



RAPID SITUATION ANALYSIS OF HEALTH NEEDS OF ORPHANS AND VULNERABLE CHILDREN IN RWANDA

WITH SPECIAL REFERENCE TO THOSE WHO ARE INFECTED WITH HIV AND ARE UNDER FIVE YEARS OF AGE



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March 2009

This publication was produced for review by the United States Agency for International Development. It was prepared by Gloria Ekpo, Moses Ahabwe, Mathias Yameogo, and Mary Lyn Field-Nguer on behalf of USAID/ BASICS; as well as Volanarisoa Rafaramalala and Jane Mutoni on behalf of CHAMP.

The author's views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development or the United States Government.

Abstract

This report provides findings from the assessment of the health needs of orphans and vulnerable children (OVC), conducted between March 18 and May 20, 2008, to access and document current programs at OVC social centers and health facilities to address health needs of orphans especially those infected with HIV and are under the age of five years in three districts in Rwanda and make recommendations on how to better address the health problems of orphans at community and facility levels of care.

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Appreciation goes to the participating health centers, social centers, sector social welfare officers, and districts for providing the necessary information and records to facilitate a better understanding of the health needs of orphans and vulnerable children, and how best to address those needs in the context of HIV in younger children in the country.

Much would have not been achieved in the writing of this report without the immense contribution of caregivers and child-headed households during the rapid analysis and we hope that their input will be useful in policy and program changes to better serve the orphans especially those who are also infected with HIV and are less than five years of age.



ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Treatment
ARV	Antiretroviral (Drugs)
BASICS	Basic Support for Institutionalizing Child Survival
BCC	Behavior Change Communication
CBO	Community Based Organization
CHAMP	Community HIV/AIDS Mobilization Project
CHH	Child Headed Household
CHWs	Community Health Workers
CHUK	University Central Hospital of Kigali
CHVs	Community Health Volunteers
CNLS	<i>Commission Nationale de Lutte Contre le SIDA</i>
CTX	Cotrimoxazole
DBS	Dried Blood Spot
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
FARG	Genocide Survivals Fund
FBO	Faith-Based Organization
FHI	Family Health International
FOSA	Formation Sanitaire (health facility)
HBC	Home-Based Care
HCT	HIV Counseling and Testing
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
IEC	Information, education and communication
IMCI	Integrated Management of Childhood Illnesses
MCH	Maternal and Child Health
MIGEPROF	Ministry of Gender and Family Promotion
NGO	Non-Governmental Organization
NVP	Nevirapine
OI	Opportunistic Infection
OPD	Outpatient Department
OVC	Orphans and Vulnerable Children
PACFA	Protection And Care of Families Against HIV-AIDS
PAMASOR	<i>Programme d'accompagnement des personnes vivant avec le VIH et les Orphelins Rejetés</i>
PCR	Polymerase Chain Reaction
PLHA/PLWHA	People Living With HIV and AIDS
PMTCT	Prevention of Mother to Child Transmission (of HIV)
RAAAP	Rapid Assessment, Analysis and Action Planning
STI	Sexually Transmitted Infection
SWAA	Society of Women and AIDS in Africa
TB	Tuberculosis
TRAC	Treatment Research AIDS Center
UNAIDS	The Joint United Nations Program on HIV/AIDS
UNDAF	United Nations Development Assistance Framework

UNGASS	United Nations General Assembly Special Session on HIV and AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
We-ACT	Women's Equity In Access to Care and Treatment
WHO	World Health Organization

ASSESSMENT TEAMS

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- Jane Mutoni, OVC Coordinator CHAMP
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- Alexis Mutabazi, OVC Coordinator, SWAA

SITES VISITED

Nyarugenge District

1. We-ACT Social Center
2. Kwa Nyianuma-Biryogo Health Center
3. Gitega Health Sector
4. Caregivers and Community Health Volunteers
5. Child Headed Households Headed Household

Kicukuru District

1. Pamasor Orphanage
2. Dispensaire, Gikondo Health Center
3. Gigaramu Health Sector
4. Caregivers and Community Health Volunteers

Muhanga District

1. SWAA Social Center
2. Kabgayi Health Center
3. Nyamabuye Health Sector
4. Caregivers and Community Health Volunteers
5. Keza Community Child

EXECUTIVE SUMMARY

Over 14 million children have lost one or both parents to HIV/ AIDS and these numbers are expected to almost double over the next 10 years. The most affected region is sub-Saharan Africa, where an estimated 12.3 million children have been orphaned by AIDS¹. Worldwide, efforts are increasing to address key areas of care for orphans and vulnerable children including child rights, social and education needs of orphans. Still more needs to be done to address their health needs, especially those who are infected with HIV and are under the age of five.

The DHS 2005 survey estimated that almost three in ten Rwandan children (1,264,063) below 18 years of age are considered to be orphans or vulnerable children (OVC), with the highest proportion of them (35%) living in Kigali and 25% in the North Province². This is a direct consequence of the 1994 genocide and the HIV and AIDS epidemic. It is estimated that 1,151,900 children have lost one or both parents, 100,000 live in child-headed households (CHH) and 170,000 are involved in child labor^{3,4}. The percentage of OVCs aged 0-17 whose households received free basic external support in caring for children was 12.6% for at least one type of support and 0.2% all of the types of support (educational, medical, emotional, material). Of children living with both parents, 91 percent are in school, compared to 75% of orphans who have lost both parents. Of the very few households that received support for care of orphans, 9 percent received school support, 3 percent received medical assistance, 2 percent received emotional support, and 2 percent received social or material support².

The average age of those accessing OVC service in the country is 7 years. Although national efforts are being scaled up for OVC care, many more children—especially those infected with HIV and are under five years of age—are still being underserved in OVC programs. The Government identifies addressing this gap in services to OVCs as a national priority. Thus, the MOH, TRAC, CNLS and MIGEPROF undertook a rapid situational analysis of the health needs of OVCs in collaboration with CHAMP, USAID/BASICS, TRAC and OVC partners in three districts in Rwanda. These included Nyarugenge, Kicykiru, and Muhanga.

The specific objectives of the rapid situation analysis were to: (i) identify health needs of orphans and vulnerable children infected with HIV, especially those under the age of five years; (ii) document available services, if any, to address the health needs of these children; (iii) develop strategies to improve access and quality of health care and support for OVC; and (iv) make recommendations to increase the early identification of OVC health needs (especially those who are exposed to or infected with HIV) and link them to appropriate care at the facility and community levels.

The planning and analysis team was composed of USADI/BASICS, CHAMP, TRAC, MIGEPROF, MOH, and OVC partners including, SWAA, We-ACT, PAMASOR, Caritas, Icyuzuzo. The teams reviewed the scope of work, methodology and adapted the questionnaire for the survey. The team conducted site visits to social centers for OVCs, affiliated health centers and interviewed caregivers, community health workers, heads of child-headed households, and the social welfare

¹ UNICEF/UNAIDS/USAID July 2004. Children on the Brink 2004. A Joint Report of New Orphans Estimates and a Framework for Action

² Rwanda 2006. Rwanda Demographic and Health Survey 2005

³ Taton Valere; Nabongo Chrales; Chiejine Ikem; Kamuragiye Aloys. Investing in Rwanda: Effective Choices for Orphans and Girls in Primary Education. Policy and Planning. UNICEF May 2007. Retrieved on May 20, 2008 from http://www.unicef.org/about/execboard/files/07-PL-38-Rwanda_Final_adoc.pdf

⁴ Rwanda 2006. Maternal, Neonatal and Child Health Assessment.

officer in three districts. The districts assessed were Nyarugenge, Kicikiru and Muhanga. Visits to Nyarugenge and Kicikiru districts were conducted on March 18, 2008, and Muhanga district on May 20th, 2008. The assessment team was accompanied by local staff of the social centers, health centers, health sector social staff, and by caregivers in the community.

Key Findings

The key findings from the rapid situation analysis were:

- (i) All the OVC social centers visited provide a variety of package of care for orphans, the most common being counseling and psychosocial support, educational assistance (schools fees and materials), nutritional counseling, and referral for HIV testing. Nutritional support and supplies were reserved for malnourished children and those on antiretroviral drug treatment.
- (ii) One of the OVC social centers (We-Act) also provides full range of HIV preventive, care and treatment services for eligible orphans including HIV testing and counseling, treatment of opportunistic infections and provision of antiretroviral drugs. These additional services are offered by trained health care providers, including doctors, nurses, and counselors.
- (iii) The health needs of children under five years of age were the most neglected at the household and community levels, and were under-represented at the social centers. The care of these children at the community and household level was dependent on mothers, who were equally in need of support and treatment. There were no specific services targeted at identifying OVCs under the age of five who were exposed to or infected with HIV.
- (iv) OVC social centers are ideal sites for addressing missed opportunities for the early identification and referral for children exposed to HIV. The improvement of care provider skills at these centers is essential and critical for access of OVCs to care and support at the community level, especially those infected with HIV and who are also under the age of five. To increase the number of eligible orphans identified at these sites, appropriate capacity building is needed for health care providers, including reinforced health education, and dissemination of behavior change communication (BCC) messages.
- (v) Associations of people living with HIV and AIDS in the community were the most common sources of referrals for OVCs to social centers and health facilities. Other sources of referrals were caregivers or community health workers and HIV testing centers.
- (vi) Only 11 of the 33 staff at the three social centers visited had received training in OVC special care and support in the previous three to five years before the assessment. None of the health care providers at the health facilities had received training on care for HIV-positive OVCs, with a focus on those who are under five years of age. However, there were no reports of personnel shortages at the social centers and health facilities that were visited;

- (vii) Very few of the orphans are sponsored by organizations in the districts. The support is mainly in the form of educational assistance and psychosocial support. Most of the orphans and vulnerable children are in the communities and lack any form of education, health and welfare support. This further widens the gap between identified need of an orphan and the access to the care they receive, if any.
- (viii) OVCs and their families expect more than psychosocial and counseling support from community health volunteers and caregivers. They also request more linkages to social and welfare support and services, including food, clothing and shelter. Families expect all vulnerable children in a household to be supported, as opposed to one or a select few.
- (ix) There were not enough strong community support structures and activities for OVCs and child-headed households. Very few children receive support among the increasing number of OVCs. There were no community awareness or education programs that addressed the needs of orphans in the community. The orphans were often not visited by local community leaders and neighbors do not often inquire about their welfare or show interest in their wellbeing.
- (x) Community health workers who are volunteers elected by the orphans to represent them are a great asset in linking services at social centers and the community for orphans and vulnerable children. They could be more effective in supporting OVCs if provided with communication and educational materials, and economic opportunities as incentives (as mutually agreed upon by the community).
- (xi) Orphanages or confinements do not provide a suitable environment for integration of the OVCs into the community. OVCs learn values and cultures within the context of the communities in which they live. This relevant community cultural and value system is lacking at the orphanage and may affect adequate integration or acceptance of the orphan into the community after discharge.

Key Recommendations

In general, it is recommended that services and standard of care to OVCs who are infected by or affected by HIV should be the same as those of children with parents, including our own children. This was rightly summarized by a plea from one of the caregivers: "I request that all caregivers take those children (OVCs) as theirs."

Specific recommendations following the rapid assessment findings include the following:

A. Identification of orphans and vulnerable children who might be exposed to HIV infection

1. The National policies, protocols and guidelines regarding OVCs should be revised to address the health needs of orphans who are infected with HIV and also specifically address the needs of the children who are under the age of five. The guideline should be widely disseminated and health care providers and caregivers trained in its implementation at the facility and community levels of care.

2. The design, implementation, and monitoring and evaluation plans of OVC care and support programs should take into consideration the health needs of children under the age of 5 years, and those infected with HIV. Such programs should not be limited to children aged seven years and above, or for children in or out of school programs. Children under 5 years of age need to be identified early and linked to care and support because of the increased risk from death from common childhood illnesses.
3. The capacity of OVC care providers at social centers and the community should be improved to help them identify early and provide appropriate care and or referral for OVCs who are HIV positive and are also under the age of five years. Improved human resources, skills and capacity building for staff at OVC social centers should include:
 - a. More training in psychosocial support, psychomotor development of the child, how to communicate with children, emergency preparedness to equip children with skills in the event of any emergency (health, natural and political), first aid, and how to handle domestic violence.
 - b. Provide capacity building for caregivers to strengthen their ability to identify and care for OVCs in the following areas: how to deliver basic health prevention messages for OVCs; better communication with OVCs and guardians for improved behavior change for OVC care and support; training on quality of care to HI- positive OVCs including specific care to under fives and training on children's rights and protection.
4. The association of people living with HIV and guardians are the commonest source of referral of OVC to social centers and health facilities. The capacity of these target groups should be improved to make to identify early OVCs who might be infected with HIV and make referrals not just for OVCs who are more than 6 years of age but also those under five years of age, who are most vulnerable from risk of dying from common childhood illnesses.

B. Strategies to Improve quality of Care for OVCs including those who might be exposed to HIV and are under the age of 5 years.

1. Universal comprehensive care should be provided for all OVCs and those infected with HIV, and services should not be limited to psychosocial and educational assistance alone. The packages of services defined by the national OVC policy should always be taken into account when providing these services to OVCs.
2. A family-centered model of care for OVCs should be promoted. The children in need of support in a vulnerable household should all be supported and one child should not just be singled out to receive support while other vulnerable children in the household are without any form of support for improved quality of life.

3. Establish “welcoming space” for OVCs where they can engage in recreational activities with snacks and drinks to keep them busy while waiting to be attended to at the social centers. Priority should be given to children who are under 5 years of age when they attend social service centers as well as health facilities. Additional services to make the facilities more children-friendly include:
 - a. Providing a space for Day Care for children under 5 years of age;
 - b. Adequate food supply
 - c. Clothing;
 - d. Audio visuals and interactive educational materials;
 - e. Playground with assorted toys to play with and early child development activities.
4. Improve medical records and documentation of care and support for OVCs on both MCH cards and pediatric outpatient and in-patients records, especially those under the age of five years and infected with HIV. This will create more awareness on the side of the providers to ask relevant questions and provide the expected service or make referrals for further care as necessary;
5. Improve access to service to OVCs, including:
 - a. Providing welfare support, clothing, feeding and shelter needs;
 - b. Providing nutritional support and food rations to all orphans who need food and not just only for the malnourished or children on ART;
 - c. Reducing the cost of medical services (offering free services) for young children infected with HIV;
 - d. Providing regular and constant counseling for children in need for care; and
 - e. Providing rapid services for OVCs instead of long waits before being attended to at social centers and facilities;

C. Establish or strengthen functional linkages between the OVC social centers and the community to provide the necessary support and care for OVCs infected with HIV and are under the age of five years. The referral and follow up links between orphans in the community and the social and through the care givers should be strengthened;

1. Establish community health support structures for OVCs including those infected with HIV and are under the age of five years through:
 - a. Creating awareness on OVC and pediatric HIV care and support at the community level, using the regular end of the month community meetings to address issues of OVCs and how the community could respond to these needs for improved quality of life for the OVCs especially for those who are infected with HIV and under the age of five years;
 - b. Training community caregivers and volunteers on pediatric HIV, especially on how to respond to health needs of the children who are infected with HIV, follow up, and provide messages on prevention of HIV;
 - c. Communities should respect the orphans and take care of them like their own children;

- d. Caregiver and community health volunteers should be supported and provided with incentives as determined by the community; the national recommendation to reinforce them in cooperatives should be encouraged to better link them with economic opportunities and to enable them effectively care for the orphans under their care as well care for their own children.
2. Specific IEC/BCC materials on OVC should be developed following specific action plans recommendations for OVC care and tailored to address community perceptions and beliefs concerning OVCs and pediatric HIV. These should be widely disseminated in the community through the association of people living with the disease, Radio, Media, Community outreaches, at the health centers and these similar channels should be used to promote awareness and community response to the needs of orphans in the society.

BACKGROUND

Globally, 21 percent of children below 18 years of age are orphans and about 4 percent of these have lost both parents⁵. Over 14 million children have lost one or both parents to HIV/ AIDS and these numbers are expected to almost double over the next 10 years. The most affected region is sub-Saharan Africa, where an estimated 12.3 million children have been orphaned by AIDS.

Orphans, including those orphaned by HIV and AIDS, may suffer a number of deprivations, including: economic hardship; lack of love, attention and affection; withdrawal from or interruption of school; psychosocial distress; loss of inheritance; increased abuse and risk of HIV infection; and stigma, discrimination, and isolation. In order to address these needs of orphans, UNICEF, UNAIDS and USAID developed five programming strategies as a framework for protection, care and support for orphans and vulnerable children living in a world with HIV and AIDS⁵. These five broad programming strategies are:

1. Strengthening the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of the parents and providing economic, psychosocial and other support;
2. Mobilizing and supporting community-based responses to provide both immediate and long-term assistance to vulnerable households;
3. Ensuring equal access to essential services for orphans and vulnerable children, including education, health care, birth registration and others;
4. Providing government protection for the most vulnerable children through improved policy and legislation and by channeling resources to communities; and
5. Raising awareness at all levels through advocacy and social mobilization to create a supportive environment for all children and families affected by HIV and AIDS⁶

Countries are in various stages of the implementation of this framework to address the needs of OVCs. As of 2003, only 17 countries with generalized HIV epidemics reported having a national policy for OVC to guide strategic decisions and resource allocation. An enormous gap still remains between what has been done and what needs to be done to protect the rights and address the needs of OVCs. Closing this gap is possible but will require the combined efforts of all those able to respond including governments, donors, nongovernmental organizations, faith based organizations, the private sector and community groups already struggling in the front line of response. Through committed partnership and collaboration, millions of children and adolescents will have a chance for a better future⁵.

The support for these orphans and vulnerable children (OVCs) is critical and in PEPFAR-focused country programs for OVC programs provide: caregiver training, support for access to education, economic support, targeted food and nutritional support, legal aid, medical care, psychological and emotional care, and other social and material support. In fiscal year 2007, Emergency Plan funding for treatment and care services for OVCs totaled more than \$289.2 million in the 15 focus

⁵ UNICEF/UNAIDS/USAID July 2004. Children on the Brink 2004. A Joint Report of New Orphans Estimates and a Framework for Action

⁶ UNICEF 2006. Scaling Up the Response for Children: East Asia and Pacific Regional Consultation on Children and HIV/AIDS. Hanoi, Vietnam. March 22-24, 2006

countries⁷. In 2007, USAID allocated \$9,583,814 in field and central support for OVC programs in Rwanda⁸. This was increased to \$13,110,193 in 2008⁹. However, there were no specific allocations for OVCs with HIV infection⁸.

Most OVC programs target orphans and children of school age who are often times above 7 years of age. Specific activities are rarely targeted to orphans who are under the age of 5 years and especially if they are also infected with HIV. There is need for concerted efforts by all stakeholders in child health including governments, donors, policy makers, program planners, private sector and non governmental organizations to address the health needs of OVCs especially those infected with HIV and are under the age of five years, in order to improve their quality of life.

Purpose and Objectives

The purpose of the rapid assessment was to:

1. Identify health needs of orphans and vulnerable children infected with HIV, especially those under the age of five years;
2. Document available services if any to address the health needs of these children;
3. Develop strategies to improve access and quality of health care and support for this group; and
4. Make recommendations to increase the early identification of health needs of OVCs exposed and infected with HIV and link them to appropriate facility and community levels of care.

Rationale

CHAMP (Community HIV and AIDS Mobilization Program) is one of the organizations providing support for orphans and vulnerable children in Rwanda through their network of partners. These OVC partner organizations included but were not limited to Caritas Rwanda, SWAA Rwanda, RWN (Rwandans women network), We-Act (Women's Equality in Access to Care and Treatment), Icyuzuzo, Pamasor, WIF (Women Investment Fund), FAWE (Forum for African Women Educationalist), EPR (Presbyterian Church of Rwanda-Eglise Prespitairean au Rwanda), ADEPR (Association De l'Eglise Pentecostal au Rwanda), AEE (African Evangelistic Enterprises) and RRP+ (Reseau Rwandais de Personnes vivant avec le V.I.H.). CHAMP in collaboration with the OVC partners has been able to provide care and support for 39,084 orphans and vulnerable children (OVC) from 2005-2007, of which 7,788 are children under five years of age. The current package of services for OVCs in CHAMP includes nutrition, education, psychosocial, protection and socio-economic support, and referral for health needs of OVCs. The OVC programs serve both infected and affected children from 20 out of the 30 districts in the country. A total of 20, 031 orphans and vulnerable children are enrolled in primary school, 9,994 students in secondary school and 1,236 are in child-headed households.

After two years of implementation of the OVC program in collaboration with partners, more and more HIV positive children were identified through the activities of CHAMP and there was a need to address the health and psychosocial needs of these children (especially those under five years of age and infected with HIV) and ensure good quality services and support at the facility and community levels. The care and support for children exposed and infected with HIV is of national priority, and the Government recommends that organization use every maternal and child

⁷ PEPFAR- Support for OVC in 15 focused countries. Retrieved on May 20, 2008 from <http://www.pepfar.gov/pepfar/press/82280.htm>

⁸ USAID/PEPFAR Approved Funding by Program Areas in Rwanda. 2007 Retrieved on 01/15/2009 from <http://www.pepfar.gov/about/82459.htm>

⁹ USAID/PEPFAR Approved Funding by Program Areas in Rwanda. 2008 Retrieved on 01/15/2009 from <http://www.pepfar.gov/about/82459.htm>

encounter and entry point to care to increase early identification of HIV exposed and infected children in need of care and support.

CHAMP, through its 5,000 OVC community volunteer and partner social centers can contribute to the early identification of children exposed to HIV infection and refer them for HIV testing at health center in the FOSA. Currently in CHAMP, there are no specific activities to create awareness of the health needs of children exposed to, infected with, or affected by HIV; ensure early identification of HIV-exposed OVCs; and refer for HIV testing and appropriate care and treatment support. To address gaps in access and quality of service for the health needs of OVCs, the Ministry of Health, TRAC, the Ministry of Gender and Family Promotion in collaboration with CHAMP, USAID/BASICS, and OVC partners planned and implemented a rapid situation analysis of health needs of OVC. The aim was to strengthen the capacity of CHAMP partner organizations for early identification and referral of exposed OVC to health facilities for subsequent care and treatment, set up support groups for OVCs, and ensure continuous psychosocial support to the children in the target areas. BASICS proposed integrated package for OVC is illustrated in the table below:

Component	Level of Care		Approaches
	Facility	Community	
Essential Newborn Care	X	X	Community and facility based integrated preventive and curative care for newborn
Child Health and Growth monitoring	X	X	Integrated approaches with infant and child feeding, immunization and pediatric HIV
Infant and young child feeding	X	X	Integrated approaches at nutrition and infant feeding programs at facility and stand alone community nutrition programs
Immunization	X	X	Integrated preventive and curative care for children under 5 years of age
Early identification and care for Pediatric HIV	X	X	Community-based integrated health information and care focused on OVCs and those infected with HIV and under the age of 5 years
IMCI/HIV	X	X	Community-based integrated health information and care focused on OVCs

Scope of Work

The scope of work for the rapid situation analysis of the health needs of OVCs, including those infected with HIV and below the age of five years, comprised the following:

1. Review existing policy documents on orphans and vulnerable children in the country with particular reference to the children infected with HIV and who are under the age of 5 years. The documents were to provide additional information to address gaps in services during the analysis;
2. Adapt survey instrument for the baseline situation analysis of health needs of children in OVC programs. USAID/BASICS pediatric HIV assessment tools used in Tanzania and Kenya, as well as the OVC Child Status Index were adapted for use in the assessment. Additional input and questions were provided by the assessment team members who are actively providing services to OVCs in the community;
3. Conduct site visits to OVC social centers, orphanages, referral health centers (FOSA) with group interviews for caregivers, community health volunteers and child headed household in three districts, namely Nyarugenge, Kacikiru, and Muhanga;
4. Compile, analyze, and write a report for the main stakeholders and partners in OVC care and support;
5. Make recommendations on addressing gaps in meeting the health needs of orphans and vulnerable children, especially those infected with HIV;
6. Develop or adapt strategic interventions to address the health needs of OVCs, based on findings from the situation analysis. This was to include adaptation of available tools and documents for care and support for OVCs who are infected with HIV namely:
 - a. USAID/BASICS pediatric job aids and tools, including pediatric HIV messages for adaptation and use at OVC social centers and at the community;
 - b. TRAC counseling cards to be adapted for the community level; and
 - c. CHAMP/SWAA/TRAC drafted guide for HIV support group and positive living education.

This report presents the major findings from the rapid analysis of the health needs of orphans and vulnerable children, including those infected with HIV and under five years of age.

METHODOLOGY

The team utilized several approaches and methods to gain a clear understanding of the health problems of orphans and the current status of care provided at social centers, health facilities, and in communities.

1. ***Holding strategic planning meetings with key stakeholders.***
There were several broadly inclusive participatory and strategic planning meetings with child health implementing partners including: CNLS, TRAC, MIGEPROF, BASICS, CHAMP Community Health Desk, and OVC implementing partners namely Caritas, We-ACT, Pamasor, Icyuzuzo and SWAA to explore ways to address health needs of OVCs at the social centers and community levels of care. These meetings outlined the critical health needs of the OVC, the logistics for the situation analysis, with the review and revision of the survey questionnaire to reflect additional needs of OVC, and selection of facilitators and the districts and sites for the rapid situation analysis.
2. ***Reviewing existing policy documents on orphans and vulnerable children.*** There was a review of available documents, guidelines and protocols for care of orphans and vulnerable children in Rwanda children, with particular reference to children infected with HIV and who are under the age of 5 years. Some of the major policy documents in the desk review were:
 - a. National Policy on orphans and other vulnerable children 2003;
 - b. UNGASS Country Progress Report for Rwanda December 2007;
 - c. OVC RAAAP Initiative Final Report. Policy Project 2005;
 - d. UNDAF 2008-2012 Vision for Rwanda;
 - e. Scaling Up Response in Children-UNICEF 2006; and
 - f. Mid-term Evaluation Recommendation from CHAMP activities for OVC.
3. ***Adapting survey instruments.*** The survey methodology involved more qualitative than quantitative methods. The qualitative methods included semi-structured pediatric HIV- OVC incorporated questionnaire; individual and group interviews, focus group discussion at community level with caregivers and observational methods at the social centers and health facilities.

The questionnaire for the rapid analysis was adapted based on:

- a. Pediatric HIV and AIDS Care and Treatment assessment tool used in the Kilimanjaro, Iringa, and Mbeya Regions of Tanzania. December 2006;
- b. Pediatric HIV and AIDS care and treatment Assessment in APHIA II Project in Western Province in Kenya October 2007.
- c. Questions from field experience of the OVC care providers in order to develop a comprehensive survey instrument adapted and relevant to the needs of the participating organizations.
- d. Adaptation of questions for orphans and vulnerable in DHS 2005 from the questionnaire
- e. The Child Status Index for health needs of OVCs was reviewed to ensure that all relevant health needs of the OVC were addressed in the Rapid Situation Analysis questionnaire .

4. **Conducting site visits:** Site visits were made to social centers, orphanages, health centers and interviews with community health workers/caregivers, social welfare officers and child headed-households in three districts (Nyarugenge, Kacikiru and Muhanga). These were selected based on availability of OVC partners in those districts, rural or urban sites, and the type of services available for orphans, such as social centers or orphanages.

The specific sites assessed were:

- a. Two social centers for OVCs implemented by We-ACT in Nyarugenge district and SWAA in Muhanga District
- b. One Orphanage coordinated by Pamasor
- c. Three affiliated Health Facility –FOSA : Biryogo Nyiranuma Health Center, Nyamirambo in Nyarugenge District, Gikondo Health Center in Kicyiro District, and Kabgayi Health Center in Muhanga Districts.

5. **Interviews with OVCs and care providers:**

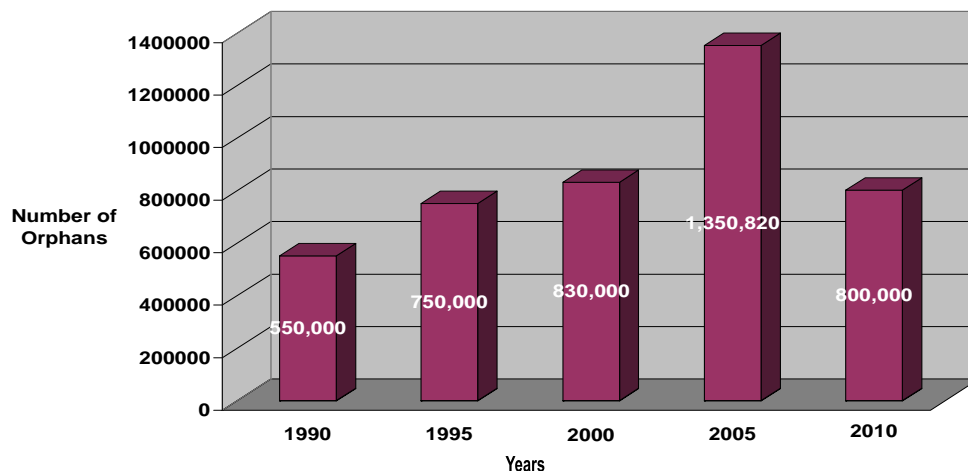
Interviews were conducted with the following target audiences:

- a. Fifteen Community Health Volunteer/ OVC Caregivers with five representatives from each the three districts.
- b. Three Social Welfare Officer in the health sector in the districts
- c. Eight child-headed households (CHH) from the three districts.

THE CONTEXT OF ORPHANS AND VULNERABLE CHILDREN IN RWANDA

The orphan population in Rwanda has been on the increase from 550,000 in 1990 to 830,000 in 2000 and 1,350,820 orphans in the 2005 RDHS. In 2003, UNICEF estimated that 810,000 (17%) of the 5 million children aged 0-17 were orphans in Rwanda and 160,000 (20%) of the total were orphaned due to AIDS.¹⁰ The number of orphans who had lost one or both parents was estimated to be 224,288 in 2006¹¹.

Trends in the Number of Orphans and Vulnerable Children (OVC) in Rwanda 1990-2010



Adapted from UNICEF *Children on the Brink 2004* and UNGASS *Rwanda Country Progress Report. 2008*

The DHS 2005 survey estimated that almost three in ten Rwandan children (1,264,063) below 18 years of age are considered to be orphans or vulnerable children (OVCs), with the highest proportion of them (35%) living in Kigali city and 25 percent in the North Province¹² This is a direct consequence of the 1994 genocide and the HIV and AIDS epidemic. It is estimated that 1,151,900 children have lost one or both parents and about 100,000 of them live in child-headed households (CHH), and 170,000 are involved in child labor^{13, 14}

¹⁰ UNICEF *Children on the Brink 2004*

¹¹ UNGASS 2008. UNGASS Country Progress Report. UNGASS Jan 2008. United Nations General Assembly Special Session on HIV/AIDS: Country Progress Report.

http://data.unaids.org/pub/Report/2008/rwanda_2008_country_progress_report_en.pdf

¹² Rwanda 2006. Rwanda Demographic and Health Survey 2005

¹³ Rwanda 2006. Maternal, Neonatal and Child Health Assessment.

¹⁴ UNICEF-Investing in Rwanda, effective choices for orphans and girls in primary education, May 2007

In a multi-country evaluation of OVC projects under PEPFAR by Catholic Relief Services (CRS) in Haiti, Kenya, Rwanda, Tanzania and Zambia¹⁵ for orphans aged 7 -17 (divided into 2 age groups), a total of 399 beneficiaries were evaluated in Rwanda. Two hundred one beneficiaries were aged 7-12 years and 198 were aged 13-17 years. The majority of those evaluated were males (50-56%) and 27%-41% in both age groups had both parents deceased. The main causes for the death of the parents were HIV and AIDS in 46% of cases and 19-31% as a result of the genocide in the country. The majority of the OVCs in both age groups (78.4%-86.3%), were cared for by female guardians with a mean age of 46.6 years. About 33-40% of the OVCs in both groups were cared for by their mother, 13.8% by the aunt, 17% by their grandparents, and between 5.6%-7.1% by a sisters.

Of those receiving assistance, 50.8% of the 7-12 year olds and 56.3% of 13-17 year olds were males, compared to 54.6% in the control group. Those in primary school were 98.5% and 93.2 % in the 7-12 year-old and 13-17 year-old age group respectively. In 21.5%-29.5% of the OVCs evaluated in the two age groups, sickness was the major reason why they missed school. The other reasons were housework, school fees and problems with uniforms.

The evaluation reported that all OVCs surveyed in Rwanda were enrolled in the national health insurance plan through a third party (PACFA), however the ability to attain treatment was between 53.0%-70.1% in the 13-17 year-old age group and 7-12 year-old group respectively. Treatment access was also noted to favor male orphans in Rwanda. Delays in payment of enrollment fees affected access to care for OVCs. Rwandan orphans were more likely to resort to informal or no treatment at all when ill. The ability to utilize a formal health facility when ill ranged from 50-71% among 13-17 and 7-12 year olds respectively. In addition, female orphans had greater difficulties accessing healthcare in Rwanda compared to males. The knowledge of HIV prevention was very low among the orphans in Rwanda (2.8%), compared with 61% in Tanzania¹⁵

The evaluation of children who are HIV positive and are under the age of five was missing in the CRS report, further stressing the need to create more awareness among policy makers and program planners and implementers to develop specific strategies and activities to address the health needs of children in this category.

Definition of an Orphan

In the Rwanda context, orphans and vulnerable children are defined as children under 18 years of age who are exposed to conditions that do not permit fulfillment of fundamental rights for their harmonious development, and have lost one or both parents. The categories include:

1. children living in households headed by children
2. children in foster care
3. street children
4. children living in centers
5. children in conflict with the law
6. children with disabilities
7. children affected by armed conflict
8. children who are sexually exploited and/or abused
9. working children (child labor)
10. children affected/infected by HIV/AIDS
11. infants with their mothers in prison,
12. children in very poor households,

¹⁵ Catholic Relief Services. Multi-Country CRS PEPFAR OVC: Project Evaluation Report. 2007

13. refugee and displaced children,
14. children of single mothers
15. children who are married before the age of maturity¹⁶

The Government is committed to implementing laws, policies and programs to ensure that children in difficult circumstances are integrated in a socially economically sustainable environment.

Challenges of OVCs in Rwanda

Orphans are disadvantaged academically, socially and health wise. Of children living with both parents, 91 percent are in school compared to 75 percent of orphans who had lost both parents. They are also more malnourished than the children of their age and sex and are also subject to more sexual abuse and violence^{4,6}. According to RDHS data, households of 12.6 percent of OVCs aged 0-17 received free basic external support in caring for children, while less than one percent of households received all three types of recommended support. In 87 percent of cases, the households do not receive any support for orphan care. Of the few households who received support for care of orphans, 9 percent received school support, 3 percent received medical assistance, 2 percent received emotional support and 2 percent received social or material support¹¹. There was no specific documentation of services or assistance provided for OVCs who are infected with HIV and are under the age of five years.

Some of the specific challenges encountered by the orphans and vulnerable children themselves include lack of family support, lack of or limited access to education, health and rehabilitation services, lack or limited psychosocial support and counseling services, lack of appropriate shelter, marginalization and stigmatization, exposure to sexual abuse and exploitation, family conflicts due to war and genocide and lack of access to inheritance and other properties left behind by parents or guardians.

The vulnerability of orphans in the education system was well illustrated by the 2005 RDHS, which highlighted the inability of households with orphans to meet the costs of schooling. Children living in child-headed households were experiencing the greatest difficulties. While 91 percent of children aged 10-14 whose parents are both alive and who are living with one of their parents attend school, just 75 percent of children who have lost both parents attend school. A 2006 study followed 692 young heads of household and noted, among other issues, their difficult living conditions, the problems in accessing education, and the psychological distress suffered by many OVC. As the responsibility for caring for OVC is often absorbed by families and communities, it is essential that these households are supported in their efforts to look after these children.

For orphans and vulnerable children living with HIV and AIDS who have lost one or both parents to HIV, the challenges in life are enormous. Children caring for sick parents often drop out of school and the cost of health expenses affect the status of the household economy. Specific objectives and strategies to address their needs should include integration of assistance for HIV exposed and infected OVCs in the general program for OVCs to avoid stigmatization; ensure nutritional and health assistance, provide psychosocial support and counseling and ensure access to inheritance by the affected household. These are expected to be carried out through sensitization of community members regarding needs of OVCs, increase access to the assets they had inherited, capacity building for family members, caregivers and care providers on how to address the health needs of OVCs and provide health and nutritional support.

¹⁶ Rwanda 2003: National Policy for Orphans and Vulnerable Children. Ministry of Local Government, Information and Social Affairs.

The average age of OVCs accessing care and support is 7 years, with those under five years of age grossly under represented in these services¹⁷. The health needs of children in OVC programs have been poorly understood, especially for children who are HIV positive and are under five years of age.

National Response, Policies and Strategies to address needs of OVCs

The main objective of the national policy on OVCs is to protect the rights of the child and to ensure physical and psychosocial long-term development of orphans. This specifically addresses the rights of the child, access to health services, free primary education, psychosocial support, socio-economic support through income generation activities, with coordination of programs and interventions for OVC.

Some of the constraints identified in the carrying out of these objectives include lack of resources for all programmatic areas, a partially developed legal framework, inadequate enforcement of existing laws and conventions, weak coordination, lack of monitoring and follow up systems at all levels and changing traditional values with increase in modernization. The National Government strategies advocated to address the needs of the OVCs in a cross cutting framework, including raising stakeholders' awareness on all matters concerning orphans and vulnerable children among parents, caretakers, service providers, community and the general public to support OVCs; improve research and identification of OVCs, develop legislation, procedures and regulations to protect and promote child rights; establish community based support structures for OVCs, strengthen capacity of care providers to care for OVC, establish coordinating mechanism and facilitate and improve access to basic services for OVCs including education, health, nutrition, housing, extension services, income generation and credit and counseling services.

Since 1994, The Government, in close collaboration with civil society partners, has worked to address the problems of vulnerable children. There have been impressive achievements in the areas re-unification and fostering of children following the genocide and programs initiated for destitute children, street children and child headed households. Widespread poverty and impact of HIV and child abuse necessitates sustained and comprehensive efforts with appropriate financial and human resources allocation to address the problems of OVCs¹⁸ including those infected with HIV

Civil society has responded in various degrees to the social and educational needs of OVCs in Rwanda. In one of the PEPFAR support programs, the Nkundabana (I Love Children) project, which was specially designed for child-headed households, assistance is provided through volunteers within the community for child headed households. The volunteers receive training in active listening, nutrition, HIV/AIDS and hygiene, and provide the children with needed support and assistance¹⁹. Faith-based organizations have played an important role in the HIV and AIDS response, including providing support for orphans and vulnerable children. The FBOs reported reaching virtually all Rwandans of all faiths (including Muslims, Protestants, Evangelicals, Episcopalian and Catholics) through their networks of churches, mosques, dioceses and parishes. The efforts by FBOs include the provision of health insurance schemes to about 12,200 orphans, food aid to 5,000, and secondary school fees for 8,600 children and about 90 have benefited from

¹⁷ 3rd National Pediatric HIV Conference December 2-4, 2008. Kigali, Rwanda

¹⁸ President Emergency Plan for AIDS Relief. 2008. Retrieved on May 2008 from <http://www.pepfar.gov/pepfar/press/82280.htm>

¹⁹ President Emergency Plan for AIDS Relief. 2008. Retrieved on May 20, 2008 from <http://www.pepfar.gov/pepfar/press/82280.htm>

vocational training²⁰.

Several other multi sectoral efforts have addressed education programs for girls and orphans. With \$70 million through the Fast-Track Initiative, adequate and safe learning spaces were created, including classrooms and sanitation facilities for over 50,000 children in 50 primary schools, and key policies for the education of girls and OVCs were developed. The program contributed to a five-year school campaign aimed at girls' retention and achievement in primary and secondary school; developed capacities for quality education that focus on outcome-based curriculums which integrate life skills and gender sensitivity; and increased access, retention and participation for 18,000 OVCs through the "Catch Up" program and 9,000 OVCs through child-friendly schools, and integration of care and support in 50 model schools²¹.

There has been much progress on the educational and social support for OVCs, however, more still needs to be done for early identify the health needs of OVCs exposed and infected with HIV and are under the age of five years, and provide or link them to where they can receive appropriate quality services and standard care.

Funding support for OVC interventions in Rwanda.

The total spending for orphans and vulnerable children in 2006 was US\$3.88 billion. This includes an estimated proportion of 20 % from Genocide Survival Funds (FARG) to support education of OVCs affected and infected with HIV in the country. Much of the amount spent on OVCs was towards education assistance, in terms of payment of school fees. Most of the funding source was from the central or national government (\$1.3 m), the second largest contributor was the Medical Assistance Program (MAP) with 1.3 billion Rwanda francs (US \$2.4 million) to support OVC activities in 2006,² and an additional \$1.2 million was gained from other donors².

In contrast, the total amount of spending on HIV in 2006 in Rwanda was US \$48.3 million, with 92 percent of the HIV and AIDS spending incurred by donors. Government contributions to HIV and AIDS increased by US\$1.4 million from 2005 levels. Private AIDS expenditure is largely based on out-of-pocket (OOP) spending on health by people living with HIV and AIDS. This represented 2.7 of the total HIV expenditure.

Through the Strategic Plan for OVC 2007-2010 adopted in May 2007, Rwanda has established a specific political body for the protection of orphans, with the aim of defining the areas for intervention of public services and NGOs, and orienting these services to their needs. A minimum package for OVC support has been defined and intervention practices among partners harmonized. The package covers elements of health (including PMTCT, HIV prevention services and VCT), nutrition, formal and non-formal education, protection, psychosocial and socioeconomic support. The decentralization process in Rwanda is contributing to the implementation of a rigorous follow up strategy for OVC at the peripheral level.

As part of national efforts to support children who are exposed or infected with HIV, including orphans and vulnerable children, USAID/BASICS, in collaboration with TRAC, EGPAF, and other partners in child health, organized a national workshop of key stakeholders in pediatric HIV and AIDS in June 2007. The purpose of the event was to draft action plans to scale up the early identification of children who are exposed and infected with HIV. The workshop outlined strategies for the identification of pediatric HIV patients at multiple entry points to care at the health facility

²⁰ World Bank/AIDS Getting Results. MAP Rwanda May 30, 2007

²¹ Taton Valere; Nabongo Chrales; Chiejine Ikem; Kamuragiye Aloys. Investing in Rwanda: Effective Choices for Orphans and Girls in Primary Education. Policy and Planning.UNICEF May 2007. Retrieved on May 20, 2008 from http://www.unicef.org/about/execboard/files/07-PL-38-Rwanda_Final_adoc.pdf

level and in communities. Such entry points to care include PMTCT, ART, pediatric inpatient and out-patient services, HIV counseling centers, MCH, home based care, nutrition services, OVC and community level programs.

This report is to provide further guidance on how to scale up the early identification of health needs of OVC who might be infected with HIV and are under the age of five years at OVC social centers, refer and link the children to appropriate care and treatment in the health facilities.

FINDINGS

The findings reported in this document focused primary on the health needs of orphans. The report addresses how OVCs access health care and what care is provided at the health facility, social center and community level in support of orphans. It also documents the challenges encountered by health care providers, caregivers and child-headed households while caring for orphans and vulnerable children at all levels of care. Other aspects of OVC care regarding educational support, social and legal assistance were not addressed in detail in this analysis because these had been assessed and documented in previous reports.

A. General Findings from all sites and people interviewed

In general, the key findings from the rapid situation analysis of the health needs of OVCs, especially those infected with HIV and under 5 years of age, include the following:

- 1) All the OVC social centers visited provide a variety of package of care for orphans, the most common being counseling and psychosocial support, educational assistance (schools fees and materials), nutritional counseling, and referral for HIV testing. Nutritional support and supplies were reserved for malnourished children and those on antiretroviral drug treatment.
- 2) One of the OVC social centers (We-Act) also provides full range of HIV preventive, care and treatment services for eligible orphans including HIV testing and counseling, treatment of opportunistic infections and provision of antiretroviral drugs. These additional services are offered by trained health care providers, including doctors, nurses, and counselors.
- 3) The health needs of children under five years of age were the most neglected at the household and community levels, and were under-represented at the social centers. The care of these children at the community and household level was dependent on mothers, who were equally in need of support and treatment. There were no specific services targeted at identifying OVCs under the age of five who were exposed to or infected with HIV.
- 4) OVC social centers are ideal sites for addressing missed opportunities for the early identification and referral for children exposed to HIV. The improvement of care provider skills at these centers is essential and critical for access of OVCs to care and support at the community level, especially those infected with HIV and who are also under the age of five. To increase the number of eligible orphans identified at these sites, appropriate capacity building is needed for health care providers, including reinforced health education, and dissemination of behavior change communication (BCC) messages.
- 5) Associations of people living with HIV and AIDS in the community were the most common sources of referrals for OVCs to social centers and health facilities. Other sources of referrals were caregivers or community health workers and HIV testing centers.

- 6) Only 11 of the 33 staff at the three social centers visited had received training in OVC special care and support in the previous three to five years before the assessment. None of the health care providers at the health facilities had received training on care for HIV-positive OVCs, with a focus on those who are under five years of age. However, there were no reports of personnel shortages at the social centers and health facilities that were visited;
- 7) Very few of the orphans are sponsored by organizations in the districts. The support is mainly in the form of educational assistance and psychosocial support. Most of the orphans and vulnerable children are in the communities and lack any form of education, health and welfare support. This further widens the gap between identified need of an orphan and the access to the care they receive, if any.
- 8) OVCs and their families expect more than psychosocial and counseling support from community health volunteers and caregivers. They also request more linkages to social and welfare support and services, including food, clothing and shelter. Families expect all vulnerable children in a household to be supported, as opposed to one or a select few.
- 9) There were not enough strong community support structures and activities for OVCs and child-headed households. Very few children receive support among the increasing number of OVCs. There were no community awareness or education programs that addressed the needs of orphans in the community. The orphans were often not visited by local community leaders and neighbors do not often inquire about their welfare or show interest in their wellbeing.
- 10) Community health workers who are volunteers elected by the orphans to represent them are a great asset in linking services at social centers and the community for orphans and vulnerable children. They could be more effective in supporting OVCs if provided with communication and educational materials, and economic opportunities as incentives (as mutually agreed upon by the community).
- 11) Orphanages or confinements do not provide a suitable environment for integration of the OVCs into the community. OVCs learn values and cultures within the context of the communities in which they live. This relevant community cultural and value system is lacking at the orphanage and may affect adequate integration or acceptance of the orphan into the community after discharge.

B. Findings from OVC Social Centers at Nyarugenge, Kacikuru and Muhanga Districts

- 1) **Policies and guidelines for OVC HIV-positive care.** Policies, guideline or protocols on OVC HIV-positive care and support were not available at the sites that were visited during the rapid situation analysis of health needs of orphans and vulnerable children (OVC). Some centers (We-ACT) depended on On-the-Job Training (OJT) on OVC care for their staff. The 2003 National Policy on OVC was not visibly seen in any of the centers that were visited.
- 2) **Identification of orphans and vulnerable children infected with HIV at the social centers.** The criteria used for the identification of orphans or vulnerable children at the social centers include: (i) children without both parents; (ii) children with single parents who are unable to support themselves with the basics needs of life; or (iii) children with parents who are mentally or physically disabled. The main sources of OVCs to the centers are referrals from the association of PLWHA, local authorities (Umurenge), caregivers/community health volunteers, HIV Testing and counseling centers, and health centers. Other OVCs who are HIV-positive are identified through maternal history or participation in PMTCT programs. Very few cases walk in to receive care at OVC social centers without appropriate referrals. Older orphans often access services at the social centers by self-referral while the younger children in primary school and those under the age of 5 years come in with their mothers or guardian. There were no specific activities targeted at early identification of OVCs HIV positive and under the age of five years at any of the social centers.
- 3) **Common health problems reported by OVC.** The most common health (and social) complaints of OVCs as reported by the service providers at the social centers were:
 - (i) Malaria,
 - (ii) Diarrhea diseases,
 - (iii) Malnutrition,
 - (iv) Acute respiratory infections and pneumonia,
 - (v) Poor and stunted growth,
 - (vi) Tuberculosis
 - (vii) Herpes zoster
 - (viii) Skin rashes

The common health complaints reported for OVCs who are infected with HIV include:

- (i) Falling sick frequently
- (ii) High fever and malaria,
- (iii) Flu and cold like symptoms
- (iv) Coughing
- (v) Eye complaints
- (vi) Headaches
- (vii) Scalp wounds
- (viii) Malnutrition, despite eating quality food
- (ix) Diarrhea
- (x) Hair changes
- (xi) Skin infections, like boils
- (xii) Adherence problems (refusing to take ART)

The medical and health problems of OVCs were often associated with social needs. Social challenges identified by the caregivers include:

- (i) Poverty,
- (ii) Physical abuse of children
- (iii) Drug abuse
- (iv) Loneliness
- (v) Repetitive questioning by orphans on the whereabouts of their parents.

1. Services provided to OVCs at Social Centers (Refer to Table 1)

Services provided for OVCs at the centers that were visited are summarized in Table 1. In general, there is a variety of services provided for orphans at social centers. The services vary depending on skills and capacity of the staff working at the social centers as well as funding support for programs.

The major basic component of health care provided for OVCs who are infected with HIV at the social centers include:

a. Medical (Clinical) services

Two out of the three social centers visited during the situation analysis (including the orphanage) do not provide any medical services to OVCs infected with HIV. Orphans in need of medical attention are referred to the nearby health center for care and treatment support. However, at We-ACT social center, the staff provides comprehensive medical care for OVCs infected with HIV. This includes HIV testing and counseling, CD4 testing, and cotrimoxazole prophylaxis and ART for eligible HIV-infected. Only those with severe disease or complications were referred to the affiliated district hospital or reference hospital like Central University Hospital of Kigali (CHUK), King Faisal, Muhima, and Kibagabagaba hospitals. Children under the age of five were under-represented in all these services.

b. HIV Counseling and Testing Services

HIV counseling and testing for OVCs is provided by one out of the three centers that were visited. This is mainly through direct on-site service at the centers and through mobile HCT services upon request from the Association of People Living with HIV and AIDS (APLWHA). This service is provided on a daily basis at the We-ACT social center. However, centers like Pamasor and SWAA depend on TRAC or the

health center for testing and counseling services for OVCs infected with HIV. They send all new children to the health center or TRAC for medical evaluation before providing support to the child. Additional psychosocial support is provided to the OVCs at TRAC pediatric HIV support group on Saturdays.

At the We-ACT social center, all OVCs receiving services are tested for HIV. On average, 30-60 HIV tests are conducted every month. Of these, only one percent may have a positive result. For vulnerable children who are accompanied by their parents, the parents are often tested first for HIV before conducting the test on their children.

Although some women and mothers were often afraid to learn their HIV status, they were however able to consent to HIV testing and receive their results. Pregnant women often obtain permission or consent from their spouses before accepting to be tested for HIV. One of the care providers at the social center reported that, at ANC, women must consult with their spouses and come along with them for HIV testing. The men are encouraged to come with their spouses for the testing at ANC clinics. In families where men are not very supportive of their partners, the women often hide their HIV test results and would not disclose to spouse for fear of discrimination and abuse.

c. Psychosocial services

All the sites provided psychosocial counseling support to the OVCs, including those infected with HIV on a needs basis. Subsequent follow-up counseling support at the community level is provided by caregivers.

d. Educational support

All the social centers visited provide educational support to OVCs, including orphans infected with HIV, in the form of school fees, school materials and books. Vacation camps are also organized for some of the youths in the We-ACT program.

e. Nutritional Support.

Service providers at the social centers report providing nutritional counseling to orphans under the age of 18 years. However, there is limited nutrition support for OVCs who are infected with HIV. The available nutritional supplements are mainly for children who are malnourished, infected with HIV and receiving ART. The food ration is once a month and consists of 8 kilograms of Sosoma (a nutritional mixture of sorghum, soya and maize flour) and 2 kilograms of sugar per child. Other centers also provide flour, cooking oil, biscuits and powdered milk.

f. Other Services

Other services provided for OVCs who are HIV-infected include legal support, transport assistance to the health centers for blood check up and follow up counseling. One of the social centers operated by SWAA also provides teaching sessions to mothers on family planning and nutrition. And, PAMASOR orphanage also provides sporting and game activities.

On some of the challenges and success stories from OVC service centers, one of the service providers said:

“The center (SWAA) has been helping a 17 year old girl who is HIV positive and hated her mother because the mother refused to tell her that she was sick all along. She does not know the HIV status of her mother and her other siblings because the mother is living in denial. The center has managed to help the girl go back to school and she has accepted herself. The mother has not consented to do HIV test yet”.

“Another 20 year old girl is HIV positive and is in school. She is always very sick and her parents have denied her of any help socially or financially, but the center is helping her with her social and financial needs.”

—OVC care provider in Muhanga District

2. Human Resources and Training for OVC care providers

The capacity to provide care to OVCs (especially those who are HIV positive), vary at the different social centers and social welfare services. The skills ranged from teachers, to graduate social workers, accountants, educationist, social scientist, trauma counselors, nurses and doctors. The training received by the providers is different from one social center to the other depending on the nature of work of the social center. In We-ACT and SWAA social centers, not all staff providing care for OVCs had received formal training on OVC care and support. The trainings and capacity building for some of the staff providing care for OVC in these two centers varied, some had been trained on trauma counseling mainly through on-the-job training (OJT), mental health, PMTCT and on how to conduct home visits for OVCs.

The We-ACT social center also has nurses, doctors, a pharmacist and laboratory technician among its staff. These form the team to serve health needs of OVCs at the center. At Pamasor center, an orphanage with the primary focus on care and support for OVCs, all eight members of staff had been trained in OVC care in the last three to five years but now require re-training. However, there was no specific training in competencies linked to early identification of OVCs who are infected with HIV and are below the age of five years.

In the three centers, the OVC care providers noted that they required additional training and skills to assist them in more effectively providing support for the health needs of HIV-positive OVCs in their programs. The additional training needs reported by the staff include training on:

- (i) Mental health,
- (ii) Pharmacology and side effects of drugs used in the care of orphans including ART and antidepressant drugs
- (iii) Adherence counseling, communication skills, child protection
- (iv) Nutrition and infant/child feeding
- (v) General training on OVC care and support with particular reference to those who might be HIV positive and are below five years of age.

There were no complaints of inadequate staff capacity to perform duties at the social centers that were visited.

3. Referrals, Follow Ups and Home Visits for OVCs infected with HIV

The referral of OVCs and those infected with HIV to other services depended on the capacity of the social center. There was no systematic follow up organized for OVCs at the centers. Home visit is based on identified need. At We-ACT, the medical and social needs of the orphans under their program were managed at the center and had no need for referral except for complicated cases. However, the other social centers referred all health needs of OVC and HCT to the health center within the sector.

At We-ACT social center, when OVCs are identified, they are screened, examined and followed up by the corresponding teams. They also conduct home visits, which are complemented by the home visits made by caregivers to OVCs in the community. Only children on ART are visited at home by counselors from the social centers. A counselor at one of the social center reported that, on the average, home visits are made to three OVCs in a week.

4. Community involvement on OVC care and support

All three social centers had a good link to the community through the service of caregivers or community health workers. These are women and men who volunteer to take care of the orphans in the community. In one of the districts (Nyarugenge) it was reported that the caregivers are selected by the orphans themselves to represent their interest at the community level.

The number of available caregivers varied from one social center to another depending on the number of orphans being cared for. For example, there were 126 caregivers in Muhanga districts in SWAA program compared with 60 in Nyarugenge District under We-ACT program and 15 in the Pamasor orphanage. However, there are no community mobilization activities to create awareness on the health needs of orphans including those infected with HIV and are under the age of five years.

Table 1: Summary of services provided for OVCs at Social Centers in Nyarugenge, Kacyiru and Muhanga districts.

	Districts	Nyarugenge	Kacyiru	Muhanga
1	Participating OVC Social Centers/facilities	We-Act Social Center	Pamasor Orphanage	SWAA Social Center
2	Number of staff at OVC social center	18	8	7
3	Number of staff trained in OVC care and support in the last 3-5 years	1	8	2
4	Number of staff trained in HIV positive OVC care	0	0	0
5	Number of caregivers supporting the social center	60	15	126
6	Total number OVCs served at each social center	785	73	856 (total in H/sector)
6	Number of OVCs sponsored by an organization or receiving any assistance	500		243
7	Estimated number of OVCs who are HIV positive	600	13	150
8	Number of OVCs under 5 years of age	200	13	30
9	Services provided for HIV positive OVCs			
9.1	Medical	√	-	-
	1. HCT	√	-	-
	2. OIs	√	-	-
	3. ART	√	-	-
9.2	Nutritional Support (for malnourished)	√	√	√
9.3	Psychosocial counseling and support	√	√	√
9.4	Educational Support	√	√	√
9.5	Legal Support			√
9.6	Transport assistance for HIV infected children	-	-	√
9.7	Nutrition and family planning education for mothers and caregivers	-	-	√
9.8	Sports and Games	-	√	-
9.9	Specific services for children under five years and infected with HIV	-	-	-
9.10	Referral of OVCs for medical care	-	√	√
9.11	Home Visits to OVCs	√	-	-
10	Number of caregivers at OVC social center/facility	60	15	126
11	Other Organizations providing support for OVC in the district	Icyuzuzo, Caritas, Pamasor,		FHI, CRS, Twubakane, SWAA
12	Funders & Donors for OVC programs	CHAMP, Mc-AID, Steven Lewis Foundation	CHAMP, KBF from Germany	

C. Findings from supporting health facilities in Nyarugenge, Kacikiru and Muhanga Districts

The rapid situation analysis team visited the supporting health centers for OVC social centers in the districts. These were Biryogo Nyirnuma Health center in Nyarugenge district, Gikondo health center in Kicukuru district and Kabgayi Hospital in Muhanga district. These health facilities were located in urban and semi urban cities in Rwanda. Some of the health centers are private, government aided faith-based health centers (Nyirnuma, Kabgayi). Referrals are commonly made to the nearest district hospital; patients are not directly transferred to Specialist or Tertiary hospitals like CHUK.

Orphans and vulnerable children visiting health facilities for their health needs are identified by health care providers through information from their patient or guardian. Some are identified from their dress, nutritional status and information obtained from the caretaker. The social welfare officer at the health centers makes home visits to the OVCs to confirm their claim of being orphans, before they are enrolled into care. There were no specific activities at the health centers to help early identification of OVCs who might be infected with HIV and are under the age of five years.

Medical and nutritional services were available to eligible OVCs at the health facilities. These services were provided by the healthcare worker, social welfare officer and the nutrition officer.

1. Policies and guidelines for OVC care

There were no guidelines for care and support for orphans and vulnerable children at the facilities that were visited. However, some of the facilities had guidelines for PMTCT and HIV counseling and testing. In addition, the health facilities also lacked the Handbook on Pediatric AIDS in Africa, a recommended handbook for pediatric HIV care and treatment support in the country.

Information, education and communication (IEC) materials on HIV, PMTCT and ARVs are often provided by supporting partners in the districts. However, IEC materials on care and support for OVCs are lacking, and none also for those infected with HIV and are under the age of five years. In the clinical setting, FHI provides support for child health, PMTCT, ART, pediatric HIV and Home Based Care in some of the districts that were visited.

2. Services provided to OVCs infected with HIV at Health Centers

In principle, all services provided at the health centers are also available for OVCs. Yet, in practice, only the few OVCs who could afford the medical expenses or have medical insurance could access these services. The services provided at the health centers visited in the three districts are summarized in Table 2.

a. Medical services

Some of the services available at the health centers include: Provider-initiated Testing and Counseling (PITC) for adults and older children, PMTCT services, ART, maternal and child health services like immunization, growth monitoring, and nutrition services. However, there were no systematic routine offer of testing for infants and children at the facilities (Gikondo). Facilities with VCT services do not refer children for testing at outside facilities, all the testing are conducted within the health facility. Partner counseling is rare at some of the facilities (Gikondo HC). Cotrimoxazole prophylaxis for the treatment of opportunistic infections is offered as an emergency in one of the health centers visited (Nyirnuma-Biryogo) and children in need of cotrimoxazole prophylaxis treatment are referred to nearby hospital (Muhima Hospital).

Other medical services available for OVCs include screening for health problems, immunization services, nutritional support, provision of cotrimoxazole for HIV exposed and infected children and ART for the eligible children. Bed nets are also provided at the facility for children and for pregnant women at the antenatal clinics. At Biryogo, the health center also provides school fees for orphans and child-headed households, has built houses for some of them to live in and often also take care of their health needs. Family planning services are also available for parents and caregivers at the health centers.

The identification of children who are exposed to or infected with HIV is done by the nurses in the PMTCT programs. Delivery is conducted at the hospital level. The mothers are counseled and followed up. At the age of 9 months the child is screened for HIV and referred for HIV testing. The health center also conducts monthly meetings with HIV positive mothers. The women are counseled to breastfeed for 6 months and thereafter wean their babies with some nutritional support. This made mainly of soya bean pottage and fish. The children are subsequently followed up at 3 months and at 9 months.

The OVCs attended to at the health centers are often identified by health care workers during sensitization and community mobilization activities, during follow up of children of parents with known HIV status, those who look feeble and vulnerable, and also during home visits. The OVCs with medical and social needs are attended to daily based on needs. The hospital staff often works as a team in order to meet both medical and social needs of OVCs. The social workers are part of the team for the care of the orphans. For psychosocial support, some of the health centers like Nyiranuma health center are requesting a psychologist to help meet the demand for psychosocial counseling of OVCs at their facility.

The common health problems of HIV-positive OVCs encountered at the health facilities are coughing, malaria, diarrhea, skin infection, tuberculosis and malnutrition. These symptoms are reported to improve when the children are placed on ARVs. Some of the social problems also identified by the health workers were poverty and lack of food to take drugs with while on ARVs.

At Gikondo HC, an average 20 orphans are seen at the facility each week, of which 50 percent were reported to be under the age of 5 years. However, in Biryogo Nyiranuma health center, 142 children received cotrimoxazole, 96 were tested for HIV, of which only four tested HIV positive. And, of the total of 77 people receiving ART at the health center, 13 were under the age of 14 years. There was no documentation for children under 5 years of age or particular services for orphans and vulnerable children accessing services at the health center (CMS Biryogo Rapport Annuel 2007). Services for OVCs and those infected with HIV are provided similar to any other child at the health facility and for those with additional needs these are referred to social centers or orphanages. The HCWs do not hesitate to refer OVCs to nearby orphanages including Pamasor, Kiyovu orphanage center and Saint Famille (Calcutta nuns) orphanages for the additional support that orphans might require. The HCWs do not normally follow up the children that had been referred to the orphanages to confirm how they are faring.

One of the health centers (Biryogo Nyiranuma) indicated that there were few barriers for OVCs in accessing health care at the facility. Financially, the cost of medical care is covered with the Government medical insurance (*Mutuelle*) and is

also supported by donors like CHAMP and FHI. The workers report that OVCs have medical insurance which makes the work easier for the healthcare worker; drugs are available, doctors evaluate their health needs, and vehicles were available for home visits to the orphans. However, this important activity was not reported in the 2007 Annual Report for the health center.

At Gikondo Health Center, one of the greatest challenges to access to care for orphans is the payment of medical bills and this is also a challenging experience for the HCWs who provide care for an orphan. For children under the age of five years with unknown HIV sero status, it is equally challenging to explain to them and their caretakers about HIV. When such children are tested and found to be HIV positive, they are started on treatment without them knowing why they are taking the various drugs.

Other challenges encountered while providing medical support to OVCs were:

1. Legalizing counseling with partners
2. Child protection
3. Sustainability of the programs
4. Legal services for the orphans
5. Providing accommodation for the orphans
6. Mothers coming back to the clinic pregnant despite being counseled on family planning.

There was no specific distinction between the services they might provide for orphans infected with HIV and under 5 years of age from the general services for OVCs at the facility.

b. Psychosocial services

Health centers also provide psychological support to OVCs and their families, both at individual counseling and within support groups. Home visits are also conducted for children with HIV and AIDS.

c. Educational support

One of the health centers visited (Biryogo-Nyiranuma HC) also provides educational support to orphans in their care. They also run a small nursery for the younger children above five years of age. No specific activities targeted to children under five years of age and might be exposed or infected with HIV.

3. Human Resources and Training in OVC care for HIV infected children

Of the total 168 health care providers working in three of the health centers (Gikondo HC, Nyiranuma HC and Kabgayi HC), none had received training in pediatric HIV care and support. Only two nurses from one of the health center had received training in integrated management of childhood illnesses (IMNCI-HIV).

4. Laboratory Services

The ability to perform simple and advanced laboratory tests varied from one health center to the other. Some of the health centers had limited laboratory capacity. The available basics laboratory services at health centers include Rapid HIV test, Hemoglobin, Total Lymphocyte count, renal and liver function tests. Other tests required for patient management are referred to the TRAC Laboratory and the National Reference Laboratory

(NRL). CD4 count for patients are sent to the NRL daily on week days and DBS-PCR sent out twice a week and this may take two weeks to 2 months to obtain results.

5. Pharmacy

Both first line and second line antiretroviral drugs were available at the health centers that were visited. No pediatric patient is yet in need of the second line drugs. The available first line ART include Zidovir/Retrovir Suspension (Zidovudine, AZT, ZDV, 110mg/ml), Efavir (Lamivudine, 3TC, 10mg/ml), Viramune (Nevirapine, NVP, 50mg/5ml), and cotrimoxazole syrup, with one year expiration date- 2009. There were no stock outs of ARVs , and there was a sufficient supply in the main pharmacy.

6. Medical Records

A review of the child MCH Card, kept by the caretaker/guardian, revealed that all the cards had unique patient identification, date of birth, sex and height of the child. In addition the name of the caretaker, mother's HIV sero-status (if in PMTCT program) and disclosure of the HIV status of the child to the caretaker were documented on the MCH cards. However, the weight of the child at birth and current weight of the child were not document on the card.

On the pediatric care and treatment card, the child's unique identification number, date of birth, sex of the child, weight at last visit, cotrimoxazole and date of starting CPT were documented on the cards. However, the weight at birth, height at last visit, name of caretaker, mother's HIV serostatus, child HIV status and disclosure of HIV status of the child to the caretaker were not documented on this card.

7. Home Visits, Follow up and Referrals

Orphans and vulnerable children are not followed up with home visits except when establishing or confirming their status as orphans. Referrals to outside services are for laboratory test at the National Reference Laboratory (NRL), to the orphanages, NGO like FHI, and the local government authority in the sector for other services that the health centers can not provide. The orphans and vulnerable children including those infected with HIV are tracked and follow up through their parents, child headed households or through the caregivers.

8. Linkages between facility and community involvement

There are very limited linkages between the health centers and the community for care of orphans except when caregivers or social worker visits home of vulnerable child to confirm their status as orphans in need of social and welfare support.

Table 2. Selected demographic and service statistics from health centers in the three Districts

Service Statistics	Nyirama HC (Nyarugenge District)	Gikondo HC (Kicukuru District)	Kabgayi Hospital (Muhanga District)
Number of staff at the health facility	88	46	34
Population of catchment area	243,152	75,118	35,548
Population of children < 15 years	-	-	-
Population of children < 5 years	20,143	3,172	1,501
Number of Immunizations 2007 (DPT 1)	1971	2,762	3,000
Number of BCG immunizations	3,037		-
Number of women attending PMTCT in 2007	1379	2,853	2,400
Total number of HIV test carried out at the facility in 2007	5,625	6,577	-
Women tested for HIV in the past year 2007		2,839	
Women testing positive for HIV in 2007	184	230	81
Women receiving Nevirapine in 2007	166	147	81
Babies received Nevirapine in 2007	-	200	79
Number of children tested for HIV in 2007	101	-	92
Number of children < 5 years tested for HIV in 2007	-	-	92
Number of children testing positive for HIV in 2007	-	-	4
Number of babies on cotrimoxazole prophylaxis	140	133	61
Number of children < 15 years currently on ART		97	-
Number of infants born to HIV positive mothers who return to the facility for follow up	-	-	-
Number of children referred for ART from OPD/MCH/ in the last month before survey	-	1	-
Number of OVCs attended to at the health center in 2007	80	Reports 20 every week	-
Number of orphans < 5 years attended to at the health center in 2007	0		-
Number of children enrolled into nutrition program in 2007	-	217	-
Number of staff trained in care and support for OVCs	0	0	0
Number of OVCs due to HIV	334	-	-
Services provided for OVC care			
Medical: 1. HCT	√	√	√
2. OIs	√	√	√
3. NVP/ART	√		√
Services specific to under 5s	-	-	-
Nutritional support (for malnourished children)	√		√
Psychosocial counseling	√	√	√
Educational Support o children infected with HIV	√		-
Home visits for OVCs	Occasionally	Occasionally	None
Linkages with OVC social centers	None	√	None
Linkages with Communities	None	√	None
Referral of OVC to other services or NGOs	None	√	No
Organizations working at the site/facility			FHI, CRS, Twubakane,

D. Findings from Community Health Volunteers/Care Givers and Communities perspectives for care and support for OVCs.

Community Health Workers/Volunteers serve as caregivers for OVCs at the community level and provide good liaison for OVC care between the community and the social centers. These are highly motivated women (often widows) and men living in the community with the orphans and are selected by the orphans to represent or provide psychosocial support to them. The summary of the variety of services provided as well as the number of OVC the caregivers attend to in their communities are outlined in Table 3.

On average, each of the volunteered interviewed provided care and support for 10-50 OVCs, and the majority of the OVCs are also HIV positive. Of the total number of 140 OVCs care for by the five caregivers that were interviewed, 117 (83.6 percent) were also HIV infected and only 4 (2.8 percent) were children under the age of five years. The age range of OVCs in the programs is from 5 to 18. The orphanage at PAMASOR still provides support to youths who are 24 years old because they have not yet been fully absorbed in to the community or had employment opportunities. Young girls form a greater part of the OVCs under their and some of the orphans are children heading households. Communities also think that OVC centers have only HIV-positive children and would not want to be associated with such services.

The common health conditions identified in orphans by the caregivers include: abdominal pains, stomach ulcers, fever, cough, malnutrition, lack of food, TB, skin rashes, general pains and herpes zoster on the face. The children who are also infected with HIV are likely to present with diarrheal diseases, skin diseases, headache, scalp wounds and eye complaints and pneumonia.

The caregivers provide a variety of services to the orphans and these include home and school visits, educational support and payment of school fees, guidance and counseling, with coping strategies. The two main reasons why a caregiver might not be able to take a sick child to the health facility are transportation cost and cost of medical care. The *Mutuelle* (Health Insurance) pays for the cheaper medical services and does not cover all the essential services required by the orphan.

Other barriers to access to care of orphans include lack of easy access to the social center. One of the centers, PAMASOR, is far from the main road and not easily accessible by car. However, the caregivers and family members do know where to refer orphans in need of medical care and very often to the nearest health center for further evaluation and care.

Street Children are not common in the community and they are not easily identified, but could be suspected to be street children if not in school and do not stay with any family in particular. There is usually no direct support for this group of children but are included in the OVC waiting list for support. Although Government primary school fee is free, parents still have to pay about 15,000 Rwandan Francs per year (\$US 30) for other educational materials and most of the parents and caregivers are not able to afford this additional cost.

There was no other community support available for OVCs apart from those provided by the community health workers/volunteers. One of the male caregiver reported personally bearing the total cost for taking care of orphans and street children and was challenged by the health needs of the orphans.

A notable impact of the support provided by community volunteers to orphans, as reported by one of the caregivers, was that the OVCs including those infected with HIV are happier now that have received support from them than before the support. One caregiver noted:

“The children who are under 5 years of age require both health insurance and nutritional support. We do not take care of children under five years of age, their mothers take care of them”

Community Health Workers –Nyarugenge District

The majority of orphans are not sponsored by any program or organization. Of the 140 OVCs who are being looked after by the five CHWs in Nyarugenge Districts, only 31 (22%) of these have received any form of support from organizations. However, the CHWs know where to refer orphans in need of medical care.

The CHWs reported that mothers could suspect that their children are infected with HIV, when certain symptoms are common, including:

- Frequently getting sick
- Diarrhea disease
- Cough
- Skin disease
- Not thriving well
- Sick Hair
- Malnutrition
- Swollen lymph glands
- Tuberculosis
- Herpes infection.

The CHWs also reported that mothers were aware that babies could be infected with HIV during birth, breastfeeding, direct contact of blood with injuries on the baby and injury through sharp objects. Only one of the caregivers knew that ARV prophylaxis could be given to the mother to prevent transmission of HIV to the child during pregnancy and child birth.

Some of the ways to prevent HIV transmission to babies and children as reported by the mothers include:

- Not to share sharp objects'
- Children in orphanages should not sleep together in the same bed if they have open wounds and
- Teach orphans how HIV infection occurs

Attitude of Community Health Workers (CHWs) towards OVCs.

For the majority of the CHWs, it is a painful experience to hear that a child is HIV-positive. One CHW expressed what motivates her and her colleagues to help care for and support OVCs:

...bringing back hopeless lives to great and useful people. Through our hands, we have raised University students who are doing well and likely to become future leaders of our country. That is our incentive.

--CHW from Kacikuru District

Another CHW said:

"Giving care to those hopeless children like those without families and hearing those who had hopeless lives reinforcing others is gratifying"

CHW from Kacykiru Districts

The community health volunteer's time and efforts are not often compensated and some are widows and also need to support their families. The CHWs requested the following to assist them effectively support OVCs in their care including:

- (i) Incentives and stipends to match with the cost of living (Rwf 80,000ge (minimum wage \$300/year).
- (ii) Transportation to support their work especially in making home visits to follow up orphans in the communities;
- (iii) Establishment of association for caregivers to address their social and emotional needs;
- (iv) Income generation activities (Bakery, rearing of poultry) to provide additional support for their activities. Through the income generating activities they can also take care of the orphans who have no sponsors in the community;
- (v) The community health volunteers also want to be upgraded to the status of community health workers and not volunteers alone.

Table 3: Summary of services provided to OVCs by the caregivers at the community

Community Health Workers/Caregivers	Respondents				
	First	Second	Third	Fourth	Fifth
OVCs cared for					
Number of OVCs under his/her care	30	14	36	50	10
Number OVC < 5 years of age	0	0	0	0	4
Number of OVCs infected with HIV under their care	30	14	0	20 (F=14)	3
Age Range of OVC under care	5-18 years	School Age	12-24 years	7-22 years	Not Indicated
Male/Female ratio	Not Sure	Not sure	Not sure	Males 15; Females 35	M=6; F= 4
Services provided to OVC	Home & School visits, educational fees	Home & school visits, guidance and counseling, coping strategies and living positively	Counseling	Counseling, educational support Home visits	Counseling Educational support
Number supported by NGOs	10 supported by We-Act 20 referred from PLWHA	4 OVCs under going vocational training	9 children support by We-Act. 27 OVCs are without support	8 OVCs with support from We-Act	Not indicated
Remarks	The children are happier than before the received support	The U5 require health insurance and nutritional support- <i>Sosoma</i>	We do not take care of those U5s. The mothers take care of them	U5 are cared for by their mothers. Orphan categories include those from prison, genocide and the child headed households	4 of the OVCs are children heading households 3 of them are HIV positive

The OVCs have high expectation when they are visited by the community health workers/caregivers. They believe that the caregivers have resources to meet their social needs, and are disappointed when those needs are not met. One of the caregivers reported that when they visit OVCs in the communities, they do not have money, food, or educational materials to give to OVCs, and this is a painful and disappointing experience for both the children and the caregivers.

E. Experience from Child Headed Household

Child-headed households (CHH), are young children or teenagers who are compelled to care for their siblings because their parents or guardians are no longer alive or are incapable of caring for them due to ill health and other predicaments. These children heading households are more often than not are young girls who over the responsibilities of caring for their younger ones in the absence of their parents or immediate family members.

The age range of some of the children heading households who were interviewed during the rapid situation analysis was between 16 and 19 years of age. They were most often caring for four or five children in their households, some of whom were infected with HIV and receiving ARVs.

Children heading households reported that the health problems they encounter as orphans are numerous and that the most common causes of ill health are malaria, flu, and pneumonia. The sick children in the household are often taken to the nearby health center for treatment. The main reasons that the CHH may not take a sick sibling to the health center is lack of money to support both transportation and the cost of medical services.

Children heading households have learned through experience what to do with a sick child in the household. For those who are HIV negative, they consider this as a small matter, as the children are able to take care of themselves. However, when children infected with HIV are sick, they are taken immediately to the health center for further medical care. The other more pressing problems are lack of food and medical insurance to care for the sick, including children who are infected with HIV in the household.

Life is generally hard for OVCs. Surviving on one meal a day is not easy said one of the child household heads. Access to food ,especially for the child on ARVs, is very difficult and the sick child with HIV is often preferred above others who are not HIV infected. This provokes jealous feelings among the other children in the house. Also, when a child is sick, there is often no more money to pay for consultation at the health facility. These health problems and challenges are well illustrated by comments from OVCs heading households:

“ The life of an OVC is generally a hard life, having food to eat just once a day. Food especially for the child on ARV is very difficult. And when the sick child with HIV is preferred above other children in the household, they other siblings become jealous and question why I should take care of the sick one more than them”

--OVC child headed household from Nyarugenge District

“It is difficult for children to take care of children. It affects them psychologically”

--CHH from Nyarugenge District

“ My challenge is how to take care of that one child who is sick with HIV with little money. With my little money, I will like to buy things for the sick child because he has special needs. The younger ones who are not sick with HIV are jealous and question why I favor the sick child more. But I will like to take care of all the children in my house, if I had money or all the support I needed”.....

--A 17 year old female CHH from Nyarugenge District, Rwanda

Another major barrier in meeting the needs of OVCs in the community is fear of HIV and a general lack of knowledge about the disease. Children heading households believe that by getting all children tested for HIV, it will be possible to identify all the children in need of care and support them accordingly.

Families' response to OVCs infected with HIV

Families feel very bad and disappointed when they know that their children tested positive for HIV. It is a very traumatic experience for family members. They find it difficult to accept the results and do not accept medication for the disease. However, with good counseling, they often come around to accept and cope with the situation. One of the child household heads reported that she had a similar experience, but availed her whole family of counseling and testing after the death of her parents. One of the children tested positive and is currently on ARV treatment. The OVCs are careful about disclosing their HIV status to other children for fear of stigma.

Community response to OVCs

The child household heads reported that they do not receive any support from the community. No neighbors come to visit them, and no local leader has ever visited them to see how they are faring. The psychosocial support they receive is from outside the community as TRAC personnel do pay home visits to their households.

Expectations of CHH when they visit OVC social centers:

The CHH expect to receive the following support from OVC social center:

1. Psychosocial support
2. Medical and Health insurance
3. Nutritional support
4. Support for sick children who are on ARVs

Expectations of CHH from family members and the community:

The OVCs and children heading households expect families and community members to support them in the following ways:

1. Medical support for health needs and medications
2. Nutritional support
3. Psychosocial support
4. Others like helping her mend her leaking roof, and support for shelter

Motivation for providing on-going care to sick siblings:

A 17 year old female head of household reported that she is motivated to care for the orphans in her household because of her strong believe in God. She is obliged to take care of her younger ones and she could not bare leave them alone. When asked if she is not considering getting married soon, she noted that she receives advances from men, but she wants to take care of her younger ones first so that they can be independent before she could get married herself.

In addition, the household heads expressed the need to be better prepared for caring for their siblings by improving their skills in the following areas:

1. Skills to help support OVCs in the CHH role including:
 - i. Caring for the health needs of the sick children;
 - ii. Provision of key health messages regarding care for the sick children;
 - iii. Vocational skills to help them be gainfully employed to meet their financial needs
2. Linking with other CHH: Programs should provide opportunities for the CHHs to link up with other CHHs in the community.

F. Attitude of family members to OVC care, especially those infected with HIV

Family attitudes in response to the knowledge of an OVC's HIV positive status are mixed. Women and parents who are HIV-positive and are on treatment easily accept HIV testing for their children. Parents with unknown HIV status are afraid that by consenting to HIV testing for their children, they will indirectly be disclosing their own HIV status and they are not yet ready for such disclosure. Some family responses to the knowledge of an OVC being positive for HIV are often very sad. They are in a state of denial and may remain in this state for a long time. Meanwhile, it might be difficult for the orphan to access care as they disbelieve that he/she is infected with HIV. Some of the family members do react strongly to the news of an OVC's HIV status. Some can't believe that the child is infected and delay taking the child to the health center for further care. Some parents also find it difficult to accept the situation and develop psychological consequences. For other couples, it leads to confusion and conflicts as information is shared with them. Though a difficult situation for the parents, they could benefit from continued support and counseling.

On the other hand, some parents have a positive attitude towards testing their children for HIV. It is also Government policy, says one of the caregivers, for women to go get tested along with their spouse. Though difficult to accept the HIV positive status of their children, they would prefer to have healthy children. When families accept the testing of the child and when advised on how to give the drugs to the child, they can be very supportive in this activity to ensure the health of their children.

Most community members learn about pediatric HIV and ways to get babies tested through associations, Radio, Media, Community outreach, and at health centers. It is not easy for people to ask about the HIV status of an OVC. The children often ask many questions as to what happened to their parents and why they died. Family education and awareness on the needs of OVCs will help reduce the stigma and assist families and communities respond positively to the knowledge of HIV status of OVCs.

G. Community support for OVCs including those infected with HIV and under 5 years of age.

It is often difficult for the community to easily understand how children get infected with HIV. With more awareness regarding HIV infection, they become more willing to follow instructions on care and support as a right for the HIV infected child and ensure they are treated and are fed adequately. Parents wish to have healthy and strong children who do not fall sick easily.

There is not enough community awareness and support for care of OVCs and street children. Also, not enough is being done at the community level to support orphans and vulnerable children and

those infected with HIV. One of the children heading a household, who is caring for a sibling who is 14 years old and infected with HIV, reported that she had not received any visit or support from the community or community leaders as an orphan. The only care she had received in support of her four younger siblings was from TRAC and she requested that more be done to support them, including provision of food, clothes and shelter. This same person reported that the roof of the house in which she stays with her younger siblings was leaking at the time of the assessment, putting the building at great risk of collapsing with the frequent rains during the rainy season.

Children under five years of age, including those infected with HIV, are left to the care of their mothers who are also often sick and equally in need of care themselves. Health care providers and caregivers do not know how to respond to the need of children under 5 years of age and who are infected with HIV.

In response to the question on what the OVCs and the children heading households expect from the communities the children requested for:

1. Adherence support and follow up when the children are on ARV medications,
2. Educational support for the children to be in school
3. Satisfying the nutritional needs of the orphans

Similarly, the community and family members expect that when they visit health facilities with a sick OVC who might also be affected or infected with HIV, the following should be done or provided:

1. All HIV and ARVs services should be provided together and in the same setting
2. Integrate nutrition services for all OVC care
3. Teach OVCs and their families how to prepare the right food and provide follow up support
4. Provide school fees and other educational materials to OVC

H. Challenges in providing health care and support services for OVCs and those infected with HIV

Most of the health care providers caring for orphans and vulnerable children are highly motivated to continue their services to orphans. However, they also reported challenges they encounter while attempting to provide services to OVCs in their settings. Some of the challenges are listed below.

1. **Lack of a full package of services for OVCs:** The ideal situation in attending to the needs of OVCs would be to provide the full package of services to all eligible OVCs at all levels of care, both in the private and public sector. However, health care providers and caregivers are challenged because they are not able to offer or link OVC to comprehensive services to address the basics health and social needs of the orphans. The needs of the OVCs are often multiple including psychosocial counseling, nutritional support, health insurance coverage, education assistance, welfare support with food and clothing, shelter and legal protection and these may not be delivered at the same facility;
2. **Lack of continuity of care and services for OVCs at specific site:** Although services are free for OVCs, the children are only referred when necessary; it is still a challenge to provide continuity of services for the orphans. Several referrals are often required and majority of them are lost to follow up on account of multiple referrals;

3. **Limitation of Funds:** There is limited or complete lack of funds to provide care and support to all OVCs in need at the social centers and health facilities. Only those OVC who have sponsorship or have medical insurance are able to receive the basic care package they require. Most of the orphans are not sponsored.
4. **Lack of IEC materials on care and support for OVCs:** Information and educational resources on OVC care for caregivers, orphans and the general public are lacking. The community and the public are not fully aware of the challenges OVCs face in their lives as they try to forge an identity for themselves;
5. **Stigma and Denial:** Some of the orphans who test positive for HIV may not want to accept the result of their HIV test, and in the process they isolate themselves and are easily stigmatized. They also find it difficult to accept and adhere to instructions regarding their care. In addition, some caregivers or guardians of OVCs do not easily accept the HIV status of the children under their care, especially if they are found to be HIV positive. This further delays access to much-needed care for the OVC. This is rightly exemplified by the report from one of the orphans interviewed in Muhanga district:

“ There was a one year old child in our community. She fell sick and no one took her for treatment. Her mother had been so weak and was suspected to have HIV infection, but she had not started any treatment. When the child became very sick, people began to say that she lost a lot of blood due to being HIV infected and the child died. Her mother also died a few days later”

--Reported by an orphan from Muhanga District

6. **Adherence support for OVCs infected with HIV:** It is often challenging to convince OVCs who are infected with HIV and are receiving ART to comply with the treatment regimen, as well as get their drug refills and do regular medical check-ups as appointed. And, as not all OVCs are followed up, it becomes difficult to track these children and provide support as might be required. It is also difficult to explain to the children why they are taking ARVs, and they would be more receptive to services offered at the social centers if they are accompanied by someone in the community, like the community health worker or the caregiver. This challenge is well illustrated by the story of one of the OVCs who is also receiving ART treatment

“Linka, a 10-year old orphan had lost both parents when he was 6 years old and is presently staying with his Aunt, who has been encouraging him to take his “drugs”. However, the young boy did not know why he was taking the medications. When the Auntie could not cope with the care and support for Linka, she decided to seek additional support from the social center and took Linka to an orphanage home at Pamasor, one of the social centers that care for orphans and vulnerable children. On arrival at the orphanage, after making Linka comfortable, the care providers informed Linka of his HIV positive status and the reason he had to be on medications as provided.

With that knowledge of his HIV status, Linka started taking ARVs easily knowing that he was HIV positive. Later Linka informed the caregiver that, “I used to take those drugs before but did not know the reason why I was taking them, but now I have come to understand the reason”.

--Linka’s story: OVC from Kaicikiru District

The story illustrates the need to effectively communicate with children about their health conditions and what is expected of them. If the caregiver had had the courage and skills to inform Linka about his HIV status and why he was taking the drugs, Linka would have so easily accepted to take the drugs and would still be living happily with the Auntie. However, Linka was still living in the orphanage at the time of writing the report.

7. **Limited support for nutrition:** The basics and critical needs of orphans include food, clothing and shelter. Presently, in all the OVC programs, there is limited nutritional support for OVCs. Nutritional support and food rations are provided only to those children who are malnourished and on ART. The other orphans who are sick also need food rations.
8. **Attitude of care providers:** Some care providers are afraid to treat OVC for psychosocial problems. They find the experience very emotionally overwhelming and may not want to add additional burden to the care of their own children;
9. **Lack of support for care providers:** It is challenging, demanding and not an easy task for care providers to care for OVCs. Care providers are not receiving the help and emotional support to cope with the challenges caring for orphans in their settings. This is depressing to the caregivers and would want more support for stress management regarding their job. They lack association of caregivers and would want to be supported for the establishment of the support group for caregivers.
10. **High cost of medical care for orphans:** Some of the orphans are not able to afford the cost of medical care. The *mutuelle* (health insurance) pays for the cheaper services and do not cover for all the health treatment that an orphan might require. Supporting that equally essential aspect of their care could be challenging to the providers and caregivers.

11. **Enumeration for caregivers or community health workers:** The community health volunteer time and efforts are not paid for. These volunteers are often widows and also need to support their families. The volunteers want to be paid incentives, payment of stipends to match with the cost of living (Rwandan franc 80,000 (minimum wage \$300/year). They need means of transport to support their work. They also lack association for caregivers that will provide psychosocial support for their work. Assisting the caregivers in income generation activities (Bakery, rearing of poultry) to provide additional support for their activities will be helpful.
12. **Rejection of OVC by family members:** Some of the orphans are rejected by their family members when they learn about their HIV positive status. This puts a lot of psychological stress on the orphan and increases stigma among his family and community;
13. **Identified barriers to access to care and support by OVCs who are infected with HIV include:**
 - (i) The cost of transportation is identified as a major limiting factor for the orphans to access available services at the health facility and social centers.
 - (ii) Cost of medical care, lack of health insurance especially those services not covered under the health insurance creates a great limitation to access to care for the orphans.
 - (iii) Lack of welfare support to the children apart from counseling. The orphans and family members often demand more than counseling for their needs. They request welfare support, food, clothing, shelter and educational assistance from the caregivers.
 - (iv) Limited home visits and reaching out to the OVCs by communities.

DISCUSSION

A rapid situation analysis of the health needs of orphans and vulnerable children— especially those infected with HIV and are under the age 5 years—has been presented in this report. The use of OVC social centers to identify orphans who may have been exposed to HIV is an ideal and essential entry point at the community level, linking them to appropriate care and services. And, because these centers are within the communities (where the children live), it is important to utilize the social centers to increase awareness, create demand for OVC services, as well as links to comprehensive services required by the orphans.

The analysis indicates a significant interest by care providers to care for the health needs of orphans, including those infected with HIV and AIDS. There was a general positive response towards OVCs from the providers, and caregivers are interested in improving both their skills and the services for orphans under their care. There was a general concern, however, that most of the orphans at the communities do not receive any support and it is a constant area of challenge for the caregivers in the communities to respond both to the educational and health needs of the orphans. There were no specific programs at the social centers or communities to address the health needs of OVCs who were under the age of five years. There is a need to develop effective strategies to integrate the health needs of HIV infected children especially those under 5 years of age into the general OVC care package at both facility and community levels of care.

In general, there is mix of services provided for OVCs, depending on the level of care and the facility. This package of services varied from partner to partner. Certain services were common to all partners at the social centers, including services like counseling and psychosocial support, educational support (school fees and materials), and referral for testing for HIV or provision of care and treatment for HIV. Other additional services provided by OVC social centers include testing for HIV, provision of ART, and treatment of opportunistic infections. The center at We-ACT offering additional services had skilled staff trained by TRAC to provide these services. This presents an opportunity to improve the skills of OVC social center staff to be able to offer HIV counseling and testing, provide OVC care, provide adherence counseling for children on be able to reduce the frequency of appointments at the health center. However, initiation of ART for eligible orphans should be undertaken by trained staff according to the national guideline for HIV prevention, care and treatment.

Families expect more than counseling support from community health workers and volunteers; they request social and welfare support for clothing, food, and shelter. Nutrition support in some centers was only available to children who were malnourished or are on antiretroviral therapy. The nutritional supplements consist of Sosoma porridge, flour, cooking oil, sugar and powered milk. The other services provided at the social centers include legal services for orphans, and transportation assistance to health centers for follow up and blood investigations.

In general, the health needs of children under five years of age were the most neglected at the household and community levels. The health needs of these children were often left to their mothers, who were equally in need of HIV care and support. Notably, except for one social center, there were no specific programs targeting the needs of orphans who are under the age of five years both at community and at social center levels of care. Priority is not given to orphans and children under the age of five years who are infected with HIV when referred to the health facilities. They are attended to with the rest of the children at MCH clinics. Policies and innovative programs are necessary in order to support orphans who are HIV positive and are under the age of 5 years. These are the most vulnerable among the orphans and every opportunity should be utilized to

identify and link them to available care and support. Leaving the care of these children in the community to mothers who are equally in need of care and support is not an effective strategy in improving child survival in this context. In order to reduce barriers to care, social centers and facilities should be empowered to provide a comprehensive package of services for OVCs. It is important to use social centers for the identification and provision of basic comprehensive services for orphans including those infected by HIV and under the age of five years in order to improve survival and quality of life for OVC.

The medical insurance (*mutuelle*) provided for some of the orphans cover some and not all the essential health services for the orphans. One of the caregiver reported that the *mutuelle* covers only the simple and cheap services; for other health costs, the families still have to find a source for funds. OVC programs and health facilities should be able to adequately care and respond to the health needs of orphans and relieve families and caregivers of the additional burden of cost of medical care. This will reduce barriers and further improve access to care and support for health needs of orphans.

There is a need to integrate OVCs, including those who are infected with HIV, into general community life in order to provide a cultural and societal context for their physical, social and emotional maturity. The institutional care for orphans in orphanages is gradually being de-emphasized. The orphans should live, play, go to school and mix with other children in the community. They should stay in home with other families or foster parents who are available to provide mentorship, care and love to the orphans along with their other children. Some of the orphans are not easily absorbed into society after they are beyond a specified age (18 years in Rwanda). These orphans are still compelled to stay at the orphanages because they have no job placement, a place to live or any income generating activities. This further emphasizes the need to integrate OVCs within the community, its values and networks for a better transition from adolescence to adulthood. The efforts made by PAMASOR orphanage to find foster parents to these orphans are challenging, as the communities and households are already poor and may not be able to care for additional children.

Some of the challenges in the provision of services to OVCs include limited funds to support all identified OVCs in need of care, as so many unsponsored OVCs in need of support are not cared for. There is limited nutritional support for OVCs, as current nutritional support is only provided to those children who are malnourished and on ART. The community health volunteers lack knowledge and skills on how to assist children under five years of age who are also exposed to or infected with HIV. It is also difficult for the caregivers to explain to the children why they are taking ARVs. The OVCs also experienced rejection by family relations, especially when they are known to be HIV infected. IEC materials on OVC are also limited for patients, caregivers and the community health volunteers and caregivers. These barriers highlight the need for community mobilization and sensitization to create more awareness on the health and social needs of orphans, as well as develop effective strategies to meet those needs in a very cost-effective way.

The community health workers and caregivers provide a very essential link between the social centers and the community for the care of orphans and vulnerable children. And, because they are respected people in the community, elected by the orphans to represent them and living among the people, they serve an important role to provide additional support for orphans in the communities. Most of the caregivers are widows, with families of their own to support and their time and efforts are not compensated. There is need to review policies to further support this essential arm of OVC care through provision of incentives (as mutually identified and agreed by the community), transport assistance to facilitate their home visits, adequate supervision and mentorship in their various communities, capacity building to adequately respond to the health needs of orphans and support them with income generating activities. They are an important asset to be harnessed to

improve care and support for OVCs in the communities, including those infected with HIV and are under the age of 5 years.

Finally, policy makers, implementing partners and donors should support comprehensive packages to address the health and social needs of orphans and vulnerable children at all levels of care, especially those who are HIV infected and are under the age of five years.

RECOMMENDATIONS

The key Recommendations from the rapid situation analysis of health needs of orphans and vulnerable children include the following:

A. Identify orphans and vulnerable children who might be exposed to HIV infection

1. The National policies, protocols and guideline on OVC should be revised to address the health needs of orphans who are infected with HIV and also specifically address the needs of children who are under the age of five years. The guideline should be widely disseminated and health care provider and caregivers trained in its implementation at facility and community levels of care.
2. OVC care and support program designs, implementations, monitoring and evaluations should take into consideration the health needs of children under the age of 5 years, and those infected with HIV. Such programs should not be limited to children aged 7 years and above, or for children in or out of school programs. Children under 5 years of age need to be identified early and linked to care and support because of the increased risk from death from common childhood illnesses.
3. The capacity of OVC care providers at social centers and the community should be improved to help them identify needs early and provide appropriate care and or referral for OVCs who are HIV positive and are also under the age of five years. Targets for improving human resources, skills, and capacity building for staff at OVC social centers should include:
 - a. More training in psychosocial support, psychomotor development of the child, how to communicate with children, emergency preparedness to equip the children with skills in the event of any health, natural and political emergency, first aid and how to handle domestic violence.
 - b. Provide capacity building for caregivers to strengthen their ability to identify and care for OVCs in how to deliver basic health prevention messages for OVCs; better communication with OVCs and guardians for improved behavior change for OVC care and support; training on quality of care to HIV- positive OVCs, including specific care to under-fives and training on children's rights and protection.
4. The association of people living with HIV and guardians are the most common source of referral of OVC to social centers and health facilities. The capacity of these target groups should be improved to enable early identification of OVCs who might be infected with HIV and make referrals, not just for OVCs who are over six years of age but also those under five years of age, who are most vulnerable from risk of dying from common childhood illnesses.

B. Strategies to Improve quality of Care for OVCs including those who might be exposed to HIV and are under the age of 5 years

1. Universal comprehensive care should be provided for all OVCs and those infected with HIV and services should not be limited to psychosocial and educational assistance alone. The packages of services defined by the National OVC policy should always be taken into account when providing these services to OVC;
2. Family centered model of care for OVCs should be promoted. The children in need of support in a vulnerable household should all be supported and one child should not just be singled out to receive support while other vulnerable children in the household are without any form of support for improved quality of life;
3. Establish “welcoming space” for OVCs where they can engage in recreational activities with snacks and drinks to keep them busy while waiting to be attended to at the social centers. Priority should be given to children who are under 5 years of age when they attend social service centers as well as health facilities. Additional services to make the facilities more children-friendly include:
 - a. Providing a space for Day Care for children under 5 years of age;
 - b. Adequate food supply for them;
 - c. Clothing;
 - d. Audio visuals and interactive educational materials;
 - e. Play ground with assorted toys to play with and early child development activities.
4. Improve medical records and documentation of care and support for OVCs on both MCH cards and pediatric outpatient and in-patients records, especially those under the age of five years and infected with HIV. This will create more awareness on the side of the providers to ask relevant questions and provide the expected service or make referrals for further care as necessary;
5. Improve access to service to OVCs and should include:
 - a. Providing welfare support, clothing, feeding and shelter needs;
 - b. Nutritional support and food rations should be to all orphans in need and not just only for the malnourished or children on ART;
 - d. Reduce cost of medical services (offer free services) for young children infected with HIV;
 - e. Provide regular and constant counseling for children in need for care; and
 - f. Provide rapid services for OVCs instead of long wait before being attended to at the social centers and facilities; and

C. Establish or strengthen functional linkages between OVC social centers and communities to provide necessary support and care for OVCs who are infected with HIV and are under the age of five. The referral and follow up links between orphans in the community and, social centers and caregivers should be strengthened by:

1. Creating awareness on OVC and pediatric HIV care and support at the community level, using the regular end of the month community meetings;
2. Training community caregivers and volunteers on pediatric HIV, especially on how to respond to the health needs of the children who are infected with HIV, follow up, and provide messages on the prevention of HIV.
3. Ensuring that communities respect orphans and take care of them like their own children.
4. Supporting caregiver and community health volunteers and providing them with incentives as determined by the community. The national recommendation to reinforce them in cooperatives should be encouraged to better link them with economic opportunities and to enable them to effectively care for the orphans under their care as well care for their own children.

11. Specific IEC/BCC materials on OVC should be developed following specific action plan recommendations for OVC care and tailored to address community perceptions and beliefs concerning OVCs and pediatric HIV. These should be widely disseminated in the community through the association of people living with the disease, Radio, Media, Community outreaches, at the health centers and these similar channels should be used to promote awareness and community response to the needs of orphans in the society.

CONCLUSIONS

The report has highlighted the range of services available to orphans and vulnerable children, and the limited services for those infected with HIV, especially if they are also under 5 years of age. Because they are located in the communities where children live, OVC social centers are an important entry point for the identification of orphans who are also affected by HIV and are under the age of five years. This report has documented the lack of community structures to support the health needs of OVCs— especially those infected with HIV—and the necessity to engage communities in the care of orphans. Policy makers and program planners should develop more innovative ways to build community capacity to respond to the health needs of orphans, including those who are infected with HIV and are under five years of age.

APPENDIX A: CONTACTS

S/No	Name	Title	Organization	Contact Telephone	Email
Nyarugenge Districts					
Community Health Volunteers					
1	Marie Nyarahabimana	Caregiver	Icyuzuzo	250 0862 4796	
2	Rose Mugeni	Caregiver	APIA Tubeho (We- ACT for Hope)	250 0860 4136	
3	Rose M. Mimana	Caregiver	AVVAIS (We-ACT for Hope)	250 0866 4140	
4	Appoline Mukanyamwasa	Caregiver	Icyuzuzo	250 0862 4796	
5	Jovain Gatarayiha	Caregiver	New Life (We-ACT for Hope)	250 0862 7070	
Nyiranuma Health Center					
6	Bellancilla Mukamurara	Service social Sida au CMS Bilyego	Nyiranuma Health Center	250 0888 6834	
7	Veneranda Nyirakanyana	Responsible du service nutritionnel Bilyogo	„	250 0883 3769	
8	M. Nkubito Euneck Josiune	Responsible de service CPN. CMS Bilyogo	„	250 0875 4622	
9	N. Nusogora Ecephrarie	Infirmiere/ARV	„		
Child Headed Households					
10	Twizerimana Apolline- Pauline (17yrs)	Caritas Child Headed Household			
11	Nhezireyago Narcisse (18 yrs)	Caritas Child Headed Household			
12	Uwamahono Esperence (16 yea)	Caritas Child Headed Household			
13	Mukayizere Januiere (18yrs)	Caritas Child Headed Household			

S/No	Name	Title	Organization	Contact Telephone	Email
We-ACT					
14	Jeannette Uwineza	Clinical Psychologist and Pediatric Program Coordinator	We-ACT	250 0830 1804	jeanuwineza@yahoo.fr
15	Chantal Dusabe M	Infirmere Responsable de la Clinic	We-ACT	250 0882 6442	dusachanty@yahoo.fr
16	Chantal Mukazayire	VCT Coordinator	We-ACT	250 0841 8386	Chayire1@yahoo.fr
17	Niyibizi Amle Pacifique	Community Mobilization Program Coordinator	We-ACT	250 0845 4975	Npacif79@yahoo.fr
Social Welfare Officer at the Sector					
18	Ingabire Justine	Chargee des Affiars Sociales-Sector Gitega		250 0850 2109	
Kacikiru District					
PALMASOR Orphanage -Rwanda					
19	Uwera M. Providence			250 0889 0796	
20	Gisele				
Community Health Volunteers					
21	Batamuliza Judith				
22	Shozamihigo Floduard				
23	Mukamulisa Beata				
Gikondo Health Center					
24	Sr. Berthelede Uwamaliya			250 0857 1509	
25	Mukakimemenyi Annie Marie				
26	Nyirashumbusho Francine				

S/No	Name	Title	Organization	Contact Telephone	Email
Muhanga District					
27	Sr. Assumpta Mujawamaliya			250 0847 8878	
28	Pelagie Mukansanga				
Child Headed Household					
29	Musafiri Alphonse (18 years)				
SWAA Socila Center					
30	Cecile Mukahirwa			250 0864 7274	
Community Health Volunteer					
31	Jeanne Kamutamu	Care giver			
32	Uwitonze Prisilla	Care giver			
33	Musabe Juliane	Care giver			
Social Welfare Officer					
34	Alexia				

APPENDIX B: RAPID SITUATION ANALYSIS SURVEY TOOLS FOR CARE AND SUPPORT TO OVCS INFECTED WITH HIV AND UNDER THE AGE OF FIVE YEARS

Interview Guide

Pediatric HIV Case Identification, Referral and Care for orphans and vulnerable children (OVC) as Child Headed Household

For interviews with orphans and vulnerable children who are also child headed household, and Caregiver at the household level

Date:

Name of District

Interviewer(s)

Name of Community

Interviewee(s)

Team: _____

Contact Person: _____

Phone: _____

General

Ask to speak with the identified child headed household in the community served by the social center. Introduce yourself, briefly explain the purpose of your visit and ask if she/he would be willing to answer few questions about orphans and vulnerable children and HIV and AIDS

Twifuzaga kuvugana n' Umuyobozi w' ikigo

Hello. My name is _____. My colleagues and I are here on behalf of to conduct a joint situation analysis to learn more about your services related to HIV/AIDS and OVCs. The information you provide us is very important and valuable, which will help to inform social centers, health facilities, care givers, to support and improve OVC related policies and the delivery of services. We do appreciate your time and responses.

Ivuge, iki kugenza naho uturutse

Murakoze!!

1. Do you know any orphan and vulnerable children in your family or household? Yes No
Hari abana binfubayi nabatagira kivurira mufite mu miryongo yanyu? Yego Oya

2. **Are you a child heading a household?** Yes No
Niwowe mwana ukuri umuryango?

3. **How old are you?**
Ufite imyaka ingahe?.....

4. **How many people are living in your household?**
Muribangahe munzu yanyu?.....

5. **How many orphans do you care for in your family?**.....
Urararera unfubayi zingaha mu muryago wawe?.....

a. How many of the OVCs are under the age of 5 years?
Nibangahe murabo bana binfubayi nabatagira kivurira bari muni y' imyaka 5 yamavuko?.....

6. **Do you care for any orphan living with HIV AIDS in your household?** Yes No

a. How many of the orphans living with HIV and AIDS do you care for in the household?
Nibangahe munfubayi urera nabatagira kivurira babana n' ubwandu bwa VIH/SIDA?.....

b. How many of these orphans are less than five years of age?
Nibangahe murabo bana bana nu' ubwandu bari muni y' imyaka 5 yamavuko?.....

5. **What are the key health problems for orphans and vulnerable children in this household?**

.....
.....
Nibihe bibazo byingenzi by'abana binfubayi nabatagira kivurira murera bahuranabyo?.....
.....
.....

List what is mentioned spontaneously:

Hitawandika ukwavuze:

Probe: Pneumonia? Diarrhea? HIV?

Wamubaze: Nkumusonga? Nkimiswi? Nkubwandu bya VIH?

6. **What are the key health problems for orphans and vulnerable children infected with HIV (living with AIDS) in this community?**

Nibihe bibazo byihariye abana binfubayi nabatagira kivurira babana n'ubwandu bwa VIH bahura nabyo?.....
.....

List what is mentioned spontaneously:

Hitawandika ukwafuze:

Probe: Pneumonia? Diarrhea?
Wamubaza nkumusonga kumusonga? Imwishi?

**7. Where do you take your sick brothers or sisters for treatment?
Aba bana iyo barwayi mubavuriza hehe?**

First place
Ahambere.....
Second place
Ahakababiri.....

Probes:

Wamubaza:

? government. clinic, government. hospital, private doctors, faith healers, traditional healers

?certain places for certain types of illnesses?

Mu mavuriro ya leta mumavuriro yigenga, mubemera Imana, mubavuzi ba kinyarwanda?

8. What are the reasons that you might not go take a sick orphan to a health facility?

Ninkizihe mpanvu zishobora gutuma utafata umwana winfubyi kwivuriro umusanzeyo arwaye?

.....
.....
.....
.....

Probe for transport, cost reasons.

Byaterwa nokubura itike umuzanase?.....

9. What challenges or difficulties do your experience identifying or caring for the health needs of the orphans in your household?

Nizihe ngorane muhurana nazo mukazi kanyu iyo mugerageza gushakisha notwita ku bana binfubyi nabatagira kivurira mu miryango?

.....
.....
.....
.....

10.What are the barriers to meeting the health needs of orphans in your household?

Nizihe nzitizi muhura nazo iyo mugerageza gushakira izo nfubyi nabatagira kivurira ukobagira ubuzima byiza mu miryango yanyu?

.....
.....
.....

11. What are the ways you think might help identify children who are infected with HIV in your household ?

Nubuhe buryo mwibaza ko bwakoresha gushakisha abana babana n'ubwandu mumiryango?

.....
.....
.....

12. What do you do when you encounter a sick orphan in the household?

Niki mukora iyo mubonye umwana ubana n'ubwandu mu muryango?

.....
.....
.....

13. What supports are available for orphans with HIV in this community?

Nizihe nkunga ziboneke muri communataire mutuyemo zogufasha abana babana n'ubwandu?

.....
.....
.....

14. How would a person learn which babies in the household might have been exposed to HIV?

Nonese umuntu yamenyate umwana mu muryango ushobora kuba abana n'ubwandu bwa VIH?

.....
.....
.....

(Best way to least effective way)

Uburyo bwiza bwo gutegura imikorere.

15 How can you know that a child has been infected with HIV? List Signs? List the symptoms?

Numubuhe buryo wamenya ko umwana yanduye viurusi ya VIH? Byandikemo hepfo.

Signs	Symptoms

--	--

16. What are the ways in which a baby can be infected with HIV? List ways.
Nimubuhe byuryo umwana ashobora kwandura virusi ya VIH?

<u>1</u>	<u>4</u>
<u>2</u>	<u>5</u>
<u>3</u>	<u>6</u>

17. What are the ways in which HIV infection could be prevented in children including OVCs?

Nizihe nzira umwana winfubuyi nutagira kivurira ashobora kwurindwamo VIH?

18. Identification and referral of OVCs suspected of HIV or exposed to HIV for care:
Gushakisha no kwohereza abana binfubuyi nabatagira kivurira baketweho ubwandu bwa VIH aho bavurirwa:

a. Who usually identifies and refers OVC suspected of being infected with HIV?
 Ninde ubundi ushakisha akanohereza abo bana bakestweho ubwandu bwa VIH?

.....

b. What does this person/these groups do when they suspect that an OVC is HIV exposed or HIV infected?

Iyo uwo muntu asanze/abo Bantu babonye abo bana bakeka ko bafite ubwandu bakora iki?

.....

c. Are people comfortable asking a person about OVC having HIV? Yes No
 Nonese mu bona ntacyo bitwaye kubaza umuntu ngo iyo nfubuyi cyangwa uwo mwana utagira kivurira nta bwandu afite?

c. To where are OVCs referred if someone suspects they might have or been exposed to HIV?

Mbese abo bana iyo baketseho kugira ubwandu boherzwa hehe?

.....
.....
.....

19. Who are the people that take care of OVC in the community, including those with HIV?

Nibande bakurikirana abana binfubyi nabatagira kivurira muri communautaire hamwe na babana n' ubwandu?

.....
.....
.....

20. What do families do when they learn their OVC have HIV? How do they feel and what do they do about their feelings?

Niki imiryango ikora iyo imenye ko abana binfubyi cyangawese batagira kivurira irera bafite ubwandu?

.....
.....
.....

21. What is it that helps children and adults with HIV before they need ART drug treatment?

Niki gifasha abana ndeste nabakuru babana n' ubwandu mbere yuko batangira imiti igabanya ubukana?

.....
.....
.....
.....

21. What challenges do you experience when you try to get a child with HIV:

Nizihe mbogamizi muhura nazo iyo mugerageza gushakira abana mukekaho Ubwandu:

(a). tested?

(a) Uko bapimwa?

.....
.....
.....
.....

(b). cared for or treated?

(b) Uko bavurwa cyangwa bakwitabwaho?

.....
.....
.....
.....

22. What is your attitude towards getting an orphan under your care tested for HIV?
Kubwawe wowe ubibona ute gupimisha umwana winfubayi urera virusi itera SIDA?
.....
.....
.....

- Which is the stronger reaction
Niki kigukomeye kuruta ibindi?
.....
.....

23. How are you and your household members learning about pediatric HIV/AIDS and ways to get babies tested, treated, etc.
Wowe nabagenz bawe mubana mwunva mute HIV/SIDA, ukuntu abana bashobora kuba bapimwa ukuntu babona imiti etc.
.....
.....
.....

24. What support should the family and community provide to children who are infected with HIV?
Nizihe nkunga imyirango na communautaire bikwiye gutanga kugirango hafashe abo bana babana n' ubwandu?
.....
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.....
.....

25 What support should the family expect from the social center when they take their children for testing and treatment for HIV?
Niyihe nkunga umuryango cyangwa communautaire ikwiriye gutegereza iturika mu kigo kimibereho myiza iyo batwaye umwana ku mupimisha ubwandu?
.....
.....
.....

26 What support should the family expect from the health facility when they take their children for testing and treatment for HIV ?
Niyihe nkunga umuryango cyangwa communautaire ikwiriye gutegereza iturika mu kigo nderabuzima, iyo batwaye umwana ku mupimisha ubwandu?
.....
.....
.....

27. Please tell us one story about an OVC with HIV in this household?
Nonese, ushobora kutubwiraho kubuzima bwa umwana umwe muruyu muryango wawe ubana n' ubwandu?

.....
.....
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.....
.....

28. If you were the pediatric HIV and OVC advisor for this District/community, what would you do about OVC under 5 years old with HIV?
Ubaye ufite ubushobozi bwo kugira inama district/communautaire, wakorera iki abana binfubyi nabatagira kivurira bari munsi y' imyaka 5 yamavuko bafite ubwandu?

.....
.....
.....

29. Are there any community services for OVC with HIV? Yes No
Hari service za bana binfubyi nabatagira kuvurira muri cummunautaire? Yego Oya

? Adherence support, Counseling?
Gukurikirana gahunda neza nokugirwa inama?

.....
.....
.....

30. Are there any street children in the community? Yes No
Harabana baheze mu mihanda baturuka muri communautaire? Yego Oya

31. What do you do for street children in the community?
Abana bo mumihanda mubakorera iki muri communaute?

.....
.....
.....

32 Please check all that apply in your surrounding community.
Reba ibishoboka muri community ikwitoroye

___ When a child is referred from the household to a health facility; there is a form that the provider gives to the parent to take with the child to the facility or organization to which the child is being referred.

Iyo umwana ajyanywe Kwa muganga, hari urupapuro abamugyanye cyangwase abarwaza ngo bazaruhe icyigo kizamwakira? Yego Oya

Comment:

___ There are clear messages to the community about OVC with HIV, such as where to get care, what the signs and symptoms are, etc.

Hari ubutumwa bugyanye nibyo ubwandu bwa VIH/SIDA, urugero nkaho gukura imiti, ibimenyetso byindwara nibindi Yego Oya

Comment:

___ There are village/community health workers who talk to mothers about common childhood illnesses, and HIV symptoms, care and treatment.

Hari abajyanama bu buzima baza kuvugana na babyeyi kubyerekeye indwara za bana, HIV, ibimenyesto bya HIV, uko bita kubarwayi hamwe no kuvurwa. Yego Oya

Comment:

___ Adults in the community commonly get tested for HIV.

Abantu bakuru bakunda kwipimisha HIV? Yego Oya

Comment:

___ People know about HIV disease, such as how people get sick, who needs ART and who does not.

Abantu bazi uburwayi bwa HIV, urugero uburyo abantu barwara, ninde ukeneye imiti iganya ubukana ninde utayikeneye Yego Oya

Comment:

___ People know where to go for treatment.

Abantu bazi aho bagomba gukura imiti. Yego Oya

Comment:

___ People trust health care workers to treat them well if they have HIV/AIDS.

Abantu bizeye abaganga to babavura neza iyo bafite ubwandu bwa SIDA. Yego Oya

Comment:

33 What motivates you to care for other orphans in your household?

Niki cyaguteye ingufu zo twita kubandi y' umuryango?

.....
.....
.....

34 Are you currently in school? Yes No

Ese ubu uri mwishuli? Yego Oya

35 How many of your brothers and sisters are in school?
Ufite barumuna bawe, cyangwa bashiki/basaza bawe bari mwishuli? Yego Oya

36. What is the average household income in this family?
Nibura mushobora kwinjiza iki mu muryongo wanyu ?
.....
.....

37. What do you think caused the death of your parents? Yes No

38. Wabuzi ikishe ababyeyi bawe? Yego Oya
Bakubwiye ko ariki?.....

39. What additional information would you like to provide on this subject?
Niki wifuza kutwongera kubijyanye nibyo umaze kuturwira?
.....
.....
.....

40. Do you have any questions for us? Yes No
Hari ikibazo nawe ufite ukeneye kutubaza? Yego Oya

THANK YOU FOR YOUR TIME!

Murakoze!!

Interview Guide

Pediatric HIV Case Identification, Referral and Care at the Community Level for orphans and vulnerable children (OVC)

For interviews with Community Health Volunteers, PLHA Support Group Members, Village Health Committees and Community Dialogue Groups

Date: _____ Name of District _____
Interviewer(s) _____ Name of Community _____

Interviewee(s)

Group: _____

Contact Person: _____ Phone: _____

General

General

Ask to speak with the identified child headed household in the community served by the social center. Introduce yourself, briefly explain the purpose of your visit and ask if she/he would be willing to answer few questions about orphans and vulnerable children and HIV and AIDS

Twifuzaga kuvugana n' Umuyobozi w' ikigo

Hello. My name is _____. My colleagues and I are here on behalf of to conduct a joint situation analysis to learn more about your services related to HIV/AIDS and OVCs. The information you provide us is very important and valuable, which will help to inform social centers, health facilities, care givers, to support and improve OVC related policies and the delivery of services. We do appreciate your time and responses.

Ivuge, iki kugenza naho uturutse

Murakoze!!

7. **Do you know any orphan and vulnerable children in your community?**
Hari abana binfubayi nabatagira kivurira mufite muri communaute yanyu? Yego Oya

8. **Do you attend to OVCs in the community?** Yes No.
Mukurikirana abana binfubayi nabatagira kivurira muri community?
Yego Oya

- a. If yes, how many OVCs do you attend to each week/month?.....
Niba mubafite, nibangahe?
- b. How many of these OVCs are under the age of 5 years?
Nibangahe murabo bana bari muni y' imyaka 5 yamavuko?.....

9. **Do you know of any OVCs that are living with HIV AIDS in your community?**
Hari abana binfubayi nabatagira kivurira babana n' ubwandu muri communaute yanyu?

4 . **How many children/OVC do you know of in this community who are HIV infected?**

.....
Nabana bangaha muzi muri communaute yanyu babana n' bwandu bwa VIH?.....
(just an estimate/impression ugereranyije)

5 . **How many children/OVC do you know of in this community who are HIV infected and are under the age of 5 years?**

Nabana bangaha muzi muri communaute yanyu babana n' bwandu bwa VIH?.....
(just an estimate/impression ugereranyije)

6. **What are the key health problems for orphans and vulnerable children in this community?**

Nibihe bibazo byihariye abana binfubayi nabatagira kivurira babana n'ubwandu bwa VIH bahura nabyo?

.....
.....

List what is mentioned spontaneously:

Hitawandika ukwafuze:

Probe: Pneumonia? Diarrhea? HIV?
Wamubaza nkumusonga? Impishwi?

6. **What are the key health problems for orphans and vulnerable children infected with HIV (living with AIDS) in this community?**

Nibihe bibazo byihariye abana binfubayi nabatagira kivurira babana n'ubwandu bwa VIH bahura nabyo?

.....
.....

List what is mentioned spontaneously:

Hitawandika ukwafuze:

Probe: Pneumonia? Diarrhea?
Wamubaza nkumusonga? Imwishi?

7. Where do parents and caretakers take sick vulnerable children for treatment in this community?

Aba bana iyo barwayi mubavuriza hehe?.....

First place
Ahambere.....

Second place
Ahakababiri.....

Probes:

Wamubaza:

? government. clinic, government. hospital, private doctors, faith healers, traditional healers

?certain places for certain types of illnesses?

Mu mavuriro ya leta mumavuriro yigenga, mubemera Imana, mubavuzi ba kinyarwanda?

8. What are the reasons that a caregivers might not go take a sick child to a health facility?

Ninkizihe mpanvu zishobora gutuma utafata umwana winfubyi kwivuriro umusanzeyo arwaye?

.....
.....
.....
.....

Probe for transport, cost reasons.

Byaterwa nokubura itike imuzanase?.....

9. What services are available for OVC in your community? Please list

10. What services are available for OVC who are exposed or infected with HIV at this center? Please list

11. What services are available for OVC who are exposed or infected with HIV and below 5 years of age at this center? Please list

12. What challenges or difficulties do your experience identifying or attending to the health needs of OVCs in the community?

Nizihe ngorane muhurana nazo mukazi kanyu iyo mugerageza gushakisha notwita ku bana binfubyi nabatagira kivurira mu miryango?

.....

13. What are the barriers to meeting the health needs of OVCs in their communities?

Nizihe nzitizi muhura nazo iyo mugerageza gushakira izo nfubyi nabatagira kivurira ukobagira ubuzima byiza mu miryango yanyu?

.....

14. What are the ways you think might help identify children who are infected with HIV ?

Nubuhe buryo mwibaza ko bwakoresha gushakisha abana babana n'ubwandu mumiryango?

.....

15. What do you do when you encounter a sick OVC at the community?

Niki mukora iyo mubonye umwana ubana n'ubwandu mu muryango?

.....

16. What supports are available for OVCs with HIV in this community?

Nizihe nkunga ziboneke muri communataire mutuyemo zogufasha abana babana n'ubwandu?

.....
.....
.....

17. What supports are available for OVCs with HIV and are under the age of 5 years in this community?

Nizihe nkunga ziboneke muri communataire mutuyemo zogufasha abana babana n'ubwandu?

.....
.....
.....

18. If a pregnant woman goes for an antenatal care checkup and is counseled by the nurse to get an HIV test for the health of the baby, how will she respond?

Iyo umubyeyi agiye, kwisuzumisha afite inda, bakamugira inama yokwipimisha ubwandu bwa SIDA hamwe numwana , abasubiza ate?

.....
.....
.....

▪ How will she feel? Azabyunva ate?

.....
.....

▪ Can she make this decision by herself? If not, whom does she have to consult with? Ashobora kwifatira icyo kmenzo wenyine? Yego oya

Iyo bitagenze bityose, yitabaza nde?

.....
.....

F/u question:

Group responded:

How will her (married) partner react if he is not consulted and he finds out about the test? What will he do/say?

Nibyiza kubaza aba mama kubwerekeranye na VIH igihe baje gukingiza?

▪ If a woman participates in the PMTCT program at the local health facility what happens to her baby after delivery?

Iyo umu mama waje muri PMTCT kuri kigo ndera buzima abyaye, umwana we bamugenza bate?

.....
.....
.....
.....

- For most women, how long after delivery is it before the baby is seen by a health provider or a community health worker?
Kuba mama benshi, bamara igihe kingana gite batarageza abana babo kwa muganaga?

.....
.....
.....

**19. In this community, what happens to babies who are born to mothers who have HIV?
Muri iyi communautaire, iyo abana bavutse ku babyeyi banduye bigenda bite?**

.....
.....
.....

(Probes: no one knows baby has problems, babies dies quickly, mothers don't want anyone to know)

Wababaza: ntacyomubiziho?, abana baba bagira ibibazo?, bapfa vuzase? Ba mama babo ntabwo bashaka kubivuga?

20.. How would a person learn which babies in the community might have been exposed to HIV?

Nonese umuntu yamenyate umwana mu communaute ushobora kuba abana n'ubwandu bwa VIH?

.....
.....
.....

(Best way to least effective way)

Uburyo bwiza bwo gutegura imikorere.

F/U Question: Is it ok to ask mothers about HIV at the immunization visit?

Home testing?:

Nibyiza kubaza aba mama kubwerekanye na VIH igihe baje gukingiza? Yego Oya

21. How can a mother or anyone know that a baby has been infected with HIV? List Signs?

List the symptoms?

Numubuhe buryo wamenya ko umwana yanduye viurusi ya VIH?

Byandikemo hepfo.

--	--

**22. What are the ways in which a baby can be infected with HIV? List ways.
Nimubuhe byuryo umwana ashobora kwandura virusi ya VIH?**

23. What are the ways in which HIV infection could be prevented in children including OVCs?

Nizihe nzira umwana winfubyi nutagira kivurira ashobora kwurindwamo VIH?

24. What are the common health problems encountered in OVCs at this center?

25. What are the common health problems encountered in OVCs infected with HIV at this center.

26. What are the common health problems encountered in OVCs infected with HIV and are below 5 years of age?

27. Identification and referral of OVCs suspected of HIV or exposed to HIV: Gushakisha no kwohereza abana binfubyi nabatagira kivurira baketweho ubwandu bwa VIH aho bavurirwa:

a. Who usually identifies and refers OVC suspected of being infected with HIV?
 Ninde ubundi ushakisha akanohereza abo bana bakestweho ubwandu bwa VIH?

.....

b. What does this person/these groups do when they suspect that an OVC is HIV exposed or HIV infected?

Iyo uwo muntu asanze/abo Bantu babonye abo bana bakeka ko bafite ubwandu bakora iki?

.....

c. Are people comfortable asking a person about OVC having HIV?

Nonese mu bona ntacyo bitwaye kubaza umuntu ngo iyo nfubyi cyangwa uwo mwana utagira kivurira nta bwandu afite?

.....

d. To where are OVCs referred if someone suspects they might have or been exposed to HIV?
 Mbese abo bana iyo baketseho kugira ubwandu boherezwa hehe?

.....

28. Who are the people that take care of OVC in the community, including those with HIV?

Nibande bakurikirana abana binfubyi nabatagira kivurira muri communautaire hamwe na babana n' ubwandu?

.....

29. What do families do when they learn their OVC has HIV? How do they feel and what do they do about their feelings?

Niki imiryango ikora iyo imenye ko abana binfibyi cyangawese batagira kivurira irera bafite ubwandu?

.....
.....
.....

30. Please estimate how many OVCs in this community are being treated for HIV?

Responses:

Ugereranyije, n' abana baba OVC bangahe muri yanyu communate babona imiti y' ubwandu?.....

31. What is it that helps children and adults with HIV before they need ART?

Niki gifasha abana ndeste nabakuru babana n' ubwandu mbere yuko batangira imiti igabanya ubukana?

.....
.....
.....
.....

32. What challenges do community members experience when they try to get a child with HIV?

Nizihe mbogamizi muhura nazo iyo mugerageza gushakira abana mukekaho Ubwandu:

(a). tested?

(a) Uko bapimwa?

.....
.....
.....
.....

(b). cared for or treated?

(b) Uko bavurwa cyangwa bakwitabwaho?

.....
.....
.....
.....

33. What is the attitude of parents towards getting an OVC tested for HIV?

Kubabyeyi wowe ubibona ute gupimisha umwana winfubyi urera virusi itera SIDA?

.....
.....
.....

- Which is the stronger reaction
Niki kigukomeye kuruta ibindi?

.....
.....

34. How are community members learning about pediatric HIV/AIDS, ways to get babies tested, treated, etc.

Muir communnate, mubana mwunva mute HIV/SIDA, ukuntu abana bashobora kuba bapimwa ukuntu babona imiti etc.

.....
.....
.....

35. What support should the family and community provide to children who are infected with HIV ?

Nizihe nkunga imyirango na communataire bikwiye gutanga kugirango hafashe abo bana babana n' ubwandu?

.....
.....
.....
.....

36. What support should the family and community expect from the health facility when they take their children for testing and treatment for HIV ?

Niyihe nkunga umuryango cyangwa communataire ikwiriye gutegereza iturika mu kigo nderabuzima, iyo batwaye umwana ku mupimisha ubwandu?

.....
.....
.....
.....

37. What are the attitudes of community health volunteers about children and OVC with HIV?

Niyihe myifatire abakorana bushake mu by'ubuzima bakwiye kugira ku bana hamwe ninfubyi nabatagira kivurira babana n;ubwandu?

.....
.....
.....

38. Please tell us one story about an OVC with HIV in this community?

Nonese, ushobora kutubwiraho kubuzima bwa umwana umwe muruyu muryango wawe ubana n' ubwandu?

.....
.....

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.....
.....

39. If you were the pediatric HIV and OVC advisor for this District/community, what would you do about OVC under 5 years old with HIV?
Ubaye ufite ubushobozi bwo kugira inama district/communaire, wakorera iki abana binfubyi nabatagira kuvurira bari muni y' imyaka 5 yamavuko bafite ubwandu?

.....
.....
.....

40. Are there any community services for OVC with HIV?

Hari service za bana binfubyi nabatagira kuvurira muri cummunautaire?
Yego Oya

Adherence support, Counseling?
Gukurikirana gahunda neza nokugirwa inama?

.....
.....
.....

41. How many OVCs does an average community health worker visit in a week
Harabana baheze mu mihanda baturuka muri communaire? Yego Oya

Deleted: .

42. Are there any street children in the community?

Hari abana baba mumihanda bava muri communaute? Yego oya

43. What do you do for street children in the community?

Mukorera iki abana bo mu mihanda, muri communaute yanyu?

.....
.....
.....

44 What incentives are provided to community health volunteers in your community?

45. Please check all that apply in your surrounding community.

Reba ibishoboka muri community ikwitoroye

____ When a child is referred from the household to a health facility, there is a form that the provider gives to the parent to take with the child to the facility or organization to which the child is being referred.

Iyo umwana ajyanywe Kwa muganga, hari urupapuro abamugyanye cyangwase abarwaza ngo bazaruhe icyigo kizamwakira? Yego Oya
Comment:

____There are clear messages to the community about OVC with HIV, such as where to get care, what the signs and symptoms are, etc.
Hari ubutumwa bugyanye nibyo ubwandu bwa VIH/SIDA, urugero nkaho gukura imiti, ibimenyetso byindwara nibindi Yego Oya
Comment:

____There are village/community health workers who talk to mothers about common childhood illnesses, and HIV symptoms, care and treatment.
Hari abajyanama bu buzima baza kuvugana na babyeyi kubyerekeye indwara za bana, HIV, ibimenyesto bya HIV, uko bita kubarwayi hamwe no kuvurwa. Yego Oya
Comment:

____Adults in the community commonly get tested for HIV.
Abantu bakuru bakunda kwipimisha HIV? Yego Oya
Comment:

____People know about HIV disease, such as how people get sick, who needs ART and who does not.
Abantu bazi uburwayi bwa HIV, urugero uburyo abantu barwara, ninde ukeneye imiti iganya ubukana ninde utayikeneye Yego Oya
Comment:

____People know where to go for treatment.
Abantu bazi aho bagomba gukura imiti. Yego Oya
Comment:

____People trust health care workers to treat them well if they have HIV/AIDS.
Abantu bizeye abaganga to babavura neza iyo bafite ubwandu bwa SIDA. Yego Oya
Comment:

**45. What motivates you to do the work you are doing for OVCs?
Niki cyaguteye ingufu zo twita kubandi y' umuryango?**

.....
.....
.....

**46. What additional information would you like to provide on this subject?
Niki wifuza kutwongera kubijyanye nibyo umaze kuturwira?**

.....
.....
.....

47. Do you have any questions for us?

Hari ikibazo nawe ufite ukeneye kutubaza? Yego Oya

THANK YOU FOR YOUR TIME!

Interview Guide

Pediatric HIV Case Identification, Referral and Care at Health Facilities for orphans and vulnerable children (OVC)

For interviews with health care providers at provincial and district hospital level and health center and dispensary level providing care, treatment support for Pediatric HIV, ART, PMTCT, HCT, MCH, IPD and OPD

Date:

Name of District

Interviewer(s)

Name of Health Facility

Interviewee(s)

Team:

Contact Person:

Phone:

General

Ask to speak with the person in charge for social center or NGO who is present today.

Introduce yourself, briefly explain the purpose of your visit and ask if she/he would be willing to answer few questions about orphans and vulnerable children with HIV and AIDS

Hello. My name is _____. My colleagues and I are here on behalf of to conduct a joint situation analysis to learn more about your services related to HIV/AIDS and OVCs. The information you provide us is very important and valuable, which will help to inform social centers, health facilities, care givers, to support and improve OVC related policies and the delivery of services. We do appreciate your time and responses.

THANK YOU

Interview Guide: Health Facility Assessment of Pediatric HIV Services
(for use at provincial and district hospital level and district health center and dispensary level)

Type of Facility: <input type="checkbox"/> Referral Hospital <input type="checkbox"/> Regional Hospital <input type="checkbox"/> District Hospital <input type="checkbox"/> Health Center <input type="checkbox"/> Dispensary	Linked to: Regional Hospital Name..... District Hospital Name..... Health Center (1)..... Health Center (2)..... Health Center (3)..... Health Center (4)..... Dispensaries (Number).....
---	---

Site Characteristics

Type of site

Public (government)
 Private, (NGO)
 Private, (FBO)
 Other (specify: _____)

Location of the site

_____ Urban
 _____ Rural
 _____ Semi-urban/peri-urban

Services offered at the site

Out-patient MCH
 ANC
 Labor and Delivery
 Out-patient pediatric
 In-patient pediatric
 General/Family practice/OPD
 Other (specify: _____)

TB clinic
 Nutrition

ALL OF ABOVE

Selected Services Statistics

Population of catchment area (adult +children)..... _____

Population of children under 5 years of age
..... _____

Number of hospital
beds..... _____

Number of pediatric
beds..... _____

Number of deliveries
(2007)..... _____

Number of immunizations (DPT 1)
(2007)..... _____

Number of women attending PMTCT (2007)..... _____

Number of women tested in the past year (2007) _____

Number of women who tested positive in the past year (2007)..... _____

Number of women receiving NVP (2007)..... _____

Number of babies receiving NVP ART
(2007)..... _____

Number of HIV tests done (2007)..... _____

Number of children tested for HIV
(2007)..... _____

Number of children less than 5 years of age tested for HIV (2007)

Number of infants or children who tested positive for HIV (2007)..... _____

Number of children seen outpatient
(2007)..... _____

Number of children enrolled in nutritional programs
(2007)..... _____

Number of orphans seen in the health facility (2007)
..... _____

Number of orphans less than 5 years of age seen in the
facility..... _____

Services Available at Health Facility

**HIV counseling and Testing
(check those that apply)**

(Check all that apply)

Provider Initiated Testing and Counseling (PITC)
 ___ inpatient: ___ adults ___ children
 ___ outpatient: ___ adults ___ children

VCT ___ adults ___ children

Routine offer of testing for infants and children:
 ___ inpatient ___ outpatient

Adults Yes No Start Date: ___/___/___

Children Yes No Start Date: ___/___/___

Referral of HIV positive women to ART
 If yes, when? ___ ANC _____ (post partum or antenatal)

Partner counseling and testing – rare

___ Growth monitoring

___ Immunization

___ IMCI

___ Cotrimoazole for HIV exposed children @ART

___ Bednets/ITN

ART Yes No

When initiated at this facility
(mm/yyyy)

PMTCT Yes No

Pediatric/MCH/Child Health services

Psychosocial support to families with HIV? (check all that apply)

___ Individual counseling ___ support groups ___ outreach to community Other _____

If outreach workers find a child in the home of a family who is sick/suspected of being HIV infected, what do they do?

Services and support provided for orphans and vulnerable children at the health facility

- ___ Psychosocial support
- ___ Screening for health problem
- ___ Immunization
- ___ Nutritional Support
- ___ Cotrimoazole for HIV exposed children with HIV
- ___ ART for eligible children
- ___ Bednets/ITN

For infants and children exposed to HIV, who/which service is responsible for each of the following elements of care:

Complete items at right with following codes (more than one code can apply)

- ART at Provincial level hospital (ART-P)
- ART at District level (ART-D)
- ART at sub-district level (ART-SD)
- Dispensaries (Dis)
- HBC workers/CHWs/OVC workers

- ___ Identification of HIV- exposed infants and children
- ___ Prescribe ART
- ___ Monitor ART after 3 months
- ___ Provide adherence support
- ___ Provide CTMZ prophylaxis
- ___ Refer for HIV testing
- ___ Conduct clinical assessment

In the MCH clinic, when an infant or child is suspected of being HIV exposed or HIV infected, what does the provider do?

- Refer to ART
- Refer to OPD
- Refer for HIV testing.

If yes, to where?

- _____
- Conduct HIV test
 - Start cotrimoxazole
 - Start ART

Where are pediatric HIV care services located?

- MCH
- OPD
- CCC
- Pediatric HIV specialty clinic
- Other (specify: _____)

CARE AND SUPPORT FOR ORPHANS AND VULNERABLE CHILDREN (OVC)

- How do the health providers identify OVCs (indigent, orphan and vulnerable children) in the facility?

- What specific services are available for OVC in your facility? Please list
 - Who provides these services?
 - When are the services provided?
 - Where are they provided at the health facility?

- How do OVCs access services at the facility?

- How many OVCs are attended to at the facility each week/month?
 - How many of the OVCs are under 5 years of age?

- What are the common health problems of OVC that you encounter in this health facility? Please list

- What do you do when you encounter a sick OVC at the facility?

- What are the barriers to access to health services by OVCs? Please list

- What challenges do you encounter while providing services for OVCs in your facility?
 - Getting OVC tested for HIV?
 - Providing treatment for OVCs?
- What support do you think should be provided to OVCs who are infected with HIV that visit your facility?
- Do you refer OVCs to other services or NGOs in the community? And to where?
- Do you follow up OVCs that receive care in your health facility? And how?
- What additional information would you like to provide on this subject?

ORGANIZATIONS WORKING AT THE SITE

- Name:* Child Health Maternal Health STI
 Care and Treatment /Adults
 Care and Treatment /Peds PMTCT VCT
 HBC OVC
- Name:* Child Health Maternal Health STI
 Care and Treatment /Adults
 Care and Treatment /Peds PMTCT VCT
 HBC OVC
- Name:* Child Health Maternal Health STI
 Care and Treatment /Adults
 Care and Treatment /Peds PMTCT VCT
 HBC OVC
- Name:* Child Health Maternal Health STI
 Care and Treatment /Adults
 Care and Treatment /Peds PMTCT VCT
 HBC OVC
- Name:* Child Health Maternal Health STI
 Care and Treatment /Adults
 Care and Treatment /Peds PMTCT VCT
 HBC OVC

Guidelines

Guidelines present on site

Guidelines for Clinical Management of HIV/AIDS (ART, OIs)

Guidelines for PMTCT

Response

Yes, specify: _____ N/A
 No

Observed TOLD AT NEARBY OFFICE

Yes, specify: _____ N/A

No

Observed TOLD AT NEARBY OFFICE

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Guidelines for counseling and testing for adults

- Yes, specify: _____ N/A
 No
 Observed

Guidelines for care and support for orphans and vulnerable children

- Yes, specify: _____ N/A
 No
 Observed

Handbook on Pediatric
AIDS in Africa (ANECCA)
Other relevant guidelines

- Yes No
Told it is In a Medical Officer's office – did not observe

Are there information, education and communication (IEC) materials available for the patients

-
.....
 General HIV education
 General ART issues
 ARV side effects and their management
 Opportunistic infections
 Medication use
 Adherence support

 Pediatric HIV and AIDS

STAFFING AND CAPACITY FOR PEDIATRIC HIV CARE AND TREATMENT

	Total Number	# of each type provider providing pediatric HIV Care	# trained in IMCI-HIV	# trained in pediatric HIV care
Medical Officers (1 ENT, 2 surgeons, 1 physician, 1 pediatrician, 1 gynecologist) Asst MO				
Clinical officer				
Nursing Officer				
Nurse Midwife				
Nurses (all other levels)				
Nurse attendant or hospital assistant				
Health Assistant				
Others				

LABORATORY DIAGNOSIS AND MONITORING

Question

Response

Does your site have laboratory facility

Yes No

Laboratory services performed in this lab

- CD4 count
- CD4 percentage
- Rapid HIV test
- Elisa
- DNA-PCR
- RNA-PCR
- Hemoglobin
- Total lymphocyte count
- Liver Function Tests
- Renal Function Tests
- Other (specify: _____)

Are other laboratory facilities available offsite?

- Private or commercial lab
- Public lab
- Not available

If yes, please provide the name(s)

A. _____
B. _____

For the following lab tests, specify as indicated at right:

CD4: Lab to which test is sent (A or B) _____
 _____ # days a week specimens are sent out
 On site _____ # days to receive results
 _____ method of dispatching results (post?, fa?)
 Others: _____

DBS-PCR
 Lab to which test is sent (A or B) _____
 _____ # days a week specimens are sent out
 _____ # days to receive results
 _____ method of dispatching results (post?, fa?)

Practice	
	Expiration/supply comment
meds ordered over 3 weeks ago (10/2565 pts need needed yet)	
10mg caps	
suspension 110 MG/ML	
50mg/ml	
50 mg/5ml (1 bottle on hand) 5	
50mg/5ml	
azole SYRUP	

CLINICAL PRACTICE

Condition	Question Mode of determining Diagnosis	Response Treat on Site or Refer
HIV in children	<input type="checkbox"/> Rapid Test <input type="checkbox"/> ELISA <input type="checkbox"/> DBS-PCR <input type="checkbox"/> None	<input type="checkbox"/> Treat on site <input type="checkbox"/> Refer
HIV in children <18 m	<input type="checkbox"/> Rapid Test <input type="checkbox"/> DNA-PCR <input type="checkbox"/> DBS-PCR <input type="checkbox"/> None	<input type="checkbox"/> Treat on site <input type="checkbox"/> Refer
What opportunistic infections are you seeing in infants and children? Answered in terms of symptoms; did not ask about management	1. _____ 2. _____ 3. _____	
Staging of HIV infection	<input type="checkbox"/> Done at baseline only <input type="checkbox"/> Done at each follow-up <input type="checkbox"/> Not done <input type="checkbox"/> CDC <input type="checkbox"/> WHO	Not asked
Staging system in use		

SERVICE STATISTICS

Question

Response

Number of infants born to HIV positive mothers who return to the facility for follow-up

Number of HIV exposed infants on CT prophylaxis

Number of HIV-infected children who are currently on ART in the facility

_____ < 15 years
 _____ below 2 years
 _____ above 2 years

How many children (<15 y.o.) have been put on or referred for ART while on the in-patient ward (2007).

None
 Number: _____

How many children have been put on or referred for ART from the MCH/OPD/Ped OP clinic in last month?

None
 Number: _____

How many children have been put on or referred for ART because their parents are on ART?

None
 Number: _____

PATIENT RECORDS AND MANAGEMENT

Sample of 5 patient records/unit at the facility

MCH CARD #1 (kept by caretaker)

Item completed

Unique patient identifier

Yes No

Date of birth

Yes No

Sex of patient

Yes No

Weight at birth

Yes No

Weight *

Yes No

Height *

Yes No

Who is the caretaker? (Mum/dad/family member/institution...)*

Yes No

Mother's HIV serostatus (PMTCT Status)

Yes No

Disclosure of HIV status of the child to caretaker

Yes No
 N/A

Immunizations

OPV 1 AND BCG Yes No

OPV 2-4;DPT 1-3 Yes No

Measles Yes No

Select 5 records of children suspected of being HIV infected who are currently on the inpatient ward
REVIEWED ONE CHART TO DETERMINE WHAT IS REQUESTED ON THE FORMS

Pediatric Inpatient Ward Medical Record

Unique patient identifier	Yes <input type="checkbox"/> No
Date of birth	<input type="checkbox"/> Yes <input type="checkbox"/> No – used Age instead
Sex of patient	Yes <input type="checkbox"/> No
Weight at birth	<input type="checkbox"/> Yes No
Weight *	Yes <input type="checkbox"/> No
Height *	<input type="checkbox"/> Yes No
Who is the caretaker? (Mum/dad/family member/institution...)*	Yes <input type="checkbox"/> No
Mother's HIV serostatus (PMTCT Status)	<input type="checkbox"/> Yes No
Child's HIV status	<input type="checkbox"/> Yes No
NOT REQUIRED BY THE STANDARD FORM but told it is put into narrative notes	
Disclosure of HIV status of the child to caretaker	<input type="checkbox"/> Yes
ONLY IN NARRATIVE NOTES	Not required on the form
	<input type="checkbox"/> N/A
Clinical assessment findings and assignment of clinical stage (WHO/CDC staging) * IN NARRATIVE NOTES	<input type="checkbox"/> Yes Not required on the form
	<input type="checkbox"/> N/A
Active opportunistic infection* IN NOTES	<input type="checkbox"/> Yes Not required on the form
	<input type="checkbox"/> N/A
Cotrimoxazole prophylaxis*	<input type="checkbox"/> Yes
In notes	not required on the form
	<input type="checkbox"/> N/A
Date of starting cotrimoxazole prophylaxis	<input type="checkbox"/> Yes
In notes	not required on the form
	<input type="checkbox"/> N/A

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- | | | |
|----------------------------------|----------------------|-------------------------------------|
| Tuberculosis treatment* | | <input type="checkbox"/> Yes |
| In notes | | <i>not required
on the form</i> |
| | | <input type="checkbox"/> N/A |
| Antiretroviral therapy (ART) | | Yes |
| | | <input type="checkbox"/> No |
| | | <input type="checkbox"/> N/A |
| Total lymphocyte count* | | Yes |
| | | <input type="checkbox"/> No |
| | | <input type="checkbox"/> N/A |
| Hemoglobin * | | Yes |
| | | <input type="checkbox"/> No |
| | | <input type="checkbox"/> N/A |
| CD4 cell count (cells/ μ L)* | DONE AT THE ART SITE | <input type="checkbox"/> Yes |
| | | <input type="checkbox"/> No |
| | | <input type="checkbox"/> N/A |
| CD4 cell percentage (%)* | “ | <input type="checkbox"/> Yes |
| | | <input type="checkbox"/> No |
| | | <input type="checkbox"/> N/A |
| Severe Rash* IN NARRATIVE NOTES | | <input type="checkbox"/> Yes |
| | | <input type="checkbox"/> No |
| | | <input type="checkbox"/> N/A |
| Document mother's death | IN HISTORY NOTES | <input type="checkbox"/> Yes |
| | | <input type="checkbox"/> No |
| Document father's death | IN HISTORY NOTES | <input type="checkbox"/> Yes |
| | | <input type="checkbox"/> No |

<i>Select 5 random charts of children under 5 years old</i>	
CARE AND TREATMENT ON PEDIATRIC PATIENT RECORD	
Unique patient identifier	<input type="checkbox"/> Yes <input type="checkbox"/> No
Date of birth	<input type="checkbox"/> Yes <input type="checkbox"/> No
Sex of patient	<input type="checkbox"/> Yes <input type="checkbox"/> No
Weight at birth	<input type="checkbox"/> Yes <input type="checkbox"/> No
Weight at last visit	<input type="checkbox"/> Yes <input type="checkbox"/> No
Height at last visit	<input type="checkbox"/> Yes <input type="checkbox"/> No
Who is the caretaker? (Mum/dad/family member/institution...)	<input type="checkbox"/> Yes <input type="checkbox"/> No
Mother's HIV serostatus (PMTCT Status)	<input type="checkbox"/> Yes <input type="checkbox"/> No

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Child's HIV status	<input type="checkbox"/> Yes <input type="checkbox"/> No
Disclosure of HIV status of the child to caretaker	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Clinical assessment findings and assignment of clinical stage (WHO/CDC staging)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Active opportunistic infection	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Cotrimoxazole prophylaxis	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Date of starting cotrimoxazole prophylaxis	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Tuberculosis treatment	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Antiretroviral therapy (ART)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Total lymphocyte count	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Hemoglobin	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
CD4 cell count (cells/ μ L)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
CD4 cell percentage (%)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Severe Rash	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Document mother's death If yes, date?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Document father's death If yes, date?	<input type="checkbox"/> Yes <input type="checkbox"/> No

Comments

Key Questions for Health Care Providers at the Facility

Providers at MCH Site

What do you do for children who are falling below expected weight on the growth chart?

What do you do when a mother you know is HIV infected brings her baby for an immunization?

Clinicians in Pediatric Outpatient Department

If you see a six month old with the fourth episode of pneumonia what would you do?

Probe: suggest an HIV test?

Clinician on Pediatric Inpatient Unit

How many HIV tests have you ordered for children under 5 this past month?

Pharmacist

In the past three months, how many prescriptions have you filled for Cotrimoxazole for prophylaxis in a child under 5?

12. How many staff are working at this social center?

13. What skills and training do you have for OVC care and support?

14. What additional skills do you require to more effectively support OVCs in your program

15. How many of your staff members have been trained on OVC care?

16. How many care givers do you have at your center?

17. What services are available for OVC at this center? Please list

18. What services are available for OVC who are exposed or infected with HIV at this center? Please list

19. What services are available for OVC who are exposed or infected with HIV and below 5 years of age at this center? Please list

--	--

20. Who provides these services to OVCs at the center?

21. When are these services provided ? How often?

22. Where are these services provided for OVC including those infected with HIV at this center?

23. How do the social workers identify OVCs (indigent, orphan and vulnerable children) in this center?

24. What is the criteria used to define orphans who receive care at your center?

25. How many OVCs do you know of in this center who are HIV infected?

26. How many OVCs do you know of in this center who are HIV infected and are under the age of 5 years?

16. How do OVCs access services at the Social center?

17. How many OVCs are attended to at the facility each month?

18. What are the common health problems for orphans and vulnerable children in this center?

List what is mentioned spontaneously:

Probe: Pneumonia? Diarrhea? HIV?

19. What are the common health problems for orphans and vulnerable children infected with HIV (living with AIDS) that present at the center?

List what is mentioned spontaneously:

Probe: Pneumonia? Diarrhea?

20. What are the common health problems for orphans and vulnerable children infected with HIV (living with AIDS) and are below 5 years of age at this center?

List what is mentioned spontaneously:

Probe: Pneumonia? Diarrhea?

21. How do you respond to the health needs of the OVC that come to the center?

22. What do you do when you encounter a sick OVC at the center?

23. What do you do when you encounter a sick OVC with HIV infection at the center?

24. What do you do for sick OVC with HIV infection who are under 5 years of age visiting your social center?

25. Where do caretakers take sick vulnerable children for treatment in this community?

First place

Second place

Probes:

? government. clinic, government. hospital, private doctors, faith healers, traditional healers
?certain places for certain types of illnesses?

26. What are the reasons that a caregivers might not go take a sick child to a health facility?

Probe for transport, cost reasons.

27. What challenges or difficulties do your experience identifying or attending to the health needs of OVCs at your center?

28. What are the barriers to meeting the health needs of OVCs in this center communities?

29. What are the ways that help you identify children (OVCs) who are infected with HIV at your center?

30. What are the ways that help you identify children (OVCs) who are infected with HIV and are under the age of 5 years at your center?

31 What supports are available for OVCs with HIV at this center?

32. If a pregnant woman goes for an antenatal care checkup and is counseled by the nurse to get an HIV test for the health of the baby, how will she respond?

▪ How will she feel?

▪ Can she make this decision by herself? If not, whom does she have to consult with?

33 In this community, what happens to babies who are born to mothers who have HIV?

(Probes: no one knows baby has problems, babies dies quickly, mothers don't want anyone to know)

**34. How would a person learn which children might have been exposed to HIV?
(Best way to least effective way)**

**F/U Question: Is it ok to ask mothers about HIV at the immunization visit?
Home testing?:**

**35. How can a mother or anyone know that a baby has been infected with HIV? List Signs?
List the symptoms?**

34 What are the ways in which a baby/child can be infected with HIV? List ways.

35. What are the ways in which HIV infection could be prevented in children including OVCs?

--	--

36. What are the common health problems encountered in OVCs at this center?

37. What are the common health problems encountered in OVCs infected with HIV at this center.

38. What are the common health problems encountered in OVCs infected with HIV and are below 5 years of age?

Do you conduct HIV counseling and testing at this social center?

39. How many children are tested for at your center each month?

b. How many of these children are under the age of 5 years:

40. How many children do you refer to the health facility health problems per month?

41. How many children do you refer to the health facility for HIV testing month?

42. Identification and referral of OVCs suspected of HIV or exposed to HIV:

a. Who usually identifies and refers OVC suspected of being infected with HIV?

- b. What does this person/these groups do when they suspect that an OVC is HIV exposed or HIV infected?

- c. Are people comfortable asking a person about OVC having HIV?

- d. To where are OVCs referred if someone suspects they might have or been exposed to HIV?
- e. What do you provide to the OVC with HIV before referral?

43. How do you provide follow up for OVCs in you program?

44. What do families do when they learn their OVC has HIV? How do they feel and what do they do about their feelings?

**45. Please estimate how many OVCs in this center are being treated for HIV?
Responses:**

46. What is it that helps children and adults with HIV before they need ART medication for their HIV infection?

47. What challenges do experience at the center when they try to get a child with HIV?

a. tested?

b. cared for or treated?

48. What is the attitude of parents towards getting an OVC tested for HIV?

- Which is the stronger reaction or most important reaction?

49. What is the attitude of care providers at the center towards getting an OVC tested for HIV?

- Which is the stronger reaction or most important reaction?

50. How are community members learning about pediatric HIV/AIDS and OVC, ways to get babies tested, treated, etc.

51. What support should the family and community provide to children who are infected with HIV ?

52. What support should the social center expect from the health facility when they take their children for testing and treatment for HIV?

53. What are the attitudes of care providers/counselors community health volunteers about children and OVC with HIV?

54. Please tell us one story about an OVC with HIV in this center?

55. If you were the pediatric HIV and OVC advisor for this District/community, what would you do about OVC under 5 years old with HIV?

56. Do you conduct home visit for OVC infected with HIV at the community?

57. How many OVCs on average does a counselor/care provider visit in a week

58. Are there any street children in the community?

59. What do you do for street children in the community?

60. Please check all that apply in your surrounding community.

___ When a child is referred from the household to a health facility, there is a form that the provider gives to the parent to take with the child to the facility or organization to which the child is being referred.

Comment:

___ There are clear messages to the community about OVC with HIV, such as where to get care, what the signs and symptoms are, etc.

Comment:

___ There are village/community health workers who talk to mothers about common childhood illnesses, and HIV symptoms, care and treatment.

Comment:

___ Adults in the community commonly get tested for HIV.

Comment:

___ People know about HIV disease, such as how people get sick, who needs ART and who does not.

Comment:

____ People know where to go for treatment.
Comment:

____ People trust health care workers to treat them well if they have HIV/AIDS.
Comment:

61. What motivates you to do the work you are doing for OVCs?

62. What model of care do you propose for OVC care?

63. What other partners are working with OVC in the community? Please list

**64. Are there organizations supporting people living with HIV and AIDS at the community?
Please list.**

65. What are your recommendations for OVC programs

67. What additional information would you like to provide on this subject?

68. Do you have any questions for us?

Interview Guide

Pediatric HIV Case Identification, Referral and Care at Health Facilities for orphans and vulnerable children (OVC)

For interviews with health sector Social Welfare Officer responsible for OVC care and support at the district level.

Date:

Name of District

Interviewer(s)

Name of Sector

Interviewee(s)

Team: _____

Contact Person: _____

Phone: _____

General

Ask to speak with the person in charge for social center or NGO who is present today. Introduce yourself, briefly explain the purpose of your visit and ask if she/he would be willing to answer few questions about orphans and vulnerable children with HIV and AIDS

Hello. My name is _____. My colleagues and I are here on behalf of to conduct a joint situation analysis to learn more about your services related to HIV/AIDS and OVCs. The information you provide us is very important and valuable, which will help to inform social centers, health facilities, care givers, to support and improve OVC related policies and the delivery of services. We do appreciate your time and responses.

THANK YOU

Interview Guide: Health Sector Social Welfare for OVC and Pediatric HIV Services
(for use at provincial and district levels of care)

Type of Facilities in the Sector:	Linked to:
<input type="checkbox"/> Referral Hospital	Regional Hospital Name.....
<input type="checkbox"/> Regional Hospital	District Hospital Name.....
<input type="checkbox"/> District Hospital	Health Center (1).....
<input type="checkbox"/> Health Center	Health Center (2).....
<input type="checkbox"/> Dispensary	Health Center (3).....
<input type="checkbox"/> Others	Health Center (4).....
	Dispensaries (Number).....

Site Characteristics

Types of site for OVC and pediatric HIV care in the Sector

- Public (government)
- Private, (NGO)
- Private, (FBO)
- Other (specify: _____)

Location of the site

- Urban
- Rural
- Semi-urban/peri-urban

Services offered in the Sector

- Out-patient MCH
- ANC
- Labor and Delivery
- Out-patient pediatric
- In-patient pediatric
- General/Family practice/OPD
- Other (specify: _____)
- TB clinic
- Nutrition

ALL OF ABOVE

Selected Sector Statistics

Population of catchment area (adult +children)....._____

Population of children under 15 years of age
....._____

Population of children under 5 years of age
....._____

Population of orphans and vulnerable children_____

Population of orphans and vulnerable children under 5 years of age
....._____

Number of orphans seen at the health facilities (2007)
....._____

Number of orphans below 5 years attended to in the
sector....._____

Number of orphans known to be HIV positive (2007)
....._____

Number of orphans under 5 years known to be HIV positive
(2007)....._____

Services Available in the Sector

**HIV counseling and Testing
(check those that apply)**

(Check all that apply)

Provider Initiated Testing and Counseling (PITC)
 ___ inpatient: ___ adults ___ children
 ___ outpatient: ___ adults ___ children

VCT ___ adults ___ children

Routine offer of testing for infants and children:
 ___ inpatient ___ outpatient

Adults Yes No Start Date: ___/___/___

Children Yes No Start Date: ___/___/___

Referral of HIV positive women to ART
 If yes, when? ___ANC_____ (post partum or antenatal)

Partner counseling and testing – rare

___ Growth monitoring

___ Immunization

___ IMCI

___ Cotrimoazole for HIV exposed children @ART

___ Bednets/ITN

ART Yes No

**When initiated at this facility
(mm/yyyy)**

PMTCT Yes No

Pediatric/MCH/Child Health services

Psychosocial support to families with HIV? (check all that apply)

___ Individual counseling ___ support groups ___ outreach to community Other _____

If outreach workers find a child in the home of a family who is sick/suspected of being HIV infected, what do they do?

Services and support provided for orphans and vulnerable children at the Sector level

- ___ Psychosocial support
- ___ Screening for health problem
- ___ Immunization
- ___ Nutritional Support
- ___ Cotrimoazole for HIV exposed children with HIV
- ___ ART for eligible children
- ___ Bednets/ITN

For infants and children exposed to HIV, who/which service is responsible for each of the following elements of care:

Complete items at right with following codes (more than one code can apply)

- ART at Provincial level hospital (ART-P)
- ART at District level (ART-D)
- ART at sub-district level (ART-SD)
- Dispensaries (Dis)
- HBC workers/CHWs/OVC workers

- ___
- ___ Identification of HIV- exposed infants and children
- ___ Prescribe ART
- ___ Monitor ART after 3 months
- ___ Provide adherence support
- ___ Provide CTMZ prophylaxis
- ___ Refer for HIV testing
- ___ Conduct clinical assessment

Where are pediatric HIV care services located?

- MCH
- OPD
- CCC
- Pediatric HIV specialty clinic
- Other (specify: _____)

CARE AND SUPPORT FOR ORPHANS AND VULNERABLE CHILDREN (OVC)

- How does the Sector identify OVCs (indigent, orphan and vulnerable children) in the facility?

- What specific services are available for OVC in the Sector? Please list
 - Who provides these services?
 - When are the services provided?
 - Where are they provided at the health facility?

- How do OVCs access services in the Sector?

- How many OVCs are attended to in the Sector each year?
 - How many of the OVCs are under 5 years of age?

- What are the common health problems of OVC that are encountered in the Sector? Please list

- What do you do when you encounter a sick OVC in the Sector?

- What are the barriers to access to health services by OVCs? Please list

- What support services are available to OVCs in the Sector
- What challenges do you encounter while providing services for OVCs in the Sector ?
 - Getting OVC tested for HIV?
 - Providing treatment for OVCs?

- What support do you think should be provided to OVCs who are infected with HIV in the Sector?
- Do you refer OVCs to other services or NGOs in the community? And to where?
- What interventions are available for OVC in the sector?

ORGANIZATIONS WORKING IN OVC AND PEDIATRIC HIV IN THE SECTOR

Name: Child Health Maternal Health STI
 Care and Treatment /Adults
 Care and Treatment /Peds PMTCT VCT
 HBC OVC

Name: Child Health Maternal Health STI
 Care and Treatment /Adults
 Care and Treatment /Peds PMTCT VCT
 HBC OVC

Name: Child Health Maternal Health STI
 Care and Treatment /Adults
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 HBC OVC

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 Care and Treatment /Peds PMTCT VCT
 HBC OVC

Name: Child Health Maternal Health STI
 Care and Treatment /Adults
 Care and Treatment /Peds PMTCT VCT
 HBC OVC

Guidelines Available for OVC and Pediatric HIV services

Guidelines present on site

Guidelines for Clinical Management of HIV/AIDS (ART, OIs)

Response

- Yes, specify: _____ N/A
- No
- Observed TOLD AT NEARBY OFFICE

Guidelines for PMTCT

- Yes, specify: _____ N/A
- No
- Observed TOLD AT NEARBY OFFICE

Guidelines for counseling and testing for adults

- Yes, specify: _____ N/A
- No
- Observed

Guidelines for care and support for orphans and vulnerable children

- Yes, specify: _____ N/A
- No
- Observed

Handbook on Pediatric AIDS in Africa (ANECCA)
Other relevant guidelines

- Yes No
- Told it is In a Medical Officer's office – did not observe

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Are there information, education and communication (IEC) materials available for the patients

- General HIV education
- General ART issues
- ARV side effects and their management
- Opportunistic infections
- Medication use
- Adherence support
- Pediatric HIV and AIDS

STAFFING AND CAPACITY FOR PEDIATRIC HIV CARE AND TREATMENT

	Total Number	# of each type provider providing pediatric HIV Care	# trained in IMCI-HIV	# trained in pediatric HIV care
Medical Officers (1 ENT, 2 surgeons, 1 physician, 1 pediatrician, 1 gynecologist)				
Asst MO				
Clinical officer				
Nursing Officer				
Nurse Midwife				
Nurses (all other levels)				
Nurse attendant or hospital assistant				
Health Assistant				
Others				

SERVICE STATISTICS

Question

Response

Number of infants born to HIV positive mothers who return to the facility for follow-up

Number of HIV exposed infants on CT prophylaxis

Number of HIV-infected children who are currently on ART in the facility

_____ < 15 years
 _____ below 2 years
 _____ above 2 years

How many children (<15 y.o.) have been put on or referred for ART while on the in-patient ward (2007).

None
 Number: _____

How many children have been put on or referred for ART from the MCH/OPD/Ped OP clinic in last month?

None
 Number: _____

How many children have been put on or referred for ART because their parents are on ART?

None
 Number: _____

Comments