, and treatment continuum, the case worker’s role, and interaction with staff providing HIV services. Graphic 1.2 depicts the comprehensive case management approach for HIV positive infants, children, and adolescents, and social support service referrals.
GRAPHIC 1.1. SBH’S HIV LINKAGES ACTIVITY – HIV CARE AND TREATMENT CONTINUUM

HIV Care and Treatment Continuum

HEls, HIV+ Children, Adolescents and Their Families

HIV Services
- HIV Testing
- ART Initiation
- HIV Care and Retention
- Patient Monitoring and VL Testing
- Adherence and Disclosure Counseling

Tasks
- Identification – HEls, HIV+Infants, Children, Adolescents
- Enrollment
- PedTrack (Client Appointment Scheduler and SMS Reminder System)
- Follow-up

Case Worker

- Maternal and Child Health Nurse
- ART Clinician
- Data Clerk
- Laboratory Technician
- Pharmacist
- Psychosocial Counselor
- Health Facility In-charge
- CBV
- Growth Monitoring and Promotion
- Home Visits
- Counseling and Home-based Testing

GRAPHIC 1.2. SBH’S HIV LINKAGES ACTIVITY – COMPREHENSIVE CASE MANAGEMENT AND REFERRAL TO SOCIAL SUPPORT SERVICES

Comprehensive Case Management and Referrals to Social Support Services

HEls, HIV+ Children, Adolescents and Their Families

Parental Counseling
- HIV Services
- Sexual Reproductive Health
- Food and Nutrition
- Education and Vocational Training
- Child Welfare and Protection
- Social Protection (Social Cash Transfers)
- Psychosocial Support

HIV Services
- Health Facility

Case Worker

- Religious Institutions and Leaders
- Schools and Teachers

Tasks
- Partner Mapping
- Referral Network
- Identification of Vulnerability
- Case Plan and Referral
- Follow-up
- Coordination

Community-based Volunteers

Civil Society Partners
An overview of the HIV Linkages Activity interventions is provided below.

**THE CASE WORKER**

The case workers were recruited by SBH’s HIV Linkages Activity and placed within the health facilities. They received training on the MOH-approved “Community Comprehensive Childhood and Adolescent HIV Care” (CCCAH) training curriculum and the “Case Management Module” which forms part of the CCCAH training, as well as a training in DBS and HIV testing. They were supervised by the health facility in-charges.

The case worker worked with different departments and staff in the health facility and used facility registers, or SmartCare, to identify HIV index cases. The case worker ensured their family members, HEIs, children, and spouses (or partners) were tested for HIV. If the infants, children, and adolescents tested HIV positive, the case worker helped health facility staff to ensure that they were initiated on ART and retained in HIV care and treatment services. The case worker used a project-developed form to register clients in the HIV Linkages Activity, obtain parent/guardian’s contact details, and confirm willingness to receive SMS messages from the health facility and to be followed-up by the case worker and/or a CBV. The case worker worked with the health facility staff to determine when a HEI, HIV positive child, or adolescent was due for a specific HIV service (DBS/HIV testing, medical refills, reviews, and VL testing and other laboratory test). They entered these dates into the HIV Linkages Activity database and PedTrack which generated SMS reminders to the clients, they followed-up to determine if clients fulfilled their appointments, and set new dates if they missed one. Initially, case workers conducted the home visits to clients, but after the redesign of the Activity in 2018, the home visit responsibility was shifted to CBVs.

The CBVs were supervised and mentored by the case workers. In some health facilities, trained CBVs supported the health facility to administer the DBS tests to HEIs, to conduct growth monitoring and promotion (GMP) sessions, while others (under Zambia Family Activity [ZAMFAM] Lusaka and Central) were trained to conduct home-based HIV testing. The CBVs roles in the Activity were to:

- Support the case worker in tracing clients who missed appointments through home visits;
- Conduct counseling sessions with clients during home visits and reinforce key messages around HIV testing, disclosure, adherence, and living positively with HIV;
- Support the case worker in identifying vulnerability and social support service needs of HIV positive children and adolescents, identify social support service providers in the community, and follow-up on referrals;
- Participate in monthly coordination meetings at the health facility.

All CBVs supporting the Activity were Neighborhood Health Committee (NHC) members, while some were also Safe Motherhood Action Group (SMAG) members, volunteers supporting GMP or prevention of mother-to-child transmission of HIV/AIDS (PMTCT) focal points. Some were linked to other institutions such Ndola Diocese (under ZAMFAM), John Snow Inc. (JSI), or Copperbelt Health Education Project (CHEP). The CBVs received training by the Activity and DHO in HIV/AIDS, adherence support, disclosure and psychosocial counseling, DBS testing, community engagement, confidentiality and how to work with adolescents, linkages and referrals, and teamwork.
The case worker was responsible for data management and created a file for every HIV positive child and adolescent enrolled in the Activity. The file included a registration form, a vulnerability assessment, a case plan with referral needs, as well as feedback from referrals to social services. The case worker entered client data into the HIV Linkages Activity database and into PedTrack and synchronized this information with data from the facility registers, patient files, and SmartCare to avoid discrepancies between the systems. The patient files kept by the case worker included the same ART numbers generated by SmartCare.

**PEDTRACK SYSTEM**

The PedTrack system sent SMS reminders to clients for scheduled health facility appointments. It was introduced at the five health facilities 10 months after the case worker’s placement, as it required clearance by the MOH for its use in Zambia. The PedTrack system was managed by the case worker, who registered clients in, and regularly updated, the system. The system was designed to capture client information including names, addresses, phone numbers, appointment dates for specific services, and contact details for the CBV (linked to the specific clients) and health facility staff responsible for specific HIV services linked to the client. SMS reminders for appointments were sent to clients three days and one day prior to the appointment. The case worker followed-up with health facility staff to determine if clients attended appointments. In the event that the client missed an appointment, the case worker either called the client to understand the reason for missing the appointment and to set a new date, or sent a CBV to conduct a home visit. The case worker updated PedTrack on a daily basis. The system generated graphs and reports such as appointments fulfilled, not fulfilled, and for which services. The screenshots below provide an example of such reports.
The case workers were trained in the management of PedTrack. The training was extended to the data clerks and other health facility personnel to continue its use when the Activity phased out and to ensure ownership and sustainability.

**COMPREHENSIVE CASE MANAGEMENT AND REFERRALS TO SOCIAL SUPPORT SERVICES**

The HIV Linkages Activity aimed to ensure children and adolescents are retained in the HIV care and treatment continuum and provided with comprehensive health and social services to respond to their vulnerabilities.

At the start of the Activity, the case worker established a referral network between health facilities and social support service providers in each health facility’s catchment area. The case worker facilitated a mapping exercise of these providers and the services offered. These services included: educational support, life skills and entrepreneurship skills training, child welfare and protection, food and nutrition support, and economic strengthening (including social cash transfers [SCT]). The providers included volunteers representing GRZ line ministries such as members of the Community Welfare Assistance Committee (CWAC) and Area Coordinating Committee (ACC) representing the Department of Social Welfare at the community level. It also included the Victim Support Unit (VSU) under the police, government schools, community schools, and civil society organization (CSO) partners such as Ndola Diocese under ZAMFAM, CHEP-Determined, Resilient, Empowered, AIDS-free, Mentored and Safe (DREAMS), Clinton Health Access Initiative, Afya Mzuri, JSI, Luapula Foundation, Zambia Civic Education, and Bwafwano. The case worker visited the stakeholders and invited them to the monthly stakeholder meetings at each health facility. The mapping resulted in laminated lists of these partners which were strategically placed around the health facility and used for referrals.

The case worker used a case management approach to ensure comprehensive health and social support services were provided to HIV positive children and adolescents. This included: vulnerability assessments for HIV positive children and adolescents, identification of social support service needs, development of case plans, referrals to social support service providers, and follow-up to determine if services were rendered.

**COLLABORATION AND COORDINATION BETWEEN STAKEHOLDERS AT DISTRICT, HEALTH FACILITY, AND COMMUNITY LEVELS**

The HIV Linkages Activity placed a project manager at the DHO, who shared an office with the senior nursing officer for maternal and child health (MCH), and the tuberculosis (TB) and laboratory coordinators. The project manager oversaw the implementation of the Activity in the Copperbelt Province and worked closely with the DHO staff, case workers, and health facility in-charges. This person also engaged with district level partners and other line ministries including the Ministry of General Education (MOGE), Ministry of Community Development and Social Services (MCDSS), Ministry of Youth, Sport, and Child Development (MYSCD), and Ministry of Home Affairs (MOHA), specifically the police. Quarterly meetings were held with stakeholders which included the DHO,
different line ministries, and HIV partners. The objectives of the meetings were to share updates from various projects and discuss areas of convergence in programming, including data.

Collaboration and coordination between health facility and community-based partners were linked to the efforts to retain children and adolescents in the HIV care and treatment continuum and link them to needed social services. Monthly coordination meetings were organized by the case worker and included health facility staff, CBVs, and social service providers identified during the mapping exercise. The objectives of these meetings were to provide updates, share information and data, discuss challenges and referrals, and agree on action items.
2. END-OF-PROJECT DOCUMENTATION

SBH’s HIV Linkages Activity ended in December 2018 making it imperative to document intervention outcomes. The documentation process was undertaken between December 2018 and March 2019 and triangulated program data with qualitative data obtained from GRZ stakeholders, health facilities, community-based service providers, CBVs, case workers, and project staff.

2.1. OBJECTIVES OF THE DOCUMENTATION

The specific objectives of the End-of-Project Documentation for the HIV Linkages Activity were to:

1. Describe key factors that contributed to what did and did not work well in the Activity in reaching project objectives through the following interventions:
   - Placing case workers at health facilities;
   - Implementing the PedTrack system;
   - Providing comprehensive management for HIV positive children and adolescents, and providing referrals to social support services;
   - Facilitating coordination and collaboration at the district and community levels between health facilities, community-based partners, and CBVs.

2. Document lessons learned during project implementation.


2.2. METHODOLOGY

The End-of-Project Documentation for the HIV Linkages Activity was carried out, under the guidance of the SBH project team, to respond to the aforementioned objectives. The documentation was conducted using a mixed method approach which included qualitative and quantitative methods covering a wide range of primary and secondary data sources. Qualitative data collection included a document and literature review and focus group discussions. Quantitative data was collected on key indicators tracked under the HIV Linkages Activity namely: retention, LTFU, and missed appointments. Details for each method are provided below.

2.2.1. QUALITATIVE DATA

2.2.1.1. SAMPLING

Focus group discussions (FGDs) were used to comprehensively address the documentation objectives. FGD participants were invited based on their Activity contributions and included:

- DHO staff;
- GRZ ministries forming coordination meetings at the district level (i.e., MYSCD, MCDSS, MOGE, and MOHA which includes the police);
- CSOs, teachers, police officers, CWAC, and ACC members within the health facility catchment areas who participated in referral networks and coordination meetings;
- Case workers employed by the Activity and placed in the five health facilities;
- CBVs working in the health facility catchment areas;
• Health facility staff at the five health facilities.

Five of the 11 health facilities were selected based on the period of implementation of 18 months. These were Ipusukilo, Kawama, Mulenga, Twatasha, and Wusakile health facilities. Although the expansion to six new health facilities took place in August 2018, they were not included as the implementation period was too short to collect relevant Activity data.

2.2.1.2. ELIGIBILITY

All respondents in the FGDs were adults aged 18 and over. No children were interviewed.

2.2.1.3. DEVELOPMENT OF DATA COLLECTION TOOLS

Data collection tools for FGDs were developed in close collaboration with the SBH team. The tools were designed to address the documentation objectives and focused on implementation strategies:

1. Placement of case workers;
2. Implementation of PedTrack;
3. Comprehensive case management for HIV positive children and adolescents, and referrals to social support services;
4. Coordination and collaboration between stakeholders.

The tools solicited feedback from respondents on what did and did not work well with the implementation approaches and their recommendations for intervention sustainability.

2.2.1.4. PRE-TESTING OF TOOLS AND TRAINING OF DATA COLLECTORS

The data collection tools for health facility staff and CBV FGDs were pre-tested at Wusakile health facility. Changes were incorporated into the final tools. All qualitative data collection tools are provided in Annex 1. At the end of November 2018, a training was delivered to the three data collectors on data collection tools, protocol, research ethics (including confidentiality and voluntary participation), and child safeguarding.

2.2.1.5. DATA COLLECTION

In December 2018, qualitative data were collected using notepads and recorders and were transcribed in Microsoft Word. FGD transcripts with CBVs were translated from Bemba into English. In total, 114 people participated in the FGDs. Table 2.1 summarizes the respondents.

| TABLE 2.1. QUALITATIVE SAMPLE ACHIEVEMENT |
|-------------------------------------------|-----------------------------------------------|
| RESPONDENTS IN FGD                       | DESCRIPTION                                  | # RESPONDENTS |
| District Health Office Staff (Senior Health Staff for PMTCT, Adolescent Reproductive Health, TB, Environmental Health, Planning, Pharmacy, and Data) | DHO staff with whom the Activity project manager interacted regularly and who participated in district coordination meetings | 11 |
2.2.1.6. DATA MANAGEMENT AND ANALYSIS

In January 2019, transcriptions were reviewed in Microsoft Word and categorized according to the themes of the qualitative documentation objectives. Key factors contributing to successes and challenges were captured as they related to: placement of the case worker to reach the project objectives, PedTrack, comprehensive case management and referrals to social support services, and collaboration and coordination and lessons learned during project implementation including recommendations by respondents.

2.2.2. QUANTITATIVE DATA

Quantitative data were collected on key indicators tracked under the HIV Linkages Activity, namely:

- Retention within the ART program for a 12-month period following enrollment;
- LTFU within the ART program for a 12-month period following enrollment;
- Missed appointments following enrollment.

2.2.2.1. DATA SOURCES

Data were derived from multiple sources which included the HIV Testing Services (HTS) facility registers, ART registers, SmartCare, PedTrack, HIV Linkages Activity database, monthly tracking data, and social support services data. During the final stages of data analysis, access was provided to local data from the President’s Emergency Plan for AIDS Relief (PEPFAR). These data were associated with only the retention indicator as PEPFAR data did not capture LTFU or appointment fulfillment. Detailed descriptions of the multiple data sources used in this report are described in the sub-sections below.

PRE-INTERVENTION DATA SOURCES

Data sources for the baseline period of documentation were based on routine data collection and management procedures implemented before the Activity began at the five health facilities. No
additional systems or procedures were introduced to expand or improve on the current practices at the time. Three different systems were used at the five health facilities to monitor clients:

1. **HTS Facility Register**: The initial HIV client data were recorded in an HTS facility register. These clients included all individuals who received testing services. If the test result was negative, the client was no longer followed in any health facility register.

2. **ART Register**: HIV positive clients were documented in the ART register as they moved from testing to treatment services. These registers only documented enrollment into the ART program and did not support any follow-up of cohorts or specific clients.

3. **SmartCare**: Clients enrolled in the ART register were recorded in SmartCare. Once a client was included in SmartCare, information regarding missed appointments, LTFU, and retention (among other variables) were documented and followed for the duration of the client’s utilization of the health facility services. SmartCare permits following cohorts; the ART register is unable to do so.

No single system contained all client information and some effort was required to link these different sources. The HTS facility register was not required, other than for those clients who tested positive. The ART register information was entered into SmartCare for long-term follow-up of HIV positive clients. As some discrepancies were noted between clients documented in the ART register and those in SmartCare, the latter was deemed the “system of record.” SmartCare was the primary source of data for the pre-intervention period.

**POST-INTERVENTION DATA SOURCES**

Several new systems and processes were introduced during Activity implementation. All electronic data originated from a paper-based system and were manually entered into the electronic systems. No processes existed to move digital information from one system to another. One additional metric was considered in this segment of the analysis, namely data regarding the receipt of social support services. The sources below were used to capture data during the post-intervention period.

1. **HIV Linkages Activity Database**: The HIV Linkages Activity database was created in response to the lack of formal access to SmartCare and became the primary source of information for the post-intervention period. The start date for this record was in March 2017, just as three components of the Activity (i.e., case workers, referral networks for social support services, and coordination) were launched. Given the utility of this system to document all client activities, clients were enrolled into the database from March 2017 up to December 2018. Clients who were already in the ART program prior to the start of the Activity were included in the system from March 2017 and continued in subsequent months. Those identified as HIV positive in later months were included in the system as they enrolled. Data elements collected included client demographics, registration information, HIV status, monthly engagement with the program, and current status at the end of September 2018 when the data were consolidated for this documentation.

2. **Monthly Tracking Data**: PedTrack was launched to support a reminder system for client appointments and to track if appointments were fulfilled, among other features. PedTrack could not be launched at the same time as other components at the health facilities as it required clearance by the MOH. This, and related issues like poor network access (as PedTrack was designed to be a ‘live’ tool), and familiarity of use by case workers resulted in delays of PedTrack’s launch, which eventually took place in January 2018. The project, however, utilized a
monthly tracking tool to track appointments before and after PedTrack’s launch, and this alternative served as the data source from which analysis of the missed appointment indicator was made. Data used to populate this tool was extracted from the HIV Linkages Activity database and patient files (extracted and consolidated weekly by case workers) and aggregated on a monthly basis.

3. **Social Support Services Data:** The social support services data documented client referrals to a variety of social support service providers, and feedback if the client received these services. Data content included client identification, health facility where clinical services were received, date of referral, type of social support service to which the client was referred, social support service provider, and—if the client received the service—the date. These referral dates were consistent with those of the HIV Linkages Activity data.

**2.2.2.2. DATA ANALYSIS**

The quantitative analysis was performed with the use of the STATA 15.0 statistical software package (StataCorp, 2017). Descriptive statistics were calculated for key demographic and indicator metrics, and bivariate analyses were performed utilizing chi-square statistics. The p-value for significance was set at $p < 0.05$.

**PRE-INTERVENTION DATA ANALYSIS**

**Retention:** Reporting on retention in HIV care and treatment services was limited to 12 months following enrollment in ART and was based on the standard PEPFAR definition of retention. For example, where a client enrolled into the ART program in June of 2015 and remained in the program at least until June 2016, this client was considered retained at 12 months.

SBH’s HIV Linkages Activity started implementation in March 2017. A complete 12-month pre-intervention cohort of HIV positive children and adolescents enrolled in HIV care and treatment services was selected to compare with the 12-month post-intervention cohort. The timeframe for the pre-intervention cohort was from January 2015 to February 2016.

Data from PEPFAR for these same five health facilities were examined as a means to verify the results for this pre-intervention period. The specific data were from fiscal year 2016 (i.e., October 2015 through September 2016).

**LTFU:** LTFU was defined in accordance with the PEPFAR definition, stipulating a client missing appointment(s) at the health facility for at least a 90-day period. The Zambia national definition for LTFU is for a 60-day period, but the data sources were not organized for this alternative. Consequently, it was not possible to compare the results between the two scenarios.

Tracking appointments made was not possible for the period before the Activity started. Only missed appointments were recorded, on a monthly basis. When a client missed appointments for three consecutive months after the previous appointment, this client was classified as LTFU. This was relatively simple when clients have monthly appointments, but for clients who have quarterly appointments, documenting LTFU required up to a 6-month absence from the program. Data from the pre-intervention period at the five facilities included information for 236 clients. Following completion of the final data cleaning processes, 14 clients were excluded due to inaccurate or incomplete data.
POST-INTERVENTION DATA ANALYSIS

Retention and LTFU analyses were calculated on the basis of the HIV Linkage Activity database. For the analysis of retention and LTFU trends, the calculations were restricted to complete 12-month cohorts which required the exclusion of clients who enrolled after September 2017. Based on the exclusion criteria, seven 12-month cohorts were included for these analyses, starting with March 2017 through to September 2017.

**Retention:** The complete HIV Linkage Activity database included data for 570 HIV positive clients for the five health facilities. Clients from cohorts of less than 12 months in duration (i.e., those enrolling after September 2017) were excluded (these included 301 clients). Therefore, the remaining total for the analysis from eligible cohorts (i.e., March 2017 through September 2017), included 269 clients.

Data from PEPFAR for the same five health facilities were examined in order to compare with the pre-intervention PEPFAR data at the same facilities. The specific data were from fiscal year 2018 (i.e., October 2017 through September 2018). The PEPFAR data examined patients (<15 years and >15 years) newly enrolled in ART and their retention in the program 12 months after ART initiation.

**LTFU:** LTFU is defined as the absence of a client from the program for a minimum of three consecutive months. The monthly monitoring data were used for these determinations for each cohort. A client might restart in the program after such a break and be reclassified again as “Retained.” Using the monthly monitoring data to calculate LTFU determinations required “No” for the last three months of the 12-month cohort period.

**Missed Appointments:** A descriptive analysis of the aggregate data from the monthly monitoring tool was done to provide simple summaries of the appointments made, appointments fulfilled, appointments missed, appointments rescheduled, and appointments fulfilled after rescheduling.

**Social Service Referrals:** The social support services data documented those social services deemed essential to the well-being of the client. The available services included child maintenance support, child protection, counseling, economic strengthening, education support, health support, HIV services, nutrition support, skills training, and SCT. The social support services data were aggregated for the entire period rather than disaggregated to the months of the eligible cohorts. The data suggest that all clients who were identified as in need of a social support service were referred. Referral, therefore, stands at 100%. A differential arose in terms of whether or not services were received. This latter metric was included in the analysis. The sample for this documentation included 66 clients, those found in both the social support services content and in the HIV Linkages Activity database.

2.3. ETHICAL CONSIDERATIONS

An ethical approval from ERES-Converge (Zambia Ethics Review Board) was obtained to conduct the End-of-Project Documentation for the HIV Linkages Activity and clearance was sought from the DHO in the Copperbelt Province prior to data collection. Written informed consent was obtained from all respondents prior to conducting FGDs and no personal identifiers were used. Participation in FGDs was voluntary and the respondents could choose not to answer any question. No undue inducements for participation were made. No names of participants were presented in any reports or documents produced as a result of the data collection. Due to the small numbers of respondents in some categories, the report used broad categories (e.g., male respondent, health facility staff FGD, and Kawama).
HIV Linkages Activity data collected by the SBH project team contained aggregated information on children and particular care was taken during the data collection, analysis, and presentation of the results to ensure that no single individual could be identified.

2.4. LIMITATIONS

Data from five of the 11 health facilities were used for this analysis as they had been providing the HIV Linkages Activity’s interventions for the longest period of time. Therefore, findings are not representative of the entire Activity, of the district, the province, nor of the country. However, the findings are to be used to help Zambia better understand some of the best practices from this intervention that contribute to informing national strategy to improve care, treatment, and retention of HEIs and HIV positive children and adolescents in the HIV care and treatment continuum.

No FGDs were held with beneficiaries in the Activity (i.e., mothers or guardians of HEIs, HIV positive children or adolescents, or with HIV positive children or adolescents themselves). Obtaining ethical approval both within Zambia and from the Institutional Review Board used by Abt Associates in the United States, and obtaining assent (for children) and informed consent from parents or guardians of HIV positive clients, would have exceeded the time and budget allocated for the qualitative component of the documentation exercise. Although responses from beneficiaries would have enriched the qualitative findings, 14 FGDs were conducted across six different target groups for a total of 114 participants. This wide range of responses led to valuable lessons learned and emerging themes to inform national strategies to improve care, treatment, and retention of HEIs and HIV positive children and adolescents, as well as referrals to social support services.

SBH’s documentation of the HIV Linkages Activity was designed to document improvement in retention, LTFU, and appointment fulfillment using quantitative and program data. In order to do so, SBH considered pre-intervention and post-intervention 12-month cohorts to determine these improvements. However, during data analysis it became evident that a comparison was not advisable as different data sources were used for the pre- and post-intervention cohorts and several data quality issues were of significant concern.

The data source used for the pre-intervention period were based on SmartCare. The cohort period was from January 2015 to February 2016. Data collection started with the ART register to identify HIV positive infants, children, and adolescents. Only those clients also found in SmartCare were subsequently registered in the 12-month cohorts. Pre-intervention data showed a small proportion of HIV positive children and adolescents as retained (14%) and a large proportion as LTFU (86%). It is important to note that these results indicate poor program performance, but they might also reflect inconsistent entry of client data into SmartCare. Other evidence suggests that many clients may have continued to receive services at these facilities, but that information was not documented in SmartCare. Other indications from overall data quality for this period suggest that this latter circumstance likely contributed to the indicated poor program performance, especially when considering the PEPFAR data for the same facilities over the same period.

At the start of the Activity, the MOH did not approve use of SmartCare to track HIV positive clients in the HIV Linkages Activity. The Activity, therefore, developed the HIV Linkages Activity database to track both HEIs and HIV positive infants, children, and adolescents (employing client identifiers from SmartCare). Post-intervention monthly cohorts were created on the basis of the HIV Linkages Activity database for HIV positive infants, children, and adolescents who were enrolled in the Activity during the intervention period and at least 12 months before the end of the project (September 2018). The HIV Linkages Activity database included clients existing in HIV care and
treatment services before the Activity started, as well as those newly enrolled in ART services during implementation. Using a single database for the entire pre-post analysis was planned originally, but restricted access to SmartCare for the post-intervention data precluded this capability. In addition, data quality issues with the pre-intervention data from SmartCare diminished confidence in the use of these data, and compounded the problems in the pre-post comparisons. Due to these limitations, pre-intervention data were excluded from this report.

PEPFAR retention data were introduced to validate pre-intervention data findings. A comparison between PEPFAR and HIV Linkages Activity data is not advisable as differences exist between the two data sources: timeframes for both cohorts were different and PEPFAR data overlapped with the HIV Linkages Activity data for only 7 months; age delineations were different in that PEPFAR data included all age groups disaggregated by <15 years and >15 years, while the HIV Linkages Activity database included 0-24 years disaggregated in 5-year intervals; and PEPFAR data included HIV positive clients newly enrolled in ART and retained for 12 consecutive months, while the HIV Linkages Activity cohort included both existing and newly enrolled clients followed-up for 12 consecutive months.

The PedTrack system could not be launched at the same time as the other components of the HIV Linkages Activity as it required clearance by the MOH. In addition, poor network access and lack of familiarity of use by case workers resulted in PedTrack’s eventual launch in January 2018. No clients were exposed to this part of the intervention for than seven months, many fewer than required for analyzing complete 12-month cohort patterns. In addition, even though data from PedTrack was used to track missed appointments, the project used a monthly tracking tool to track appointments before and after PedTrack’s launch. Monitoring of PedTrack data was not consistent and the monthly monitoring data continued to be used to report on missed appointments. Consequently, the monthly tracking data was used as the data source from which analyses of the missed appointments indicator was made. As these data were in aggregate form for each month, analyses were more limited than those performed on individual client data in other sources.

Another limitation associated with the multiple data sources was that linking of these data sources required the use of the client identifier to combine data. This manual process resulted in reduced sample sizes for different analyses. In addition, the multiple layers of data entry among health facility staff and case workers presented an opportunity for introduction of errors in the recording of data into the systems. The data cleaning processes for these analyses revealed these inconsistencies and where it was impossible to reconcile, such data points were excluded.
3. RESULTS

3.1. PLACEMENT OF CASE WORKERS AT HEALTH FACILITIES

During the qualitative documentation, questions were asked about what did and did not work well related to the placement of case workers in health facilities in contributing to HIV testing of family members and HEIs, initiation of HIV positive infants, children, and adolescents on ART, and retention on ART.

3.1.1. HIV TESTING OF FAMILY MEMBERS AND HEIS – WORKING TOWARD THE FIRST 90 TARGET

“The case worker helped with index follow-ups. When the mother is HIV positive, she [the case worker] will follow-up to ensure that other members in the family are HIV tested, especially children ...”

Male Respondent, Health Facility Staff FGD, Kawama

“What also worked well was ... children coming back for their tests. For instance, the DBS, the rapid test, before we went there most children never used to complete their tests. They would do the first test at 6 weeks and that was all. But after we went there, since last year the number has drastically improved. I can give an example when you compare to May 2016. There was a total number of exposed children who registered, they were 10. And out of those children, only two completed the tests. But with our going at the facility, so far, the month of November, we had all seven children completing their tests. So, that really worked well when you compare to previously. The way it was and the way it is now, the completion of the DBS and rapid test until the child graduates.”

Female Respondent, Case Worker FGD

The placement of the case worker at each health facility was considered by respondents as the most important implementation strategy under the HIV Linkages Activity to ensure that index cases were identified (e.g., HIV positive mothers and pregnant women) and that their children and spouses/partners tested for HIV and knew their status. At all five health facilities, respondents mentioned an increase in HEIs adhering to the DBS/HIV testing protocol (i.e., testing at 6 weeks, 6 months, 12 months, and 18 months). The case worker’s presence at the health facility contributed to the reduction in the number of babies who were LTFU before the final HIV test result was known.

From the responses, a number of emerging themes were identified for what worked well with the placement of the case worker to contribute to the increase in HIV testing including HEIs.

1. Case Management, Sensitization, and Close Collaboration with CBVs

Responses indicated that the case worker contributed to the results through use of the case management approach which included close follow-up of HEIs, knowing when they were due for HIV services, triggering SMS reminders, and CBVs conducting home visits to ensure parents or guardians brought HEIs to the health facility for necessary HIV tests. The case worker and CBVs increased efforts in the communities to raise awareness of the importance of HIV testing, knowing one’s status, and of disclosure and adherence counseling.
2. Administering DBS Tests and Provision of Prophylaxis

An important factor which contributed to the increase in HEIs completing HIV testing schedules was that, in some health facilities, the case workers were assigned the task of administering DBS tests and provision of prophylaxis, as well as oversight of CBVs who were trained to do so.

“We were happy to have the case worker on site. Because that was the challenge, in the beginning when we had no case workers, usually we depended on the community members, though those were trained to do the DBS. But with the case worker, there was monitoring, and they could also do the DBS collection ... they were also able to supervise the community members who were doing that. But most of the time, like I mentioned, they [the case workers] were on site all the time, whenever we found a mother, the community members were not here, the case worker was here to take the sample to ensure that the DBS is done on that child.”

Female Respondent, Health Facility Staff FGD, Kawama

3. Using Different Entry Points to Identify HEIs and Service Integration

Respondents noted that the case workers, health facility staff, and CBVs created linkages between services and used opportunities, such as during GMP sessions or under-five clinics, to find HEIs who may have missed appointments.

“During growth monitoring and promotion, it became easy for us to identify exposed children and capture lost to follow-up children using under-five card numbers. We use the ages ... those that are exposed ... those that have not done DBS, because this is written in the under-five card. And if we find one who has not been tested for DBS and who falls within the months during which this should be...
At Kawama health facility, before the placement of the case worker, the health facility staff asked mothers (during the under-five clinic) to return on a different day to receive HIV services. As services were not integrated, the follow-up was difficult. However, this changed with the placement of the case worker, as the case worker’s availability made it possible to provide integrated same-day services to the mother and baby.

“Whenever the mother passes through, there was someone [case worker] to attend to that mother ... before we said “come on this day” because of the schedules. But now the presence of the case worker, it is like she was the focal point person to help us in that area ... As we attend to these mothers who bring their children for under-five clinic, when you come across a mother who is HIV positive, there is someone [the case worker] who helps with screening that child and ensures that child is taken care of. But in the past, we would say, you could come, all of you, on Wednesday, so that there is a staff person there on that day.”

Female Respondent, Health Facility Staff FGD, Kawama

3.1.2. INITIATING HIV POSITIVE INFANTS, CHILDREN, AND ADOLESCENTS ON ART, RETAINING THEM ON ART, AND REDUCING LTFU – WORKING TOWARD THE SECOND 90 TARGET

“The case worker has made a contribution, especially if you look at initiation of new clients on treatment and treatment in terms of numbers.”

Male Respondent, Health Facility FGD, Mulenga

“... the pediatrics, we used to have a lot of LTFU but this time they are very few, most of them they come, for drug pick-up and for reviews. At least each Monday we have a lot of pediatrics, so it is working well even for the facility.”

Male Respondent, Health Facility Staff FGD, Twatasha

Follow-up of HEIs and HIV positive children and adolescents by case workers has led to respondent feedback that more children completed the HIV testing schedule up to 18 months, and that those that tested positive were initiated on ART and retained in the HIV care and treatment continuum.

Multiple themes were identified for what worked well with the placement of case workers at health facilities to support the initiation of HIV positive infants, children, and adolescents on ART, retention in the HIV care continuum, and reduced LTFU.
1. Intra-Facility Case Management and Improved Coordination

The interaction of case workers with the health facility staff, often times sharing offices with the ART or MCH services or working in adjacent offices with the data clerks, facilitated the follow-up of HEIs, HIV positive children, and adolescents, and contributed to increased retention and reduced LTFU rates.

“I saw that the case worker was working together with the MCH department. This brought linkages in terms of pediatrics when they are brought for under-five clinic and also pregnant mothers when they come for antenatal clinics. This created a working relationship between the case worker and MCH department ... when a child tests positive they are immediately initiated on treatment when they are identified ... I can say they really worked well in terms of follow-ups and sometimes they will even remind you to book a second viral load test for that child.”

Male Respondent, Health Facility Staff FGD, Mulenga

“... we are working together with the JSI data DEC [data entry clerks] ... we have a DEC who is in charge of viral load ... they go through the physical files and they check on the last date of the viral load test. After that she will compile a list, she will look at maybe the age that we as case workers are dealing with ... She will give me that list. I get their phone numbers and call them ... Others will come, others will not come. For those who do not come, I will engage the CBVs to do the follow-up.”

Female Respondent, Case Worker FGD

2. Follow-up by Case Worker, Increased Sensitization, and Home Visits by CBVs

Respondents felt that case worker follow-ups ensured comprehensive care was provided to children and adolescents, in close collaboration with the CBVs who conducted home visits. They felt these activities contributed to a reduction in clients defaulting or being LTFU, and increased clients initiating ART and staying on ART.

“From the time we started working with the case worker, a lot of children are on treatment and stay on treatment. Earlier, we had some that defaulted but, due to the fact that we would follow them up and educate them on the consequences that come as a result of defaulting and the benefits that come in as a result of staying on treatment, most of them are on treatment and they are staying on treatment.”

Female Respondent, CBV FGD, Mulenga

“I have seen a difference with where the case worker was placed, we have seen less LTFU and children who are exposed because there was someone who was keenly interested in them, checking how the child was compared to those facilities where they were not placed. Even the numbers have gone up, we are able to track the infected child and put them on treatment on time, where there was a case worker compared to where there was no case worker because there, maybe if a child is lost it would take time for a child to be found. But where there is a case worker it will be a day or two for that child to be found.”

Female Respondent, DHO FGD
3. Collection of Medications on Behalf of Clients

Although not the norm, CBVs at three health facilities, shared that they sometimes collected medications on behalf of the mother or guardian. This facilitated a relationship with the client and contributed to ensuring that the child(ren) stayed on treatment.

“What makes it easy when we go in the community is that we live with them in same community. We interact with them as friends, handling it as any other chat until you even talk about what took you to their house. We find ways and means of encouraging these people to come to the clinic for medical test ... There are others who feel shy to come collect their treatment and they ask us to get medicine on their behalf and we do get the medicine and take for them and [they] ... come for reviews.”

Female Respondent, CBV FGD, Wusakile

“Others who are difficult to convince, some of them we help them out, especially if they are simply coming to get medicine and not to be reviewed, we tell them to say if at all you won’t manage ... am asking for the card so that I get the drugs for the child as the child needs to stay on treatment and should not miss a day of taking medication. Showing such compassion to these mothers, most of them change and they continue collecting drugs themselves.”

Female Respondent, CBV FGD, Mulenga

“Most of the time, like if it is in my zone where we have transport challenges, they give me ... cards to pick up drugs for them because I come here frequently.”

Male Respondent, CBV FGD, Ipusukilo

3.2. ENABLING FACTORS CONTRIBUTING TO PLACEMENT OF CASE WORKERS AT HEALTH FACILITIES TO SUPPORT HIV TESTING, ART INITIATION AND RETENTION

Several enabling factors were identified from the transcripts which contributed to what worked well with the placement of case workers at health facilities for HIV testing, initiation, and retention of HIV positive infants, children, and adolescents on ART.

1. Dedicated Focus on Children and Adolescents

Health facilities were understaffed and the case worker became an additional staff member with a dedicated focus. Respondents felt that this exclusive focus on children and adolescents contributed to increased numbers of HEIs, children, and adolescents tested, initiated, and retained on ART.

“I think the department for children in most clinics has been neglected compared to other departments. From the MCH they mostly concentrate on pregnant women. So, you find that the children, the exposed ... they had a lot of LTFU because that department for children has been neglected. In short, there is no one specifically to focus on children except for us.”

Female Respondent, Case Worker FGD

“The children felt honored because there was someone [the case worker] who was specifically caring for them and the other thing is that without those people, it was going to be very difficult to manage..."
the children because we have a lot of things to do but now, we have that group specifically for the children. So, that helped us a lot.”

Male Respondent, Health Facility Staff FGD, Ipusukilo

2. Empathy, Respect, Compassion, and Confidentiality

Empathy, compassion, respect, and confidentiality are important principles in case work. Respondents cited that case workers were able to develop trusting relationships with clients and to demonstrate these principles in their interactions with the parents/guardians, children, and adolescents. Many respondents reported the case worker becoming a “focal point person” and leading clients through the trajectory of HIV care.

“Ever since the coming of the case worker, women have been set free. Every person that the case worker wants to see, she has respect for women, and she reminds mothers to bring children for DBS. Mothers listen to her a lot.”

Female Respondent, CBV FGD, Wusakile

“I must mention that the case worker has built a very good rapport with these clients that we attend to, that is the mothers. She has built a good rapport and she helps because we are overwhelmed … She is there to focus on specific people, and it has been easy for us to provide quality health care to our clients because of her as she is always in touch with the guardians and mothers.”

Female Respondent, Health Facility Staff FGD, Wusakile

“After the coming of a case worker, a lot has changed. Women no longer fear to talk about their status, they come here on their own, openly ask that they want to see the case worker or anyone in charge of HIV testing. When they are received by these people, they sit in private and talk to each other. Women are open and free to talk to the case worker.”

Female Respondent, CBV FGD, Wusakile

3. Encouraging Peer Support

Case workers facilitated meetings with HIV positive mothers or guardians of HEIs and HIV positive children. This fostered peer support and, according to respondents, helped build the confidence of mothers, leading them to feel more positive about living with HIV and disclosing their status.

“There are times when they [the case workers] call for a meeting and they tell us to go in the community to inform them [the mothers] about the meeting … When they are informed, they come here on their own, and … get to meet other friends whom they know. This makes them feel that they are not alone but there are other people in the same situation as them … They can have neighbors whom they never thought where HIV positive but through these meetings when they are put together … they get to encourage each other, they remind their friends that the child has turned 6 months and
“he/she needs to be taken to the clinic [for DBS testing]. They do this on their own and this is what shows the distinction of what used to happen before and what is happening now.”

Female Respondent, CBV FGD, Wusakile

“There is a lot that has been taught on HIV by the case worker. HIV is something that most mothers have accepted, and this has lessened the burden of being positive. This is because they get to meet with other positive mothers. It’s a good program and it should continue.”

Female Respondent, CBV FGD, Twatasha

4. Capacity Building of CBVs and Strong Community Engagement

Respondents highlighted that case workers built CBV capacities in many areas: HIV prevention, care, and treatment, psychosocial counseling, social services support, and engagement with adolescents. Case workers were responsible for identifying those who missed appointments and worked closely with CBVs, so the CBVs could find out where they lived and conduct home visits. This, coupled with sensitization and improved counseling, resulted in stronger community engagement.

“I saw improvement in coordination with our community health workers. There was coordination because they used to work in the community together with our community health workers to trace the lost to follow-up children. There was also knowledge transfer. Most of the time we used to send our community health workers who had little knowledge on how to go about the counseling in the community. With them [the case workers] we have seen that they have transferred knowledge which the health community workers learned from.”

Male Respondent, Health Facility Staff FGD, Ipusukilo

“In the past, we lived without knowing how to follow-up these children in the community, but when they [the case workers] came, they started showing us how to look for lost to follow-up children ... and bring them back ... a lot of children we had lost, we found them. Even most HIV positive mothers who didn’t want to be seen by other people are now free to talk about their status, they even bring their friends.”

Female Respondent, CBV FGD, Wusakile

“Most of these people we just used to see them when they came during that time when we never had a case worker and only knew few people. But this project helped us to know where most of these people stay. And this is how our work was made easier, because when we realize one client is not seen at the clinic ... that would not worry us because we know where to find them.”

Female Respondent, CBV FGD, Twatasha
5. Data Management

Case worker efforts to improve data quality and record keeping were highlighted as enabling factors for the results of the Activity.

“... we had difficulties in data elements because what is studied and what is recorded in the registers, there is a disparity. I think, if we did not have the case workers who had been specifically assigned to look into HIV challenges, it would have been compounded so in a sense the placement of the case worker in the facility helped us in data quality generated from those sites.”

Male Respondent, DHO FGD

“Another thing is when the case workers came, they went through files to know how many HIV positive mothers we have and also how many HIV positive children we have. This makes it possible to know when one is not coming through to the clinic and when we follow-up we get to know even those that have died. So, now we have an updated record.

Male Respondent, CBV FGD, Ipuskilo

3.3. CHALLENGES TO ENSURING HIV TESTING, ART INITIATION AND RETENTION

Respondents provided feedback on their perceptions of barriers to HIV care for mothers, children, and adolescents. Insights were also provided on strategies to overcome these barriers.

3.3.1. ADOLESCENTS: NON-DISCLOSURE AND LACK OF ADOLESCENT-FRIENDLY SERVICES

The majority of respondents from health facility staff and CBV FGDs said that adolescents aged 10-19 were the most complex age group to work with, and that ensuring adherence to medications and retention was a challenge. Non-disclosure of the adolescent’s HIV status by the parent or guardian was a key issue. The reason for non-disclosure varied and examples included stigma, fear that the adolescent may harm them, non-disclosure of the mother’s status to the father, and orphan status (where a child or adolescent lives with grandparents or extended family who are not vested in the person’s health or does not have the means to cater for his/her needs).

“When they start as infants there is no need to know what drug they are taking and why they are taking it, so when they start acquiring more knowledge, it is hard for some to convince them to continue taking ART. That age group is really difficult from our own experience. Especially for adherence to drugs.”

Male Respondent, Health Facility Staff FGD, Twatasha

“Maybe because of stigma. They are thinking if I tell the child, who or how and where did s/he get it from. Another thing is, they fear that the child is going to hurt them. The other reason is they think they are young, and they should not know. They will tell them when they grow up but at school, they learn these things.”

Male Respondent, Case Worker FGD
"The mother, because of fear of being blamed by the child, she cannot dare to tell the child, that the child is HIV positive and is taking those drugs ... We’ve had children brought to the facility by their guardians, but stopped taking the drugs, despite collecting the drugs.”

Male Respondent, Case Worker FGD

"Most of these children who have HIV, you find that their parents even died, they are living with their grandparents or they are living with someone who just thought okay let me take responsibility of this child since I am a member of the family before people start saying I am neglecting this child ... Because of those wrong reasons of taking in the child, they will have also wrong reasons to manage the child’s health. They will never even manage to concentrate to see if the child is taking the medications, when they are going for reviews. Some of these children keep their own cards for medicine collection, sometimes they will just escort them and reach the gate and tell the child to go inside and collect the drugs, and you will find me outside... so, they may not receive the positive support.”

Female Respondent, Health Facility FGD, Ipusukilo

Initially the lack of adolescent-friendly services at some facilities resulted in adolescents missing appointments. Adolescents found it intimidating to go a health facility and encounter adults only, especially those whom they may know.

"We’ve had cases where this adolescent is willing, when she is tested, she is told, maybe she even accepts, but as they come back, mostly mingling with people that are older. Maybe this child will come back for drug collection, and then she finds that there are older people. Most of them have had some difficulties in coming back for their drug collection. Like at the facility where I am, the room there has so much congestion ... So, when this adolescent comes, the way we are, this adolescent is 16, she will come in the room and find all of us are adults, most of them go. Like that.”

Female Respondent, Case Worker FGD

"We realized it would be important to make a group for children .... In the past they would feel ashamed to see maybe the friend’s grandfather standing in the queue for drug pick-up.”

Male Respondent, CBV FGD, Ipusukilo

3.3.1.1. MITIGATING ACTIONS

Disclosure counseling for parents and guardians, establishing adolescent support groups, and facilitating different days for HIV services for children and adolescents were strategies that case workers and health facility staff implemented to address these barriers.

| Disclosure Counseling | “We’ve had a role to play. In such a case where a child is refusing to continue taking their drugs, we’ve sat with those children and talked to them about the importance of adherence ... when it failed, we’ve referred such cases to volunteers because they are also trusted by such children because they are people that live within these communities, they are known people to these children. So, we’ve used volunteers, we have also used our psychosocial counselors who are based at the clinic. It has been a kind of referral ... In some cases, it has worked well, but in some cases, especially |

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"The mother, because of fear of being blamed by the child, she cannot dare to tell the child, that the child is HIV positive and is taking those drugs ... We’ve had children brought to the facility by their guardians, but stopped taking the drugs, despite collecting the drugs.”

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when the parent is not willing to disclose to a child (because we solely depend on the parent, to give consent to disclose to a child) ... we have left it like that.”

Male Respondent, Case Worker FGD

Adolescent Support Groups

“... to ensure retention in care one has to adhere to treatment. One of the barriers that we found for adherence was disclosure, non-disclosure of the status by the adolescents and caregivers or guardians. So, we formed groups, adolescent groups, it was like a support system because we realized that these adolescents needed a support system for them to handle any circumstance that they may face.”

Female Respondent, Case Worker FGD

“... we had a group that was formed for them so they could talk to each other, sort of a support group, they would discuss among themselves for example about the taking of drugs so that they do not default, that helped them to stay on treatment.”

Female Respondent, CBV FGD, Mulenga

Different Days for Children and Adolescents

“Placement of the case worker helped in retention and providing proper care and managing pediatrics. The time I came here we had a program where pediatrics was mixed with adults. But the case worker set up specific days for pediatrics.”

Female Respondent, Health Facility FGD, Kawama

3.3.2. CHILDREN: CARETAKER DEPENDENCY / ARRIVING UNACCOMPANIED AT HEALTH FACILITY

HEIs and children are dependent upon parents or guardians to access services. Children either missed appointments or arrived unaccompanied if caretakers were unavailable, as respondents from Ipusukilo and Twatasha experienced. Reasons for the absence of caretakers included: work, long distances, and other factors including the child’s orphan status or alcohol abuse by the caretaker. Children who arrived unaccompanied at the health facility were seen by the medical personnel and case worker. It was challenging for the case worker and health facility staff when the parent or guardian was not present.

“Especially for this community, this age group 5-9, they have been having a lot of issues. Some come unaccompanied (no parent) for clinical reviews and medications. Especially this age group, they don’t know when their appointment date is, they just come, maybe even after the appointment date ... it has been difficult to retain them because they are on and off the drugs.”

Male Respondent, Health Facility Staff FGD, Ipusukilo

“Most of these children we see come on their own without their parents or guardians. So, sometimes as he [the case worker] wants to talk to the parents to that child, it will be more of a challenge”

Female Respondent, Health Facility Staff FGD, Twatasha
3.3.2.1. MITIGATING ACTIONS

Case workers worked to mitigate the issue of unaccompanied children by discussing the concerns with the parent or guardian and linking them to the health facility staff to identify solutions. Some case workers also acted as a “buddy” for children whose caretakers were busy or unavailable to accompany them to the clinic. The case worker not only conducted the follow-up in person, but also helped the child navigate within the facility and explained how to take medications.

“They were also acting as buddies. Some of these caretakers who look after these children, others are orphans and you find that their parents who are taking care of these are busy. You find that him or her when they go for follow-ups, they promise clients that they should come to the facility and I will stand on your behalf … I will escort you to explain how to take it [the medication]. So, they [case workers] were acting as buddies to those whose parents are busy.”

Male Respondent, Health Facility Staff FGD, Ipusukilo

3.3.3. NON-DISCLOSURE OF HIV STATUS

A key challenge cited by respondents included non-disclosure by HIV positive mothers, especially when her husband is not HIV positive. Disclosure could result in mothers being ostracized from the family home and left to care for children without support. Non-disclosure of the mother or child’s status to her husband created additional challenges in adhering to medications.

“In our area we had a challenge, we had certain clients, about three households, who failed to disclose their status to their husbands as they knew they would be chased out of their homes. We brought the reports to the case workers. After two months of trying to talk to them, we brought them here at the facility … After one month though we don’t know what happened, she just started to neglect the child and she stopped giving the child medication, the child even died. Then these other households, up to now they have not disclosed to their husbands, but they have continued giving the children medicine. They say they hide the medicine so that their husbands don’t get to know of it. And so, these mothers have not disclosed to their partners. This is a challenge to us.”

Male Respondent, CBV FGD, Ipusukilo

3.3.4. INADEQUATE FOOD AND NUTRITION

Poverty leading to inadequate food and nutrition at home were cited multiple times as key barriers to adherence (i.e., medication and appointments). Several examples were cited, clearly showcasing case worker compassion and commitment to finding solutions.

“I will talk about a child who the case worker has helped so much. This child never used to walk, this child has been on treatment for over 5 years. So, at some point this child became very sick, as we speak this child is 15 years, so after getting very sick this child stopped walking, he would just push himself around when trying to move. When the case worker came here and started working with us, as the CBVs, we would go into the community to identify children who are on treatment. When we brought the names of the children on treatment, she really worked hard especially on this specific child. We got up with the case worker to go to the house of this child. I took her there and she looked at how the members of that house lived, how many they are, and what was the source of income for this family. Then she wrote down the names of the guardians because this child is an orphan … She realized that this child did not have any
other illnesses, he did not even have polio, he was just lacking food. So, she got her own money k200 and gave the caretakers of this child. She gave her so that she could start-up even a small business so that she could be able to buy food for this child, who is our client ... this child was given a wheelchair and he would use it when coming for treatment mostly with someone pushing him. Now last week, he came without the wheelchair and he was walking by himself. This is all because of the hard work of the case worker.”

Female Respondent, CBV FGD, Mulenga

“The children who are on ART aged 5-14, the treatment is both morning and evening. We have a challenge ... when that child takes the medicine and has not eaten food it would affect the child. They opted to be taking once, in the evening and not in the morning ... And so, the medicine was not working accordingly, sometimes parents would tell them not to take the medicine because of the side effects ... The solution was that we have people called PREP who sponsor children’s school and give them food. We have seven children who learn with them. From 2016 these children have a suppressed viral load.”

Female Respondent, CBV FGD, Ipusukilo

“I will talk about the zone I work in ... I try to develop a close relationship with these children, so I get to see how they are taking their treatment ... I start by asking them how they are taking their treatment, when the last time was and how many days, and if they missed taking drugs. If for example, she says I missed a week or maybe 5 days I will ask why she missed 5 days. Maybe she will say I didn’t have food, then I will enquire who the child lives with. Then the child will explain, maybe the stepmother, the sister, or uncle and so the child might perhaps just take the drug once a day. Normally children take drugs twice in a day, you might get to find out that this child just takes once a day in the evening and not in the morning when they manage to find food so that helps us to see that this child is vulnerable as they don’t have proper means of finding or buying food.”

Female Respondent, CBV FGD, Mulenga

### 3.3.5. INCORRECT CLIENT PERSONAL INFORMATION

The most common challenge mentioned by respondents is that some clients do not provide the correct phone numbers or correct physical addresses (or do not have permanent addresses). This phenomenon has been noted by other research conducted in Zambia and reasons for not giving accurate information are often linked to stigma or anticipated stigma (18).

““One of the challenges is that most of the clients from this community do not have their residential addresses which is a permanent one. They shift from time to time without a number. It used to give him [the case worker] a challenge when he wants to go and visit a client, he might find that they have shifted, or the client gave him the wrong address.””

Female Respondent, Health Facility Staff FGD, Twatasha

“Another thing is communication, the phones. Sometimes it is a trend, the community we are serving has a tendency of not giving correct information most of the times. So, sometimes you might find that the phone numbers that he has are not going through. Then that challenge coupled with a wrong address becomes a very big challenge altogether. So, if someone has given you an address where they are not at at the moment you can track them by phone, but worse if their phone is off, it was a big challenge for him.”
3.3.5.1. MITIGATING ACTIONS

Respondents shared strategies that they used to trace clients. Examples included finding clients through GMP sessions or under-five clinics and raising awareness in communities. Some CBVs also inquired after clients without disclosing health affiliations.

“The only challenge that was there was that of people providing wrong addresses ... And for us to capture this child, we used to get the number for the under-five card and during GMP we pay attention checking every person that comes and if they come, we capture them during this time, then talk to them in privacy. Through counseling, they end up providing the correct address and sometimes they will give you the correct phone number ... we had lost about 13 children due to wrong addresses but through working with under-five cards during GMP... all these children have been found.”

Female Respondent, CBV FGD, Wusakile

“I would go in my chitenge, like the way am dressed, and when I don’t find them, I would leave word that: ‘someone from church came and would come tomorrow.’ So, you would find them when you go there the following day.”

Female Respondent, CBV FGD, Kawama

3.3.6. IMPACT OF ACTIVITY CHANGES ON IMPLEMENTATION

Changes in the Activity resulted in implementation impacts. Examples cited from respondents included the change from case workers conducting home visits to the use of phones and SMS reminders (which was challenging in communities where clients did not have phones or did not provide correct phone numbers) and ending support for adolescent support groups. Several respondents noted the importance of peer support groups in relation to adherence and were frustrated when it stopped.

“... we used to have meetings when all of them [adolescents] could be there, a lot of them used to learn from their friends. For example, when they ask them, what time do you take your drugs? They would say and even the importance of taking the drugs, some would say and others would learn from them ... but now that program has just stopped. We don’t know why.”

Male Respondent, Health Facility Staff FGD, Twatasha

3.3.7. SHORTAGES OF GRZ STAFF AND WORKLOAD
Respondents stated that a shortage of GRZ paid staff at health facilities resulted in case workers assuming multiple roles, including health service provision (i.e., DBS testing and administering prophylaxis to HEIs). The reduction in case workers per health facility led to an increased number of children each case worker followed, substantially increasing the work load. Due to inadequacy of some GRZ psychosocial counselors, one case worker indicated she had to also assume the psychosocial counseling responsibility.

“When the case workers came to this facility, they were the three of them. At one time, these two left the facility and he remained alone. It became challenging for him because when they were the three of them, they had shared responsibilities and when his other two friends left all these other responsibilities were put on his shoulders. He was overloaded with work, he had to attend to all zones and because of this he used to work even on weekends.”

Female Respondent, CBV FGD, Twataka

“We have a lot of work for one individual. It is in my view, that in future, maybe there should be a different person doing the data entry and the person who is doing the case management. But for one person it was quite a lot of work. Because, we are also being used by the clinic to do other things that are not even part of our job description.”

Male Respondent, Case Worker FGD

3.3.8. LACK OF INCENTIVES FOR CBVS

CBVs are volunteers in the community. Although the Activity provided CBVs with in-kind incentives such as bags, pens, umbrellas, chitenge, aprons, and bicycles (per zone), they do not receive remuneration for the work. The case workers collaborated well with CBVs, yet, the latter being unpaid volunteers could opt-out of an activity any time which made their support to the case worker less reliable. In addition, CBVs were not provided with funds for travelling far distances which was noted as a challenge to conduct home visits for clients living far from health facilities.

“The other thing was work load ... At one time they [the case workers] couldn’t even go in the field, then they said that they should not even be following up and said volunteers should be following up. Now you know volunteers do things how they feel it. If they want to work, they can work, if they don’t want, they cannot work. But then, if there is a case worker, they have to go in the field no matter what.”

Female Respondent, Health Facility Staff FGD, Ipusukilo

“On the part of the volunteers ... they complain that they are not being paid. So, it’s not working well, they are demotivated because, some distances, they are far distances, to track down the clients. So, on that part, there is no motivation for them. There is no incentive when you are sending them out.”

Female Respondent, Case Worker FGD

3.3.9. REMOVAL OF CASE WORKERS WILL ADVERSELY IMPACT HIV PROGRAMMING

Health facility staff perceived case workers as essential staff contributing to the work of the health facility. With the Activity ending, respondents expressed concern that losing case workers will negatively impact HIV programming.
"I can speak on behalf of maybe MCH because the gap will be there, if she [case worker] is not there or if we don’t have someone to replace her, the gap will be there and it will be seen because she is able to see each and every child who comes for DBS, she has the contacts, unlike us who are overwhelmed with work."

Female Respondent, Health Facility Staff FGD, Wusakile

"... the placement of the case worker has already yielded good results. Firstly, the manpower that we had was increased by the number of case workers that we had. So, it becomes a plus to the team to serve the community better. The second thing is that, the Linkages program ... we have already seen that there is an increase in retaining people on treatment and reducing the LTFU for pediatrics and adolescents. ... when it is phased out, we will go back to the same challenges we had before the project was implemented, which will cause more trouble now because people had already accepted the project and they had seen a positive change ... we will still have a shortage in manpower ... so there will be a breakdown, a big blow in service delivery."

Male Respondent, Health Facility Staff FGD, Twatasha

3.4. CASE WORKER SUSTAINABILITY AND RECOMMENDATIONS

Respondents from FGDs unanimously agreed that the case worker function filled a critical gap and allowed health facilities to serve an increased number of mothers, children, and adolescents. When respondents were asked if the MCH nurse, psychosocial counselor, or data clerk could assume the case worker’s role, responses included:

- Data clerks were overwhelmed with work and not able to manage PedTrack.
- MCH nurses were short-staffed and, with the exception of Kawama, not able to sustain the quality and intensity of the case worker’s role.
- There was only one psychosocial counselor per health facility. It would not be feasible for that person to dedicate time to case worker functions without hiring a new psychosocial counselor.
- Health facility staff at Ipusukilo felt that follow-up and referrals were part of the psychosocial counselor’s role, but that the counselor would require support to do case worker functions. They could identify a strong NHC for the role, but this person would require remuneration.
- With the exception of PedTrack, Kawama was the only health facility that indicated case worker activities would continue using existing staff.
- All health facilities recommended that GRZ or partners invest in case worker positions.

Sustainability

"For this project to continue, it might need an independent person because I have seen how much work it involves and so once you are overloaded with work you lose quality, so it needs someone who is going to concentrate on what the case worker was doing apart from any other duties ..."

Male Respondent, Health Facility Staff FGD, Twatasha

"... understaffing is what kills the whole system. For example, this facility only has one psychosocial counselor gazetted by government. So, there is need for a system..."
where the psychosocial counselor can be supported by others who are oriented, just like the case worker was. It was more like support to the psychosocial counselor because s/he [the case worker] handled the follow-ups which is also part of the psychosocial counselor’s job … To identify who has the strength to take up the role of a case worker, I think that is not even a problem because we have already seen the people that can do this … It becomes a challenge because the word “volunteer” - you can choose to be there or not. What is needed is financial support, identification of who can take up the role is not an issue, these people are there, but there is a part where we have no voice because they have to fend for their families …”

Female Respondent, Health Facility Staff FGD, Ipusukilo

“For certain aspects of the program, it is also in our line of work to actually handle them … Initiations will continue, follow-ups will continue, retention will continue. As for PedTrack, that one I have a question mark. Because we also have our own SmartCare which we run on a daily basis. So that one might be a challenge to manage.”

Male Respondent, Health Facility Staff FGD, Kawama

“With the current staffing it will be a challenge. If we give the role to the psychosocial counselor, then we need to replace the counselor. It is more like, MCH will take up certain roles, the psychosocial counselor will take up others. But one person alone … this will not be feasible. It is better to just retain the case worker.”

Male Respondent, Health Facility Staff FGD, Mulenga

<table>
<thead>
<tr>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I personally would like to recommend that if we are given a chance or if the organization can help us with her to continue or if the government will take it up, I would recommend they send us two case workers because we are having children under 14 and adolescents. The number is growing and she is doing a lot of things at the same time, like she is supposed to check their nutrition status, reviews, appointments.”</td>
</tr>
</tbody>
</table>

Female Respondent, Health Facility Staff FGD, Wusakile

“I would recommend that they reconsider funding the project again, we can really appreciate because this program has really helped us in number of ways, we have found stakeholders whom we are working with, we are making sure that all HIV positive children are taken care off, we have been helped with staffing because you know in the government staffing in a challenge.”

Female Respondent, Health Facility Staff FGD, Mulenga

“Actually, the placement of the case worker has really helped us a lot to capture a lot of children who need to be tested. But now that this program has come to an end there is need for the Ministry to employ a case worker, so that there is no significant drop in the number of children that need to be tested for HIV.”

Female Respondent, Health Facility Staff FGD, Mulenga
3.5. QUANTITATIVE AND PROGRAM DATA

3.5.1. RETENTION AND LTFU

Program data corroborate the qualitative responses that HIV positive children and adolescents were returning for HIV care and treatment services during the HIV Linkages Activity. Based on cohort data from the HIV Linkages Activity database collected during the implementation period, retention and LTFU rates were strong. Figures 3.1 and 3.2 show a retention rate as high as 89% with an average of 84% while LTFU is as low as 10% with an average of 16%. As expected, LTFU is the mirror of retention; the higher the retention, the lower the LTFU. Figure 3.2 provides absolute numbers for monthly cohorts with the highest retention rates for the April 2017 cohort and the lowest the September 2017 cohort.

**FIGURE 3.1. PROPORTION OF CLIENTS RETAINED IN HIV CARE DURING THE HIV LINKAGES ACTIVITY BY MONTHLY COHORTS**

**FIGURE 3.2. NUMBER OF CLIENTS RETAINED IN HIV CARE DURING THE HIV LINKAGES ACTIVITY BY MONTHLY COHORTS**
Figure 3.3 provides a breakdown of the numbers of clients enrolled, retained, and LTFU in HIV care during the HIV Linkages Activity by health facility.

**TABLE 3.1. POST-INTERVENTION FREQUENCIES BY AGE GROUP, GENDER, AND FACILITY (PERCENTAGES IN PARENTHESES)**

<table>
<thead>
<tr>
<th>RETENTION</th>
<th>YES</th>
<th>NO</th>
<th>TOTAL</th>
<th>P-VALUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE GROUP</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1</td>
<td>12 (85.7)</td>
<td>2 (14.3)</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>1-9</td>
<td>88 (84.6)</td>
<td>16 (15.4)</td>
<td>104</td>
<td></td>
</tr>
<tr>
<td>10-14</td>
<td>67 (84.8)</td>
<td>12 (15.2)</td>
<td>79</td>
<td></td>
</tr>
<tr>
<td>15-17</td>
<td>45 (83.3)</td>
<td>9 (16.7)</td>
<td>54</td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>14 (77.8)</td>
<td>4 (22.2)</td>
<td>18</td>
<td></td>
</tr>
</tbody>
</table>
As LTFU should be a mirror of retention and results in Table 3.2 confirm this expectation. Table 3.2 shows no significant differences were revealed among age groups and gender, but significant patterns were observed at facilities. Women had a higher rate of LTFU, and Kawama had the highest rate among facilities followed by Twatasha.

**TABLE 3.2. POST-INTERVENTION LTFU FREQUENCIES BY AGE GROUP, GENDER, AND FACILITY (PERCENTAGES IN PARENTHESES)**

<table>
<thead>
<tr>
<th>LTFU</th>
<th>YES</th>
<th>NO</th>
<th>TOTAL</th>
<th>P-VALUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE GROUP</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1</td>
<td>2 (14.3)</td>
<td>12 (85.7)</td>
<td>14</td>
<td>0.959</td>
</tr>
<tr>
<td>1-9</td>
<td>16 (15.4)</td>
<td>88 (84.6)</td>
<td>104</td>
<td></td>
</tr>
<tr>
<td>10-14</td>
<td>12 (15.2)</td>
<td>67 (84.8)</td>
<td>79</td>
<td></td>
</tr>
<tr>
<td>15-17</td>
<td>9 (16.7)</td>
<td>45 (83.3)</td>
<td>54</td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>4 (22.2)</td>
<td>14 (77.8)</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>43 (16.0)</td>
<td>226 (84.0)</td>
<td>269</td>
<td>0.959</td>
</tr>
<tr>
<td>GENDER</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>26 (19.6)</td>
<td>107 (80.5)</td>
<td>133</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17 (12.5)</td>
<td>119 (87.5)</td>
<td>136</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>43 (16.0)</td>
<td>226 (84.0)</td>
<td>269</td>
<td>0.115</td>
</tr>
</tbody>
</table>
3.5.2. PEPFAR PRE- AND POST-INTERVENTION DATA

PEPFAR data were obtained for the pre- and post-intervention period. While analyses were limited to retention only, given the direct relationship between retention and LTFU, this constraint was not a significant problem. Pre-intervention data from PEPFAR describe a retention rate of 89.6% for clients <15 years and a rate of 90.9% for all clients during fiscal year 2016 (Table 3.3), while post-intervention data show a retention rate of 90.9% for clients <15 years and 89.0% for all clients during fiscal year 2018. Expanding the context to the larger Kitwe District, patterns are notably different. Among the <15-year-old clients, retention rates dropped from an average of 85.9% to 83.8%, while among all clients the rate dropped from 90.8% to 80.8% (Table 3.4). The district-wide pattern documents a decrease in retention, while the rates at the five Activity sites remain stable, suggesting a positive and attributory impact or consequence of the HIV Linkages Activity.

<table>
<thead>
<tr>
<th>FACILITY</th>
<th>&lt;15 Years</th>
<th>All Ages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Numerator</td>
<td>Denominator</td>
</tr>
<tr>
<td>Ipusukilo</td>
<td>60</td>
<td>80</td>
</tr>
<tr>
<td>Kawama</td>
<td>26</td>
<td>40</td>
</tr>
<tr>
<td>Mulenga</td>
<td>56</td>
<td>62</td>
</tr>
<tr>
<td>Twatasha</td>
<td>75</td>
<td>92</td>
</tr>
<tr>
<td>Wusakile</td>
<td>18</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>43 (16.0%)</td>
<td>226 (84.0%)</td>
</tr>
</tbody>
</table>

<p>| TABLE 3.3. PEPFAR RETENTION RATES FOR FIVE HIV LINKAGES ACTIVITY HEALTH FACILITIES |</p>
<table>
<thead>
<tr>
<th>Numerator</th>
<th>Denominator</th>
<th>Numerator</th>
<th>Denominator</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;15 Years</td>
<td>%</td>
<td>All Ages</td>
<td>%</td>
</tr>
<tr>
<td>Numerator</td>
<td>60</td>
<td>80</td>
<td>89.6%</td>
</tr>
<tr>
<td>Denominator</td>
<td>67</td>
<td>88</td>
<td>90.9%</td>
</tr>
</tbody>
</table>

<p>| TABLE 3.4. PEPFAR RETENTION RATES FOR KITWE DISTRICT |</p>
<table>
<thead>
<tr>
<th>Numerator</th>
<th>Denominator</th>
<th>Numerator</th>
<th>Denominator</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;15 Years</td>
<td>%</td>
<td>All Ages</td>
<td>%</td>
</tr>
<tr>
<td>Numerator</td>
<td>238</td>
<td>98</td>
<td>85.9%</td>
</tr>
<tr>
<td>Denominator</td>
<td>277</td>
<td>117</td>
<td>83.8%</td>
</tr>
</tbody>
</table>
3.5.3. NUMBER OF CLIENTS ENROLLED AND FOLLOWED-UP IN HIV LINKAGES ACTIVITY

An additional analysis was done to track the trend for clients enrolled and followed-up in the HIV Linkages Activity per month (Figure 3.4) using the monthly tracking data. The data are cumulative for HIV positive children and adolescents confirmed to be in the Activity per month as opposed to the cohort data presented in Figure 3.1. These results span the time period between March 2017 and September 2018, with an overall average proportion for enrollment and follow-up in HIV care of 87.1%. For 12 months, from March 2017 to February 2018, this average remained at 91%. The trend peaked in April 2017 (at 95%), remained at 90% for five months and dropped consistently until the end of the project. This decreasing trend might be attributed to programmatic changes made to the HIV Linkages Activity at the time. This included a change from the more experienced case workers conducting home visits to CBVs doing so, and an increase in overall facility-to-case worker-ratio (i.e., increase in the number of health facilities and a reduction in the number of case workers per health facility).

![Figure 3.4. Cumulative number of clients enrolled and followed-up in HIV Linkages Activity by month](image)

3.6. PEDTRACK SYSTEM

3.6.1. PEDTRACK SUCCESSES

Respondents identified several PedTrack successes.

1. **Client Adherence to Appointments**

   Respondents indicated that the PedTrack system contributed to an increase in clients returning for appointments, as the system generated appointment date reminders.
“Yes, I think this system can work especially for those that provide correct phone numbers. The system works well as a reminder. People are reminded the day before their appointment and they do comply, and I can love this system to continue.”

Female Respondent, CBV FGD, Twatasha

“The messaging system worked well. It really helped us retain a lot of pediatric clients. If the guardian who keeps the child is not available they used to tell the person who is at home to take the child for clinical reviews tomorrow and the most good part is that they used to confirm with us that they have received the message and they have sent me to bring the child.’”

Male Respondent, Health Facility Staff FGD, Ipusukilo

2. Generic SMS Messages to Safeguard Confidentiality and Written in Local Language

Respondents from Ipusukilo mentioned that the messages were disseminated in local languages and contained generic appointment information to safeguard confidentiality.

“And these messages are sent in local languages. They type the message that is in local language and send to guardians to remind them and they are normally done in local language so that everyone can read.”

Female Respondent, Health Facility Staff FGD, Ipusukilo

“The messages ... were general and if the guardian ... doesn’t know how to read, they can give someone to read and interpret for them and they would not know the purpose of going to the facility. Because the message was: ‘We are reminding you to come to the facility.’ It was not specified for what reason, so anyone can read that message and they can know that it’s their appointment day. Only the guardian would know that it’s my refill date.”

Male Respondent, Health Facility Staff FGD, Ipusukilo

3. SMS Messages Facilitated Health Facility Staff Planning of Client Appointments

Health facility staff were also sent SMS reminders on appointment details (i.e., medical review, VL test, medication refill, or DBS). This allowed health workers to plan more efficiently and know how many clients to expect, which files to prepare, and which medications or tests would be needed.

“... we also used to receive the messages of the names of clients, so we were able to pull all of the files for those due for viral load and this helped us a lot in scheduling of appointments.”

Male Respondent, Health Facility Staff FGD, Mulenga

“I think PedTrack has really helped us in so many ways ... not just the clients, even us, to remind us as staff to know the number of clients that we are going to have on a particular day, to prepare the files, and check if their files are okay and if they need some investigations.”
4. **SMS Messages Helped CBVs who Received SMS Messages in Conducting Home Visits and Extending HIV Counseling and Testing Services**

Case workers at Wusakile, Kawama, Mulenga, and Ipusukilo included CBV phone numbers in PedTrack. This helped in a variety of ways. For instance, after receiving the message, the CBV conducted client home visits to remind clients of appointments (some could not read, or did not pay attention to messages). CBVs also used these visits to counsel family members and, at times, conduct HIV testing.

> “PedTrack works by sending messages to clients to remind them of the appointments they have .... There are others who don’t know how to read and when these messages are sent to us, we also go in the community to ask clients if they received the message and to tell those that did not receive the message that they have an appointment on a set date.”

**Female Respondent, CBV FGD, Wusakile**

> “The thing of messages is good, because to us counselors, things have become easier for us. When the message is sent, we pick our bags and aprons then go. They welcome us in their homes and start discussing. They ask us if there are some testing kits so that their children are tested. They sometimes call all the children and you do index contact testing. You then start counseling them. Once tested and results are confirmed, if there is anyone positive, we make an appointment for them and they bring the children and initiate treatment. They are now coming once you make an appointment with them. The system of SMS is working.”

**Female Respondent, CBV FGD, Kawama**

### 3.6.2. PEDTRACK CHALLENGES

PedTrack was a helpful reminder tool for clients and health facility providers, but respondents also raised concerns.

1. **Wrong Phone Numbers**

> “There just some clients that are difficult to deal with. When they are asked to receive details, they give wrong numbers, wrong addresses and when it’s time to remind them of their medication, they cannot be reached. This is when the case worker now sends us to go and look for these people. Even if they have shifted, we get to ask where they are until we find them.”

**Male Respondent, CBV FGD, Twatasha**

> “We have those who are difficult to convince, so as we are doing DBS, we explain to them saying this is the child’s life, we tell them the truth and counsel them. Others get to realize that the child is innocent and just from there they are moved. Even when they wanted to give the wrong address, they give us the correct one and leave behind the phone number.”
2. Other Phone-Related Issues

Key challenges in reaching clients included lack of phones or phones not working, as well as illiteracy or clients ignoring the messages.

“They also don’t get when their phones are off. Maybe they were drinking and dropped their phones ... In the end, they even forget their appointment because they appreciate the message but don’t get the message because of their problems.”

Female Respondent, Health Facility Staff FGD, Kawama

“Others don’t know how to read the messages. They can receive the messages but due to illiteracy they are unable to interpret the messages.”

Female Respondent, Health Facility Staff FGD, Mulenga

“So, the PedTrack system works well but it created a condition in some clients’ minds. So, if they don’t get the message, they would not come. They will come and say: ‘The reason I did not come is because I did not receive a message.’ That was one of the problems.”

Male Respondent, Health Facility Staff FGD, Kawama

“I receive that message from PedTrack and try to call the client. If the phone is not going through, I ... go to look for the name of the client and house number in the DBS register. I then go to look for the client.”

Female Respondent, CBV FGD, Kawama

3. Technical Complications

With the exception of Wusakile, which had a reliable power supply, all other health facilities noted that power outages and unreliable internet connectivity caused messages to be sent with a delay, or not at all. Some respondents commented that for four weeks in June and July, the PedTrack system was down due to a malfunction after an upgrade. Instead of automated messages, the case workers called clients or CBVs conducted home visits.

“When there is no power, you cannot operate the computer and messages won’t be sent. This is common, especially in low-income areas. That’s where our facilities are in very low-income areas with erratic power outages.”

Male Respondent, Case Worker FGD

“I have had that challenge, for some time, where you connect to the internet, but its access is limited. So, messages won’t go. So, they should at least come up with a reliable source of network. So that messages will be going every time, because our clients are used to being
reminded. Then when that time comes, if the messages does not come, they think the appointment is still far.”

Male Respondent, Case Worker FGD

“There was a period when the system was crashing ... they could try to send some messages and they were not going through. Later on, they called the technician; he repaired the system and it started working well.”

Female Respondent, Health Facility Staff FGD, Ipusukilo

“We are normally given talk time. In such case, we’ll call some clients who have phones. We will remind them using our phones. The other one is that, if they are nearby, we use the community health volunteers, to remind them.”

Male Respondent, Case Worker FGD

3.6.3. PROJECT DATA RELATED TO APPOINTMENT FULFILLMENT

As noted above, the late launch of PedTrack and the associated technical and data quality problems precluded use of those data in the analysis of appointment fulfillment. Analysis of the monthly tracking data mirrored the qualitative responses in that patients adhered to their scheduled appointments (Figures 3.5 and 3.6). Figure 3.5 shows that of a total of 1,583 appointments made for HEIs and HIV positive children and adolescents, 1,265 (80%) were fulfilled on the first appointment while 308 were missed. However, of those 308 missed appointments, 281 (91%) were fulfilled after rescheduling.

Figure 3.6 shows the number of appointments made and those fulfilled for HEIs and HIV positive children and adolescents by month. The tracking of appointments using the monthly monitoring tool effectively started in March 2018 and shows an increase in appointments made and fulfilled over time. Client fulfillment was 80%, on average.
3.6.4. SUSTAINABILITY AND RECOMMENDATIONS FOR PEDTRACK

The case worker managed PedTrack and although trainings were conducted with health facility staff and data clerks to continue its use, it was done toward the end of the Activity. When asked whether health facility workers could assume case worker functions, respondents indicated that they would not be able to manage their own work as well as updating and managing PedTrack. They would need full-time staff to implement the case worker functions. Despite the challenges, PedTrack was recommended by respondents for future use. DHO staff recommend not only its use at the current health facilities, but to expand it to other health facilities in the district. Some respondents felt that the system worked very well for children and recommended that it be used for adults as well.

**Sustainability**

“The challenge is that … we were introduced a little bit late to PedTrack as other health workers or as other stakeholders. It wasn’t a case whereby SBH came and implemented the system then a full orientation for all the workers. As a result, we are not at par with what the case worker can do on the PedTrack because of that.”

*Male Respondent, Health Facility Staff FGD, Twatasha*

“As for PedTrack, that one I have a question mark. Because we also have our own SmartCare which we run on a daily basis. So that one might be a challenge to manage.”

*Male Respondent, Health Facility Staff FGD, Kawama*

“I also manage SmartCare. I don’t think I can manage to do the data part.”

*Male Respondent, Health Facility Staff FGD, Mulenga*

**Recommendations**

“This system I think I recommend for the government to use it especially to the adult ART clients. For the pediatric it did most of the work and now we are having challenges to the adult clients whereby they are involved in different types of
business where they move from place to place, so if that PedTrack is put in place to remind them wherever they are so that they know that on such a date they are supposed to go to the facility. Most of them they come and tell you that, “I just forgot, I don’t even know what made me to look at the card that is when I realized that it’s my clinical day and I have just come.” Now if there is a system like that whereby it’s reminding them the day before the actual day it would help in retaining a lot of clients.”

Male Respondent, Health Facility Staff FGD, Ipusukilo

“Just like making the recommendation for the placement of the case worker, even with the system itself, like the PedTrack system, I think I will recommend the government to continue ... Because we saw, even if there could be some challenges ... in all it was helping us.”

Female Respondent, Health Facility Staff FGD, Kawama

“I feel it should continue even with the leaving of SBH, the program is continuing so we have intentions of lobbying it to supporters who may have intentions of taking it to other facilities, it is a good system.”

Female Respondent, DHO FGD

3.7. COMPREHENSIVE CASE MANAGEMENT FOR HIV POSITIVE CHILDREN AND ADOLESCENTS AND REFERRALS TO SOCIAL SUPPORT SERVICES

As indicated in the description of the interventions, case workers facilitated the establishment of referral networks. They conducted mapping exercises with health facility staff and CBVs which resulted in a list of stakeholders and service providers, including contact information.

3.7.1. IDENTIFICATION OF VULNERABILITY AND NEEDS OF HIV POSITIVE CHILDREN AND ADOLESCENTS

In order to provide comprehensive care to children, adolescents, and their families, it is important to understand their needs. Based on feedback from respondents, identification of social service needs for HIV positive children and adolescents were determined by health facility staff, case workers, and CBVs.

Health facility staff identified specific needs during medical consultations with clients. Referrals were done within the health facility, for instance, if a child was identified as malnourished during an ART consultation, the child would be referred to the nutrition department within the health facility. Alternatively, if the referral could not be completed within the health facility, for instance, cases of child sexual abuse or child maintenance support or education, the referral was extended to the VSU, the one-stop center, or social service providers in the community. When a social service need was identified, the health facility or CBV linked the child to the case worker to do the referrals. Health facility staff also did referrals directly (e.g., in cases of child sexual abuse).

Case workers ensured that a vulnerability assessment was conducted for every child in the program using the Child Status Index (CSI). Either the case worker or CBV (trained under ZAMFAM) conducted the CSI. Once the CSI was completed, the case worker or CBV went to the
household to verify the information. Once the need(s) was confirmed, the case worker developed a case plan and referrals and follow-up took place.

**CBVs** know the communities they serve well and often identified needs of children during home visits or by being approached by community members directly. Some CBVs were trained (under ZAMFAM) to conduct vulnerability assessments. CBVs then referred clients either directly to health facilities, organizations, or to the case worker.

**Other stakeholders** also helped in the identification of vulnerable people, for instance, the police through the VSU or a CSO dealing with child protection. These groups identified children who needed medical services and referred them to a health facility.

> “We all use the CSI. Then we do the [case] plan. Then we do the referral. When I do the referral, I will engage the parent, as there is a place where the parent is to sign. Then after the parent has signed, I will go with the child. I will give the example of Champion Community School, they have taken a lot of our children. I will go with the family to the service provider, to introduce them and that this child is in need of educational services ... Then, I will make sure that the service provider signs ... I will keep that form for the records and then photocopy the other one for the provider.”

*Male Respondent, Case Worker FGD*

### 3.7.2. SOCIAL SUPPORT SERVICES REFERRALS AND FOLLOW-UP

When a child or adolescent’s vulnerability was identified, referrals were conducted using a form, a letter, or verbally through mobile phones. Delivery of the referral varied, as at times, the case worker or CBV would take the child, and other times the client(s) would go unaccompanied.

Case workers typically followed up with CBVs to determine if clients received the services. Referrals were discussed during monthly coordination meetings and through calling or asking clients directly.

> “Usually when we were having meetings, they [service providers] used to give us feedback. Sometimes when they fail to give the feedback, the case worker would do the follow-up.”

*Female Respondent, Health Facility Staff FGD, Kawama*

> “When we identify them and they are linked for social services, the case worker sends us to go and verify. We go and see if they started going [to school] or not .... The case worker has organizations where they are linked to get help. If it is education, for example, Social Welfare ... helps. So, we follow-up to see if the child has gotten the service. For example, in my zone, there is a child and he has started going to school.”

*Female Respondent, CBV FGD, Mulenga*

> “Sometimes we use referral forms, sometimes it is on phone telling them that this person is coming to your institution and if they say yes then it’s done. I can give an example of the case they took to one-stop center ... it was a referral but it was on phone, we communicated to them that we are bringing such a case.”

*Female Respondent, Health Facility Staff FGD, Ipusukilo*
3.7.3. SUCCESSES WITH COMPREHENSIVE CASE MANAGEMENT AND REFERRALS TO SOCIAL SUPPORT SERVICES

1. **Children and Adolescents Received Social Support Services**

Several respondents thought the referral system worked well, as a number of children and adolescents received social support services.

“I cannot give you the specific number, but a lot were being helped. The issue of referral really helped, in the sense that it gives the mothers confidence so that they cooperate ... And it even makes them feel good because there was someone who was able to understand their problem.”

Female Respondent, Health Facility Staff FGD, Kawama

“As far, this time around it has helped, we have never had a negative response, am proud to say we have three girls who have been sponsored by higher learning institutions through the same meetings that we have been having. We are able to interact with their teachers they were able to recommend from the schools to Social Welfare and these children have been co-opted for free education it has been successful and helpful to us.”

Female Respondent, Health Facility Staff FGD, Wusakile

“... if you want educational support, the school will only accept the child if you go through Social Welfare. Those endorse to say, you can go ahead, then that child can have access to any government school. We used to go through ... Social Welfare.”

Female Respondent, Health Facility Staff FGD, Kawama

“I remember very well we have a successful story where a child less than 3 years was abandoned and dumped at the grandmother. This grandmother tried to scout for the father and the father came up and could not support the child. So, that child was brought to the clinic in order to get help. The best person [the case worker] who works there, she was able to write a letter to Zambia Civic Education ... they were able to track that man and the child has been put on support, and at least that child is now healthy.”

Female Respondent, Health Facility Staff FGD, Wusakile

2. **Increased Information Sharing, Documentation, and Coordination**

The case worker facilitated the establishment of a referral network and coordination mechanism at the health facility which helped stakeholders better understand the partners and services available in the communities surrounding the health facilities. The case management approach also improved documentation as the case worker established a filing system, developed case plans for vulnerable HIV positive children and adolescents, and documented referrals and feedback. The improved documentation was perceived by some respondents as a positive contribution to the way that CBVs worked in the community.

“... she [the case worker] brought us all together. We didn’t know there was legal help within the community. We didn’t know the Social Welfare can be directly linked up to us. We didn’t know we had other organizations to do supplementing of food. We didn’t know. We got to realize
when we started having these meetings with other non-governmental organizations and they would come up and say we have been coming for two consecutive meetings we have never had any cases from the clinic whatsoever. It awakened everyone and made us alert to say we need to send these people to the department. It was a good initiative, it actually opened our eyes to say we can link as far as that.”

Female Respondent, Health Facility Staff FGD, Wusakile

“... the school, the ACC and ourselves ... come together in these meetings to discuss and help each other. This is where in fact, some of the referrals start. For example, someone within the discussions would say we have such a problem and if there is an organization who can take up that problem, this organization says, “we can help in that matter”. So, there is this collaboration which is very vital, and it is working ... in fact let me say it has been working very well.”

Male Respondent, Community-Based Organization (CBO) FGD

“Through SBH we managed to mitigate our community volunteers who were now able to document because when you go into the field you need to document but people didn’t know, they used to identify people who were vulnerable, those who were affected, without this documentation it was difficult looking for someone.”

Male Respondent, DHO FGD

3.7.4. CHALLENGES WITH COMPREHENSIVE CASE MANAGEMENT AND REFERRAL TO SOCIAL SUPPORT SERVICES

Although substantial effort was put into establishing a strong linkages and referral system between the health facility, CBVs, and the community-based social support service providers, respondents cited reasons that it did not work as expected. These included:

- Demand for services outstripped the supply.

- Organizations relied on donor funding to provide specific services and these donors and organizations have their own policies or inclusion criteria:
  - The Department of Social Welfare has clear inclusion criteria for SCT beneficiaries and also a limitation in the number of clients they can serve based on available financial resources.
  - Ndola Diocese (ZAMFAM) provide services to children and adolescents registered in their project database. While some of the Activity beneficiaries were registered with ZAMFAM and received services, others were not and, therefore, could not access these social support services.

- Reliance of schools on student fees and often having more pupils attending school but unable to pay than those who can afford to pay, subsequently limiting enrollment.

- Some partners only enroll children with high grades.

- Disenchantment with the lack of decision-making by the Department of Social Welfare representatives at the community level (ACC and CWAC members) and the centralization of decision-making by DSWOs, who were overwhelmed by requests, resulting in long delays.
• SBH’s HIV Linkages Activity and Social Welfare created expectations in the communities which could not be fulfilled, frustrating clients.

• Insufficient or sporadic support for Ready-to-Use Therapeutic Food (RUTF).

• Lack of partners in the health facility catchment area with the ability to provide specific services, such as nutrition support.

• Community members sometimes did not embrace the support provided.

Key challenges are highlighted through anecdotes below.

### Demand is greater than supply

“Where nutrition is concerned, we had a challenge because we cannot find a partner up to now, who can help us with that consistently because in the past we used to have RUTF ... So now it’s really a challenge. We don’t even know where to refer them.”

*Female Respondent, Health Facility Staff FGD, Ipusukilo*

“You find that a child needs school, the child is taken to Twatasha then Twatasha Primary School will say we need 50% to be paid by the parents then the 50% by the organization. Now the parents will say they don’t have the 50%. Those are the challenges we are facing. But if they take them to Champion Community School it is free, but even they will ... say maybe we just have two positions then you have four children so you will take two then the two will remain.”

*Male Respondent, Health Facility Staff FGD, Twatasha*

### Organizational policies linked to programs and funding

“The response from Social Welfare to render help to these children takes time whether positive or negative. What we know is that Social Welfare only considers the old, aged and the sick for their sponsorship and for the kind of people we are working with, I have never seen if they help them. This criterion limits a lot of people that require this assistance.”

*Female Respondent, CBV FGD, Twatasha*

### Schools dependent on student fees

“As MOGE when you talk of a teacher, we don’t receive more funding or any teaching or learning equipment ... Instead, running the school depends on the few fees that you are collecting from the learners. Start from January to December, a grant is 2,100 Zambian Kwacha (ZMK) and that grant maybe can come in 3rd term and we have challenges ... We have maybe 80 pupils in grade 8; but the 80 pupils will screen them and maybe about seven pupils are able to pay the school fees and the rest are vulnerable. So, if we get the money from ... seven pupils can that run the school?”

*Female Respondent, CBO FGD*

### Slow responses from partners, particularly the Department of Social Welfare
“Then also the issue of Social Welfare. They could take long to respond. It was also a challenge going through them. But that was the only hope. It was a challenge because the response was too slow. They say that this is not the only thing they are working on, so we just have to wait.”

Female Respondent, Health Facility Staff FGD, Kawama

“The social providers in the community for example, CWAC, they delay to offer assistance to these children. Like I said earlier on, we usually have meetings with stakeholders, and we hear how they respond to these situations but the main issue is that it takes time for assistance to be rendered to these children.”

Female Respondent, CBV FGD, Twatasha

3.7.5. PROGRAM DATA RELATED TO CASE MANAGEMENT FOR HIV POSITIVE CHILDREN AND ADOLESCENTS AND REFERRALS TO SOCIAL SUPPORT SERVICES

Program data was collected and analyzed for HIV positive children and adolescents who were in the social support services data content and in the HIV Linkages Activity database. The data for social support services were examined using two methods. The first method analyzed the number of HIV positive children and adolescents who received, and did not receive, social support services based on the type of service sought. The second method analyzed the average proportion of those not receiving services after referrals by individuals across different strata.

Program data revealed that only six of the 10 possible types were identified including: child protection, counseling, education support, nutrition, skills training, and SCT. A total number of 85 referrals were associated with the 66 clients of the eligible cohorts. As shown in Figure 3.7, over half of the referrals (n=56) were for educational support, followed by nutrition (n=15). The remaining four service types were much less common.

![Figure 3.7: Number of referrals made by type of social support services](image)

As shown in Figure 3.8, the largest proportion of services not received after referrals occurred in education (80.4%), nutrition (60.0%), and SCT (50.0%). Percentages for areas other than education had few referrals so the data should be interpreted accordingly.
Overall the “not received” proportion was 71.6%. Some variation existed among age groups, gender, and facilities, but these differences were not statistically different (Table 3.5). Similarly, variation across cohorts also was not statistically different.

### Table 3.5. Post-Intervention Social Support Services Received Frequencies by Age Group, Gender, and Facility (Percentages in Parentheses)

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Received</th>
<th>Not Received</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Protection</td>
<td>1 (100)</td>
<td>0 (0)</td>
<td>1</td>
</tr>
<tr>
<td>Counseling</td>
<td>3 (75.0)</td>
<td>1 (25.0)</td>
<td>4</td>
</tr>
<tr>
<td>Education Support</td>
<td>11 (19.6)</td>
<td>45 (80.4)</td>
<td>56</td>
</tr>
<tr>
<td>Nutrition</td>
<td>6 (40.0)</td>
<td>9 (60.0)</td>
<td>15</td>
</tr>
<tr>
<td>Skills Training</td>
<td>6 (85.7)</td>
<td>1 (14.3)</td>
<td>7</td>
</tr>
<tr>
<td>Social Cash Transfer</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>28</strong></td>
<td><strong>57</strong></td>
<td><strong>85</strong></td>
</tr>
</tbody>
</table>

*Includes clients who had more than one appointment.

### Figure 3.8. Number of Clients Who Received or Did Not Receive Social Support Services by Service Type

![Figure 3.8](image-url)
3.7.6. RECOMMENDATIONS AND SUSTAINABILITY

Respondents provided many recommendations for improving referrals and coordination including:

- GRZ and donors to increase funding for social support services for vulnerable children and adolescents;
- Service delivery and provision of social support services to be linked to the project/Activity;
- Social Welfare to decentralize decision-making to the community level;
- Reduce dependency on donor funding;
- Continue coordination and collaboration despite funding;
- Request additional donor support to continue activities.

Anecdotal recommendations from respondents are highlighted in the box below.
Include service provision as part of the project

“Next time when a project like this has been made, let’s have a provision where we support the social services. If we have children lacking in education, let’s have a provision for educational support within the project. That way, our clients will be accessing services that they need. Instead of being cued up and then they don’t receive any services.”

Male Respondent, Case Worker FGD

Social welfare should decentralize service delivery

“As also the stakeholders are in Social Welfare. If they can decentralize their system. Because you find that all the cases go through them and maybe the officers are just there in town. So, you know, it caters for a lot of townships in the district. Maybe if they are able to decentralize their officers so that in each township maybe there is an office for them, that will maybe also help to quicken their system.”

Female Respondent, Health Facility Staff FGD, Kawama

“We can’t make recommendations direct to Social Welfare. That actually hinders the operations at community level. So, we are requesting Social Welfare to decentralize these issues to avoid the bureaucracy ... Policies limit our operations as stakeholders ... you can’t attend to a child not until ... you wait for Social Welfare. Its better Social Welfare decentralizes offices ... centralization hinders progress.”

Male Respondent, CBO FGD

Reduce dependency

“I think members of the community represented here also as we go back when we have stakeholders meeting, it’s high time we ran away from dependence. I think that has become a very big problem now ... It’s high time we started educating our communities to run away from dependence. It’s not always that will have a donor among ourselves. This is our problem with communities we live with ... we wait for other people to come and do this work for us. In as much we appreciate the external forces of course we should also partner with our friends helping us not all the time waiting for donors to come, we have also a stake ... you know ...for instance ... we live with orphans and vulnerable children (OVC) around; we just wait for someone else to come but we live next door to an orphan.”

Male Respondent, CBO FGD

Continue despite not receiving funding

“Where I am coming from, we shall continue. I just want to encourage on the stakeholders to continue collaboration and coordination. Where they know this case is supposed to be linked to this side, they have to report that case. We just have to continue to work together to make sure our community where we are coming from is safe ... so let’s continue never to give up. It is our responsibility to save our children.”

Female Respondent, CBO FGD

Advocating for continued donor support
“My recommendation will be to just plead with the donors that used to fund this program so that they can continue funding the program so that these meetings and collaborations that have been happening in various areas here in Kitwe continue ...”

Male Respondent, CBO FGD

3.8. STAKEHOLDER COLLABORATION AND COORDINATION

3.8.1. DISTRICT HEALTH OFFICE COORDINATION

Respondents in the DHO FGD were positive about the district level coordination facilitated under SBH's HIV Linkages Activity. Quarterly meetings were held and respondents indicated that that data was shared during these meetings which allowed for the DHO staff and stakeholders to be updated on achievements and issues. The meetings provided an opportunity for the DHO to discuss concerns about double reporting and data duplication with partners. Additionally, respondents noted that during these meetings, DHO staff would present project achievements and data, rather than project staff, which created ownership of the data and the Activity within the DHO.

“At the district level, we were meeting quarterly. SBH would always organize a meeting quarterly together with other partners ... during those meetings, data was shared and that gave us a forum for knowing what each partner was offering because in those meetings, even the case workers were attending so that they would know who is offering what so that they could refer appropriately.”

Female Respondent, DHO FGD

“One thing that came out on time is that we had so many partners come in ... they were generating the same information because all they wanted was to meet their targets and without coordination, we had double counting ... as a result, we looked like Kitwe was being overwhelmed with cases of HIV yet, we had the same cases that we were double counting. But with the coordination that was integrated, we managed to understand that the data ... was actually the same and not double numbers. So, we definitely do need to continue with these [meetings] and we are hoping that you do come back to help us where we may be lacking.”

Male Respondent, DHO FGD

3.8.2. PLACEMENT OF PROJECT MANAGER WITHIN THE DHO

The respondents in the DHO FGD were outspoken about the valuable support they received by SBH’s HIV Linkages Activity, especially the project manager placed at the DHO office. The project manager participated in the weekly DHO staff meetings and provided real-time information to the DHO team. In addition, certain DHO staff participated in technical support visits to the health facilities, participated in monthly coordination meetings, and one DHO staff member was included in PedTrack and received text messages. This strong collaboration between the project manager and the DHO reinforced ownership by the DHO of the Activity. The DHO was able to hold the project accountable for activities included by SBH in the district plans as the project manager was part of the DHO team. In addition, the project extended its support to the district beyond the immediate project activities which was appreciated by the DHO staff.
Below are anecdotes from respondents highlighting DHO staff appreciation of the project manager and the Activity.

“In terms of coordination, working together sharing the data, holding meetings, I think he [project manager] was very helpful. He used to involve all of us in holding meetings and also attend meetings, sometimes if he is overwhelmed with work, he would send one of us to go and attend the meeting and also coordinate those meetings because there used to be stakeholders’ meetings in those facilities.”

Female Respondent, DHO FGD

“We have had so many partners promising us and they would ask us to put certain amounts in our action plan but we were not able to access those promises, but with a person actually placed at our office, we are able, to hold them accountable and say this is what you promised us, so there has been a link to accessing those resources that we have been promised unlike those that do not have any person around.”

Male Respondent, DHO FGD

3.8.3. OTHER GRZ LINE MINISTRIES AT DISTRICT LEVEL

A FGD was held with other GRZ line ministry representatives at the district level, including the MYSCD, MCDSS, MOGE, and the police, to collect insight and feedback from these stakeholders who also participated in district coordination meetings. With the exception of the MYSCD, all GRZ ministries are also represented at the community level. The respondents mentioned that they either worked with the project manager or their colleagues did. Respondents who participated in one or more district coordination meetings had a good understanding of the project’s objectives. They were aware of concerns in the communities about referrals and services either taking too long or not materializing at all.

The District Education Board (DEBS) was aware of partner challenges and discussed these with the schools. Partners were also encouraged to engage with the schools directly to identify solutions. The Service Efficiency and Effectiveness for Vulnerable Children and Adolescents (SEEVCA) program implemented by the MCDSS and the United Nations Children’s Fund (UNICEF) identified the Community Development Assistants (CDA) as the cadre to lead case management efforts at the community level. The goal is for CDAs to decrease the workload of DSWOs and to help shorten the time for delivery of services to clients.

“We have so many CWACs in the district, so the District Office is overwhelmed with so many referrals from the community. But with the coming of SEEVCA, they will be working with the CDAs ... I think it will improve the way the cases are handled. Because previously, when the CWACs, ACCs make referral to the districts, the districts are overwhelmed with the number of children needing education support. But with the coming of SEEVCA in 10 selected wards, to begin with, I think it will improve services delivery, because the CDAs will be assisting the CWACs in the community. I think that was the missing link in the issue of services delivery. Because not all the cases will be referred to the district because through the CDAs they will make the referral, anyone can refer the cases to the CDAs that come up in the community.”

Male Respondent, District Line Ministry Staff FGD
Based on the information received, the conclusion is that the district coordination meetings were helpful to the DHO and partners because the meetings integrated agenda items from other similar health meetings in the district. The Activity objectives were primarily health focused and the project manager, placed at the DHO, reinforced this. For other GRZ line ministries, the quarterly meetings played an information sharing role to keep them updated on implementation progress.

3.8.4. CHALLENGES WITH DISTRICT LEVEL COLLABORATION AND COORDINATION

Although respondents from the DHO FGD did not mention challenges with the district level coordination, a few were noted during the FGD with other line ministry staff. These included:

- None of the respondents from the GRZ line ministry FGDs had undertaken any visits (i.e., supervision or technical assistance visits) to any HIV Linkages Activity implementation sites.

- Representatives of the community level line ministries (i.e., teachers and ACCs) indicated that they included notes from the community level coordination meetings in their reports to the district. Respondents were not aware of additional Activity-related challenges, except for those that were common throughout the district.

3.8.5. COMMUNITY LEVEL

Collaboration and coordination between health facility and community-based partners were intrinsically linked to the comprehensive case management approach and referral network established by the case worker. Monthly coordination meetings were organized by the case worker and included a variety of agenda items including: information sharing by service providers as to what they do in the communities; updates on implementation, progress, and sharing of project data; feedback on referrals; discussions of challenges and solutions; and follow-up on action items.

3.8.5.1. COORDINATION AND COLLABORATION SUCCESSES AT THE COMMUNITY LEVEL

These meetings provided a forum for sharing information and problem solving. They also facilitated the coordination ability of partners.

1. Forum for Sharing Information and Problem Solving

These meetings were valued by participants as they facilitated coordination, enabled participants to identify providers in their community, strengthened referrals, allowed for follow-up on achievements, and facilitated joint planning and problem solving.

"We looked at how best we can improve our services. Like in the area of the lab, the issue of DBS, how long does it take and how long should it take? What are the problems? Do we have reagents? Are we running out of drugs? ... The issue of handling cases or patients. How are we attending to them? Even that issue of separating them according to their age, separating the pediatrics ... was also mentioned in the meeting 'let's set a date for them' ... It was helping us to improve our work."

Female Respondent, Health Facility Staff FGD, Kawama

"If the case worker links a child to a school, the stakeholders we meet with, come from various schools ... So, the case worker gets maybe four children and sends them to these schools. In our meeting we might have the head teacher from this school. We then get to ask ... in such and
such a month we sent you a list of children who need to be in school, have they come through? So, we get responses from teachers from these schools if they received children to be in school.”

Female Respondent, CBV FGD, Mulenga

“... when we meet, they try to take us through what they are doing ... and ... how we can link our clients. The same applies to people who are providing nutrition in the community, they also explain on how they do it, where they lobby help from, how they can come in to help us as well. So, it is a forum where we share this information and some of the achievements that we have recorded so far.”

Male Respondent, Health Facility Staff FGD, Wusakile

2. CBV Participation and Capacity Building

These meetings were valued by CBVs as they contributed to building their capacity in case management, planning, and implementation. The meetings also enhanced CBV abilities to effectively coordinate with stakeholders, and provided a forum for CBVs to receive recognition for their work.

“Through these meetings we have improved so much. We discuss things and through the next meeting we get to evaluate whether it was accomplished. If it hasn’t, we look at other ways to have it done. If it has been accomplished, we try and look for ways to improve and become better. So, they have helped us a lot ... we get to know what exactly we can learn from various organizations. And interactions are very good because we get to learn things we couldn’t have if we didn’t collaborate.”

Female Respondent, CBV FGD, Mulenga

“We discuss how we are working, whether we are meeting our goals and targets or not. But mostly the meetings show that we are making progress where we can even see for ourselves that working together with other organizations is helping and progressive.”

Female Respondent, CBV FGD, Wusakile

“These meetings have helped us as CBVs, we know where to take our problems. If it is police related, we go to the police, if it is education, we go to schools. So, we have improved so much.”

Female Respondent, CBV FGD, Mulenga

3.8.5.2. CHALLENGES WITH COORDINATION AND COLLABORATION AT THE COMMUNITY LEVEL

Respondents valued these meetings for the coordination, network building, follow-up on referrals, and updates on Activity achievements and challenges. Responses to the challenges related to coordination and collaboration were similar to those previously mentioned, therefore, will not be repeated here. Key challenges, specifically related to the meetings, are highlighted below.
“Most of them, they can come, it’s only that sometimes they change, most especially teachers. Sometimes it’s not the same teacher that has been coming, they change ... they will appear to have no idea of the meeting but when we read the previous minutes, they would get updated.”

Female Respondent, Health Facility Staff FGD, Mulenga

“So, I have attended these meetings before and there are some of the resolutions that we come up with and they will still be resolutions again and again so there is a lack of acting on some of the resolutions ... So, there is incomplete action by other organizations, especially Social Welfare.”

Male Respondent, Health Facility Staff FGD, Twatasha

3.8.6. SUSTAINABILITY AND RECOMMENDATIONS FOR COORDINATION AND COLLABORATION AT DISTRICT, HEALTH FACILITY, AND COMMUNITY LEVELS

DISTRICT LEVEL
Respondents provided recommendations related to district level coordination including:

- Quarterly meetings were recommended to continue and possibly change to monthly meetings. They were highly valued for bringing multisectoral stakeholders together and discussing implementation of interventions across partners.

- Field trips to Activity implementation sites were mentioned by respondents in the DHO FGD as working well to keep DHO staff informed of implementation challenges. However, GRZ line ministry FGD respondents did not participate in similar activities and, subsequently, had little knowledge of implementation challenges at the community level accept for those that were common across the district. To foster ownership of interventions, challenges, and solutions, it was recommended that USAID and SBH facilitate technical supervision visits to Activity implementation sites for multisectoral GRZ line ministries (i.e., DEBS, DSWO, and the police under MOHA).

HEALTH FACILITY AND COMMUNITY LEVEL
Recommendations related to coordination and collaboration at the community level were similar to those mentioned previously. A few additional recommendations include:

- Stakeholders should continue these meetings in a different format, for example, as community dialogue sessions.

  “Some of the proposals that came through were that we handle these meetings as ... community-based dialogue sessions because what we want is continuity. We have come up with different strategies on how we can sustain these meetings. We are hoping, by the time we will be doing our last meeting this month, we should be able to know how we are going to roll out these meetings. But one of the things that were talked about was that they should be community-based, where people will sit and do them as dialogue sessions.”

  Female Respondent, Health Facility Staff FGD, Ipusukilo

- GRZ should provide funding to health facilities to continue these meetings.
“We will need to see with government if they could look into those issues. Because if you see something works, it is worth doing it. Because we noted that at least people were attended to well. Those coming were given transportation and it motivated them.”

Female Respondent, Health Facility Staff FGD, Kawama

3.8.7. SUSTAINING IMPLEMENTATION BEYOND THE HIV LINKAGES ACTIVITY – DHO FEEDBACK

The DHO staff appreciated the Activity’s interventions and indicated that they would like to see it continue. However, respondents indicated a lack of funding from the GRZ to continue the work.

“I think it is desirable that these things continue and if the system is bringing good results it should continue. I think the problem with sustainability has to do with funding, sometimes it is erratic and quite difficult to continue ... is quite difficult to have it extended to such good functions, because if good results are coming it is just good to continue supporting that.”

Male Respondent, DHO FGD

Respondents were asked what it would take for the MOH to fund the case worker position or the PedTrack system. Responses included:

- It would require the results from the Activity be shared with higher levels in the MOH, including the provincial and national levels.
- Advocacy would be required by both SBH and MOH staff to ensure that the added value of the case worker and PedTrack system are understood and appreciated, and that a staff position would be created to fill the gap or sustain and expand PedTrack.
- Creating a new position is a long-term process and another suggestion by respondents was that the Activity and health facilities identify existing staff to be capacitated to take over the case worker functions, including the management of PedTrack.
- One respondent noted that the DHO annual plans could be an opportunity to include certain activities, and that required a variety of DHO staff being involved and endorsing the activities.

“Escalating these programs to the higher levels and the good practices that we have had as SBH if they are extended to the provincial health level and national level, so that they ... appreciate the good things happening on the ground. So, really it takes continuous communication and also providing results and reports so that they appreciate what is happening on the ground. Probably when that is done, there could be good will that support is given, both financially as well as materially. For example, on the PedTrack ... if a computer breaks down, that means that maybe that program cannot continue but if that is appreciated there could be continuous supplies, replenishing of the equipment that has been used in the program.”

Male Respondent, DHO FGD

“The only challenge that we could have is that with the human resource we cannot because the government does not allow us to locally pay anyone ... we also want to see SBH as we are closing out, we also communicate with the higher ministry level, to say with these personnel that we have left
behind, who takes them on? Because we would like the program to continue. Hopefully maybe they will have the authority to employ them then we can maintain them here. Otherwise, what it will mean now is to have our own being trained to use the system so that if we don’t carry on with the people that came with SBH, we should continue with or own staff. So hopefully that could be the last capacity building before you totally wind up. We need to look into how we capacity build them in terms of using the system.”

Male Respondent, DHO FGD
4. DISCUSSION AND RECOMMENDATIONS

4.1. DISCUSSION

The documentation was designed to understand the strengths and challenges among the four key health systems strengthening strategies implemented by SBH’s HIV Linkages Activity as they related to enhancing the continuum of HIV care for HEIs, HIV positive infants, children, and adolescents. The four strategies were: placement of case workers in five health facilities in Kitwe District; implementation of PedTrack, an appointment scheduler and SMS appointment reminder system; strengthening coordination and linkages of health facility-community stakeholders in HIV care; and strengthening linkages to social support services.

It was also designed to present the lessons learned from SBH’s HIV Linkages Activity for improved service delivery at the district level, health facility level, and in the community; to examine intervention sustainability; and to make recommendations for future programming for USAID and the MOH.

4.1.1. PLACEMENT OF CASE WORKERS AT HEALTH FACILITIES

SBH’s HIV Linkages Activity baseline assessment and the study “Understanding the situation of the continuum of care for children and adolescents living with HIV and AIDS in four PEPFAR scale up districts in Zambia” (referred to as “CoC study”) conducted in 2016 by the USAID-funded Zambia Rising project, noted that the negative behaviors and attitudes of health care providers were often deterring clients from returning to health facilities and from remaining in HIV care (18). CIDRZ conducted a qualitative study with HIV positive patients who dropped out of care and documented 10 reasons. One of these was the negative attitudes by health care providers (being rude), others included: congestion at health facilities, long waiting times, staff losing patient files, staff inefficiency, and unprofessional behavior (26).

The respondents from the different FGDs praised the investment in a case worker and noted the capacitation of CBVs and relationships of trust and confidentiality that were created with mothers, children, and adolescents, as well as their consistent follow-up of clients, as important factors which contributed to clients adhering to their appointments, increasing retention rates, and reducing LTFU. In addition, this position facilitated case management and established a referral network to link HIV positive children and adolescents in need of social support services to providers in the catchment area of the health facility. This position filled an important gap in the health facility and had an exclusive focus on children and adolescents. The people filling those positions were trained in comprehensive case work which required them to be respectful, empathetic, patient-centered, and to retain confidentiality. They also ensured proper record keeping and data management for the appointment reminders and patient tracking system to function.

Placement of case workers at the health facility offered clients a service which they otherwise might not have received at the health facilities. These dedicated resources for children and adolescents helped them through the trajectory of care. It appears that the case worker embodied all the necessary elements which would encourage people to stay in care.

HIV infections have shown an upward trend in the young population in Zambia (25) and the placement of case workers at health facilities could be a good strategy to ensure case management and comprehensive health and social services are extended to this young population.
4.1.1.1. ADOLESCENT SUPPORT GROUPS

Through the case worker, the Activity initiated adolescent support groups. Respondents reported that this was a good strategy for adolescents to share experiences, encourage adherence and positive living, as well as providing peer support for enhanced retention in HIV care. These groups were considered by adolescents in the CoC study as working well. According to the project monthly report for September 2018, adolescent support groups were included for support by partners in the DHO annual strategic plan owing to feedback on the critical role that these played in supporting adherence of adolescents to ART and retention in care.

4.1.1.2. SPECIFIC CLINIC DAYS FOR CHILDREN AND ADOLESCENTS

The five health facilities in the Activity allocated specific days for adolescent and children visits. This strategy aimed to provide a more comfortable environment for adolescents to pick up their refills and have medical reviews, as well as facilitating an opportunity for them to share experiences with peers. Reports indicated that this worked well and facilitated peer support, adherence, and retention. This is a differentiated model which was also recommended by adolescents themselves in the CoC study.

4.1.2. PEDTRACK SYSTEM

The PedTrack system was introduced 10 months after the placement of the case worker. Therefore, initially, the case worker and CBVs relied on home visits to remind clients of appointments and to trace them if they defaulted or missed appointments. The PedTrack system encountered challenges which included clients not providing correct phone numbers, phones not working, client illiteracy, power outages, unreliable networks, and system maintenance problems. If a client did not have a phone, the case worker could not register him/her in PedTrack. If the client provided a wrong number, the system did not pick that up, but the PedTrack system recorded an “undelivered” status of the message to that particular phone number. To overcome these challenges, it required the case worker and CBV to conduct home visits to the clients.

Despite these challenges, respondents were optimistic about the PedTrack system and indicated that those with phones and who received the text messages adhered to their scheduled appointments. CBVs were positive about the system because when they received the messages, they conducted home visits to clients to reinforce the SMS reminders and used the opportunity to extend counseling, information sharing, and at times, HIV testing. For the system to function, it was necessary to obtain all required information from both the clients and the health facility providers to include in PedTrack. Respondents reported that this required a dedicated person (i.e., the case worker), and that PedTrack was a tool used as part of the case management function.

During the course of this documentation, it was noted that monitoring by the HIV Linkages Activity of PedTrack data compared to the monthly monitoring data was inconsistent and resulted in inconsistencies between the two systems with regards to missed appointment data. It is recommended to maintain a routine data review and reinforce data quality procedures during implementation to ensure that program implementers and health facility providers are compliant and that data quality is assured.

4.1.3. PATIENT REMINDER AND DEFAULTER TRACKING SYSTEM

According to the ZAMPHIA, just over half of the children who were reported to be on ART were virally suppressed. This indicates a need for improved adherence, retention, and ART monitoring.
The study recommends, "more effective cohort tracking (using tracking tools to track each child’s health and development) from PMTCT ... interventions to reduce LTFU and promote medication adherence, routine VL monitoring ..."(25) and should be considered.

As mentioned in this report, the HIV Linkages Activity did not rely on the PedTrack SMS reminder system only, but it was combined with the management of the case worker and follow-up by the CBVs. These three interventions (case management by the case worker, CBV outreach, and the PedTrack SMS reminder system) constituted a client reminder and defaulter tracking system (which was also recommended by the CoC study and ZAMPHIA). Program data depicted appointment adherence of 80% to first appointments.

This client tracing and defaulter tracking system worked well and was likely due to effective linkages between the health facility (case workers), the clients (parents and guardians), and the CBVs. For it to continue functioning well, there is need to have a dedicated staff person (such as a case worker), the SMS reminder system (PedTrack) to function optimally, very strong collaboration with the community (as was the case with the CBVs), and well-coordinated networks with various stakeholders in the health facility catchment area.

### 4.1.4. CBVS PICKING UP MEDICATIONS FOR CLIENTS

The documentation did not investigate the drug refill period nor whether refills and medical reviews were integrated, but respondents noted non-adherence to appointments was often due to clients working or selling at the market or orphanhood. Some CBVs reported picking up medications on behalf of clients to help ensure the children remain on treatment. This approach echoes the innovative model of CACs by CIDRZ in Zambia. In these clubs, members (who are PLHIV) take turns collecting medication for the group (3-month refills). The group is also assigned a community health worker who maintains a feedback system with the health facility. Clients participating in the CAC meet routinely in the community to discuss adherence issues and to offer each other psychosocial support. Each member has two clinical visits per year and goes to the clinic even if it is not his/her turn to collect medications. This has reduced the number of clinic visits required by each member, permitted clinics to manage supplies without becoming overwhelmed, and has been shown to work well, particularly for stable patients. This model is already in use in a number of health facilities in Zambia. In March 2017, the MOH granted approval to CIDRZ to scale-up the model (15). This CAC model was recommended by the CoC study as well for boy and girl groups overseen by a CBV or trained lay counselor (18). CBV interventions in the HIV Linkages Activity was a rough version of the CAC model to increase adherence and retention.

### 4.1.5. STRATEGIES TO REDUCE STIGMA AND REACH 90-90-90 TARGETS

Stigma (perceived or anticipated) was mentioned several times by respondents as a barrier to HIV care. This is an old problem which could hamper the country’s drive to reach or exceed its 90-90-90 targets. ZAMPHIA data indicated that discriminatory attitudes towards PLHIV were more common in rural areas (25.3%) compared to urban areas (14.5%), were higher among those with less education, ranging from 34.3% among those with no education to 5.7% among those with more than secondary education, and were common among adolescents aged 15-19 (28.8%) compared to those aged 20-24 (21.6%). The study recommended age-appropriate sexual and reproductive health education at all levels of schooling to combat false beliefs and HIV stigma; education and community interventions to decrease stigma and to improve the lives of PLHIV; and involvement of local stakeholders and traditional leaders as crucial for effective change (21).
Case workers, psychosocial counselors, and CBVs reinforced HIV messages, disclosure, adherence, and psychosocial counseling, which, according to respondents, contributed to “mothers being free” to talk about their HIV status. However, despite their efforts, gaps remained; there was only one psychosocial counselor per health facility, and the counseling skills of some psychosocial counselors were not optimal. The non-disclosure of HIV status was still prevalent and perceptions of stigma in the community remained strong.

Integration of services were recommended by respondents in the CoC study to address stigma-related barriers to HIV care (18). Respondents from SBH’s HIV Linkages Activity qualitative data collection indicated that integrated services were taking place in some health facilities where case workers were present and where they worked closely with CBVs. Respondents expressed appreciation, as it ensured clients receive the intended services and remained in HIV care.

4.1.6. DATA QUALITY AND ACTIVITY PERFORMANCE RELATED TO HIV CARE AND TREATMENT

Respondents indicated that the case worker made a positive contribution to the numbers of HEIs, children, and adolescents tested for HIV, initiated on ART, and retained in HIV care and treatment services. The HIV Linkages Activity data also show an overall increase in the number of HEIs and HIV positive children and adolescents in continuous engagement in HIV care and treatment services. On the basis of the HIV Linkages Activity data, retention rates for HIV positive children and adolescents averaged 84% and LTFU 16% in the 12 months following their enrollment in the HIV Linkages Activity.

Data quality issues, particularly those associated with the pre-intervention period, required that this End-of-Project Documentation revise the approach to a review of the data. The suboptimal picture in the pre-intervention period could be attributed to incomplete and inaccurate SmartCare data which poses a challenge for program managers who rely on SmartCare generated reports for decision-making and planning. Additional lessons were gained with the inclusion of the official PEPFAR data. These analyses reinforced the inferences regarding the post-intervention period, but they sharply contradicted results from the pre-intervention phase. In fact, these latter circumstances supported the conclusions that data quality issues in this earlier pre-intervention period precluded use of this information in any coherent manner, and explained why no inferences were made over this period.

PEPFAR data illustrated minimal change in retention between the two time periods at these five Activity sites, while district-wide retention data showed a drop of 10% among all clients and about 2% among clients <15 years. As it was beyond the scope of the documentation, this data was difficult to explain especially given the strong support for the HIV Linkages Activity interventions found in the qualitative data and minimal change in PEPFAR data between the time periods. The causes of the overall Kitwe District trend cannot be explained based on these data, but there is a clear indication that the placement of a case worker at the health facility, use of a case management approach, an SMS reminder system, and close collaboration with CBVs to track clients who missed appointments, all contributed to maintaining these patterns at the five HIV Linkages Activity sites.

4.1.7. PROVISION OF SOCIAL SERVICES FOR HIV POSITIVE INFANTS, CHILDREN, AND ADOLESCENTS

Respondents indicated that the referral network which was established—with the support of the case worker and the monthly coordination meetings—were valuable in creating connections between service providers, referrals to health and social services, and for following-up on referrals. However, despite respondent appreciation, qualitative and program data showed that the number of
successful referrals to social support services were far less than the number of referrals made, and education and nutrition services were in high demand. Reasons for incomplete referrals given by respondents included: the demand for services outstripped the supply, inadequate funding for social services (e.g., education, nutrition, and economic strengthening), institutional policies and limitations on the numbers to be served, lack of decision-making by the Department of Social Welfare representatives at the community level, and an overwhelmed DSWO contributed to delayed responses (whether positive or negative) to clients.

The HIV Linkages Activity did not include social service delivery nor the provision thereof as part of its interventions, but strengthened referrals to existing social support service providers. However, in the event that services were not rendered (due to the challenges mentioned previously) or were unavailable in the communities, the case workers were unable to extend social support services to clients directly. Although they continued to follow-up with social support service providers, the reality in these communities was that the demand outnumbered the supply. Hence, the recommendation by respondents to include social support service delivery as part of future projects/activities or to increase the number of programs providing these services.

Numerous initiatives exist in Zambia to accelerate development efforts in response to the 7th National Development Plan. The examples below, also implemented in the Copperbelt Province, are worth mentioning as activities intended to create pathways out of poverty for vulnerable families.

- The SCT scheme led by the MCDSS, is one of the components of Zambia’s social protection interventions through which monthly grants are given to vulnerable households who meet the required benchmarks.

- The SEEVCA Activity, implemented by the MCDSS together with UNICEF, is funded by USAID. It is a system strengthening Activity which endeavors to improve the MCDSS ability to provide integrated case management to beneficiaries from the SCT program. It is also referred to as “Cash Plus Care.” By the time the data collection was conducted in December 2018, SEEVCA was in 10 wards in the Copperbelt Province.

- The GRZ Girls Education, Women Empowerment, and Livelihoods (GEWEL) project is supported by the World Bank (2016-2021). GEWEL is an inter-ministerial initiative designed to empower women through improved livelihoods of 75,000 rural women and providing secondary school bursaries to 14,000 girls who are currently not in school due to poverty but have potential; it will cover 51 districts. The two GEWEL target groups are drawn from extremely poor households (24).

- The USAID/PEPFAR-funded ZAMFAM (Copperbelt and Lusaka) Activity is implemented by Expanded Church Response (2015-2019). ZAMFAM is an OVC service delivery activity which extends economic strengthening, education, and parenting services to vulnerable children, adolescents, and their families in the Copperbelt and Lusaka Provinces.

4.1.8. SUSTAINING THE CASE WORKER POSITION

The HIV Linkages Activity was implemented for one year and nine months and underwent design modifications after a year of implementation. The time was inadequate to make an evidence-informed case for the absorption of the case worker by the GRZ payroll or PedTrack to be included in the MOH national and district budgets. Integrating a new position on GRZ payroll is a lengthy process, following multiple steps and engaging multiple line ministries and stakeholders.
During the DHO FGD respondents recommended that SBH continue to lobby and advocate for the case worker position as well as PedTrack to be funded by MOH. This will require sharing data and reports through the different levels of the MOH (district, provincial, and national). Recognizing the time constraint, the respondents suggested, as an interim measure, that existing health facility staff take up the functions of the case worker. The reality is that health facilities are understaffed and even though the staff may be trained in the various roles of the case worker, they may not follow through with the implementation nor be held accountable to do so. Respondents from the health facility FGDs indicated that splitting the case worker’s tasks among existing staff may not yield the same results or may have an adverse effect on the quality of other health services and unanimously recommended the case worker position be continued.

The United States Government (USG)—through USAID, the U.S. Centers for Disease Control and Prevention, and other donors and partners—has seen the value of seconding a data clerk into USG-supported health facilities to manage SmartCare. USAID through the SAFE project implemented by JSI, funds data clerks at all five health facilities targeted in the documentation exercise and these functions have become indispensable to operate SmartCare. Other partners (e.g., AIDS Healthcare Foundation, Catholic Diocese of Ndola) also place staff within health facilities for specific functions.

4.1.9. ENHANCING CBV ROLES AND PROVIDING REMUNERATION

CBVs are unpaid volunteers. They do not receive remuneration for the work they perform in the communities, although they do receive in-kind incentives such as pens, bags, aprons, and bicycles. As a volunteer, they can opt-out of an activity at any time to support their livelihood, but this makes their support less reliable. The CBVs are a tremendous resource in the communities. They could play an even greater role in facilitating or escorting clients to ART clinics, participate in the CACs, contribute to the patient reminder and default tracking system, and play a more pronounced and recognized adherence and disclosure counseling role. However, this would require the MOH and partners to consider their incentive package so that they can contribute to epidemic control while receiving remuneration commensurate with their efforts.

4.1.10. DEVELOPING AND SUSTAINING A SINGLE OR INTEGRATED DATA SYSTEM THAT SUPPORTS DELIVERY OF QUALITY CARE AND SERVICES

The successful implementation of the HIV Linkages Activity and other interventions to improve the health and welfare of HIV positive clients is dependent on the collection, management, and use of quality data. This objective, in turn, requires a single or a well-integrated data system, not an assembly of different component systems (e.g., SmartCare, ART registers, PedTrack, HIV Linkages Activity database, monthly tracking tool). The quantitative data used for these analyses have been abstracted from multiple different sources and some issues might have been resolved if a coordinated system and formal data quality assessment procedures had been implemented from the start of the project. It is also imperative that new systems are not introduced in the middle of program implementation, as this contributes to management and quality problems. For issues of sustainability and scaling of this model for intervention, these data issues must be coordinated and addressed before programming continues or begins elsewhere. These issues will require the same commitment to personnel, salaries, equipment, maintenance and operational costs, among others as identified for PedTrack.

PedTrack, as one component of this data system, is a user-friendly system which is intrinsically linked to case management within the facility. The case management component includes obtaining details from the clients, appointment dates from different departments, triggering SMS messages, following
up on appointments to determine if clients came, working with CBVs to do home visits, updating the system, and synchronizing data with health facility registers and SmartCare. Entering data into the system is straightforward, however, obtaining the information to enter into PedTrack requires a dedicated staff position to do so. In addition to the salary, the costs associated with PedTrack’s use will be similar to the use of SmartCare, with the addition of a one-time subscription fee of 18,000 ZMK per year to the Zambia Information and Communications Technology Authority (ZICTA) as a fixed fee regardless of how many health facilities are using PedTrack, funding for talk-time (200 ZMK/health facility/month), and data bundles (200 ZMK per health facility/month).

4.1.11. SUSTAINING REFERRAL NETWORKS AND COORDINATION BETWEEN HEALTH FACILITIES AND COMMUNITY-BASED PARTNERS

Coordination of health and social services for HIV positive children and adolescents and coordination with and between partners are closely aligned with the job description of the GRZ psychosocial counselors at the health facility. This requires an additional resource to document identified needs, provide referrals to needed services, and follow-up to determine if the services were rendered. To paraphrase one respondent’s words, “It will require a person to support the psychosocial counselor at the health facility to do what the case worker did, but one who is paid.”

The appreciation of the mapping, social services referrals, and coordination meetings have been extended by respondents during the qualitative data collection. The investment from the Activity in these monthly coordination meetings included communication (talk-time to call participants), snacks and water, and transportation reimbursements for participants. The latter investment was also an incentive for CBVs. An activity such as this, with the added-value it brought to the various participants in the community, is worth the low-cost investment and even more so as HIV management becomes home- and community-based.

4.2. RECOMMENDATIONS

The recommendations from the documentation exercise are grouped in two separate sections: 1) HIV testing, care, and treatment; 2) comprehensive case management, referrals to social services, and coordination. The recommendations are targeted at the MOH, DHO, USAID, ministries, and donors funding HIV programs, partners implementing HIV programs, the SBH project, health facilities, and CBOs. It is important to note that respondents often provided recommendations without specifying the audience or included MOH, donors, or partners as audiences for the same recommendation.

4.2.1. DIFFERENTIATED STRATEGIES TO INCREASE HIV TESTING, CARE, AND TREATMENT

4.2.1.1. RECOMMENDATIONS FOR MOH

- Support funding for a case worker position at the health facility as they contributed to high numbers of clients returning for visits, being tested for HIV, initiated on ART, and retained in HIV care through case management;

- Integrate different days for children and adolescents to receive HIV services and expand to all ART sites in Zambia;

- Integrate service provision (e.g., GMP and DBS testing) and rollout to all ART sites in Zambia;

- Support and expand adolescent support groups to all ART sites in Zambia;
Consider establishing CACs for stable patients, including children and adolescents (following the CIDRZ model) with a CBV participating in the CAC and overseen by a case worker and ART clinician;

Increase the number of health care providers, CBVs, lay counselors, and child counselors who are trained and experienced in adherence and disclosure counseling and psychosocial support;

Develop an integrated strategy for Information Technology and data management in health facilities;

Fund a more inclusive, integrated, and robust data system at a relatively low cost;

Expand the data system, including PedTrack, to youth and adults and to other health facilities in the district;

Develop national standards and procedures for data quality assessments and supervision (at all levels) and require implementation at all sites providing health services to clients;

Consider the combination of the case worker, PedTrack, and CBVs as a patient reminder and defaulter tracking system and expand it to all ART sites in Zambia;

Reconsider the value of CBVs in the community and the expanded role they could play to reach epidemic control, and design an incentive package commensurate with their work;

Invest in age-appropriate sexual and reproductive health education at all levels of schooling to combat false beliefs and HIV stigma;

Invest in education and community interventions to decrease stigma to improve the lives of PLHIV in these areas. Involvement of local stakeholders and traditional leaders is crucial for effective change;

Ownership and participation by MOH at every stage of implementation to enhance sustainability.

4.2.1.2. RECOMMENDATIONS FOR DHO

Increase efforts to advocate for placement of case workers and use of improved data systems, including PedTrack, to provincial and national level MOH staff;

Include funding for the case worker, data system (including PedTrack), referrals, and coordination into the district strategic plan and advocate for MOH and partners to continue funding these interventions—and expand implementation to other health facilities in the district;

Invest in age-appropriate sexual and reproductive health education at all levels of schooling to combat false beliefs and HIV stigma;

Invest in education and community interventions to decrease stigma to improve the lives of PLHIV in these areas. Involvement of local stakeholders and traditional leaders is crucial for effective change.
4.2.1.3. RECOMMENDATIONS FOR USAID

- Integrate a case worker position in USAID HIV projects, as is currently the case with the data clerks at USAID supported health facilities;

- Develop an investment case for continued funding of a case worker function at health facilities as part of the implementation strategy to reach and exceed the 90-90-90 targets, and support GRZ to make this a long-term paid position through GRZ payroll;

- Invest in age-appropriate sexual and reproductive health education at all levels of schooling to combat false beliefs and HIV stigma;

- Invest in education and community interventions to decrease stigma to improve the lives of PLHIV in these areas. Involvement of local stakeholders and traditional leaders is crucial for effective change.

4.2.2. CASE MANAGEMENT FOR COMPREHENSIVE COORDINATED CARE AND REFERRALS TO SOCIAL SERVICES

The establishment of the referral network and the monthly coordination meetings were highly valued by respondents. Challenges existed to ensure that children and adolescent received the services they need, and respondents had several recommendations.

4.2.2.1. RECOMMENDATIONS FOR MOH

- Recognize the case management approach, which includes referrals to social services, as an important strategy to respond to the different determinants of HIV which hamper children and adolescents’ ability to remain in HIV care;

- Invest in a remunerated case worker position to support the psychosocial counselors at health facilities to ensure comprehensive coordinated care is provided to HIV positive children and adolescents;

- Invest in coordination mechanisms at the community level to enhance local ownership of the program and to ensure comprehensive coordinated care to HIV positive children and adolescents.

4.2.2.2. RECOMMENDATIONS FOR USAID

- Increase investment in social service programs to reach more children and adolescents with education, nutrition, child protection, and economic strengthening programs;

- Invest in social protection programs to intensify support to create efficient pathways out of poverty. Examples of these include the ZAMFAM Activity funded by USAID, “cash plus care” interventions, or the GRZ GEWEL project (education grants for secondary school pupils and start-up capital for lending and savings groups);

- Recognize the case management approach, which includes referrals to social services, as an important strategy to respond to the different determinants of HIV which hamper children and adolescents’ ability to remain in HIV care;

- Invest in a remunerated case worker position to support the psychosocial counselors at health facilities to ensure comprehensive coordinated care is provided to HIV positive children and adolescents;
• In addition to the DHO staff, engage more with the different line ministries at the district level (e.g., MOGE, MCDSS, MOHA, and police) to fully embrace implementation challenges at the community level and identify solutions;

• Support frequent supervision visits of line ministry staff to Activity sites;

• Invest in coordination mechanisms at the community level to enhance local ownership of the program and to ensure comprehensive coordinated care to HIV positive children and adolescents.

4.2.2.3. RECOMMENDATIONS FOR MCDSS, MOGE, DONORS, AND PARTNERS IMPLEMENTING HIV AND SOCIAL SERVICE PROGRAMS

• Advocate for the investment in increased resources for social services programs (e.g., education, nutrition, child protection, and economic strengthening) to reach more children and adolescents in need of these services;

• Invest in age-appropriate sexual and reproductive health education at all levels of schooling to combat false beliefs and HIV stigma;

• Invest in education and community interventions to decrease stigma to improve the lives of PLHIV in these areas. Involvement of local stakeholders and traditional leaders is crucial for effective change.

4.2.2.4. RECOMMENDATIONS FOR MCDSS, DEPARTMENT OF SOCIAL WELFARE

• Decentralize decision-making related to social welfare and social protection services to the community level (through CDAs) to quicken processes to render needed services;

• Invest in social protection programs to intensify support to create efficient pathways out of poverty.

4.2.2.5. RECOMMENDATIONS FOR COMMUNITY-BASED SOCIAL SERVICE PROVIDERS

• Reduce dependency on external aid and embrace local solutions;

• Continue coordination meetings and referrals to social services, regardless of funding constraints, to improve services for HIV positive children, adolescents, and families;

• Increase sensitization of community members, beneficiaries, and clients on the availability of services and responsibility of parents and guardians to embrace the opportunities and services when they are extended to their children;

• Invest in age-appropriate sexual and reproductive health education at all levels of schooling to combat false beliefs and HIV stigma;

• Invest in education and community interventions to decrease stigma to improve the lives of PLHIV in these areas. Involvement of local stakeholders and traditional leaders is crucial for effective change.
5. CONCLUSION

Respondents praised the investment in a case worker and highlighted that the case worker built the capacity of CBVs, established relationships of trust with mothers, children, and adolescents, and provided consistent client follow-up—all key factors which contributed to clients adhering to appointments, increasing retention rates, and reducing LTFU. SBH’s HIV Linkages Activity data showed an overall increase in the number of HEIs and HIV positive children and adolescents in continuous engagement in HIV care and treatment services with an average retention rate of 84% and LTFU of 16%. There are clear indications that the case worker—through placement at the health facility; use of a case management approach; SMS reminder system; close collaboration with CBVs to track clients who missed appointments; ability to maintain client records and ensure data management—contributed to the data trends at the five health facilities. It is recommended that the interventions (including the case worker, PedTrack, and collaboration with CBVs and CSOs in the community) be considered for ongoing implementation and evaluation by the MOH, USAID, other donors, and HIV implementers as the country implements the Fast-Track strategies to achieve the 90-90-90 targets by 2020 and eliminate new HIV infections by 2030.

Respondents provided positive feedback on the Activity’s case management approach, the establishment of a strong referral network, and its coordination at the community level. These interventions resulted in a number of children benefitting from education, skills training, child protection, and nutrition services. However, those in need of services far out-number the children served. The lack of means by caregivers to pay for school fees or to provide adequate food and nutrition for their children, especially those on ART, was prevalent in the communities surrounding the five health facilities. Many gaps still remain in ensuring successful referrals to social services. Recommendations include sustaining the case worker function, reducing donor and partner dependency, and increasing financial support for social services. In addition, the Department of Social Welfare should decentralize decision-making to the community level. Social protection programs enhance initiatives to create efficient pathways out of poverty. This will contribute to Accelerate Development Efforts in Zambia without Leaving Anyone Behind (23).
REFERENCES


25. UNICEF Zambia and Save the Children Zambia. (October 2015). Urban Child Poverty: A Case for Lusaka and Copperbelt. Dimensions of poverty or deprivation selected for the study were education, health, nutrition, water, sanitation, shelter, and information.
ANNEX 1 – QUALITATIVE DATA COLLECTION TOOLS

Final qualitative data collection tools are provided below.

1. Data collection tool for FGDs for health facility staff.
   01_FDG for Health Facility Staff SBH_HIV

2. Data collection tool for FGDs for CBVs.
   02_FDG for CBVs_SBH_HIV_Linkages_Activity

3. Data collection tool for FGDs for case workers.
   03_FDG for Case_Workers_SBH_HIV

4. Data collection tool for FGDs for community-based service providers.
   05_FDG_CBO_Staff_SBH_HIV_Linkages_Activity

5. Data collection tool for FGDs for DHO staff.
   04_FDG for DHO_Staff_SBH_HIV

6. Data collection tool for FGDs for GRZ line ministries.
   06_FDG_Different_Line_Ministries_Staff_SBH_HIV

7. Data collection tool for SBH’s HIV Linkages Activity project manager.
   09_IDI_SCI_HIVCoordinator_SBH_HIV_Linkages_Activity

01_FDG for Health Facility Staff SBH_HIV

02_FDG for CBVs_SBH_HIV_Linkages_Activity

03_FDG for Case_Workers_SBH_HIV

05_FDG_CBO_Staff_SBH_HIV_Linkages_Activity

04_FDG for DHO_Staff_SBH_HIV

06_FDG_Different_Line_Ministries_Staff_SBH_HIV

09_IDI_SCI_HIVCoordinator_SBH_HIV_Linkages_Activity