Balasahyoga

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Credits:
Content : Balasahyoga team & Renuka Motihar (Consultant)
Editing : Kavita Sharma (Consultant)
Design : FACET Design, D-9 Defence Colony, New Delhi
Photo : Cover (Shaju John, FHI 360); Separators (D. Srinivas, CHAI)
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FHI 360/India
H-5, Green Park Extension, (Ground Floor)
New Delhi – 110016
India

Tel : 0091.11.40487777
Fax : 0091.11.26172646
Email : fhiindia@fhiindia.org
Website : www.fhi360.org

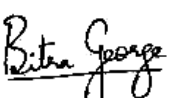
Foreword

The harsh impact of HIV and AIDS epidemic is often highlighted with images of damaged adult lives. The destructive disease, however, far transcends these images and some of its most vulnerable victims are children. The figures are significant. In India, the number of children infected by HIV stands at about 100,000, which is 3.5 percent of the people living with HIV in the country. Another group to consider are the children affected by HIV and AIDS — orphaned due to the disease or living with parents infected by HIV. It is estimated that India has 4 million children affected by AIDS (CABA), most from the high-prevalence states of Andhra Pradesh, Maharashtra, Tamil Nadu, Karnataka, and the northeast region.

The children affected by HIV and AIDS face multiple vulnerabilities: loss of parents to the disease, low food security and malnourishment, depletion of asset base and livelihood opportunities, and dropping out of school to supplement family income. In view of these risks and vulnerabilities, the Government of India has designed the CABA Scheme to support these children's access to services in the areas of health, education, nutrition, psychosocial support, legal support, socioeconomic protection, and alternate care. The scheme has been piloted in 10 districts and needs to be scaled up to make greater impact.

Aiming to improve the quality of life of these affected children, a consortium of FHI 360/India, Clinton Health Access Initiative, and CARE India implemented Balasahyoga, a five-year comprehensive care, support, and treatment program, in 11 districts of Andhra Pradesh. The program supported CABA through a comprehensive package of services with a continuum-of-care approach. Balasahyoga worked at both community and facility levels to improve demand for services and enable the Government to respond to this improved demand.

The Balasahyoga Monograph outlines the issues faced by CABA, the program's multiple strategies, its progress in improving access to services, and the outcomes and impact of the program over the five years of its implementation. The monograph also aims to provide useful lessons to those engaged in work with CABA and their caregivers. I congratulate Balasahyoga's consortium partners and the team in coming out with this valuable document that comprehensively presents the approaches, achievements, and lessons learnt in improving access to services vital to the well-being of CABA and their families.



Dr. Bitra George
Country Director
FHI 360/India

Contents

Abbreviations

AAP	Annual action plan
Ab Test	Antibody test
ADM&HO	Additional District Medical and Health Officer
AIDS	Acquired immuno deficiency syndrome
ANC	Antenatal care
ANM	Auxiliary Nurse and Midwife
APSACS	Andhra Pradesh State AIDS Control Society
ART	Antiretroviral therapy
ARTC	ART Center
ASHA	Accredited Social and Health Activist
AWC	Anganwadi Center, a Government-operated preschool
BMI	Body mass index
BSY	Balasahyoga
CAB	Community advisory board
CABA	Children affected by AIDS
CCC	Community Care Center
CEO	Chief executive officer
C&G	Contracts and grants
CHAI	Clinton Health Access Initiative
CHAHA	A care support and treatment program funded by Global Fund
CIFF	Children's Investment Fund Foundation
CTX	Cotrimoxazole
CoE	Center of Excellence
CV	Community volunteer
DAPCU	District AIDS Prevention and Control Unit
DNA PCR	Deoxyribonucleic acid polymerase chain reaction
DQA	Data quality assessment
EID	Early infant diagnosis
EJAF	Elton John AIDS Foundation
FBF	Fortified blended food
FCM	Family case management/family case manager
FGD	Focus group discussion
FSW	Female sex worker
GoAP	Government of Andhra Pradesh
GoI	Government of India
HH	Household
HIV	Human immunodeficiency virus
HRG	High risk group
HSS	HIV sentinel surveillance
IAP	Indian Academy of Pediatricians
ICDS	Integrated Child Development Scheme
ICTC	Integrated Counseling and Testing Center
IDU	Injecting drug users
IHHT	Intensive household tracking
INR	Indian rupee
KIT	Royal Tropical Institute, Netherlands
LFU	Loss to follow up
LP	Lead partner
LSE	Life skills education
MB pair	Mother-baby pair
M&E	Monitoring and evaluation
MIS	Management information system

MSM	Men having sex with men
MuAC	Mid upper arm circumference
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
NFHS	National Family Health Survey
NGO	Nongovernmental organization
NIN	National Institute of Nutrition
NRC	Nutrition Rehabilitation Center
NRHM	National Rural Health Mission
NVP	Nevirapine
OI	Opportunistic infection
OVC	Orphans and other vulnerable children
ORW	Outreach worker
PDS	Public distribution system
PIP	Project implementation document
PLHIV	People living with HIV
PPTCT	Prevention of parent-to-child transmission
QA/QI	Quality assurance/quality improvement
QoL	Quality of life
RG	Reference group
SAM	Severe acute malnourishment
SD	Standard deviation
SFI	Severe food insecurity
TAP	Technical assistance partner
UNICEF	United Nations Children's Fund
USDA	United States Department of Agriculture
WHO	World Health Organization

Executive Summary

Despite India's impressive economic and social gains in the last few decades, its abysmal health record has consistently proved challenging. In 2008, India was home to 2.27 million people living with HIV (PLHIV), exceeded in numbers only by South Africa and Nigeria. However, concerted efforts in preventing the spread of HIV infection have controlled it to the level of a concentrated epidemic, with low prevalence rate of 0.29 percent.

Although estimates for children affected by AIDS (CABA) are unavailable for India, reports indicate that 3.5 percent (nearly 100,000) of the estimated PLHIV in India are children. UNICEF estimates put India's CABA population at 4 million, located mostly in the high HIV-burden states of south and northeast India. Andhra Pradesh is among the states with the highest HIV prevalence rates in India, recording 21 percent of the country's estimated PLHIV population. The figure includes an estimated 17,500 children living with HIV. Significantly, program data shows the state's CABA population could exceed 150,000.

Existing programs have not always addressed the specific vulnerabilities of these children. The National AIDS Control Programme (NACP – III) has primarily focused on HIV prevention, restricting care, support, and treatment to the provisions of antiretroviral therapy (ART). Moreover, the specific issues of CABA have been given less priority.

In view of this critical need, a comprehensive care, support, and treatment program for CABA and their families was initiated in April 2007. Named **Balasahyoga**, the five-year program was implemented by a consortium led by **FHI 360/India** along with **Clinton Health Access Initiative (CHAI)** and **CARE India**, in partnership with **Andhra Pradesh AIDS Control Society (APSACS). Children's Investment Fund Foundation (CIFF)** and **Elton John AIDS Foundation (EJAF)** supported the program, which ended in March 2012. The driving goal of Balasahyoga was "to improve the quality of life of children and families infected and affected by HIV."

The program was launched in the high-prevalence southern Indian state of Andhra Pradesh and targeted 68,000 CABA in 44,100 families spread across 11 districts of the state. It employed innovative family case management (FCM) approach, improving the quality of life of CABA and their families by facilitating access to a comprehensive package of health, education, nutrition, psychosocial support, and safety net services. Collaboration with various departments of the Government of Andhra Pradesh (GoAP), donors, grassroots NGOs, and evaluation partners aimed to ensure the program's robust implementation.

Balasahyoga used multiple strategies to optimize catchment, including scale up to new mandals[1], placement of outreach workers, data sharing with HIV testing and treatment facilities, and broad basing community referrals to all sources. Due to its intensive efforts, the program was able to identify and register 47,976 families in the 11 districts, exceeding the estimated target of 44,100 families. The figure comprised 72,632 children (5,866 infected and 66,766 affected) and 90,232 adults (51,539 infected and 38,693 affected), with an average of 1.51 children and 1.88 adults per household.

The program's family-focused approach employed multiple tools and processes to identify eligible children and their caregivers for a range of services. Home visits, counseling, and referrals to facilities, with focus on HIV testing and treatment needs, helped minimize loss to follow up (LFU). Consequently, Balasahyoga was able to test 88 percent of the eligible children and 94 percent eligible adults, as well as register 95 percent infected children and 92 percent infected adults for ART. Ninety-eight percent children and adults initiated on ART were successfully retained in treatment.

The program's vital focus on improving the overall quality of life (QoL) of CABA and their families resulted in significant achievements in quality of care, including access to prevention of parent-to-child transmission (PPTCT) services, with 99 percent pregnant women tested for HIV, counseling on PPTCT to 100 percent of the HIV-positive pregnant women, initiation and retention of 94 percent of these positive pregnant women on ART, and institutional deliveries for 97 percent of the HIV-positive pregnant women. In addition, 62 percent of the exposed children were tested through early infant diagnosis (EID) and 53 percent mobilized for HIV confirmatory test upon reaching the age of 18 months. The program enabled school enrolment and retention of 90 percent children in ages 6–14 years; enrolment among 15–18 year olds stood at 71 percent, an increase of 30 percent over Year 1 of the program.

Balasahyoga's food security assessments of households at the time of their registration showed high levels of food insecurity (86 percent). Aiming to ensure nutritional support for children in HIV and AIDS-affected households, the program worked on two fronts: first, provision of supplementary nutrition to infected children at ART centers (ARTCs) to prevent malnourishment and improve ART adherence; and second, advocacy with the Government's Women and Child Development Department to ensure access to 'double rations' for 4,000 (56 percent) CABA in the age group of 0–6 years through Anganwadi centers. The program worked with various Government departments to link 98 percent of the registered households to the public distribution system (PDS), enabling access to subsidized or free rice, including 6,700 households accessing free food grains through the Anthyodaya Scheme[2].

Additionally, Balasahyoga enabled direct financial support to 4,795 HIV and AIDS-affected households to take up income-generation activities. An independent assessment of income-generation activities showed significant increase in monthly income from these small investments: INR 1,500 increase in monthly income for 40 percent households, INR 1,500–3,000 for 32 percent households, and above INR 3,000 for 10 percent households. Further, 33 percent of the households that were provided financial support showed enhanced food security levels.

The program also took cognizance of the psychosocial support needs of children and adults affected by HIV and AIDS. These individuals experience trauma, stigma, and discrimination at various levels. Balasahyoga provided age- and status-specific counseling to adults and children and gave life skills education (LSE) to children in ages 8–18 years. It also promoted PLHIV support groups and community advisory boards (CABs) to overcome stigma and discrimination.

Balasahyoga recognized the crucial need to improve infrastructure and systems at ARTCs, as these issues

[1]Administrative unit below the district level
[2]A Government of India scheme to provide subsidized food grain to the "poorest of the poor"

adversely impact the quality of service delivered to children and their caregivers. The program refurbished 19 ARTCs, introduced data management and QA/QI (quality assurance/quality improvement) systems, and built capacities for pediatric counseling. The efforts included advocacy with the Government for allocation of additional space and optimal use of existing spaces for ARTCs, creation of children's play areas, and prioritized service delivery to children. The resulting gains in quality of service reflected in better QA/QI[3] scores as well as improved child friendliness and reduction in waiting time. Improved data management and tracking of ART LFU clients proved important in facility strengthening. It also helped streamline the computerized management information system (CMIS) software, enabling identification of LFU cases, sharing the lists with outreach workers, and bringing the LFU cases back into treatment.

The learning from Balasahyoga was used to advocate with Government departments to significantly improve services for HIV and AIDS-affected children and their families. The program's key achievements include successful collaboration with other civil society organizations to develop operational guidelines and pilot the CABA Scheme, data sharing agreement with HIV facilities, introduction of 'double rations' for CABA below 6 years of age, and establishment of linkages with various Government departments to provide safety net and livelihood services to CABA families.

Consistent with its outcome-based approach, Balasahyoga had a comprehensive MIS for the community component and worked with the facilities to improve their monitoring systems. The MIS also supported evaluation by providing information on services delivered to each of the individuals and households registered with the program. The individual tracking system also provided line lists of CABA in the 11 districts, which would be of vital use later in the design and implementation of large-scale CABA programs.

The program conducted process evaluations of its three components — the FCM approach, facility strengthening, and income-generation activities — through external agencies to document the process of service delivery and assess the extent to which the needs of CABA and their families were met by the program. Findings of external evaluations noted that the program has overachieved on its targets and contributed substantially toward improved access to testing and treatment services, such as, getting eligible children tested for HIV, increasing registration for ART, and ART uptake. The evaluation also commented on the program's success in improving access to Government schemes, enabling CABA and their families to achieve better levels of food security. Direct financial support to the most vulnerable households not only reduced distress and improved food security levels but also enabled diversification of asset base and livelihoods. The strategy of addressing social protection needs of the household by building safety net and livelihood linkages instead of focusing only on the child helps to make the family resilient. Similarly, the program's intervention in facility strengthening improved the quality of service delivery while also building capacities and ensuring continuance of program activities.

Information from MIS, process evaluations, and the external evaluation provided a comprehensive picture of Balasahyoga's activities, strategies and processes of implementation, and the impact of the program. The scale-up of the program was most intense during its final two years, as a result of which the mean exposure time[4] of children to the program was relatively short at two years, with children enrolled in the first year having an exposure time of 3.3 years. Hence, from a broader development perspective it

[3]The QA/QI system assesses ARTCs on aspects of accessibility, patient flow, human resources, infrastructure, reports and records, supply chain management, infection control, referrals and back referrals, access to outpatient services, child friendliness, drug counseling, and assessment of ART eligibility.
[4]Exposure time is calculated based on the date of registration in the program and date of de-registration/closure of the program.

may be too early to assess the potential impact of the program, especially for children enrolled in the last two years. The transfer of specific strategies piloted by the program to the Government of India (GoI) provides a unique opportunity to further explore long-term effects on the quality of life of the target group. It could in turn inform the replication process in other states of India.

In its recommendations the evaluation stressed on the need for further support to the current transitioning and mainstreaming efforts, such as building the capacity of Accredited Social Health Activist (ASHA) and Auxiliary Nurse Midwife (ANM) and establishing and strengthening coordination mechanisms. It also suggests piloting and introducing an approach where the level of support is better geared toward the needs of the most vulnerable groups, like double-orphaned children, grandparent-headed households, and children from key populations.

Balasahyoga's implementation brought forth some important lessons, the key among them being the value of integrated family-focused programs that work in collaboration with Government agencies. The program demonstrated the strength of multi-sector programs, while pointing to the need of managing multiple stakeholders and building partnerships that are synergistic and complement each other.

One of Balasahyoga's key successes has been its contribution to the development of guidelines for GoI's CABA Scheme and demonstration of the model with a pilot in one of the program districts. The way forward for the program is to partner with state and national governments to adapt its continuum-of-care approach to other parts of the country. This is an opportune time as National AIDS Control Organisation (NACO) will shortly roll out the fourth phase of NACP, and convergence with National Rural Health Mission (NRHM) is being adopted as a key strategy to scale up HIV programs across the country. Balasahyoga's comprehensive, collaborative strategy could contribute in the design, development, and implementation of continuum-of-care approaches that can ensure need-based care and support for all affected and infected children.

HIV and AIDS and Children in India

CHAPTER

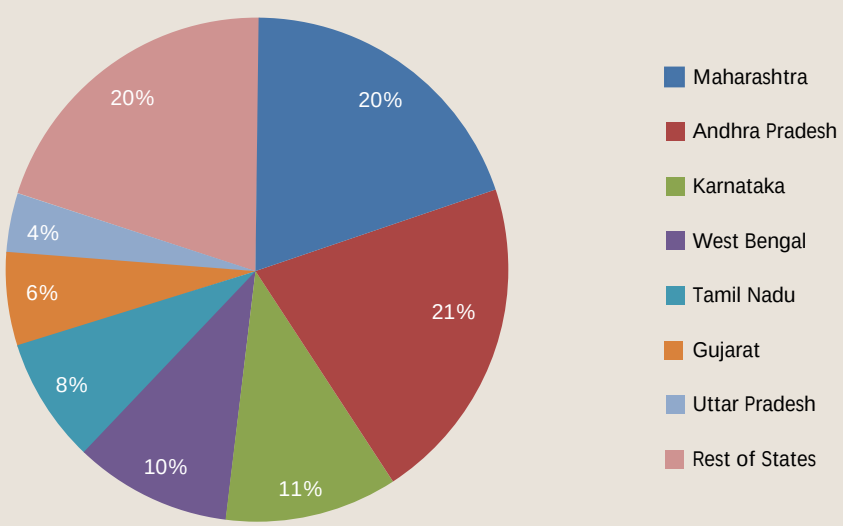
1

HIV and AIDS and Children in India

The HIV epidemic in India, first recognized in 1986, is 25 years old and ranks among the most serious public health concerns in the country. In 2008, an estimated 2.27 million people between the ages of 15–49 years were living with HIV. Although home to the world's third-largest population of HIV-infected people (following South Africa and Nigeria), India has witnessed declining spread of HIV infection and its prevalence rate stands at 0.29 percent.

Within the country, HIV prevalence shows a diverse geographic spread across states and districts, with southern states and the northeast region reporting high prevalence rates. The distribution of PLHIV across India shows that the southern states of Andhra Pradesh (21 percent), Maharashtra (20 percent), Karnataka (11 percent), and Tamil Nadu (10 percent) bear the heaviest burden of HIV. More specifically, 195 priority districts in the country were identified for

Figure 1: Distribution of PLHIV in India



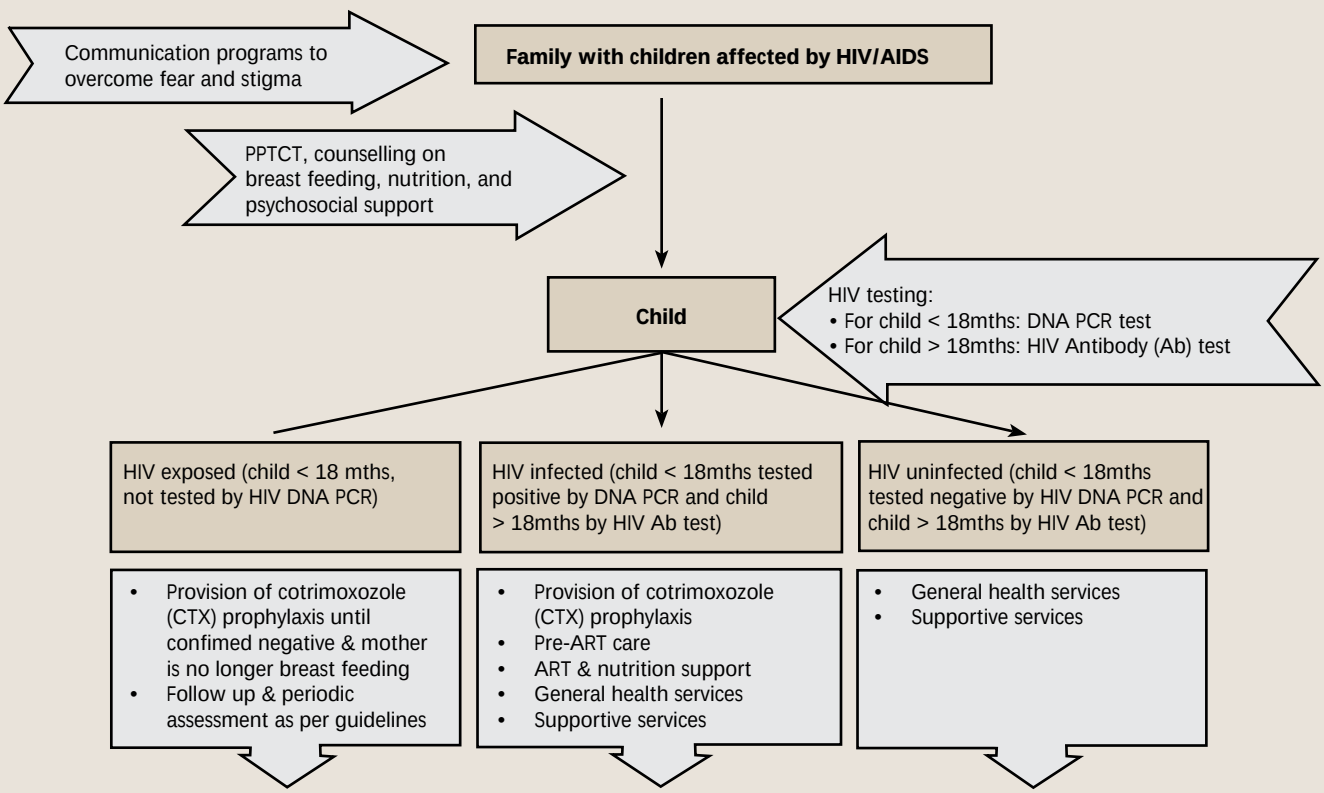
focused programmatic interventions, based on the prevalence rates recorded by HIV sentinel surveillance (HSS) 2007. The preliminary results of HSS 2008–2009 revealed dissimilar trends across states, pointing to a continuously changing distribution of the HIV epidemic in India. While the HSS noted an overall decline in HIV prevalence among antenatal care (ANC) attendees, especially in high-prevalence states, it also observed an increased trend in some low and moderate prevalence states, such as Gujarat, Rajasthan, Orissa, Uttar Pradesh, Bihar, and West Bengal.

The spread of HIV in India is primarily driven by the high-risk group of individuals engaged in unprotected/ commercial sex work, unprotected anal sex between men, and injecting drug users (IDUs). More than 90 percent of the infected women acquire HIV infection from their husbands or intimate sexual partners who are within the high-risk group. The wider implication of this situation is that in almost 6 percent of the cases in 2008, the route of HIV transmission was from mother to child.

Children Affected by HIV and AIDS

India's HIV and AIDS epidemic has made countless children vulnerable to physical, economical, and psychological risks. The affected children (below the age of 18 years) include those themselves infected

Figure 2: Services to be delivered under Government of India's CABA Scheme



Referral mechanism to access services

- **Health services** (general, paediatric HIV) and safe water, sanitation and hygiene (part of health services at the program level)
- **Psychosocial support** (counselling & life skills education)
- **Nutrition** (supplementary, fortified)
- **Education** (formal, non-formal, special and compensatory tuitions)
- **Social protection/economic support** (child rights and entitlement, legal protection & redressal)
- **Alternative care for orphans** (foster care, extended family, adoption & institutional care)

by HIV, children made orphans by AIDS, and those with parents infected by HIV or made chronically ill by AIDS-related illnesses. Programmatic interventions and research with HIV infected and affected children are internationally grouped under "orphans and other vulnerable children" (OVC). In India, NACO categorizes this group as "children affected by AIDS" (CABA).

While the estimates for children affected by AIDS are unavailable for India, reports indicate that 3.5 percent (nearly 100,000) of the estimated 2.4 million PLHIV in India are children[5]. UNICEF estimates that India could be home to about 4 million CABA, located mostly in the high HIV-prevalence states of south and northeast India. While HIV and AIDS bring significant difficulties to the lives of all affected children, those orphaned by AIDS are a particularly vulnerable group due to the social, economic, and psychological risks they face. Nearly 80 percent of the children who lose a parent to AIDS are likely to have a surviving parent with critical care and support needs[6]. In addition, loss of parents often leads to depletion of asset base and erosion of livelihood options, impacting growth and development of children and their continuance in education.

There is an urgent need to address the multiple vulnerabilities of CABA in a comprehensive manner to ensure their overall well-being and holistic development. It is important that a large-scale, multifaceted strategy be put in place to address the health, nutrition, education, psychosocial support, and economic needs of CABA and secure their rights and entitlements. The broad needs of CABA were outlined in GoI's framework for implementing the CABA Scheme (2010), which was piloted in 10 districts during 2011–2012.

HIV and Affected Children in Andhra Pradesh

The southern state of Andhra Pradesh is among the five high HIV prevalence states of India. It is home to 21 percent of the estimated 2.27 million PLHIV population of India. This includes an estimated 17,500 children infected with HIV.

- Andhra Pradesh contributes 21 percent of the country's HIV burden.
- The state's general population has low awareness about HIV/AIDS: 13.7 percent among women and 32 percent among men. (NFHS-3).
- All 23 of the state's districts are high-prevalence districts with ANC prevalence of >1 percent.

The state has consistently shown high levels of HIV prevalence. All 23 districts of Andhra Pradesh are categorized as 'A,' with 1 percent or more prevalence amongst ANC attendees. While all districts across the state have been categorized as high burden, the districts in coastal Andhra region and Hyderabad in Telangana region show higher prevalence, evident in the number of PLHIV registered at ARTCs.

Although estimates for children affected by HIV are lacking, program data has revealed the presence of more than 150,000 CABA in Andhra Pradesh. An overwhelming majority of these children have little or no access to support services that can ensure well-being and protect their future. The key factors responsible for HIV- and AIDS-affected children's poor access to services are:

- Prevention and treatment are focused on adults; pediatric ART was introduced only in 2006 and early infant diagnosis in 2010.
- Facilities are not treating the family as a unit, resulting in low identification of infected children and partners.

[5] Bharathi Ghanashyam: India failing children orphaned by AIDS. Lancet. Vol 375;2010 pg 363-4.
[6] Richter L, Stein A, Cluver L, de Kadt J: Infants and young children affected by HIV/AIDS. In: HIV/AIDS in South Africa 25 Years On: Psychosocial Perspectives. Edited by Rohleder P, Swartz L, Kalichman SC, Simbayi LC. New York: Springer Press; 2009.

- There is lack of knowledge about existing HIV care, treatment, and support services.
- Absence of continuum-of-care approach and lack of follow up result in high dropout from care and treatment services.
- Delayed testing and identification lead to high mortality rates. Of the total child deaths, only 37 percent had been tested although 87 percent belonged to HIV-positive mothers (based on Balasahyoga monitoring data).

Balasahyoga: Helping Children by Supporting Families

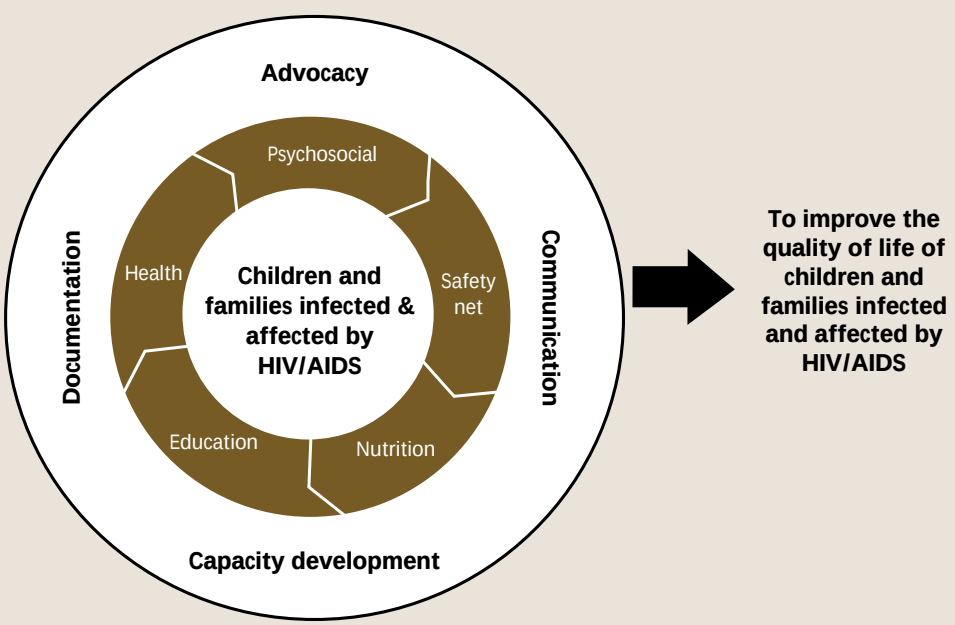
CHAPTER

2 Balasahyoga: Helping Children by Supporting Families

Balasahyoga, meaning "active support to the child," is a systematic and studied response to the wide-ranging needs of children affected by HIV and AIDS. Existing programs have not always addressed the vulnerabilities of these children and their caregivers with need-based, comprehensive services. Balasahyoga has aimed to bridge this gap by empowering the affected children's families and facilitating their access to care, support, and treatment services.

Launched on 17 April, 2007, the five-year program (April 2007–March 2012) was implemented by a consortium led by FHI 360/India along with Clinton Health Access Initiative (CHAI) and CARE India,

Figure 3: Balasahyoga's domain of services



in partnership with Andhra Pradesh AIDS Control Society (APSACS). Children's Investment Fund Foundation (CIFF) and Elton John AIDS Foundation (EJAF) supported the program. Brief profiles of these organizations have been shared in Annexure 1.

Goal and Objectives

Balasahyoga's driving goal was "to improve the quality of life of children and families infected and affected by HIV."

With its aim of improving the target population's access to a comprehensive package of vital services, the program set for itself the following impact indicators:

- Decreased mortality among children living with HIV/AIDS
- Decreased morbidity among children and/or their parents living with HIV/AIDS
- Decreased number of children orphaned by HIV/AIDS
- Decreased number of children infected by HIV

The following objectives aimed to realize the program's goal:

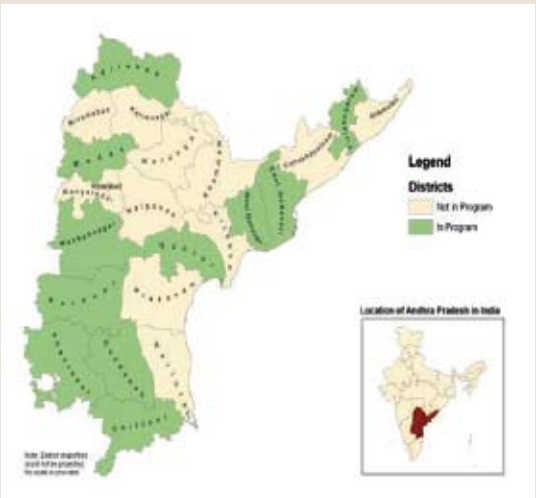
1. Improve access to continuum-of-care services for the children infected and affected by HIV/AIDS and their families

2. Demonstrate a sustainable and replicable model of HIV care, treatment, and support services delivery

Coverage of the Program

The target population for the program was 68,000 CABA in 44,100 families spread across 11 districts of Andhra Pradesh. All households with one infected individual (either alive or dead), with children below 18 years in the family, or with pregnant HIV-positive mothers were eligible to be part of the program. Balasahyoga was launched in 11 of 23 districts of the state, namely, Guntur, West Godavari, East Godavari, Vizianagaram, Chittoor, Anantapur, Cudappah, Kurnool, Medak, Mahbubnagar, and Adilabad. The remaining 12 districts were covered by the CHAHA program, supported by Global Fund and implemented by HIV Alliance India.

Figure 4: Districts covered by Balasahyoga



Implementation Guided by Critical Success Areas

Balasahyoga's design was strengthened through the development of an integrated model of service delivery, with clear definitions of critical success areas and key performance indicators to measure progress. The program defined five critical success areas to guide implementation and measure overall progress.

1. **Optimize catchment:** Cover 80 percent geographical area (districts and mandals) and saturate coverage of CABA by establishing referral systems with facilities (HIV testing, care, and treatment) and community-based sources (PLHIV networks, other NGO-run programs, and support groups)

2. **Minimize loss to follow up:** Ensure access to testing and treatment services and minimize LFU between the stages of HIV testing and treatment

3. **Strengthen quality of care:** Ensure the target population's access to superior quality of care in the areas of health, education, psychosocial support, nutrition, and safety net services

4. **Strengthen systems and capacities:** Build capacities of HIV facilities to provide superior services to CABA and their caregivers

5. **Advocacy:** Work with Government departments in health, education, women and child development, rural development, and civil supplies to improve the target population's access to services

Focus on Family

Balasahyoga worked at both community and facility levels to improve access to continuum-of-care services for CABA and their families. Central to the program was the employment of the innovative FCM approach, wherein teams of outreach workers were each assigned 125–150 households within a contiguous area to facilitate the target population's access to a package of services on the basis of eligibility. Each FCM team comprised one family case manager (FCM) and two community volunteers (CVs). These teams used various tools to assess the needs of CABA and their caregivers and prepared family care plans, outlining prioritized needs. They facilitated access to services through home visits, counseling, and referrals to facilities. The teams also coordinated and advocated with service providers to prioritize service delivery to CABA and their caregivers.

Comprehensive Package of Services

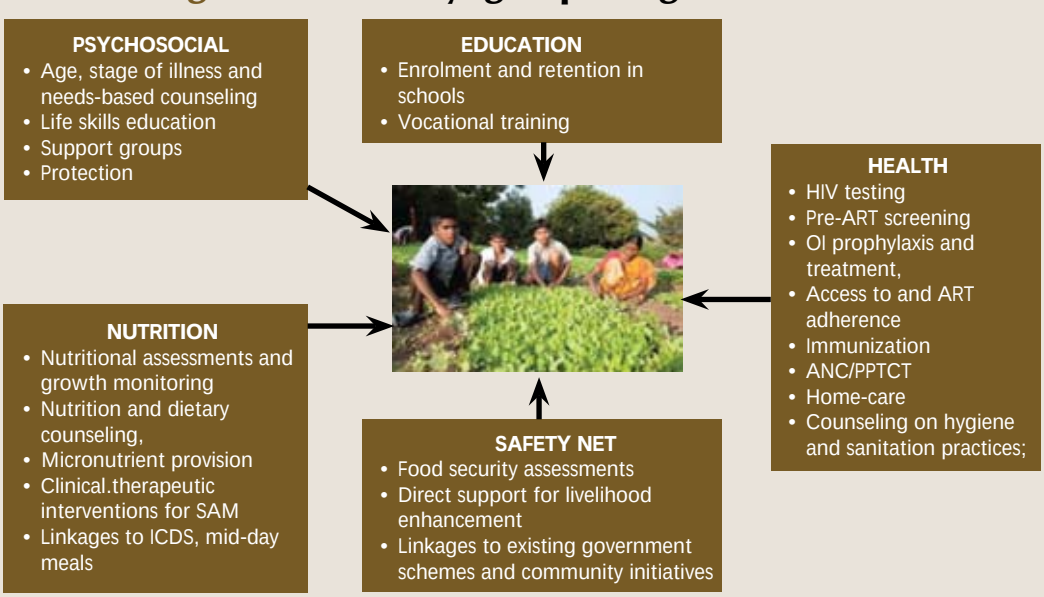
Balasahyoga aimed to ensure that CABA and their families have access to a comprehensive package of health, education, nutrition, psychosocial support, and safety net services.

Collaboration with Stakeholders

The program engaged multiple stakeholders — various departments of the Government of Andhra Pradesh (GoAP) under the guidance of APSACS, the donors (CIFF and EJAF), technical assistance partners, lead partners, and the evaluation partner. The roles of each of these stakeholders in the implementation of the program are outlined below.

Government of Andhra Pradesh: Balasahyoga worked with various Government departments at state and district levels to improve the target population's access to services within the existing Government systems. The departments included APSACS, the nodal agency responsible for implementing HIV programs and providing HIV services to the infected and affected people; Department of Women and Child Development, which addresses children's needs and is responsible for providing nutrition and preschool education to children; Department of Education, which bears the responsibility of enrolling

Figure 5: Balasahyoga's package of services



and retaining children in schools and mainstreaming the dropouts through bridge schools; Ministry of Civil Supplies, the agency responsible for providing access to subsidized food grains through PDS; and Department of Rural Development, which is responsible for ensuring access to income-generation activities and other livelihood services.

At the district level, the program worked with district AIDS prevention and control units (DAPCUs), under the guidance of Additional District Medical and Health Officer (ADM&HO), who oversees health service delivery in a district. The program also coordinated with heads of various line departments at district and mandal levels to improve access to services.

Donors: CIFF and EJAF provided financial support for Balasahyoga's implementation. CIFF supported the community-based component and the facility-strengthening component, implemented by FHI 360/India and CHAI, respectively. EJAF supported the safety net component, which was implemented by CARE India. Donor support covered program design, strategizing, and evaluation, resulting in the design and implementation of a coherent, integrated program model. It reflected in joint work plans, an integrated monitoring and evaluation framework, and the sustainability plan developed for the program.

Implementation partners: FHI 360/India led the consortium, working alongside CHAI and CARE India, its consortium partners, to implement the program.

FHI 360/India provided overall management support to the program and was responsible for the community-based component, including creation of demand and improved access to services. CHAI held the responsibility for the facility-strengthening component, encompassing facility refurbishment, capacity building of facility staff, improving data management and quality assurance systems, and ensuring provision of fortified blended food (FBF) to infected children. CARE India was responsible for implementing the safety net component through improved access to a range of safety net services, such as subsidized food grains and pensions, skill building, and income generation support to 10 percent of the families, especially those headed by children, widows, or grandparents.

"The three organizations complemented each other. They retained their own identities but worked for a common project."

— Sumita Taneja, Director, Programs, FHI 360/India

Technical assistance partners (TAPs) and lead partners (LPs): Local NGOs worked as Balasahyoga's technical assistance partners, implementing community-based and safety net components through FCM teams to identify and register eligible children and their families in the program. The program partnered with 20 TAPs across the 11 districts to implement the community-based component. The program also had four LPs, again local NGOs, who provided technical and management support to TAPs. Partnership with two TAPs was discontinued during Year 3 and Year 4, and the operational area and coverage was assigned to other partners in the district. Names of the TAPs engaged in program implementation and the duration of their engagement is illustrated below.

Figure 6: Scale up of Balasahyoga by TAPs

S#	Name of TAP / Period of engagement	Year 1	Year 2	Year 3	Year 4	Year 5
1	NATURE					
2	St. Paul's Trust					
3	Pragati					
4	RISDT					
5	DLC					

S#	Name of TAP / Period of engagement	Year 1	Year 2	Year 3	Year 4	Year 5
6	APPLE					
7	SEEDS					
8	SHIP					
9	St Xavier's					
10	WINS					
11	ROPES					
12	PASS					
13	RISE					
14	WDT					
15	PAID					
16	CERDS					
17	VWCS					
18	HCHW					
19	RMHSS					
20	MAP+					
21	Asha Jyothi					
22	ADP+					

Evaluation partner: Royal Tropical Institute (KIT), Netherlands, along with SWASTI, Bangalore, provided evaluation support to Balasahyoga, assessing its progress in achieving goals and objectives.

Key Milestones

During the course of its five years, Balasahyoga was shaped by key events, both internal and external. Internally, periodic reviews by CIFF and EJAF had a significant influence on the program, and externally, the framing of guidelines for the CABA Scheme at the national level became a defining event. Some of the important milestones of the program are highlighted below in a chronological order.

Balasahyoga: Year 1 (2007–2008)

1. Launch of Balasahyoga: The program was launched on 17 April, 2007, by the then Chief Minister of Andhra Pradesh Dr. YS Rajashekhar Reddy, signifying the importance accorded to the program by the state Government.

2. Start of field operations and first phase of scale up: Balasahyoga's community level operations started from Q2 of Year 1, with launch of community outreach in four districts through four TAPs. Its field operations expanded to one more district in Q3 and to two more districts in Q4, taking the first phase of scale up to seven districts with 10 TAPs.

Figure 7: Balasahyoga's launch

Chief Minister of Andhra Pradesh Dr. YS Rajashekhar Reddy launching the Balasahyoga program on 17 April, 2007, in presence of Ms. Jamie Cooper-Hohn, president and CEO of CIFF, and Mr. Rosaiah, Minister for Health, GoAP

3. Review by CIFF and EJAF: The donors conducted an internal review of the program in February 2008, taking stock of progress and assessing the program's operational evolution at the field level.

Balasahyoga: Year 2 (2008–2009)

4. Re-planning: After the review, CIFF suggested some strategic changes to the program, resulting in a revised implementation plan during Q1 and Q2 of Year 2. The revised plan aimed at integrating the three components — community, facility, and safety net — as well as establishing logical linkages within the various components and their contribution to the overall goal of the program. This further led to the development of a joint work plan, highlighting critical success areas and key performance indicators.

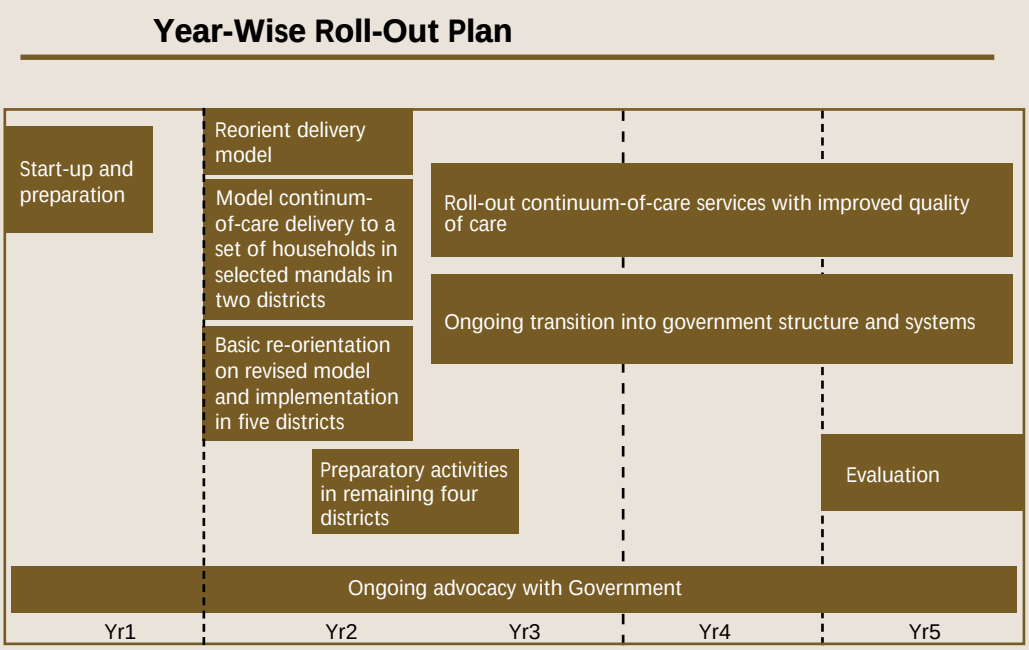
5. Pilot of the revised model: The revised model was piloted in two districts (Guntur and West Godavari) at the start of Q3 Year 2 for an initial period of six months. It was later scaled up to all the districts in Year 3.

Balasahyoga: Year 3 (2009–2010)

6. Scale up of operations: In Q1 Year 3, the revised model was scaled up to cover seven districts, with focus on saturation of coverage through expansion to new mandals. It was expanded to four more districts in Q3 Year 3.

7. Strengthening quality of care: The nutrition component was made operational in Q3 Year 3 with the roll out of FBF for infected children. The service was launched on a pilot basis at an ARTC in Kurnool district before being scaled up to seven districts by the end of Year 3. Additionally, food supplementation for all affected children was also introduced through the Integrated Child Development Scheme (ICDS). Tracking of pregnant mothers and follow up for PPTCT services started in Q2 Year 3. With the aim of reaching the most vulnerable households, the

Figure 8: Phases of the revised model rolled out in Year 2 after the re-planning exercise



targeting for safety net services was also revised to focus on households headed by children, widows, or grandparents.

8. First round of evaluation: Data collection for the first round of evaluation took place during August 2009–January 2010. This included data from intensive household tracking (IHHT) of children and caregivers in West Godavari and from facilities in West Godavari, Kurnool, and Medak.

9. Revision of key performance indicators (KPIs): Review of assumptions and incorporation of changes in the program over the preceding two years necessitated the crucial exercise of revising KPIs and targets.

Balasahyoga: Year 4 (2010–2011)

10. Second phase of safety net component: This key component, funded by EJAF and implemented by CARE India, was initially planned for three years. In Year 4, it was extended for two more years to align with the duration of other components. Extension of the component also aligned with the revised strategy of targeting 2,400 of the most vulnerable households with direct financial support for taking up income-generation activities. It also sought to ensure access to safety nets like PDS and pensions (widow, disability, old age, and on-ART) and facilitate wage and self-employment for 2,000 individuals.

11. Saturation of coverage: Following the geographical scale up in Year 3, the program focused on saturating coverage of all eligible households, reaching the estimated target of 44,100 households.

12. Transition: Discussions on transitioning Balasahyoga's processes to Government agencies were initiated in Year 4, resulting in orientation of frontline functionaries such as ASHA and ANM on the program's tools and processes to facilitate early identification of CABA and their caregivers and establishing linkage to services. The transition coincided with discussions on NACP – IV at the national level and issuing of guidelines by NACO to initiate mainstreaming of HIV services within NRHM's health service delivery structures. Further discussions involved inclusion of programs for CABA in NRHM's implementation plan for the state.

Balasahyoga: Year 5 (2011–2012)

13. Reference group (RG) study: Data for this study was collected from West Godavari and East Godavari districts for children and caregivers with less than a month's exposure to Balasahyoga to derive the baseline QoL scores.

14. Second round of evaluation: Data for the second evaluation exercise was collected during Q3 and Q4. The sample included 940 children (400 RG and 540 IHHT) and their caregivers. Data from service providers at facilities and FCM teams was also collected from West Godavari, Kurnool, and Medak.

15. Transition: Frontline health functionaries (ANM and ASHA) were oriented to the program's approach and tools, keeping in view the NACP – IV mandate of integrating HIV services with NRHM. This was accompanied by discussions with GoAP to scale up services for CABA to all the districts of the state by including them in the project implementation plan (PIP) of NRHM and the annual action plan (AAP) of APSACS.

Optimizing Coverage to Maximize Impact

CHAPTER

3 Optimizing Coverage to Maximize Impact

Balasahyoga aimed to reach and support 44,100 HIV/AIDS affected households in 11 districts of Andhra Pradesh. As one of India's first comprehensive program to support CABA and their caregivers, the program sought to saturate coverage of eligible households in the area. It employed multiple strategies to optimize coverage and succeeded in identifying eligible children and households through facility- and community-based referrals.

Difficulties in Identification of CABA

Balasahyoga's aim of optimizing coverage was made difficult by lack of information, both identity and line lists, about children eligible for the program. This was especially true for CABA, whose identities are not recorded at HIV testing and treatment facilities as neither is the family examined as a unit nor is an individual actively screened for marital and child status.

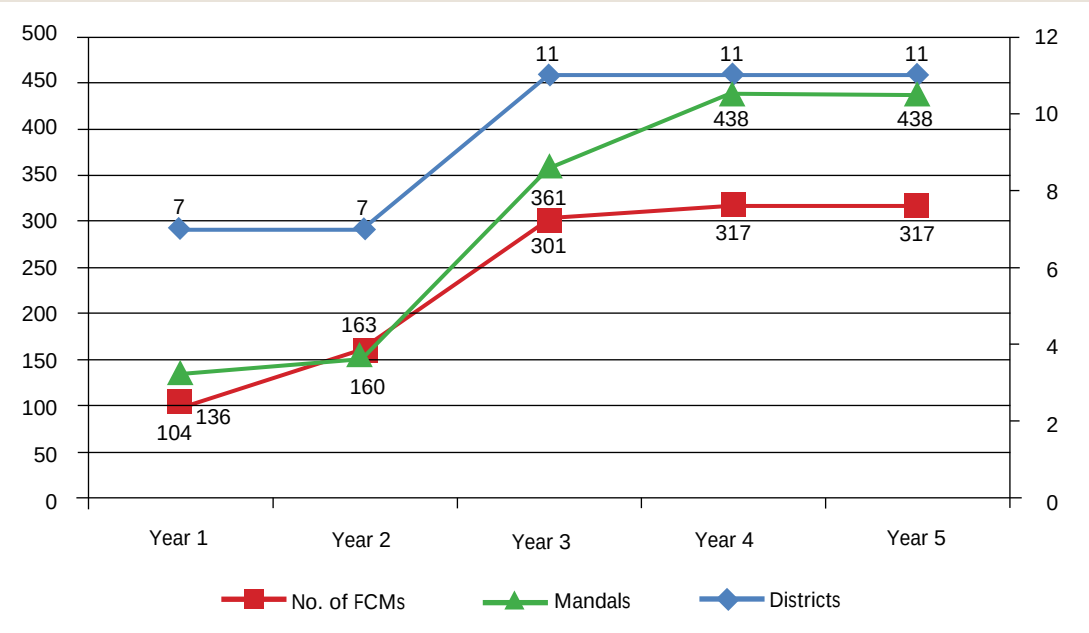
Another challenge arose from the issue of confidentiality of information about HIV-positive individuals. The identities of these individuals need to be protected due to threat of stigma and discrimination. Additionally, absence of any information-sharing mechanisms between HIV facilities and NGOs made it difficult to get information about the eligible children or their caregivers.

Multiple Strategies to Optimize Catchment

Balasahyoga employed a multipronged approach to optimize catchment, including scale up to new mandals and placement of FCMs, data sharing with HIV testing and treatment facilities, and broad basing community referrals to all sources.

District and mandal scale up: In the absence of any estimates for CABA at the state, district, and mandal levels, the program used cumulative data from HIV testing and treatment facilities to guide the scale up. The data helped in the placement of FCMs to register the identified children and their caregivers with the program as well as in follow up. The scale up also examined the feasibility of placing an FCM in a contiguous area with sufficient households available for registration in the program. The district- and mandal-wise scale up of Balasahyoga during its five years is tabulated below. The program's geographical coverage of districts and mandals witnessed a steep rise in Year 3, before saturation of coverage in Year 4.

Figure 9: Year-wise scale up in districts and mandals



Balasahyoga's district-wise scale up in terms of percentage of mandals covered is presented in the table below. A review of its geographical coverage shows that the program covered 74 percent geographical area of the 11 districts, with 100 percent coverage in the high-prevalence coastal Andhra region, 67 percent coverage in medium-prevalence Rayalseema, and 53 percent coverage in low-prevalence Telangana region.

Figure 10: District-wise and year-wise coverage (%) of mandals

District/Year	Total Mandals	Year 1	Year 2	Year 3	Year 4	Year 5
Guntur	57	54%	54%	100%	100%	100%
West Godavari	46	67%	67%	100%	100%	100%
East Godavari	59	24%	34%	93%	100%	100%
Vizianagaram	34	29%	44%	74%	100%	100%
Chittoor	66	45%	45%	68%	82%	82%
Anantpur	63	16%	16%	51%	56%	56%
Kurnool	54	19%	30%	46%	46%	46%
Cudappah	50	0%	0%	66%	84%	84%
Mahbubnagar	64	0%	0%	23%	47%	47%
Medak	45	0%	0%	44%	78%	78%
Adilabad	52	0%	0%	15%	38%	38%
TOTAL	**590**	**23%**	**26%**	**61%**	**74%**	**74%**

Data sharing agreement with NACO: In its second year, Balasahyoga negotiated with NACO to gain access to data on children and their caregivers from HIV facilities. The data sharing agreement required organizational undertaking by FHI 360/India to respect the confidentiality of clients' HIV status and to use the information only to ensure children's and their families' access to services. As part of the agreement, consent forms were placed at HIV testing and treatment facilities and offered to eligible clients to provide written consent for information sharing. Information about the consenting individuals was shared with the area's FCM team, which in turn contacted the individual for registration with the program.

Broad basing community referrals: Balasahyoga diversified its identification sources by establishing referrals through a wide range of community-based sources, including PLHIV networks, community elders/leaders, and other community-based HIV programs implemented by civil society organizations.

Engaging with the target population: Identification was only the first step in registering households with the program. The more important feat in optimizing coverage lay in locating the individuals and convincing them to engage and accept the services offered by the program. Many a times, referrals from facilities had inaccurate or incomplete addresses due to unwillingness of the identified individuals to share their contact details, mainly from fear of being stigmatized and discriminated. To overcome this problem, FCM teams consulted various community sources to triangulate information and identify cases where incomplete or inaccurate addresses had been given.

Convincing the individuals was not a one-time activity, and most households required multiple visits to be convinced to participate in the program. FCM teams successfully countered this challenge through perseverance and continued contact and by facilitating access to the services valued by the individual but beyond the mandate of the program.

Steps in the data sharing process

1. Facility counselor provides information about Balasahyoga and its services to eligible individuals.
2. Consent forms are made available to eligible individuals.
3. Consent forms and contact information of consenting individuals is collected.
4. The facility counselor periodically (weekly/fortnightly) shares this information with the FCM team.
5. The FCM team contacts consenting individuals and registers them with the program.

"We will be friendly with them, so they too will become close to us. Sometimes they will be rude to us, but we should be patient to convince them so that they can be friendly with us and share their problems with us."

— a community volunteer talks about rapport building with the target population

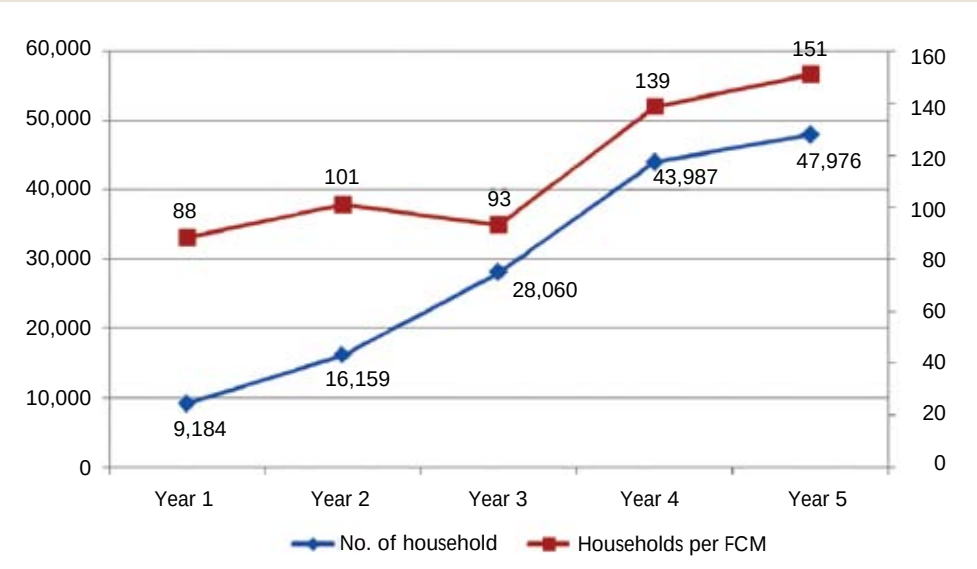
Exceeding Target Coverage

As a result of its intensive efforts in saturating coverage, Balasahyoga was able to identify and register 47,976 families, against its target of 44,100 families estimated for the 11 districts. The number comprised 72,632 children and 90,232 adults, with an average of 1.51 children and 1.88 adults per household.

A review of the scale up in household registration shows steep increases in Year 3 and Year 4, corresponding with increased geographical coverage and maturity of the data sharing agreement with facilities. The average number of households covered by each FCM also increased from 88 households per FCM in Year 1 to 151 households in Year 5.

A review of the sources of identification shows that 27,688 households (58 percent) were identified

Figure 11: Year-wise scale up for households and average households per FCM



through community sources and 20,288 households (42 percent) were identified through facility-based sources, especially from integrated counseling and testing centers (ICTCs) and ARTCs.

Referrals from ICTCs gradually increased from 12 percent (1,053 households) in Year 1 to 29 percent (4,610 households) in Year 4, contributing 24 percent (11,322 households) of the total registered number. This number denotes a significant achievement for the

Figure 12: Year-wise % of facility referrals by source

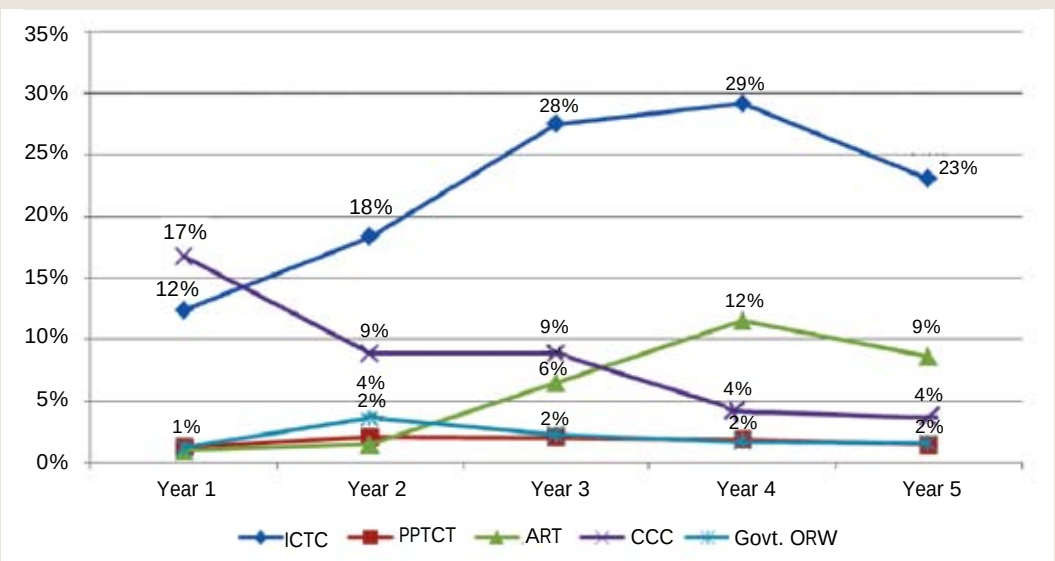
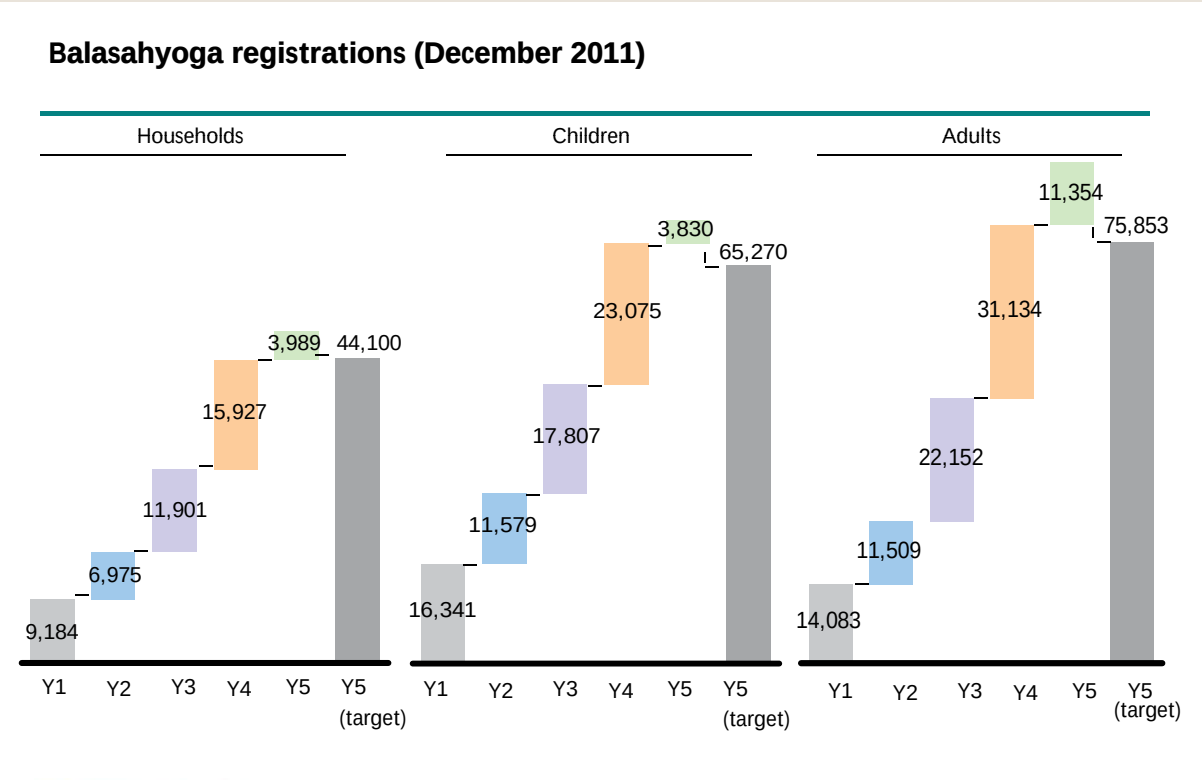


Figure 13: Year-wise registration of households, children, and adults



program, as identifying CABA and their caregivers at the testing stage is crucial in ensuring access to care, support, and treatment services.

Similarly, referrals from ARTCs gradually increased from 1 percent (83 households) in Year 1 to 9 percent (319 households) in Year 5, taking the total ARTC referrals to 7 percent (3,140 households). This reflects Balasahyoga's efforts in retaining individuals in treatment through follow up for treatment adherence and repeating CD4 test.

Examination of the registered households reveals a high percentage of vulnerable households, with 2 percent being child-headed (780 households), 38 percent widow-headed (18,008 households), and 9 percent grandparent-headed (4,158 households). Review of their income and asset base also shows high vulnerability, with mean annual income of INR 20,400 and only a few holding land (9 percent) and livestock (3 percent) as productive assets. Food security assessment of 46,027 households soon after their registration with the program found only 6 percent households to be food secure.

Age profile of the children registered in Balasahyoga showed 3 percent to be under 2 years of age, 9 percent in the 3–5 years age group, 28 percent in 6–10 years age group, 32 percent in 11–14 years age group, and 29 percent in 15–18 years age group. Profile of the registered children changed over the course of the program, with 2 percent children migrating to higher age groups and the adult category every year. Review of the living status of parents revealed that 8 percent children were double orphans and 40 percent were single orphans (35 percent paternal orphans and 5 percent maternal orphans).

Figure 14: Food security levels among households at the time of registration

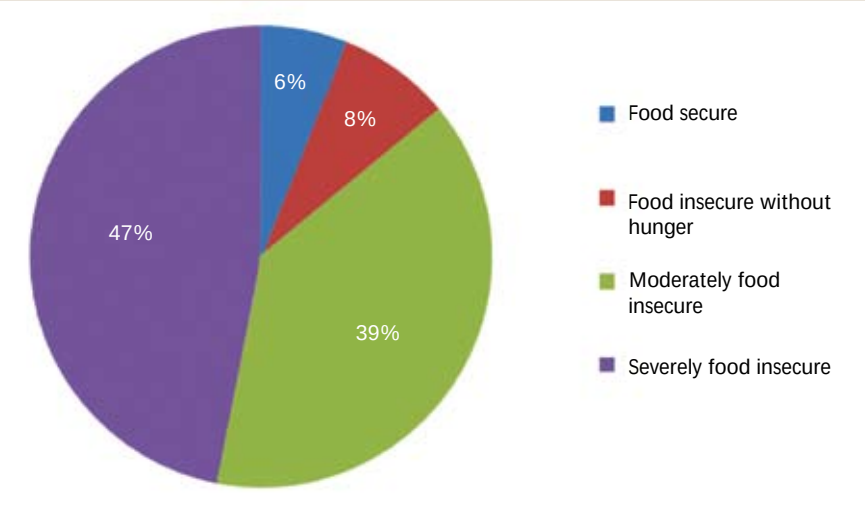
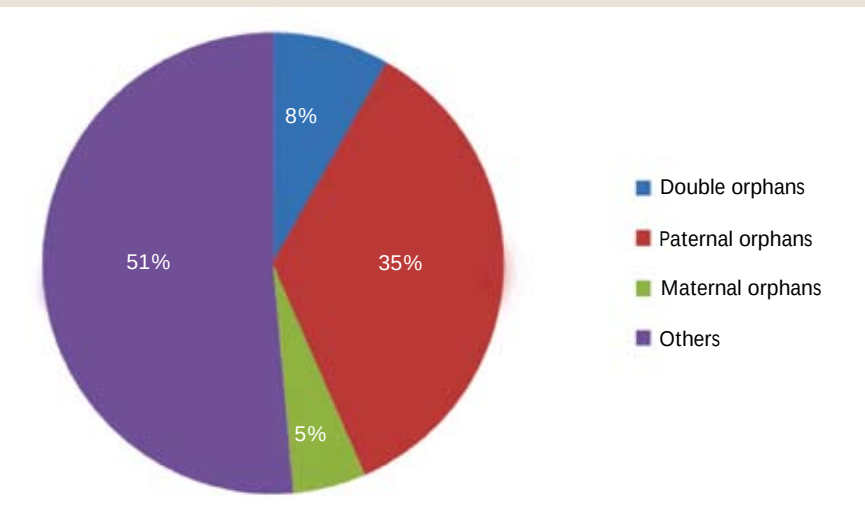


Figure 15: Orphan status of children registered in Balasahyoga



Lessons in Coverage Optimization

The program's efforts in optimizing catchment of CABA brought some important lessons that can inform similar programs and schemes and augment impact.

1. Data sharing with facilities is necessary to optimize catchment and enable early identification and linkage to life-saving services.
2. Broad basing community referrals is important and can prove crucial when the identified individuals drop out from services and cannot be tracked through facility referrals.
3. Screening all caregivers for their marital and child status is necessary to identify affected children.

Minimizing Loss to Follow Up

CHAPTER

4 Minimizing Loss to Follow Up

LFU represents a serious challenge for HIV and AIDS programs across the developing world, as significant numbers are lost between testing and treatment and through different stages of treatment. Balasahyoga's comprehensive approach for improving CABA and their caregiver's access to testing and treatment services minimized LFU through regular home visits and referrals.

Issues in Retaining HIV-Affected Individuals in Care

Several factors influence HIV-affected individuals' willingness and ability to remain part of the testing and treatment regimen. Lack of awareness about HIV and available services; high levels of stigma, both at individual and community levels; and distance to facilities reduce eligible children and their caregivers' access to testing and treatment.

Poverty-related barriers and loss of wages hinder access to services; for instance, many households cannot afford travel costs to reach treatment facilities located at a distant mandal or district headquarters. Insensitivity of service providers and lack of appropriate facilities at service delivery points also act as barriers. In addition, facilities treat clients as individuals rather than as part of a family unit, overlooking the need to screen children and spouse for eligibility to testing and treatment services. Insufficient and poor quality of counseling also contributes to LFU.

Combination of Methods to Prevent LFU

Balasahyoga adopted multiple strategies to identify eligible children and their caregivers for services and followed up with home visits, counseling, and referrals to facilities to minimize LFU. The testing and treatment cascade was accorded top priority during the re-planning process, with focus on minimizing LFU between testing and treatment stages for both children and adults.

Assessing family needs and eligibility for services: FCM teams followed the registration of

> "If the husband has HIV, the wife is tested. If the wife has HIV, they test children of up to 14 years of age. If the wife does not have HIV, we need not test the children. But those 14 to 18 years old must be tested, based on their habits. If found HIV positive, they will need to go for pre-ART registration. After checking their CD4 count we will know whether they need the medication (ART) or not."
>
> — an FCM explains the process for assessing eligibility for HIV testing and treatment

households with a comprehensive assessment of the needs of families and the eligibility of individuals and households for various services. The team made multiple visits to newly registered households to build rapport and collect information, which was documented in family case files, enabling FCM teams to plan and monitor delivery of services to each household.

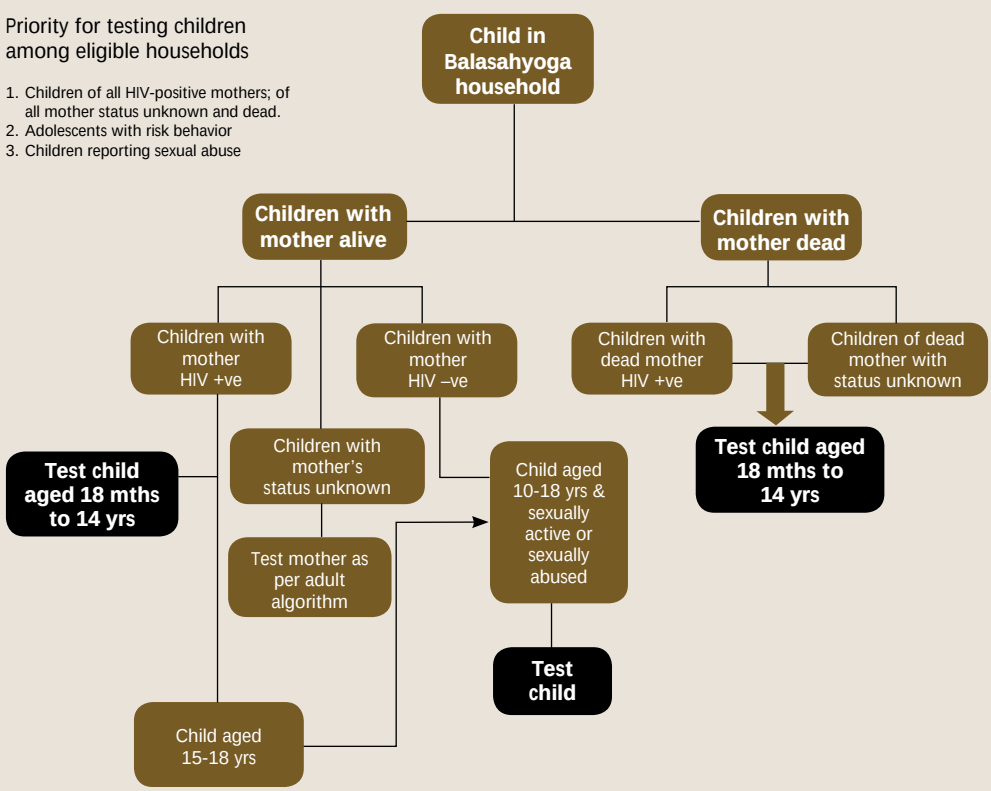
HIV testing and treatment algorithm: FCM teams used a step-by-step procedure to systematically assess the HIV testing and treatment needs of identified children and adults. Children with HIV-positive mothers were eligible for testing, as also were those whose mothers had died with unknown HIV status. HIV testing was encouraged for children below 15 years of age, while older children were mobilized for testing if they were sexually active and at risk of sexual exploitation.

Household visit prioritization tool: Home visit was a critical component of the program's strategy to reduce LFU. FCM teams made home visits to prepare individuals and families for accessing services and follow up. As each FCM was responsible for individuals in 125–150 households, home visits were prioritized based on needs of the family and its capacity to access services. The household visit prioritization tool helped manage the workload between FCM and CVs, with

"Generally we give priority to children. If an HIV-positive woman is pregnant, we take her for tests so that the newborn is not affected. We visit them once every week. We follow up after delivery also, and ask them to go for DNA test and give CTX syrup to the child."

— an FCM talks about monitoring HIV-positive pregnant women through regular contact

Figure 16: Testing algorithm for children



the latter handling routine monitoring while the FCM focused on critical services, such as mobilizing children for testing, counseling newly initiated individuals on ART, and following up with HIV-positive pregnant women.

Each area's FCM team visited all households at least once a month and was readily available for support. This continuous contact with registered families enabled FCM teams to provide information on available services, offer emotional support, prepare CABA and their caregivers to accept services, and build resilience.

Accompanying individuals and families to facilities: FCM teams accompanied identified CABA and their caregivers to facilities to familiarize them with service delivery processes, enabling them to access services on their own in future. The program also paid one-time cost of travel to most vulnerable individuals to overcome poverty-related barriers.

> "They do not know about ART center so we take them there and also to CC until they get their CD4 count. Sometimes it takes three to four days."
>
> — an FCM explains the process for accompanied referrals

Reduced LFU, Improved Outcomes

The perseverance and multipronged approach of FCM teams enabled CABA and their families to overcome barriers at both personal and facility levels. Balasahyoga achieved excellent results in testing, pre-ART registration, and retention on ART. The graph below highlights this trend.

Figure 17: Testing and treatment cascade for children in ages 0–14 years

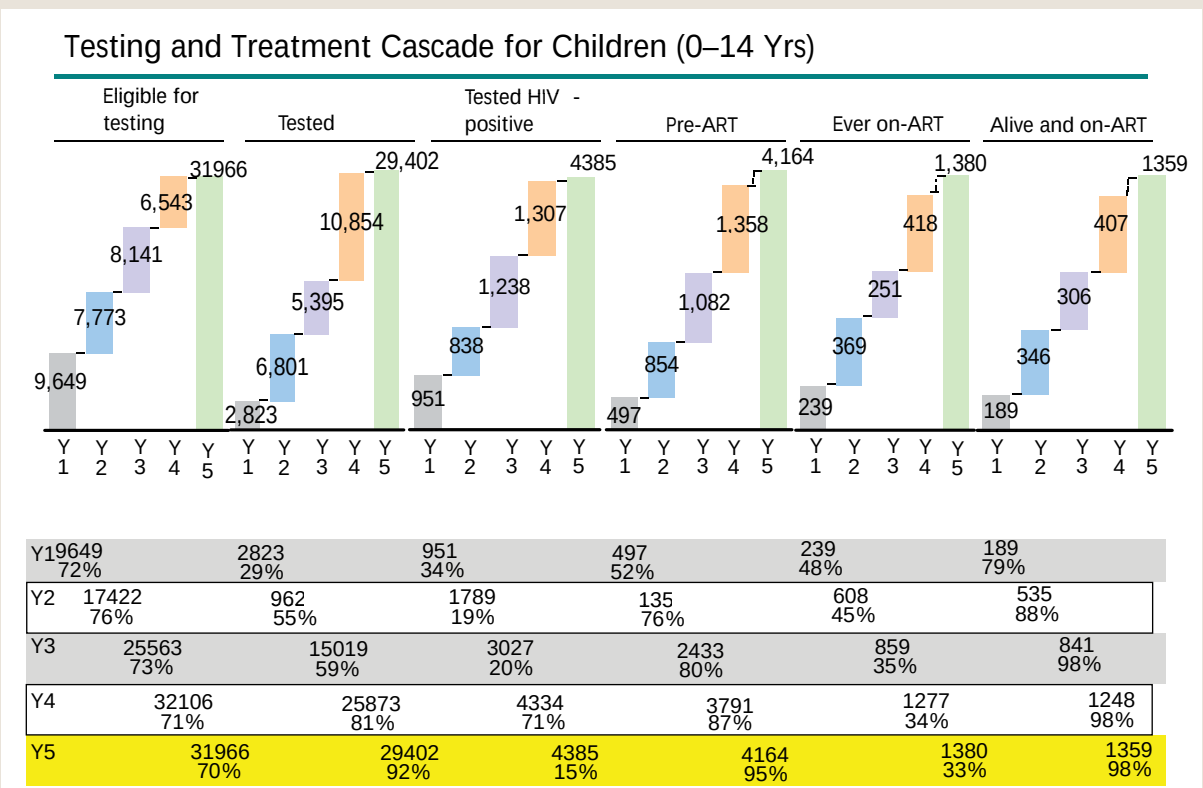
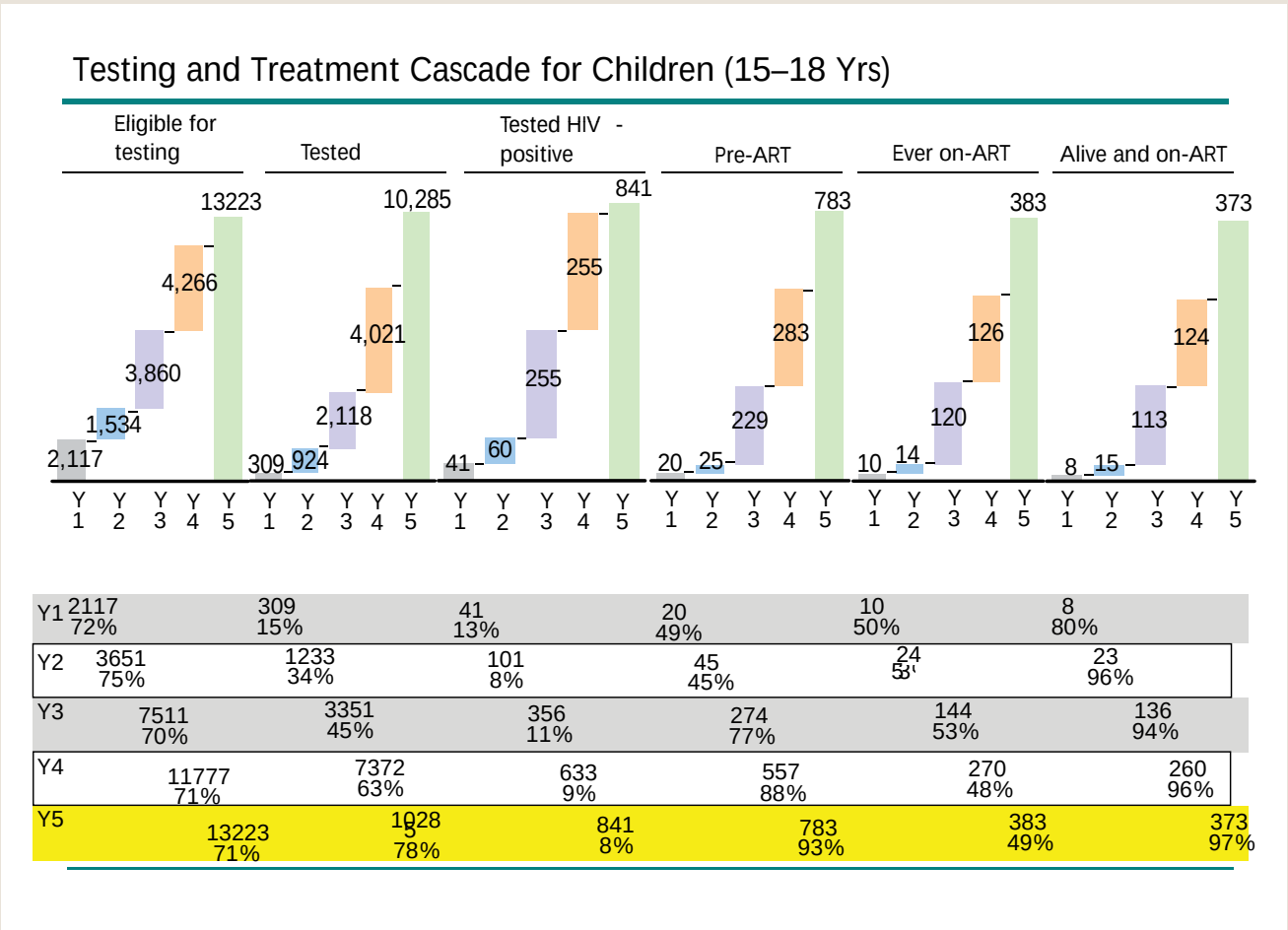


Figure 18: Testing and treatment cascade for children (15–18 years)

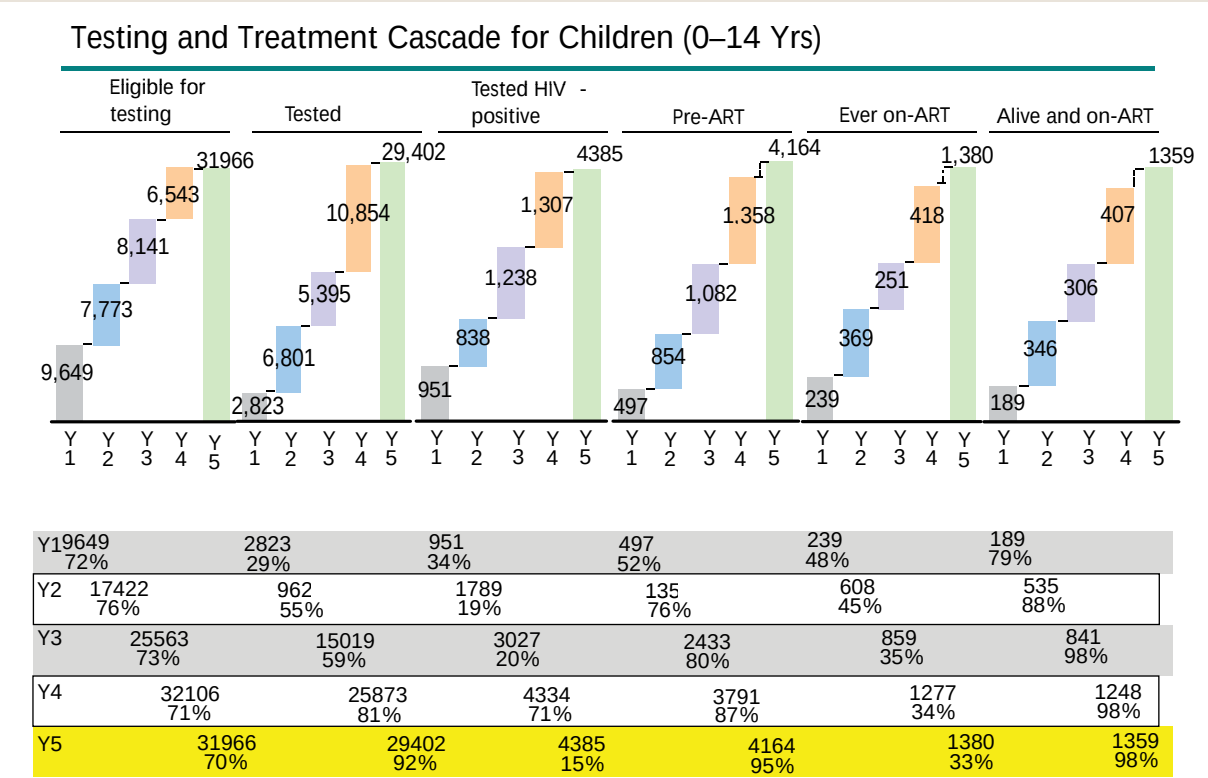


The testing and treatment cascade for younger children (0–14 years) shows that over the five years of Balasahyoga's implementation, testing rate among eligible children increased from 29 percent (2,823 children) in Year 1 to 92 percent (29,402 children) in Year 5; pre-ART registration of infected children increased from 52 percent (497 children) to 95 percent (4,164 children); and retention on ART treatment increased from 79 percent (189 children) to 99 percent (1,369 children).

The testing and treatment cascade for older children (15–18 years) shows that testing rate among eligible children increased from 15 percent (309 children) in Year 1 to 78 percent (10,285 children) in Year 5; pre-ART registration from 49 percent (20 children) to 93 percent (783 children); and retention on ART treatment from 80 percent (8 children) to 95 percent (363 children).

The testing and treatment cascade for adults shows increase in the number of tested eligible adults, from 89 percent (10,558 adults) in Year 1 to 94 percent (55,702 adults) in Year 5; infected adults registered for pre-ART went up from 25 percent (2,314 infected adults) to 92 percent (37,927 infected adults); and improved retention of those initiated on ART, rose from 78 percent (1,081 infected adults) to 98 percent (17,935 infected adults).

Figure 19: Testing and treatment cascade for adults



Analysis of CD4 Count Information for Infected Children and Adults

The program examined changes in CD4 levels for infected children and adults registered with the program. The sample included 2,940 children (1,745 in pre-ART and 1,195 on ART) and 21,204 adults (8,912 in pre-ART and 12,292 on ART) with more than one CD4 count result recorded in the MIS. The sample comprised individuals who were already on ART or in pre-ART at the time of registration to Balasahyoga as well as those initiated into ART after the registration.

Methodology

The analysis involved comparing the first CD4 count and the last CD4 count of the infected children and adults, who were categorized on the basis of their CD4 count as: very low (CD4 count < 200); low (CD4 count between 201–350); medium (CD4 count between 351–500); high (CD4 count between 501–1,000); and very high (CD4 count > 1,000). Changes in CD4 count levels of each individual were also studied and categorized as marginal (change by 1 level), moderate (change by 2 levels), significant (change by 3 levels), and very significant (change by 4 levels). Changes in CD4 count levels were classed in three primary categories (increase, decrease, and no change) and nine sub-categories (marginal increase, moderate increase, significant increase, very significant increase, no change, marginal decrease, moderate decrease, significant decrease, and very significant decrease).

"Yes, we understood that we too can lead a long life. I can't imagine how my life would have been if I had not known them. Now my CD4 count has increased from 63 to 473, with their encouragement for regular use of ART medicine."

— a registered HIV-positive woman expresses her appreciation for the efforts of the FCM team

Results

The data for both adults and children showed a significant increase in CD4 count for the group on ART and a marginal decrease for the group in pre-ART. Comparison of the first and last CD4 counts of children on ART, irrespective of the duration of ART exposure, showed an increase of 29 percentage points in higher CD4 range (very high: 14 percent; high: 15 percent).

Analysis of changes in the infected children's CD4 count (first and last count) over the duration of on-ART exposure showed a gradual increase in CD4 count as the duration increased. The increase in percentage points is detailed in the table below.

Similarly, comparison of first and last CD4 counts of adults on ART showed an increase of 33 percentage points (very high: 2 percent; high: 18 percent) irrespective of the duration between the first and the last CD4 counts.

Analysis of changes in infected adults' CD4 levels (first and last count) over the duration of on-ART exposure also showed a gradual increase in CD4 count as the duration on ART increased. The increase in percentage points is shown in the table below.

Figure 20: Baseline and end line comparison of CD4 levels in children

CD4 Levels	Pre-ART			On ART		
	First CD4 Count	Last CD4 Count	Diff	First CD4 Count	Last CD4 Count	Diff
Very Low (<200)	1%	1%	0%	27%	8%	-19%
Low (201–350)	9%	9%	0%	26%	17%	-9%
Medium (351–500)	19%	21%	2%	17%	16%	-1%
High (501–1,000)	52%	55%	3%	23%	38%	15%
Very High (>1,000)	19%	14%	-5%	7%	21%	14%

Figure 21: Increase (%) in CD4 levels among children over the length of on-ART exposure

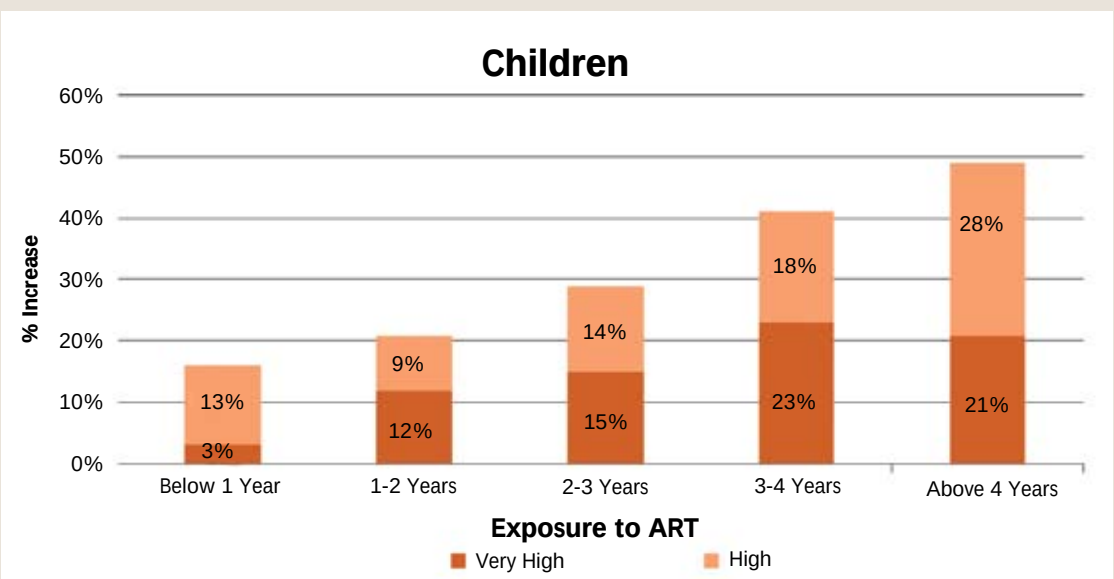
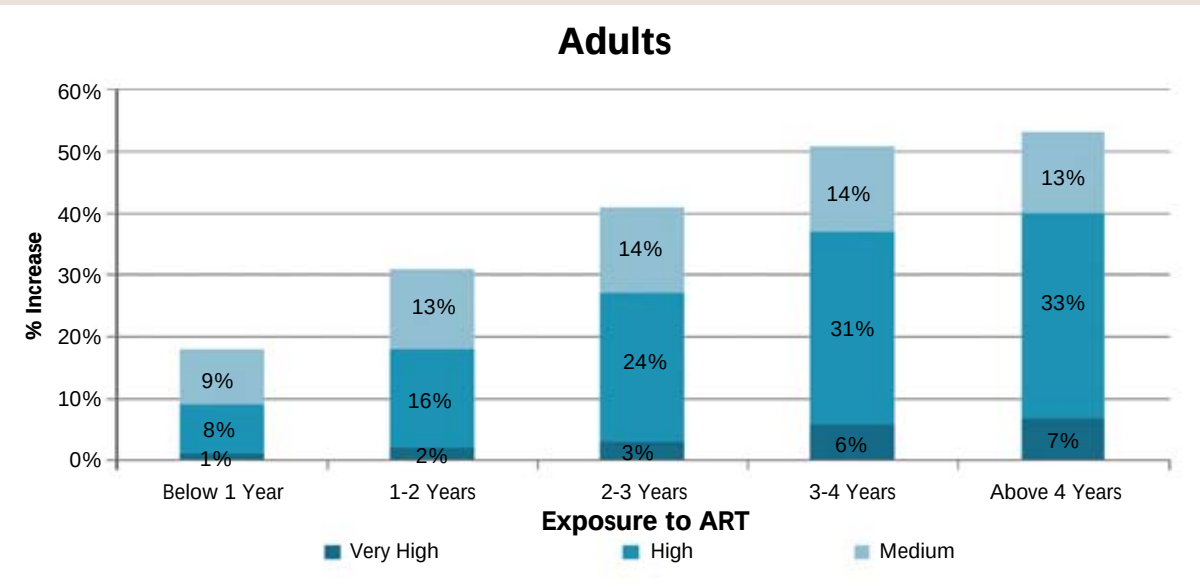


Figure 22: Baseline and end line comparison of CD4 levels in adults

CD4 Levels	Pre-ART			On ART		
	First CD4 Count	Last CD4 Count	Diff	First CD4 Count	Last CD4 Count	Diff
Very Low (<200)	3%	3%	0%	45%	14%	-31%
Low (201–350)	17%	19%	2%	31%	29%	-2%
Medium (351–500)	31%	32%	1%	13%	26%	13%
High (501–1,000)	44%	42%	-2%	10%	28%	18%
Very High (>1,000)	5%	4%	-1%	1%	3%	2%

Figure 23: Increase (%) in CD4 levels among adults over the length of on-ART exposure

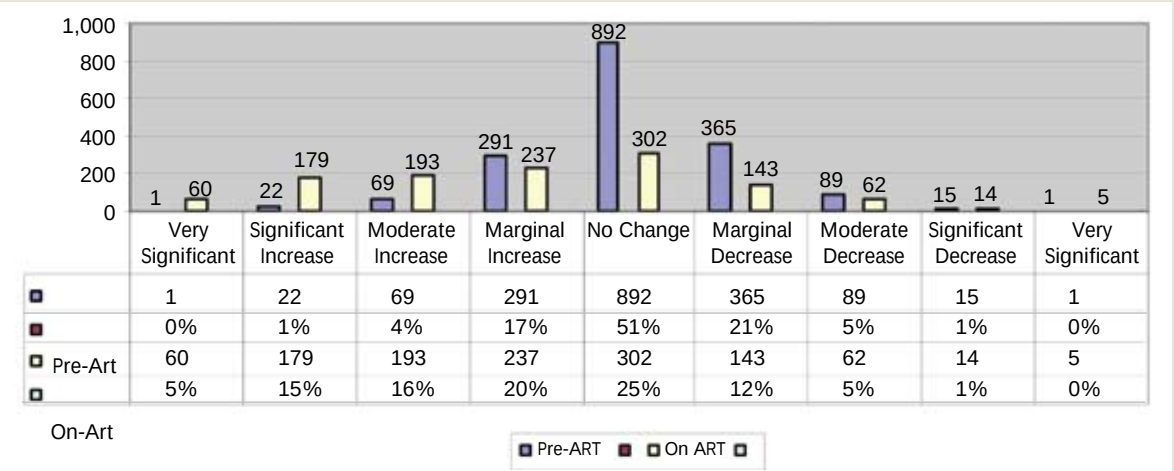


Comparison of increase in CD4 levels between pre-ART and on-ART groups

Examination of changes in CD4 levels in children showed a greater increase for the on-ART group, where 56 percent children reported increased CD4 levels, while only 22 percent children in the pre-ART group showed increased CD4 levels.

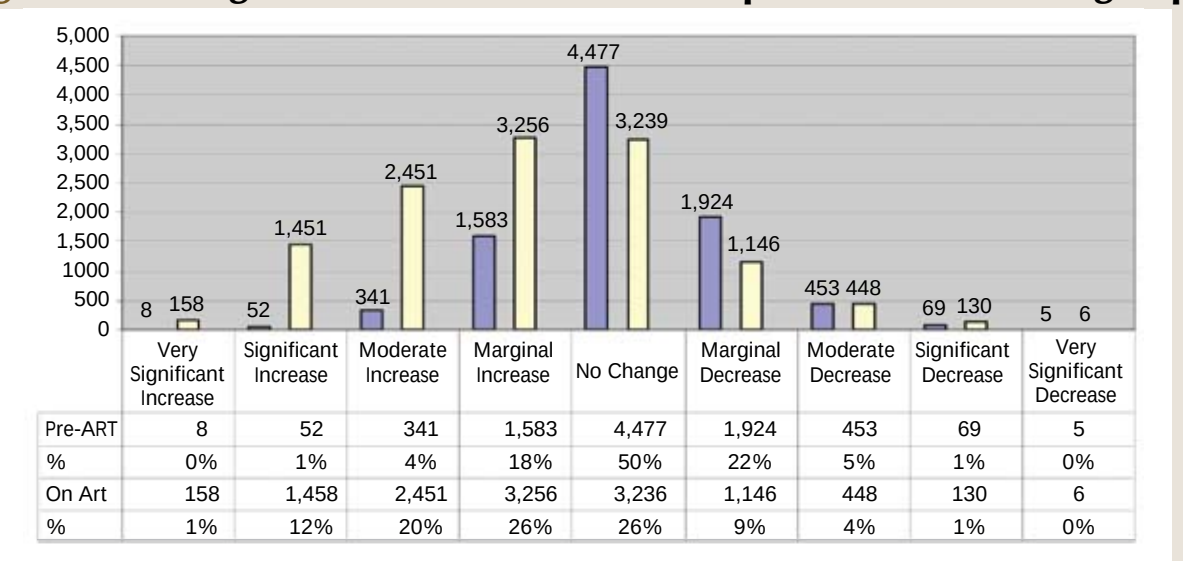
Among adults as well, analysis of changes in CD4 levels showed a greater increase for the on-ART group, where 60 percent adults reported increased CD4 levels, while only 23 percent adults in the pre-ART group showed an increase in CD4 levels.

Figure 24: Changes in CD4 levels for children in pre-ART and on-ART groups



	Very Significant	Significant Increase	Moderate Increase	Marginal Increase	No Change	Marginal Decrease	Moderate Decrease	Significant Decrease	Very Significant
	1	22	69	291	892	365	89	15	1
	0%	1%	4%	17%	51%	21%	5%	1%	0%
Pre-Art	60	179	193	237	302	143	62	14	5
	5%	15%	16%	20%	25%	12%	5%	1%	0%

Figure 25: Changes in CD4 levels for adults in pre-ART and on-ART groups



	Very Significant Increase	Significant Increase	Moderate Increase	Marginal Increase	No Change	Marginal Decrease	Moderate Decrease	Significant Decrease	Very Significant Decrease
Pre-ART	8	52	341	1,583	4,477	1,924	453	69	5
%	0%	1%	4%	18%	50%	22%	5%	1%	0%
On Art	158	1,458	2,451	3,256	3,236	1,146	448	130	6
%	1%	12%	20%	26%	26%	9%	4%	1%	0%

Lessons in Minimizing LFU

The program had considerable success in reducing LFU between testing and treatment stages for CABA and their caregivers. Efforts in the area brought some key lessons to the fore:

1. Screening of children based on their parents' HIV status is necessary to identify those eligible for testing and treatment. This is especially important in view of the poor awareness about HIV transmission modes.
2. Outreach is required to help CABA and their families overcome stigma and access available services, minimizing LFU between stages of testing and treatment.
3. Facility-based counseling, especially for children, must be strengthened to improve retention and adherence to treatment.

Improving Quality of Care

CHAPTER

5

Improving Quality of Care

HIV and AIDS significantly erode the quality of life of affected individuals. The damage is even more significant for children as the epidemic strikes at family support structures and creates new and growing vulnerabilities. Balasahyoga employed a multipronged approach to improve the overall quality of life of CABA and their families by facilitating access to superior services.

Balasahyoga's comprehensive package of services addressed needs in the areas of health, education, psychosocial support, nutrition, and safety nets. The program's specific goals, strategies, and achievements in each of these domains are examined in greater detail below.

Domain 1: Health

In the area of health, Balasahyoga aimed at ensuring access to PPTCT services and cotrimoxazole (CTX) prophylaxis for infected children and caregivers to prevent mother-to-child transmission and ensure well-being of exposed and infected individuals.

Prevention of parent-to-child transmission

PPTCT is a key intervention to control the spread of HIV among children. Lack of knowledge about routes of transmission and poor awareness about available services leads to low uptake of PPTCT services.

- Untreated, half of all HIV infected children die before the age of 24 months.
- With early diagnosis, care, and timely access to ART, mortality among HIV-infected infants and children can be reduced to 20 percent.

Coupled with limited early infant diagnosis, low PPTCT uptake contributes to high mortality among HIV-exposed children.

As part of its FCM approach, Balasahyoga focused on ensuring access to key PPTCT services for HIV-positive pregnant women. From Year 3 onward, the program placed special emphasis on services such as PPTCT counseling, ART for eligible mothers, institutional deliveries, and nevirapine for mother-baby pair (MB pair). The exposed newborns were further followed up for EID, HIV confirmatory test, and ART.

Achievement: The program identified 1,075 pregnant women and improved their access to PPTCT services, thereby contributing to reduced incidences of HIV transmission from mother to child. The table below provides details of increase in access to ANC services, HIV testing, registration and retention on ART, institutional deliveries, and access to nevirapine for eligible MB pair during the last three years of program.

Figure 26: PPTCT cascade

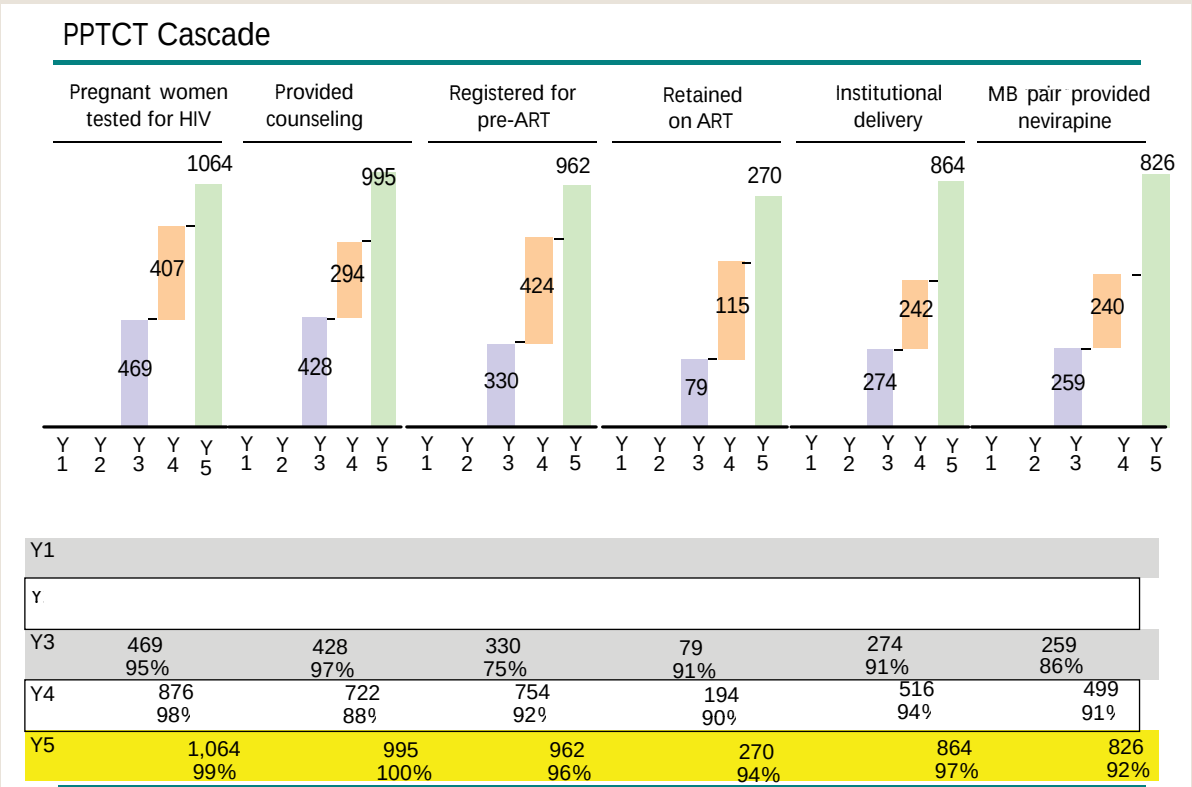
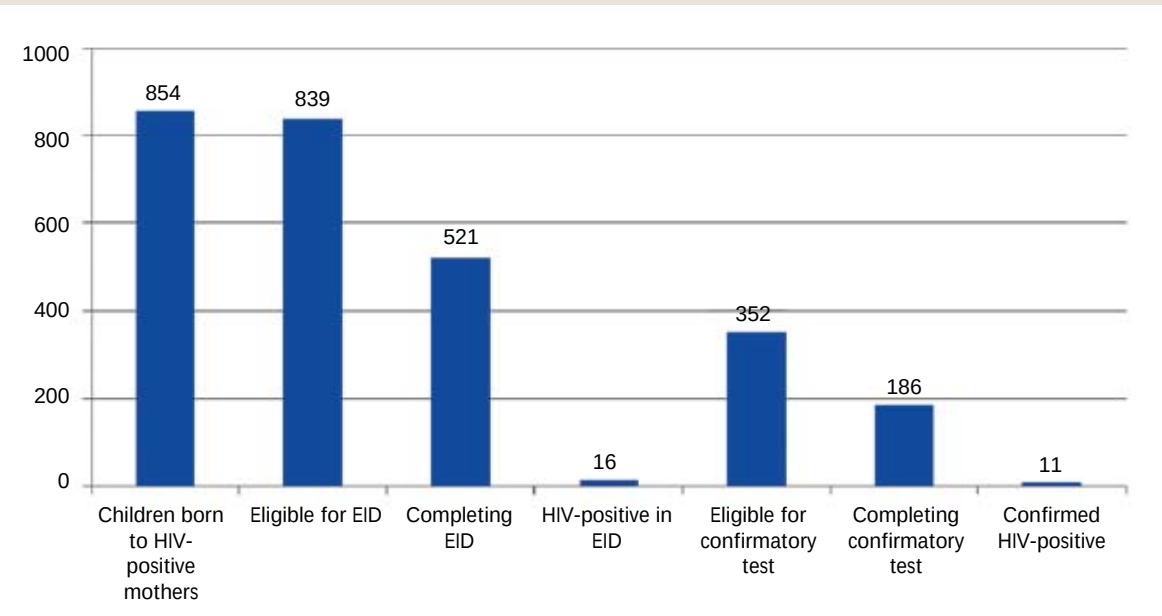


Figure 27: Testing of children born to HIV-positive mothers



PPTCT services bring hope to a young mother

Asha, 26 years, is a young mother from Kakinada. Both she and her husband are HIV positive. They have a 5-year-old daughter and a 6-month-old son. Asha is a housewife and her husband works as a night watchman. Their household was found to be moderately food insecure in the initial assessment.

Asha came in contact with the program when she was pregnant with her second child. She was given counseling and helped in accessing facilities. Asha delivered at the Government General Hospital in Kakinada, where she received ante- and postnatal care, and the MB pair was administered nevirapine. Asha also received double nutritional rations from the Department of Women and Child Development's ICDS Center for lactating mothers. She breastfed the baby and, on the advice of the FCM and the counselor, administered CTX liquid to the infant and got him immunized. The DNA PCR test for the child was found to be negative at three months. A confirmatory test is still awaited. Educational support (books and school bag) was given to Asha's elder child. Asha received family planning counseling and is preparing to undergo the female sterilization procedure at the Urban Health Centre in the near future. Both Asha and her husband are on ART and under CD4 monitoring.

Based on their eligibility, the pregnant women and exposed newborns were followed up on for access to CTX prophylaxis, HIV testing, and ART. Of the 854 children born to HIV-positive women, 98 percent (839) exposed children over 6 weeks old were eligible for EID. The program conducted EID for 62 percent (521) exposed children, of whom 3 percent (16) were found to be HIV positive. The exposed children were further administered the HIV confirmatory test on attaining the age of 18 months. Of the 352 exposed children over the age of 18 months, 53 percent (186) were mobilized for HIV confirmatory test, resulting in 6 percent (11) children being identified as HIV positive.

Access to CTX for infected children and adults

Management of opportunistic infections (OIs), both prevention and treatment, contributes to the overall health of HIV-infected individuals. Lack of awareness about management of OIs hinders timely access to CTX. Although CTX is available at health facilities for treatment of normal health ailments, vertical implementation of HIV programs impedes access to CTX at nearby health facilities.

Balasahyoga worked with Government facilities to make CTX available to infected individuals at ICTC and link ARTCs, reducing the need to travel to ARTC to avail the drug. In some districts the drug was given to FCM teams to distribute at the community level, based on physician's prescription.

Achievement: A review of information on infected children and adults accessing CTX during the five years of the program, shows increased uptake in numbers: from 1165 children in Year 1 to 3,028 children in Year 5 and from 8,093 adults in Year 1 to 23,008 adults in Year 5. However, when seen in terms of percentage of total infected children and adults accessing the drug, there are still considerable gaps, with only 58 percent infected children and 56 percent infected adults accessing CTX.

Domain 2: Education

CABA are often faced with disrupted family situations that result in loss of parental care and guidance, adversely impacting their education. Children who become orphans or have parents struggling with AIDS-related illnesses have interruption in education due to absenteeism and dropping out of school. The pressure to earn a livelihood contributes to high dropout rate,

"Now I only have to send him to school. They give school books, shoes, and uniform."

— a caregiver speaks about the support provided by the FCM team

Figure 28: Access to CTX for infected children and adults

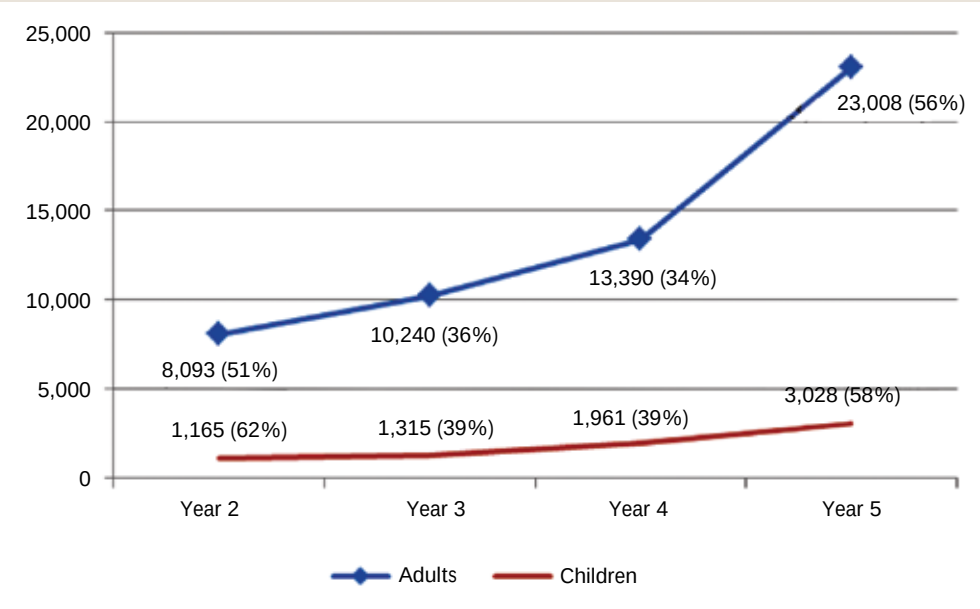
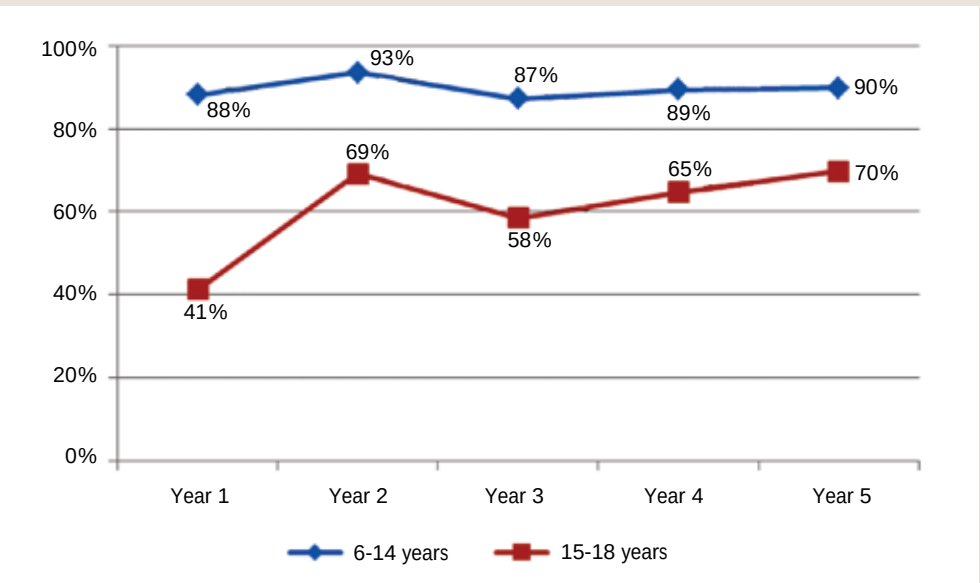


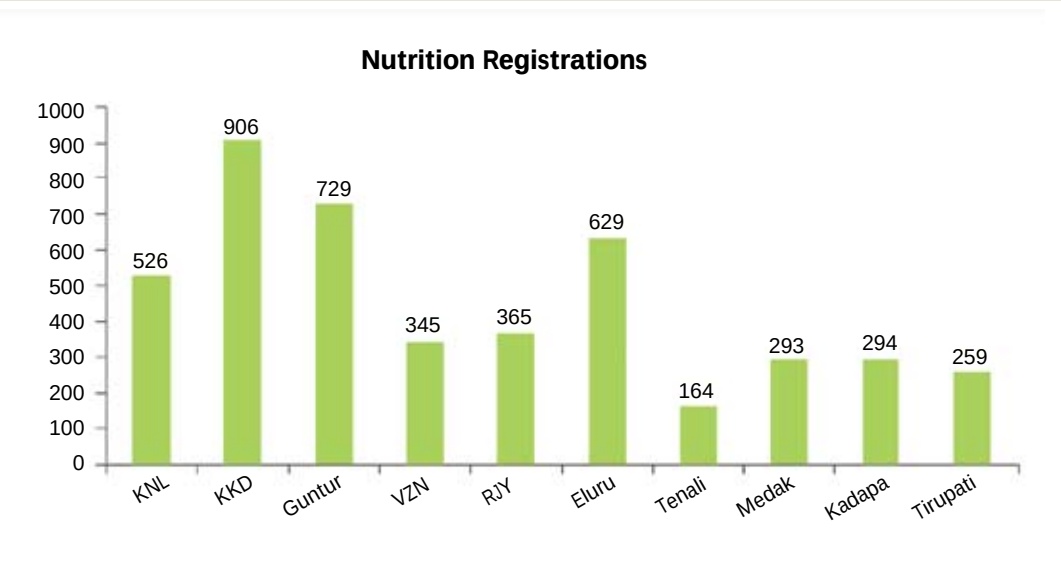
Figure 29: Children's enrolment in schools



especially among older children. High levels of stigma and discrimination further exacerbate the problem.

Balasahyoga tackled this challenge by counseling the caregivers about their children's educational requirements and mobilizing them to enroll and retain them in schools. The program also worked with schoolteachers to identify and address any issues of stigma and discrimination that impede the children's retention in schools.

Figure 30: Infected children accessing FBF at ARTCs



Achievement: The program succeeded in enrolling 90 percent of the children in ages 6–14 years into schools, an increase of 2 percent from Year 1. The enrolment of children in ages 15–18 years increased from 41 percent in Year 1 to 71 percent in Year 5, up 30 percent. The overall enrolments for children in the higher age group are lower because of the pressures they face to supplement family income due to illness or death of parents, resulting in them dropping out of school.

Domain 3: Nutrition

Malnutrition among HIV-affected children in resource-poor settings is a major concern. The problem is especially severe for the HIV-infected children, as the infection can further endanger nutrition through malabsorption and altered metabolism.

Balasahyoga aimed to improve the nutritional status of CABA through supplementary food. It provided FBF to infected children at ARTCs and facilitated access to supplementary food through Anganwadi centers of ICDS.

Supplementary food for infected children

Adequate nutrition is critical for infected children, who have low immunity levels and higher levels of malnourishment. Proper nourishment is necessary to maintain the immune system and manage infections, ensure favorable response to treatment, and support optimal quality of life.

Balasahyoga, in consultation with the National Institute of Nutrition (NIN), provided supplementary food, called 'Nutrimix,' to children (6 months–15 years) registered at ARTCs.

Nutrimix is manufactured by Andhra Pradesh Foods, a public limited company that manufactures and distributes food supplements for ICDS. To tackle the challenge arising from the short shelf life (45 days) of the nutritional supplement, the program developed a robust supply chain mechanism to ensure that the product reached ARTCs within a week of dispatch.

Achievement: As a result of the initiative, 4,764 infected children received FBF at 10 ARTCs.

Supplementary food for affected children below 6 years of age

Optimum nutrition is important for children's growth, especially during their early years. Access

to supplementary food is essential for children from households that are struggling with poverty.

Food security assessments of the households registered with Balasahyoga revealed high levels of food insecurity. The program advocated with GoAP to provide 'double rations' to CABA below 6 years of age through the ICDS.

Achievement: Due to the program's intervention, about 4,000 children below 6 years of age accessed 'double rations' from Anganwadi centers. The relatively low percentage of children accessing 'double rations' is possibly a result of the stigma associated with HIV, due to which families do not reveal their HIV status or access the services. Despite its low uptake, the provision for 'double rations' is a sustainable mechanism for distributing supplementary food through Government systems and preventing malnourishment in CABA.

Domain 4: Psychosocial Support

Children and adults affected by HIV have multiple psychosocial support needs, with most individuals experiencing trauma, stigma, and discrimination associated with HIV. Balasahyoga provided age- and status-specific counseling to adults and children and LSE to children in ages 8–18 years. It also promoted PLHIV support groups and community advisory boards (CABs) to overcome stigma and discrimination.

Counseling

Counseling needs of HIV-affected children and adults vary depending on age and status as well as the different stages of the disease. The spectrum of counseling needs spans various stages and issues, such as testing (pre- and post-test), disclosure, positive living, pre-ART and ART adherence, prevention among spouses and mother-to-child transmission, managing grief and bereavement, and overcoming stigma and discrimination.

Balasahyoga deployed FCM teams to provide age- and status-specific counseling to CABA and their caregivers. The teams were trained to provide simple counseling to children and adults, while trained counselors provided more specific and specialized counseling. In addition, FCM teams also facilitated access to counseling at testing, treatment, and care facilities, where trained counselors were available to

Figure 31: Counseling needs through the course of HIV illness

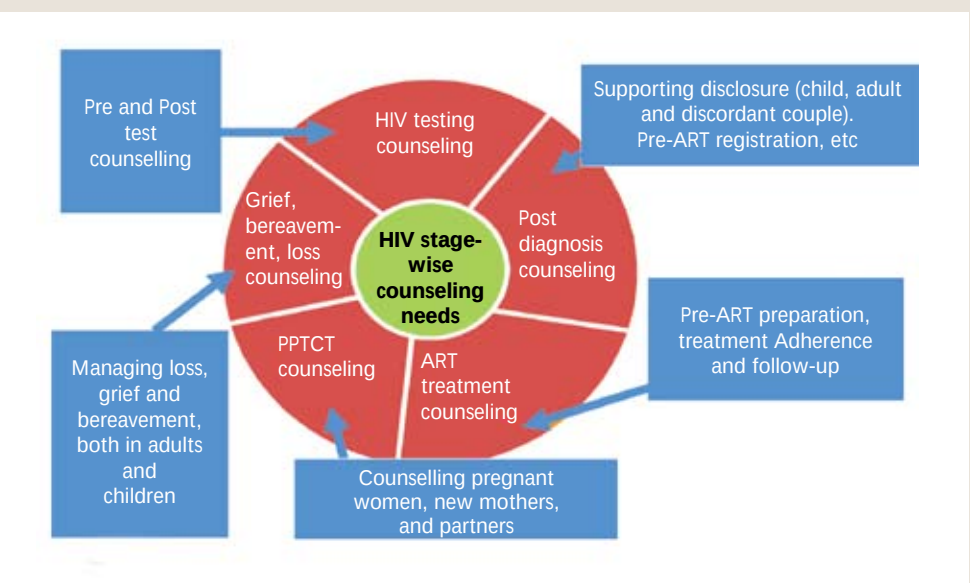
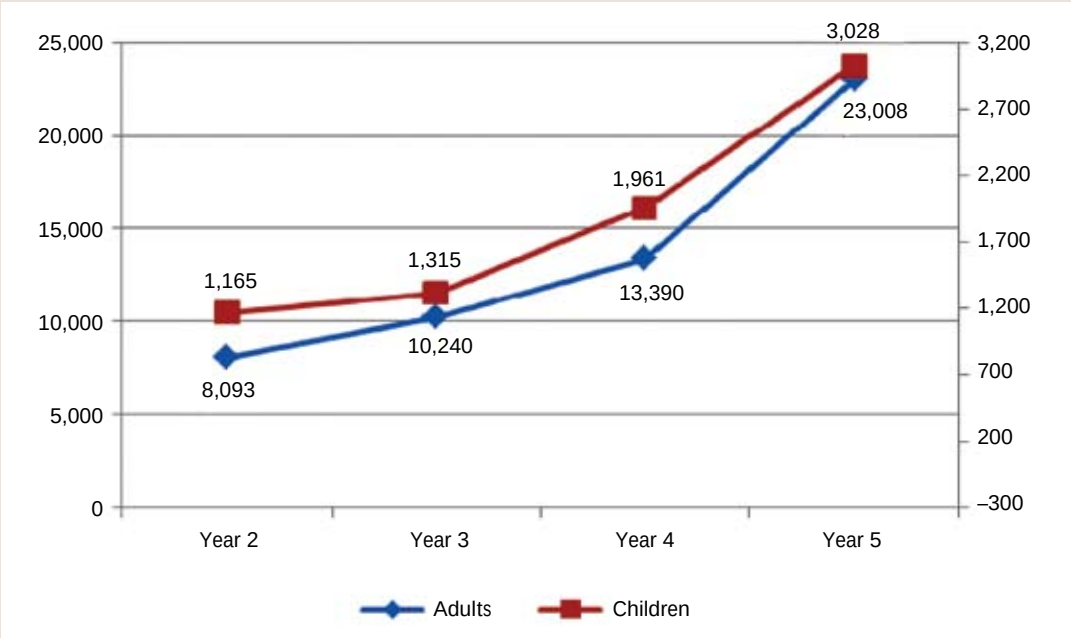


Figure 32: Children and adults provided counseling



provide support and advice on the various needs of infected children and their caregivers. Counselors at ARTCs were also trained to improve skills in pediatric counseling to increase ART adherence and retention of clients in treatment.

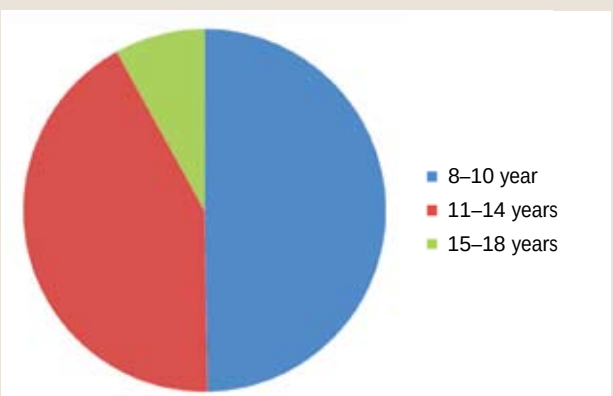
Achievement: The program provided community-based counseling through FCM teams and trained counselors, enabling children and their caregivers to overcome barriers of stigma and discrimination and access much-needed services, such as HIV testing, pre-ART registration, ART initiation, and retention. Consequently, there was increased uptake of testing and treatment services for children.

Life skills education

The challenges that CABA regularly face are many, including stigma and discrimination and problems of coping with their own or their parent's HIV status. LSE is necessary to meet the emotional requirements of these children, who need knowledge and skills to deal with the challenging situations that life throws at them daily.

FHI 360/India, the lead partner of the program, has experience in implementing LSE through a well-structured module to build skills of CABA, enabling them to deal with their status and overcome issues of stigma and discrimination in various settings. As part of the initiative, mixed groups of children (8–18 years) were formed to provide LSE through a trained facilitator in 20 weekly sessions. A significant 2,668

Figure 33: Age profile of children accessing LSE



children (40 percent infected and 60 percent affected) were provided LSE through the program.

Achievement: Although the results of LSE are difficult to quantify, the qualitative impact of the experience could be seen in the remarkable progress made by the children in accessing services across the domains of health, education, and nutrition.

Community structures

HIV has a significantly adverse impact on families and communities, depleting assets and support structures that are critical in preventing the spread of infection and ensuring care for those already infected. In the absence of proper support systems, children and their families are stigmatized and neglected, resulting in low uptake of services.

Aiming to create a sustainable and responsive community support system, the program promoted two types of community-based structures — PLHIV support groups, bringing together infected individuals to discuss issues of stigma, discrimination, and service delivery; and CABs, comprising school teachers, health workers, and local self-governance representatives to promote constructive action. The CABs, with key community influencers as members, supported HIV-affected families in overcoming community-level stigma and ensuring access to services.

"The community advisory boards have helped people come together to debate and has been a useful platform and springboard to raise awareness."

— KN Pradeep, Strategic Director, Balasahyoga

The program's field staff systematically mentored PLHIV support groups and CABs through one-on-one meetings, group sensitization meetings, and establishing systems for structured referral. The process included systematic agenda setting, monthly review and feedback, periodic follow up, and prioritization.

Achievement: Over the course of the program, approximately 15,000 PLHIV and 11,500 key influencers were mobilized to form 1,019 PLHIV support groups and 767 CABs, respectively. With their support, over 25,000 HIV-affected households were registered through community referrals and mobilized to access various services.

"During the (PLHIV Support Group) *meetings, they ask us to take care of ourselves, to use ART medicines regularly, and get the tests done."*

— a caregiver reflects on the benefits of participating in support group meetings

Domain 5: Safety Nets

Food insecurity is a real risk for households coping with HIV/AIDS in resource-limited settings. Balasahyoga worked to improve food security levels of HIV-affected families by ensuring access to Government safety nets. The program also provided direct support to about 10 percent of the most vulnerable families, identified through food security assessment and other socio-economic parameters.

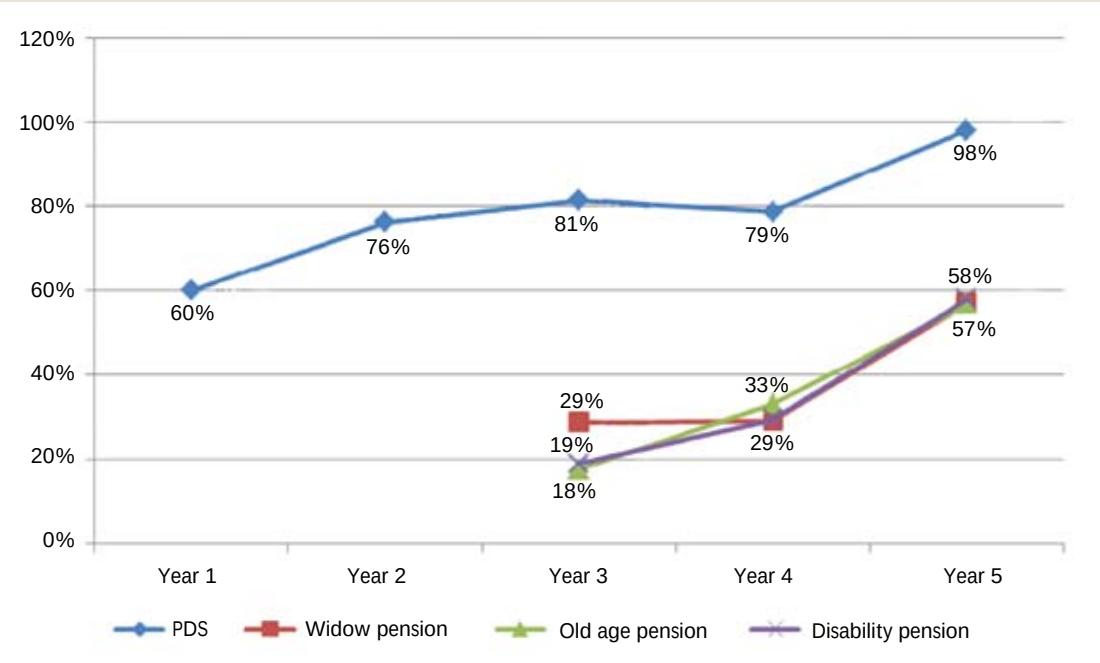
Access to Government safety net services

Food security assessments of households, conducted by the program at the time of registration, showed high levels of food insecurity, with 86 percent of the households food insecure (severely food insecure: 47 percent; moderately food insecure: 39 percent). This was also reflected in the occupational status of adults, with 70 percent employed as wage laborers. Further, as 44 percent of the registered households had lost one or both earning members, indicated by the high number of orphans, the vulnerability of households was extremely high.

"After registering the candidates there will be another procedure to select the eligible candidates to give the safety net services to them…If they are SFI (severely food insecure) *and also from vulnerable households, like child-, women-, and grandparent-headed, they are given preference for direct support."*

— an FCM explains the criteria used to identify and support vulnerable households

Figure 34: Access to PDS and pensions



Balasahyoga worked with various Government departments to help HIV-affected families leverage safety-net services, such as subsidized/free food grain, pensions through monthly cash transfers, and access to schemes for the socioeconomic development of the poor. The program also facilitated access to financial support from agencies such as District Rural Development Agency, Backward Class Welfare Corporation, Scheduled Caste and Scheduled Tribe Welfare Corporation, and Khadi and Village Industries Board.

Access to subsidized/free rations: The program enabled eligible households to access subsidized food grains through the PDS. Although cheaper food grains are already available to all households below poverty line (BPL), issues such as relocation of widows from in-laws' house and breaking up of joint families resulted in denial of these rations to many households affected by AIDS, especially the child-, widow-, and grandparent-headed families. In addition, the program advocated with district administration to consider HIV-affected households as vulnerable and provide them free food grains under the Anthyodaya Scheme.

Pensions: The state Government has schemes to provide monthly cash transfer of INR 200–500 for, among others, widows, aged, and disabled, enabling them to purchase subsidized food grains from PDS outlets. However, lack of adequate resources and bureaucratic bottlenecks hinder access to these safety net services.

> *"He (FCM) asked me whether I got pension. I said 'no', and so he made me apply for that and by next meeting I had got the pension."*
>
> — a caregiver talks about how the FCM team enabled her to receive pension

The program worked with the Government to increase eligible individuals' access to cash transfer schemes by helping with paperwork and establishing dialogue with Government functionaries. In addition, GoAP approved INR 200 monthly pension for all individuals on ART, to be provided at ARTCs, to overcome economic barriers in accessing ART and improving adherence. However, the implementation of this initiative has been delayed due to procedural gaps.

Figure 35: Food security levels of vulnerable households

Food Security Status	Type of Household			
	Child-headed	Widow-headed	Grandparent-headed	Other
Food secure	4%	5%	4%	9%
Food insecure without hunger	5%	8%	7%	9%
Moderately food insecure	34%	37%	33%	42%
Severely food insecure	57%	50%	56%	40%

Achievement: By the end of Year 4, the program was able to link 98 percent of the registered households for PDS rations, an increase of 38 percent from Year 1. This included 6,700 households accessing free monthly food grains under the Anthyodaya Scheme.

Access to widow, aged, and disability pensions also increased to 57 percent by the end of Year 5. In addition, 383 community grain banks were set up to make food grains available to households in the lean season, when livelihood opportunities are few and food insecurity is high. Further, 5,000 households were provided support to set up kitchen gardens to supplement their daily food intake. These measures facilitated availability of food for vulnerable households, especially those in the severe food insecurity category.

Direct financial support for income generation

Low asset base, insecure livelihoods, lack of employable skills, and decreasing number of employable adults makes the HIV-affected households extremely vulnerable to food insecurity. The problem is most severe in child-, widow-, and grandparent-headed households.

Balasahyoga provided direct financial support to the most vulnerable households to promote income generation activities and enable them to improve food security levels. The financial support was based on the skill and asset base available with the selected family and the opportunities available in the community to promote alternate sustainable livelihoods to supplement family income.

Achievement: The program provided direct financial support to 4,795 households to take up income generation activities. This financial support was in the range of INR 2,500–8,000. Balasahyoga also leveraged resources of INR 12,800,000 (cumulative sum) through matching contributions from Government agencies and banks. In addition 1,477 individuals were supported in securing wage employment, and 512 individuals were helped to become self-employed.

An independent assessment of income generation activities examined a sample of 178 households who had been provided financial support. The assessment showed that 40 percent households reported increased monthly income of about INR 1,500; 32 percent reported an increase of INR 1,500–3,000; and 10 percent an increase of more than INR 3,000. In addition, 63 percent households viewed the promoted economic activity as the first and most important livelihood option, while 28 percent viewed it as the second most important source of livelihood. About two-thirds of the households reported 50 percent increase in their net farm income as a result of the support and technical assistance. The assessment also showed that improved income levels allowed 40 percent households to spend more on healthcare. The remaining households spent the additional income on food and on meeting the other needs of the family.

Analysis of MIS data: Financial support resulting in improved food security

Balasahyoga measured the impact that financial support for income generation activity had on the food security levels of supported households. This was done by comparing the food security levels of households at the time of their registration in the program (baseline) and during the last quarter (end line). The sample for this analysis included a cohort of 5,278 households — 2,465 households provided direct financial support and 2,813 households not provided financial support. The tool used for the assessment was FANTA, developed by the US Department of Agriculture. Among all the families, the average duration of exposure to the program was 38 months (range: 7–54 months); average exposure to financial support stood at 20 months (range: 8–49 months); gap between two food security assessments was 30 months (range: 6–48 months); and the average amount of financial support provided to the most vulnerable families was INR 6,400 (range: INR 4,000–10,000).

The analysis included comparison of food security levels: (1) food secure, (2) food insecure without hunger, (3) moderately food insecure, and (4) severely food insecure. Comparison of scores enabled assessment of changes in food security levels between baseline and end line: increase, decrease, and no change. Further, the data was analyzed in terms of change in the number of levels and categorized as moderate (change of one level), significant (change of two levels), and very significant (change of three levels). In all, change in food security level was measured in three primary categories (increase, decrease, and no change) and seven sub-categories (moderate increase, significant increase, very significant increase, no change, moderate decrease, significant decrease, and very significant decrease).

The results showed a 5 percent reduction in severe food insecurity for households not provided financial support, while 38 percent households provided financial support graduated to better food security levels (food secure: 7 percent, food insecure without hunger: 16 percent, and moderately food insecure: 15 percent).

Further analysis of the level of change (for both cohorts) showed higher levels of food security among the households that were provided financial support.

Based on the analysis it may be concluded that the increase in income, from financial support for income generation, results in significant improvements in food security levels, but may not be enough to make each household food secure.

Figure 36: Baseline and end line comparison of food security levels of households

Food Security Levels	No Direct Support			Direct Support			Net Diff.
	BL	EL	Diff	BL	EL	Diff	
Food secure	5%	3%	-2%	2%	9%	7%	9%
Food insecure without hunger	7%	8%	1%	7%	23%	16%	15%
Moderately food insecure	36%	42%	6%	42%	57%	15%	9%
Severely food insecure	52%	47%	-5%	49%	11%	-38%	-33%

Figure 37: Level of change in food security levels among households

Change in Food Security Levels	No Direct Support	Direct Support	Difference
Very significant increase	0%	4%	4%
Significant increase	3%	13%	10%
Marginal increase	20%	40%	20%
No change	57%	35%	-22%
Marginal decrease	15%	6%	-9%
Significant decrease	4%	2%	-2%
Very significant decrease	1%	0%	-1%

Program's support helps rebuild a life

Thirty-two-years-old Maheshwari says she has "seen enough hardship to last seven lifetimes." Maheshwari is a scheduled caste woman from Tulluru village of Guntur district, Andhra Pradesh. She and her brothers lost their parents when Maheshwari was a young teenager. Today she is a widow on ART, heading a household comprising herself and her two daughters. Ten years ago, Maheshwari had been pushed out of her marital home by her husband without any source of livelihood, with two young girls in tow and an infection he had passed on to her. To support herself and her children, she started working as an agriculture laborer despite her poor health. Four years ago, Maheshwari began working as a cleaner at a local food stall. Though situated at the tail-end of the business, cleaning dishes, Maheshwari slowly learnt the business. She started a small food stall with a male acquaintance. However, she was duped by her business partner and he took over the business soon after. In the absence of any legal document related to her investment, there was little Maheshwari could do.

By late 2007 Maheshwari had been counseled by Balasahyoga to enroll herself and was provided guidance and grant support of INR 5,000 for her independent venture. She took the brave step of starting a small food stall at the local mandal headquarters, not far from her home. Slowly she also became part of the social fabric by joining the local self help group (SHG), through which she accessed a loan of INR 20,000 to build a house allocated to her under the state Government's housing scheme.

After years of hardship, Maheshwari now has a stable flow of income as well as a home for her family. She earns a monthly income of INR 5,000 and regularly pays loan installments to her SHG. Her small business is doing well and she has employed two staff members. Both her daughters are currently students of the local high school. The program has helped her secure a ration card to get PDS rations and facilitated her access to the Government's health insurance scheme.

Maheshwari's confidence and enthusiasm shines through her words: "I just hope life is not harsh with me anymore. But this time I believe I am truly prepared."

Lessons in Improving Quality of Care

Balasahyoga successfully took the issue of care beyond HIV testing and treatment. The program's efforts in ensuring a comprehensive package of services for CABA and their caregivers brought forth some important lessons:

1. Comprehensive assessment of household and individual needs is necessary to understand the underlying causes for low uptake of services.
2. Data sharing with HIV facilities is needed to identify children and assess their needs.
3. Coordination with multiple departments can facilitate access to services that cut across departments.
4. Facilitating disclosure of HIV status can open up access to non-HIV services and help in proactive targeting.

Strengthening Systems and Capacities

CHAPTER

6 Strengthening Systems and Capacities

Balasahyoga's multipronged approach has aimed to comprehensively address the needs of CABA and their caregivers. The program sought to create an enabling environment to improve access to superior prevention, treatment, care, and support services. Building the capacities of HIV testing and treatment facilities was a critical component of this approach and the program made significant progress on this front.

Refurbishment of ART Centers

Scale-up of the ART program across the state has widened the reach of treatment services, but the poor infrastructure of ARTCs, located in the premises of Government health facilities, affects the quality of service, especially for children. Lack of privacy, irregular patient flow, poor storage space for medicine, lack of private space for counseling, and shortage of furniture are among the issues plaguing service delivery.

Balasahyoga took up the work of refurbishing ARTCs to improve quality of service. It required negotiation for allocation of more space for ARTCs as per NACO guidelines, creation of children's play areas, and provision of signage, cabins, furniture, patient flow charts, and job aids. Infection control and waste management systems were also established, such as cross ventilation, aeration, exhaust fans, and disposal bins. Medical equipment like stethoscopes, blood pressure cuffs, reflex hammers, and weighing machines were also provided at the facilities.

Achievement: The program supported the Government in refurbishing 19 ARTCs and 1 ICTC, leading to improved patient flow, reduced waiting time, and increased service time, which together contributed to a three-fold increase in clients registered for ART over the last five years. Seeing improvements in the quality of service delivered at the refurbished ARTCs in the 11 Balasahyoga districts, GoAP asked the program to provide technical

Process of ART Center refurbishment:

- Site assessment
- Plan for refurbishment – furniture, equipment, children's play aids
- Quality assurance
- Capacity building of counselors
- Drug procurement
- Patient flow and quality of care
- Improving child friendliness

Figure 38: Refurbished ARTCs and waiting time (Year 5)

S. No	ART Center Name	District	Year of Refurbishment	Pre-ART (in hours)	On-ART (in minutes)
1	GGH Guntur	Guntur	Year 2	25.55	61.67
2	IDH Guntur	Guntur	Year 5	25.91	20.50
3	Narsaraopeta	Guntur	Year 5	41.72	77.00
4	Tenali	Guntur	Year 3	29.22	34.50
5	Eluru	West Godavari	Year 2	26.63	93.33
6	Tadepalligudem	West Godavari	Year 4	49.75	69.50
7	Kakinada	East Godavari	Year 3	31.89	52.67
8	Rajahmundry	East Godavari	Year 3	24.53	76.33
9	Vizianagaram	Vizianagaram	Year 2	26.28	32.67
10	Anantapur	Anantapur	Year 3	26.07	48.67
11	Kadiri	Anantapur	Year 5	NA	NA
12	Kurnool	Kurnool	Year 2	49.44	79.00
13	Cudappah	Cudappah	Year 4	25.23	53.33
14	Proddutur	Cudappah	Year 5	73.45	70.00
15	Tirupati	Chittoor	Year 5	25.13	26.67
16	Chittoor	Chittoor	Year 3	49.20	31.67
17	Adilabad	Adilabad	Year 5	26.13	66.67
18	Sanga Reddy	Medak	Year 2	27.73	27.33
19	Mahbubnagar	Mahbubnagar	Year 3	48.70	60.33

Sample: 20 patients (10 new and pre-ART patients and 10 on-ART patients)

Steps in data collection for calculating waiting time:

1. Follow the sampled patient from entry to exit
2. Record the time spent at every service point
3. Follow up with the patient over multiple days if service delivery exceeds one day
4. Calculate average waiting time for patients

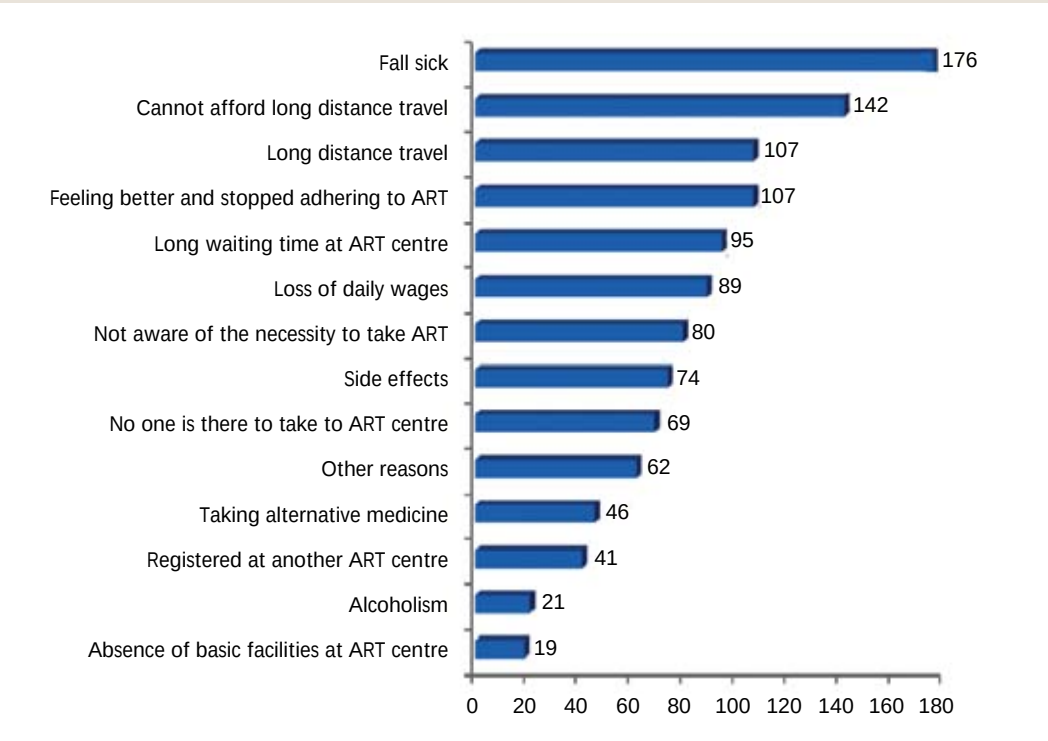
assistance for establishing 11 child-friendly ARTCs in non-program districts.

The positive impact of the refurbishment reflected in reduced waiting time at ARTCs, calculated through waiting time analysis done once a quarter.

Improved Data Management at ARTCs

Improper data management at ARTCs was resulting in huge gaps in data entry and inadequate utilization of data. Many ARTCs, especially the regional centers, had huge backlogs in data entry and inaccuracies in

Figure 39: Causes of loss to follow up



recording of client information on death, migration, and transfers. These inadequacies resulted in lack of actual estimates on LFU, inaccurate reporting, and low utilization of CMIS information. The CMIS software also had many bugs, preventing generation of reports at ARTCs.

Balasahyoga advocated with NACO and APSACS to initiate data cleaning at ARTCs and clear backlogs in data entry. It also worked with the CMIS developer to remove bugs from the software.

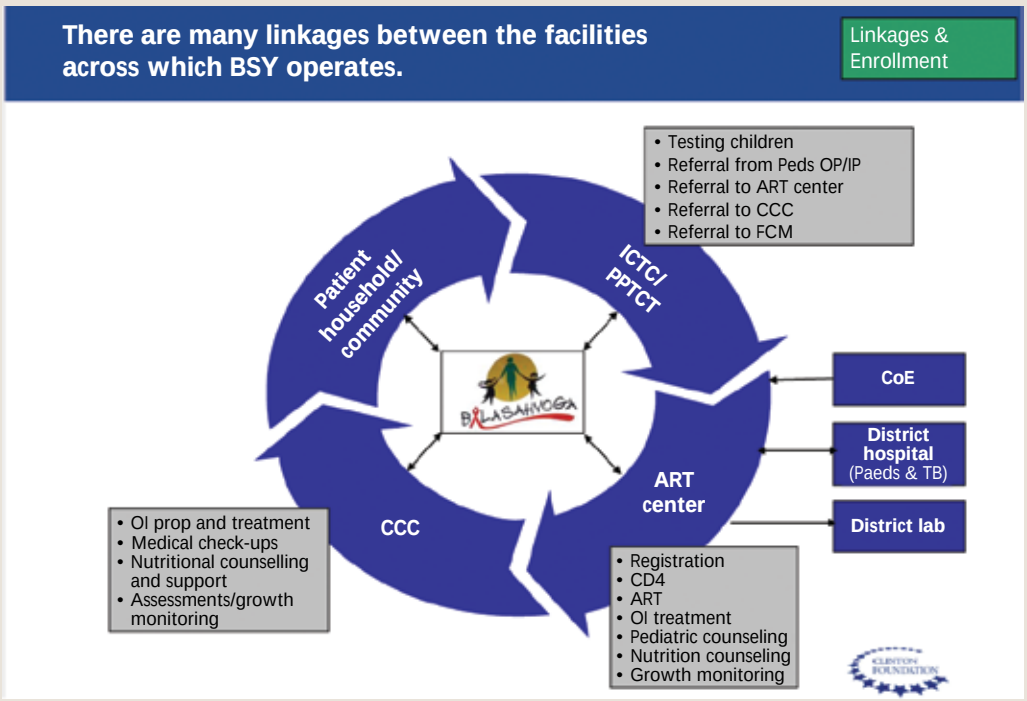
Achievement: The program, with support from NACO and APSACS, initiated data clearing in all program districts. This exercise helped in arriving at actual LFU statistics and their subsequent analysis. Streamlining of CMIS software facilitated generation of reports at ARTCs and improved data utilization. A total of 62,321 ART white cards (pre-ART: 31,804; on-ART: 130,517) were updated in the first phase of the program.

Balasahyoga continuously monitored and sensitized ART staff on CMIS data updating. Based on need, newer versions of PLHA software were rolled out on a regular basis. Regular interactions were arranged between NACO's IT help desk team manager and data manger at ARTC to sort out issues arising from the use of software. Recently the program had initiated a data management project to support ARTCs in clearing data backlog by placing extra data entry operators at ARTCs with high backlog.

Stronger Linkages to Other Health Services

Studies indicate that compared to adults, fewer HIV-infected children receive treatment at ARTCs. Issues of access and sensitivity, coupled with lack of focus on child testing, contribute to under-representation of children at ARTCs. Most children infected with HIV receive the infection through the mother-to-child transmission route and must be tested at birth for ART to be effective.

Figure 40: Linkages to other services at ARTC



Balasahyoga persuaded pediatricians and ICTC and ART staff on the importance of testing children promptly. The program succeeded in creating referrals from pediatric wards to ARTCs and established intra-hospital linkages. It also sensitized hospital administration to provide general pharmacy and laboratory services to clients without stigma and discrimination.

Achievement: Incidence of stigma and discrimination has decreased and more children now receive pediatric care at ARTCs. Cross-referrals from facilities such as pediatric wards, PPTCT clinics, and ICTCs within district hospitals have increased, along with better utilization of other general services available at hospital premises.

Capacity Building of Healthcare Staff

Lack of trained healthcare staff impedes the delivery of services to CABA and their caregivers, resulting in poor quality of service delivery and high dropout.

Balasahyoga aimed to overcome these issues through such capacity building initiatives as clinical mentoring, nurse mentoring, and counselor training for the staff working in various HIV facilities. Nurse mentors were placed at community care centers to mentor nurses, and counselors at ARTCs were trained in pediatric counseling. The program also collaborated with Indian Academy of Paediatricians (IAP) to train medical

"The existing ART centers did not meet all the requirements set both by NACO and APSACS to deliver the services they are expected to deliver… Balasahyoga undertook research into making the ART centers child-friendly...refurbishment plans were aligned to the needs of the project...and designed in such a way that the facilities could be easily and securely accessed by the patients and to make them more patient friendly...now the space is well organized and can handle high volume of patients each day... given these positive outcomes, the news has spread in the areas about the quality of services, leading towards more people visiting the center for seeking healthcare."

— APSACS, Mee Nestam, 2009

Figure 41: Refurbished ART centers and their QA scores (first and last)

S. No	ART Centre Name	District	Year of Refurbishment	First QA Score	Latest QA Score
1	GGH Guntur	Guntur	Year 2	70	77
2	IDH Guntur	Guntur	Year 5	61	73
3	Narsaraopeta	Guntur	Year 5	68	74
4	Tenali	Guntur	Year 3	NA	74
5	Eluru	West Godavari	Year 2	65	78
6	Tadepalligudem	West Godavari	Year 4	NA	72
7	Kakinada	East Godavari	Year 3	52	79
8	Rajahmundry	East Godavari	Year 3	NA	81
9	Vizianagaram	Vizianagaram	Year 2	64	82
10	Anantapur	Anantapur	Year 3	60	75
11	Kadiri	Anantapur	Year 5	NA	68
12	Kurnool	Kurnool	Year 2	65	87
13	Cudappah	Cudappah	Year 4	59	76
14	Proddutur	Cudappah	Year 5	NA	69
15	Tirupati	Chittoor	Year 5	66	87
16	Chittoor	Chittoor	Year 3	NA	83
17	Adilabad	Adilabad	Year 5	NA	78
18	Sanga Reddy	Medak	Year 2	65	88
19	Mahbubnagar	Mahbubnagar	Year 3	62	80

doctors and paramedic staff on the pediatric aspects of HIV treatment.

Achievement: As a result of the program's capacity building interventions, vast improvements were noted in the quality of services delivered at HIV facilities, especially in pediatric care and treatment.

Quality Assurance in Service Delivery

Due to the low importance accorded to ARTCs within district hospitals, where they are located, and within the overall health system, ARTCs struggle with inadequate infrastructure, lack of trained personnel, inefficient patient flow, lack of adherence to treatment protocols, issues in supply chain management, and poor data management systems, all of which reflect in poor quality of services.

Balasahyoga worked with ARTCs to improve infrastructure, build capacities, strengthen supply chain and data management systems, and introduce a QA/QI checklist to periodically assess the quality of services delivered at ARTCs and take steps for improvement. The QA/QI checklist assessed ARTCs against parameters of accessibility, availability of human resources, infrastructure, laboratory services, maintenance of reports and records, supply chain management, adherence to protocols for screening for ART, patient flow, child friendliness, drug counseling,

and infection control measures. It then identified gaps to improve performance. This exercise was undertaken with the assistance of the facility coordinator and the participation of staff at ARTCs.

Balasahyoga introduced a client satisfaction feedback system to address the stigma and discrimination faced by PLHIVs and to develop a pre-ART curriculum for children and institutionalize it. Issues highlighted in clients' feedback were discussed among ARTC staff and other partners during ART coordination meetings and decisions taken to resolve them.

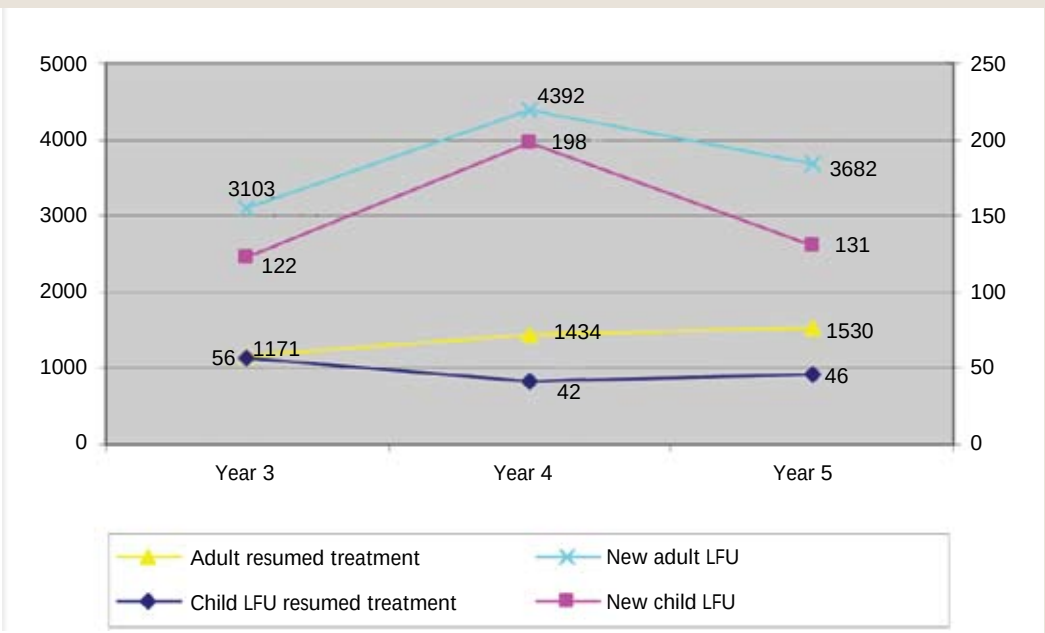
Achievement: Implementation of the QA/QI system at ARTCs showed improved scores for refurbished facilities. A recent analysis showed that QA scores increased to 90 percent in low- and medium-load ARTCs and to 78 percent in ARTCs with high case load. Standard operating procedures were developed and disseminated among ARTC staff to help them in adopting and implementing QA standards in facilities.

Balasahyoga's efforts had a significant impact on the quality of service delivery at ARTCs, evident in decreased turnaround time for clients, streamlined patient flow, reduced waiting time, child-friendly ambience, and improved facilities like waiting space and provision for safe drinking water. Most importantly, refurbishment of ARTCs ensured privacy and confidentiality of clients, especially children and pregnant women.

Efficient Tracking of LFU Clients

ART adherence is critical to ensure effectiveness of treatment regimen. According to NACO[7], 10.9 percent of the patients in Andhra Pradesh do not adhere to ART treatment. Balasahyoga conducted a study in eight program districts to ascertain the reasons for non-adherence. The results pointed to sickness due to side effects of ART medicine, long travel distance to ARTCs, cost of travel, loss of daily wage, long waiting time at ARTCs, and lack of awareness as some of the reasons for non-adherence to ART. Based on the responses of tracked LFU clients, it was found

Figure 42: New LFU and LFU brought back on treatment



[7]NACO March 2011 data

that over 50 percent LFU happens within 60 days of treatment initiation.

To reduce LFU cases, the program trained outreach workers and field staff of various organizations on the different aspects of LFU tracking. It also developed systematic and streamlined processes to track LFU cases at ARTCs. The LFU tracking mechanism protected clients' privacy and confidentiality and ensured that one client was tracked by one partner organization only, reducing the risk of duplication. Balasayoga also initiated and demonstrated pre-ART LFU client tracking in two ARTCs, at Kurnool and Vizianagaram.

Achievement: With support from NACO and APSACS, LFU tracking was initiated in all program districts. A total of 8,711 adults and 340 child LFU clients were tracked, and 3,078 adults and 108 children were brought back to resume ART treatment.

Improved data management helped in identification of LFU clients and initiation of LFU tracking systems. Pre-ART tracking was also initiated in some centers to ensure access to repeat CD4 test, as per protocol.

Capacity building of ARTC staff helped improve the quality of counseling and reduce LFU. Refurbishment of ARTCs also increased client satisfaction through various improvements such as better facilities, conveniences, and reduction of turnaround time, which resulted in reduced LFU. Consequently, on-treatment LFU among children and adults declined in Year 5. The peak in Year 4 was attributed to the identification of new clients from clearing of data backlog.

Lessons in Systems Strengthening

Balasahyoga's extensive efforts in strengthening systems and building capacities of HIV facilities brought forward some important lessons:

1. Strengthening of systems helps in resolving supply-side issues and supports individuals in overcoming barriers of stigma and discrimination.

2. QA systems help in streamlining processes and improve the quality of service delivery.

3. Efficient data management is necessary to track individuals and minimize LFU in treatment.

Advocacy

CHAPTER

7

Advocacy

Advocacy on HIV and AIDS is essential to bring together the various stakeholders and join forces to control HIV spread and provide good quality care and treatment to those affected or infected with HIV. A multi-sector, collaborative response is needed to provide the resources and policy support crucially required for the well-being of CABA and their families.

Balasahyoga worked in close collaboration with GoAP and advocated with Government departments of health, education, women and child development, rural development, revenue, and civil supplies to facilitate processes and harness resources to ensure improved access to services.

Data Sharing with Facilities

Identification of eligible individuals and families is the most critical step in increasing coverage of the program, as disclosure and sharing of information on PLHIV is restricted due to confidentiality issues. This hinders early identification of CABA and their caregivers and adversely impacts their access to services, especially for the affected children who are not registered at testing and treatment facilities.

Balasahyoga successfully advocated with NACO and APSACS in 2009 to share facility level data to optimize the program's catchment. The data sharing agreement was based on an undertaking by FHI 360/India to respect the confidentiality of clients and use the data only to improve access to services for children and their families. The agreement was made operational by placement of a second consent form at testing, treatment, and care facilities, where clients were screened for their eligibility for the program and offered a consent form, upon acceptance of which they were referred to the program by sharing their identities and contact details with FCM teams.

Achievement: As a result of the data sharing agreement, the program was able to register 43 percent of the total 47,976 households through referrals from facilities, enabling the program to optimize its coverage. In addition, referrals from facilities enabled the program to identify CABA and their families at the earliest, providing opportunity for timely intervention. Data sharing also allowed facilities to follow up with clients for services, as they do not have outreach staff to support follow up.

CABA Scheme

Given the national HIV and AIDS programs' primary focus on prevention among adults, especially the high-risk groups, the issues of CABA have not been adequately addressed. Roll out of pediatric HIV and PPTCT interventions have brought focus on issues of children, but mostly restricted to HIV prevention

and treatment. With an estimated 2.36 million PLHIV (HSS 2008) and 4 million children affected by AIDS (UNICEF), the development needs of CABA require a comprehensive and urgent response from the Government.

In view of this need, FHI 360/India and CHAI worked with other civil society organizations to advocate with NACO and constitute a task force for CABA. The task force developed operational guidelines for implementation of CABA Scheme, which aims to provide comprehensive services to children affected by AIDS, cutting across departments and agencies. The CABA Scheme was piloted in 10 districts across 6 states in the country to gain inputs about the operational challenges of implementing the scheme at scale.

Achievement: Adoption of operational guidelines for implementing CABA Scheme provided recognition to the comprehensive development needs of CABA. It brought issues of CABA into focus, providing a framework for advocacy on improved access to services. Piloting of the scheme also provided an opportunity to look at challenges in scaling up, which would call for greater coordination among multiple departments. The pilot in East Godavari, implemented by the program using its own strategies and processes, identified and registered more than 12,000 children and demonstrated an implementation model at scale.

Meeting Nutritional Needs of CABA

Nutrition is the most basic development need of children, especially critical for those in the lower age group, when inadequate nutritional intake and malnourishment cause lasting damage to the child's overall development. Nutrition assumes additional importance for children affected by AIDS, due to their increasingly inadequate access to food. For infected children, lower immunity levels further compound the effects of malnourishment. In addition, lack of options to treat children with severe acute malnourishment (SAM) leads to higher mortality levels, especially among younger children.

Balasahyoga worked on two fronts to address the issues of malnourishment among CABA: access to supplementary food and roll out of SAM treatment. The program successfully advocated with the Department of Women and Child Development to provide supplementary food to CABA (below six years of age) through ICDS at Anganwadi centers, where the affected children were provided 'double rations'. The program also advocated with the Department of Health to roll out SAM treatment through the establishment of nutrition rehabilitation centers (NRCs) across the state.

Achievement: As a result of Balasahyoga's advocacy with the Department of Women and Child Development, a Government Order was issued to provide 'double rations' to all CABA in ages 0–6 years; this order was implemented across the state to prevent children from slipping into severe malnourishment. The order is being implemented by ICDS and coordinated by APSACS at the state level and DAPCUs at the district level. The program's advocacy with the Department of Health and Family Welfare resulted in a Government Order to set up 30 NRCs across the state, with technical assistance from the program for renovation of NRCs, training of trainers, development of M&E systems, and availability of ready-made F75 and F100 therapeutic products to treat SAM in children. Procurement of F75 and F100 for the newly established NRCs is currently underway.

Refurbishment of Non-Balasahyoga ART Centers

Although scale up of the ART program across the state has made treatment available to a greater number of children and caregivers, inadequate infrastructure at ARTCs negatively impacts the quality of service.

Balasahyoga worked with the Government to improve services at ARTCs in program districts by refurbishing facilities. Among other improvements, cabins were provided to ensure privacy and confidentiality of clients, and the facility staff was given job aids to streamline patient flow and reduce waiting time. In addition, children's play areas were created to make ARTCs child friendly, thereby improving retention in ART. The program advocated with APSCAS to replicate the ARTC refurbishment exercise in non-program districts.

Achievement: Due to the program's advocacy with APSACS, 14 ARTCs in non-program districts were refurbished with resources from the Government and technical support from the program. This resulted in improved infrastructure for delivery of ART services across the state.

Linkage to Government's Safety Net Schemes

The development needs of CABA go beyond the individual level, closely linked as they are with the socioeconomic status of their family. HIV-affected households face multiple vulnerabilities and erosion of livelihoods and asset base has a strong bearing on the well-being of children.

"We go to MRO office and we enquire about the procedure and ask them to help these HIV patients. Then the officer says that he will look into the matter. Then we go to the office again and we ask him to do it again. We give the necessary documents to him. In this way we try to do things."

— an FCM describes the advocacy efforts of his team to improve HIV-affected households' access to services

Balasahyoga's FCM approach treated the family as a unit and assessed each affected family's needs comprehensively. This assessment enabled the program to identify the underlying reasons for the affected children's inadequate access to healthcare services. It also helped the program in advocating with various departments to ensure improved access to Government's safety net services.

Achievement: Balasahyoga's advocacy with Government departments ensured preferential treatment for HIV-affected families in accessing such safety nets as free/subsidized food grains and livelihood promotion schemes. The program succeeded in providing more than 6,000 families access to free food grains through the Anthyodaya scheme. Additionally, 57 percent widows, elderly, and disabled people were given pensions, and more than INR 12,800,000 contributed toward income generation activities to supplement incomes of vulnerable families.

"…35 kgs (kilograms) *of rice, so that we can have food daily. If I don't go for work some days, we have rice in our house. It is very helpful to me."*

— a widow communicates her appreciation for the free rice given to her under the Anthyodaya Scheme

Communication Needs Assessment

Lack of awareness about HIV and AIDS, local health facilities, and pediatric treatment is one of the most important reasons for the low uptake of available services. Much of this ignorance can be traced to lack of information, education, and communication material.

In order to determine its communication needs, the program conducted a communication needs assessment in 2008. By March 2009, a detailed report identifying target audience, partners, and necessary material emerged. Communication rolls outs started from March 2009 onward. In 2010, KIT-SWASTI conducted a baseline assessment and identified gaps in the communication plan.

The program then designed and developed communication material to address these gaps. This material, for use by affected families and staff, included flash cards on opportunistic infections, flipbooks on breast-feeding practices for HIV-positive mothers, flip charts, handbooks and job aids for nutrition counseling, training material for pediatric counseling, compendium of Government schemes, posters, brochures, referral forms, and ART adherence calendars. In addition, theatre performances (kalajathas) were organized at ARTCs to raise awareness about the program and emphasize the importance of adherence and care.

Achievement: The communication material developed by the program increased awareness about the available services for CABA and their caregivers and ensured retention in treatment. The material was also used in advocating with various Government departments to improve availability and quality of services for the affected children and households.

Figure 43: Snapshot of Balasahyoga's communication material

Lessons in Advocating for CABA

The program's advocacy effort with Government and other stakeholders on the issues and needs of CABA and their families resulted in some important lessons:

1. An operational framework that makes provisions for service delivery to vulnerable groups helps in establishing accountability.
2. Sensitization of Government departments beyond those directly related to health and HIV is important in improving the affected children's access to services.
3. Data sharing with other departments helps in targeting for non-HIV services.

Monitoring and Evaluation

CHAPTER

8

Monitoring and Evaluation

Key components of program implementation, monitoring and evaluation allow stakeholders and partner organizations to examine a program's outcomes and progress toward its stated goals and objectives. Monitoring and evaluation activities for Balasahyoga engaged multiple processes and agencies, examining relevance, efficiency, effectiveness, impact, and sustainability of the program's interventions at various stages.

Broadly, the program's implementation agencies were responsible for monitoring, while evaluation was entrusted to external agencies — Royal Tropical Institute (KIT), Netherlands, and SWASTI, India. Monitoring for Balasahyoga involved tracking inputs, processes, outputs, and factors that determine outcomes, while evaluation focused on measuring the program's impact and sustainability. Though undertaken by different stakeholders, monitoring and evaluation fed into each other and were closely interlinked.

Comprehensive Monitoring Systems

Consistent with its outcome-based approach, the program had comprehensive monitoring systems functioning at both community and facility levels. While the project monitoring system tracked services delivered to all individuals and households registered in the program, the facility level monitoring system captured information on all individuals accessing services at facilities. In addition, a QA/QI checklist, implemented for facility-strengthening and community-based components, examined adherence to protocols and guidelines in service delivery.

Management information system

Quantitative monitoring of the program was done through collection of data for a combination of process and output indicators logically linked to the program's outcomes, as outlined in the logical framework. Going beyond monitoring of inputs and outputs, the process also looked at actual access to and utilization of the delivered outputs by clients. This enabled the program to assess its progress against key outcomes and to continuously improve implementation by establishing accountability at all levels. Outcome monitoring thus provided the essential link between outputs and the intended impact of the program.

The monitoring system of the program tracked delivery of the package of services accessed by each individual (age- and serostatus-specific) and household registered in the program. This required collection of data from family case files, which provided baseline data for each registered individual and family. The staff visited households and facilities regularly to update these family case files. This information was

then entered into CMIS using EpiData software, which also helped in analysis of data against key performance indicators.

The program supported TAPs in implementing the monitoring system by training their staff on data collection, entry, updating, and analysis. The individual tracking system enabled the program to identify gaps in service delivery and facilitated generation of lists for more efficient targeting. MIS information was used to review progress against targets and guide in program management at all levels. The target for each indicator served as a threshold for various outcomes and helped in measuring the difference between planned and actual levels of performance.

Data quality assessment

DQA was undertaken by the program to review adherence to MIS management processes and assess the quality of data collected. All TAPs were assessed through the exercise to identify gaps and support them in improving the quality of data and reporting. DQA looked at issues of data completeness, accuracy, utilization, and management. The four-day process involved data triangulation and visits to households on a sample basis.

Quality assurance/quality improvement framework

The QA/QI framework enabled adherence to various guidelines and protocols that define quality of service delivery at HIV facilities. QA/QI checklists were used at ARTCs by facility coordinators to identify gaps in such areas as HIV testing, pre-ART screening, CD4 follow up, ART initiation, access to PPTCT and EID, and access to CTX. The results were assessed to address gaps and improve service delivery.

Process Evaluations

The program conducted three process evaluation studies to identify and document the processes that influenced implementation. This exercise gave critical insights into the determinants and dynamics of delivering a minimum package of services to CABA, providing learning that could guide other large-scale programs for CABA in India. The findings from the three process evaluations are summarized below.

Family case file

A case file was maintained for each registered family, providing a snapshot of the family, accessed services, status, and linkages with Government schemes. It contained household profile, child and adult profiles with data sheets, ANC services sheet, adherence tool, and ART formats, among others. The family case file served as an invaluable tool in tracking the progress of each registered household.

1. Process evaluation: Delivery of a minimum package of services to CABA and their families using the FCM approach

The first process evaluation aimed to document the lessons arising from the use of the innovative FCM approach to deliver health, education, nutrition, psychosocial support, and safety net services to CABA and their families. The specific questions that the evaluation aimed to answer were:

- Which processes were involved in the FCM approach of ensuring service delivery to CABA and their families?
- What were the facilitators and barriers to the provision of the minimum package of services to CABA and their families?
- Which of the families' needs were met through the FCM approach?

The mixed-method evaluation looked retrospectively at the core processes of the FCM approach that enabled the program to overcome barriers and meet needs. It used primary qualitative data collected from adult caregivers, service providers, and FCM teams and secondary quantitative data from the monitoring system. The qualitative data was used to identify barriers and facilitators at caregiver and service

provider levels, while the quantitative data determined the extent of services delivered to meet the needs of CABA and their families.

The qualitative data was collected through in-depth interviews (IDIs) with 60 caregivers who had been with the program for more than a year from two mandals each in three districts — West Godavari, Kurnool, and Medak — representing three regions of the state and the same districts as those sampled for the evaluation of the program. Qualitative data was also collected from 16 service providers at facilities through IDIs and from eight FCMs and eight CVs through focus group discussions (FGDs). The quantitative data was for all the 15,906 children and 16,891 adults from the 10,219 households registered with the program in the three sample districts. Qualitative data collection excluded all children (below 18 years) and pregnant women from its sample. An external agency was contracted to collect and analyze the qualitative data, while the program staff managed data triangulation, final analysis, and report writing.

Key processes of the FCM approach

The key processes of the FCM approach that acted as facilitators were as follows: (1) identification of eligible individuals/families – data sharing with facilities; (2) registration with the program – persuading identified individuals to be part of the program; (3) assessing family needs and eligibility for services – usage of tools like HIV testing and treatment algorithm, household food security assessment, and other socioeconomic information, and creating family case files; (4) preparing beneficiaries to access services – counseling and mobilizing individuals to access services; (5) facilitating access to services – accompanied referrals and coordination and advocacy with service providers; and (6) follow up for services – constant contact and support to ensure individuals and families continue to access services.

"They help me at the time of ill health. They visit us once a month. They give moral support and confidence. I don't feel that I have this disease while talking to them."

— a caregiver expresses confidence in the FCM team

Apart from these processes, the key crosscutting processes that FCM teams employed to support the identified families in overcoming barriers were: perseverance and being proactive through continuous home visits, supporting children and caregivers through counseling, encouraging participation in PLHIV support groups to overcome stigma, and facilitating access to services that were beyond the mandate of the program but valued by households.

Key barriers in access to services

The major barriers that prevented CABA and their families from accessing services were: (1) lack of awareness about HIV and related services; (2) stigma, both at self and community levels; (3) lack of support from family members; (4) logistical barriers such as distance to facilities; (5) economic barriers like poverty and loss of wage; and (6) insensitivity of service providers.

Needs addressed through the FCM approach

Assessment of the needs of registered families and their access to key services showed that most HIV testing and treatment needs of the families were met, except follow up for CD4 count and access to CTX, attributed to economic barriers and supply-side constraints, respectively. Access to PPTCT services also increased significantly, except ART for pregnant mothers, which was low in one of the sample districts. School enrolment among children (6–14 years) was also high at 90 percent, with higher dropout levels (30 percent) mostly reported from the older age group (15–18 years).

Access to supplementary food at Anganwadi centers (for children below 6 years) was low due to the stigma associated with HIV and the resulting reluctance of caregivers to reveal their HIV status to service providers, a requirement for accessing 'double rations'.

Access to safety net services was high, especially for subsidized/free rice through PDS, but coverage

of widows and the elderly for pensions needs to be optimized to ensure food security for vulnerable widow- and grandparent-headed households. High economic vulnerability of CABA and their families resulted from low asset base and loss of livelihood due to HIV.

2. Process evaluation: Delivery of a minimum package of services to CABA and their families through facility strengthening

The second process evaluation aimed to examine the effects of refurbishment and systems strengthening on service delivery to CABA and their families. Specifically, the assessment sought to answer the following questions:

- What is the impact of ARTC refurbishment on child friendliness and waiting time?
- How did the implementation of QA checklists improve the operational performance of ARTCs against set standards?
- What impact did community and facility inter-linkages have on referral services?

The mixed-method evaluation used primary and secondary data. The primary data was collected through interviews and interaction with clients and service providers using structured questionnaires. The secondary quantitative data was collected from facility MIS. The sample included six ARTCs in three categories — three refurbished ARTCs in Balasahyoga districts, two refurbished ARTCs in non-Balasahyoga districts, and one non-refurbished ARTC in a non-Balasahyoga district. The sample for the qualitative data included IDIs with 98 individuals, including clients, caregivers of clients, service providers at ARTCs, care coordinators, and facility coordinators.

Impact of ARTC refurbishment on child friendliness and waiting time

Refurbishment of ARTCs had the following impact on the delivery of services measured against time: faster location of ARTCs and other service points due to increased signage and navigational support; optimal usage of the personnel available at ARTCs (redefinition of roles, multitasking, separating pre-ART and ART files); segregation of services and allocation of a separate space for each type of service (pre-ART counseling, ART counseling, and registration of old cases and new cases at separate places); and streamlining of patient flow, resulting in reduced waiting time and increased service time.

The child-friendly ambience and policies of the refurbished ARTCs drew positive responses from CABA and their caregivers, while the non-refurbished ARTC lacked amenities for children and scored low on satisfaction level among children visiting the center. Refurbished ARTCs in Balasahyoga districts scored between 75–85 percent on child friendliness; refurbished ARTCs in non-Balasahyoga districts scored 55–70 percent; and the non-refurbished ARTC in non-Balasahyoga district scored 45 percent.

Analysis of client responses showed that refurbished ARTCs took less time to provide quality services while the non-refurbished ARTC showed no corresponding gains, neither in terms of time taken for service delivery nor in quality of service. For instance, 76 percent clients from refurbished ARTCs in Balasahyoga districts and 61 percent from non-Balasahyoga refurbished ARTCs indicated a moderate to substantial decrease in the time to access services. The corresponding figure for the non-refurbished ARTC was just 32 percent. A similar trend was observed in the time taken for CD4 test.

Most clients from the refurbished centers were able to spend 15 minutes or more with the counselor, whereas 80 percent of the client sample in the non-refurbished center spent less than 15 minutes with the counselor. With reference to the time spent with the doctor, about 50 percent of the sample clients from refurbished ARTCs in Balasahyoga districts spent 15 minutes or more in consulting the doctor. For the refurbished ARTCs in non-Balasahyoga districts and the non-Balasahyoga non-refurbished ARTC, the corresponding figures were 34 percent and 23 percent, respectively. As the pharmacies are

strategically located in refurbished centers, the time taken to locate and reach the pharmacies was reduced and the queues at the pharmacy did not disturb patient flow, quite unlike the situation at the non-refurbished center.

Impact of QA checklists on the operational performance of ARTCs

Quality assessment checklists evaluated the quality of service delivery at facilities against various parameters, including accessibility, patient flow, human resources, infrastructure, reports and records, supply chain management, infection control, referrals and back referrals, access to outpatient services, child friendliness, drug counseling, and assessment for ART eligibility. QA assessments of the sample ARTCs showed superior quality of service delivery at refurbished ARTCs in Balasahyoga districts (QA scores of 76–83 percent), compared to refurbished ARTCs in non-Balasahyoga districts (61–64 percent) and non-refurbished ARTC in non-Balasahyoga district (53 percent). The score for accessibility showed that the majority (89 percent) of the sample respondents (first timers) from refurbished centers said that they were able to reach and access ARTCs easily. In contrast, a larger percentage (40 percent) of the sample respondents from the non-refurbished centre found it difficult to access the center on their first visit. Similarly, a larger percentage (74 percent) of respondents from the refurbished ARTCs in Balasahyoga districts found it easy to locate and access other service points in hospital premises, compared to refurbished ARTCs in non-Balasahyoga districts (48 percent) and the non-refurbished non-Balasahyoga ARTC (35 percent).

Impact of community and facility inter-linkages on referral services

Assessments of community-to-facility referrals and back referrals within and outside facilities showed improvements in prevention and care services across program districts. Institutionalizing monthly coordination meetings for all ICTCs and ARTCs established a platform for discussions on tracking of LFU cases, referral of HIV-positive cases to ARTCs, testing of cases referred by ARTCs, and institutionalization of the second consent form for referral to care and support services.

According to the assessment, the referrals to and from ARTCs in Balasahyoga districts were higher than in non-Balasahyoga districts. There was a steady increase in referrals from facilities over the course of the program, with 43 percent referrals to Balasahyoga coming from HIV testing, treatment, and care facilities by the end of Year 5. Referrals from ICTCs increased from 29 percent in Year 2 to 56 percent at the end of Year 5, leading to early identification of eligible individuals and their timely access to care, treatment, and support services. Similarly, referrals from ARTCs increased steadily to 16 percent at the end of Year 5, up from 9 percent in Year 2.

Referrals from facilities in the three sample Balasahyoga districts of West Godavari, Kurnool, and Medak stood at 49 percent, 71 percent, and 60 percent, respectively. In non-Balasahyoga districts, referral mechanisms were not institutionalized, except in few mandals, where targeted interventions, positive networks, and NGOs sent a small number of referrals to ARTCs. In QA scores for referrals and back referrals, refurbished ARTCs in Balasahyoga districts scored 94.4 percent, while refurbished ARTCs in non-Balasahyoga districts scored 50 percent and the non-refurbished non-Balasahyoga ARTC scored 45.8 percent.

3. Process evaluation: Impact of safety net interventions on food security levels

The third process evaluation aimed to assess the impact of food security interventions on household income and food security levels. The specific questions that the evaluation aimed to answer were:

- Which specific barriers were faced by vulnerable households with CABA, especially widow-, child-, or grandparent-headed households? What was the impact of these barriers on food security?

- Which processes and interventions of the safety net component (direct financial support and linkages) enabled the households to overcome

HIV-induced vulnerability[8] and increased monthly income levels?

- What is the impact of direct financial interventions on food security levels of households, and what are the variations in food security levels among child-, widow-, and grandparent-headed households?

The study used mixed-method approach, involving both quantitative and qualitative data. An especially designed household schedule was used to collect information on the changes in livelihood sources and asset base. To assess the change in food security levels, USDA's FANTA tool was used. FGDs were conducted with FCMs and CVs, and IDIs were conducted with service providers in Government departments. In addition, monitoring data was analyzed to draw inferences. The sample comprised 178 beneficiaries, FCMs, CVs, and service providers drawn from West Godavari, Kurnool, and Medak districts.

The assessment provided information about the impact of safety net interventions on various aspects of the affected households' income level and food security status. The findings of the study are detailed below.

Improved food security

- The process evaluation found 37 percent sample households to be food secure and 24 percent on the border line without hunger, compared to the previous food security assessment that had found only 2–3 percent households food secure.

- Significant improvements were seen in food security of households that were provided direct financial support. Substantial efforts are required to ensure that these households do not slip back and to promote food security of other households.

- The percentage of food secure households among the sample was highest in West Godavari (44 percent) and lowest in Kurnool (5 percent), with Medak in between (25 percent).

- Food secure households in the sample varied from 25 percent among child-headed households to 38 percent and 40 percent among grandparent-headed and widow-headed households, respectively.

- Across social groups, the percentage of food secure households in the sample varied: 32 percent among backward classes, 40 percent among Schedule Tribes, 41 percent among Schedule Castes, and 45 percent from other classes.

Reduced distress

- Access to Anthyodaya and Annapurna cards as well as white ration cards had a significant impact on the ability of households to access PDS and keep adequate ration stocks in the house.

- The linkage has considerably and positively affected food security levels in the households that benefited (46 percent of the sample). Most households did not any longer suffer uncertainty about their next meal. This is among the most significant achievements of the program.

Diversification of assets

- In 63 percent of the households, the economic activity supported by the program, such as petty business, dairying, sheep/goat rearing, and artisan work, emerged as the first and most important source of livelihood.

- For 28 percent of the sample households these activities constituted the second most important source of livelihood.

- Linkages to Government schemes also had a significant positive impact on livelihood, as 19 percent of the sample households considered pension the second most important source of

[8]HIV-induced vulnerability is a grouping based on widow- and grandmother-headed households. It was also used as criteria to select households for safety net interventions.

livelihood and 26 percent considered it the third most important source of livelihood.

Increase in income

- About 40 percent of the sample households reported increase in monthly income of up to INR 1,500 from a relatively small investment. Given the resource constraint, the amount of increase reported was significant.

- Of the sample households, 32 percent reported increase in monthly income ranging from INR 1,500–3,000.

- About 10 percent of the households reported an increase of over INR 3,000 in their monthly income.

- About two-thirds of the sample households reported 50 percent increase in their net farm income, attributed to the support and technical assistance.

Improved health expenditure

- About 40 percent of the households were able to spend more on healthcare when needed due to improved and stable incomes.

- About 50 percent of the households indicated that there was no increase in private health expenditure and that they had begun making better use of public health services due to close monitoring and the family case approach adopted by the program.

End Line Evaluation

KIT, Netherlands, along with SWASTI, India, provided evaluation support to Balasahyoga. The key findings summarized below are taken from KIT and SWASTI's End line Evaluation Report.

The evaluation aimed to assess Balasahyoga's progress on: (1) improvements in quality of life indicators; (2) improvements in quality of care due to capacity strengthening; and (3) effectiveness of the model and the possibility of replicating it. The evaluation took place in three phases, of which the first round was implemented in 2009, the reference group (mid phase) in 2010, and the end line in 2011. The results are presented as comparisons over time between the first and the end line evaluation. Both quantitative and qualitative methods were used and a group of children were tracked over time in one district, West Godavari, based on the intensified household tracking method, to document trends in quality of life scores.

Context of the program's operations

The program's external environment presented challenges in the form of leadership change at APSCAS; an evolving Government-run HIV program; closure of some CCCs, which had served as an important link between communities and services; and new ART guidelines, among others.

"The program managed these external challenges well, however, and established a strong voice for the needs of CABA both at state and national level. FHI 360 is a member of the Children Affected by AIDS working group and substantially influenced the development of the national guidelines, building on the experiences and lessons learnt from the program."

— Endline Evaluation

Outcomes of the program

The end line evaluation report listed the following outcomes of the program:

1. Exceeded its target for registering adults (92,000) and children (73,000); recognition among key stakeholders about the program's contribution in significantly bridging gaps between children and adults in access to testing and treatment — getting eligible children tested for HIV, increasing the percentage of eligible children with a CD4 count test, and encouraging ART uptake among the target population

2. Reduced the time clients spent on travelling to ARTCs, through the establishment of more ART and link ARTCs; visit to ARTC still demands considerable time investment

3. Increased access to Government schemes for affected families, helping them achieve better food

security and ensuring support beyond the program period

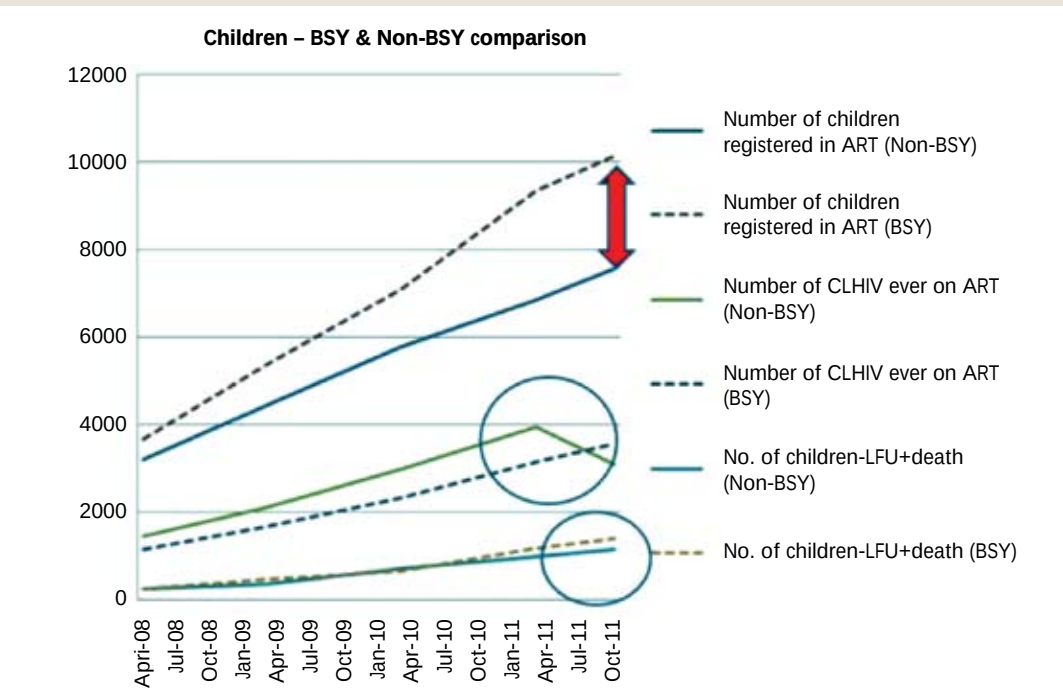
4. Compared with the non-program districts of Andhra Pradesh, the 11 program districts showed better results in mobilizing pregnant women for HIV testing in ANC clinics and testing and registration of children at ARTCs

HIV testing of pregnant women showed a steady increase in program districts, 59 percent in Balasahyoga districts compared to 47 percent in non-Balasahyoga districts[9]. In the absence of estimates for CABA in each of the districts, the evaluation team compared the actual numbers accessing the services. The number of children and adults registered in ART centers was higher in program districts[10]. The difference is less marked for adults and children ever on ART, but it seems that after the CHAHA project ART uptake decreased. A steady increase was observed in Balasahyoga districts.

Impact of the program

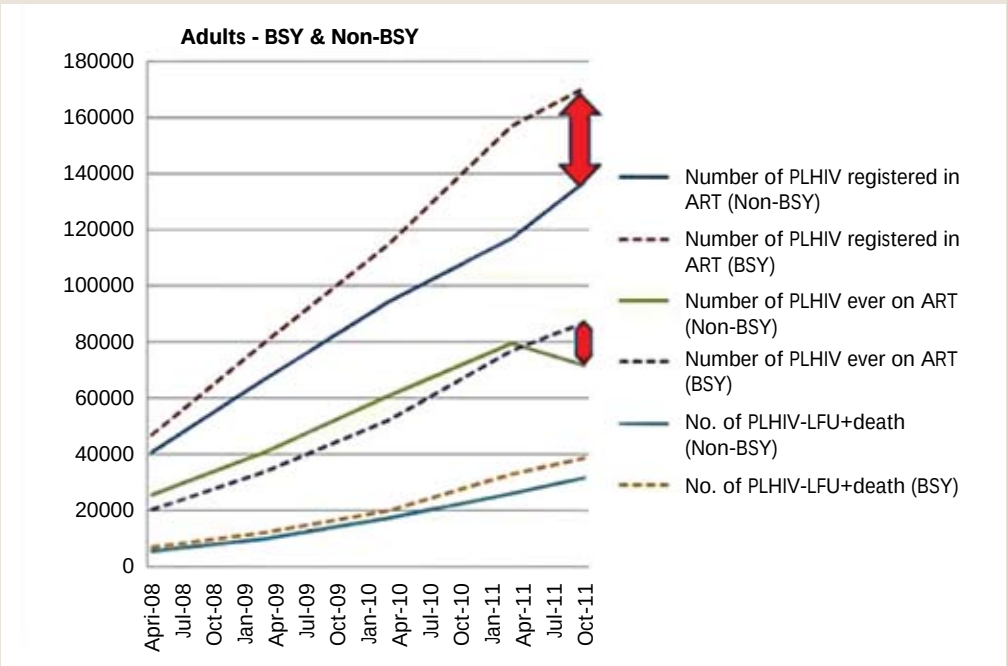
Scale-up of the program was most intense during its final two years. Consequently, the mean exposure time of children to the program's interventions was relatively short (two years on average), whereas the children enrolled in the first year of the program had an average exposure time of 3.3 years. This finding implies that the effects of the program's interventions may not yet be seen for the children enrolled in the last two years. Nevertheless, for the children tracked through the evaluation (using the intensified household tracking method) from the first round onward, the average exposure time was 3.1 years

Table 44: Comparison of uptake of services for children at ARTCs in Balasahyoga and non-Balasahyoga districts



[9]Calculations by the evaluation team using data and denominators derived from the Strategic Information Management Unit 2011 Report, APSACS
[10]Calculations by the evaluation team based on data reported on the APSACS website, excluding Hyderabad city

Table 45: Comparison of uptake of services for adults at ARTCs in Balasahyoga and non-Balasahyoga districts



for 0–8 year olds and 3.2 years for 9–16 year olds. Therefore, trends were analyzed in terms of quality of life versus exposure time. The end line evaluation showed the following findings in terms of the impact of the program:

1. For the 9–16 year old children affected by HIV, there were significant improvements in quality of life scores (from 88.8 to 90.5) and body mass index (from 14.7 to 15.4). For the younger children, quality of life scores fell significantly, from 91.3 to 89.5, except the Hope Pathway scale, which increased significantly (by 7 points). Mid-upper arm circumference and body mass index remained more or less the same for this age group.

2. For the children infected with HIV, those in ages 0–8 years showed a significant decrease in quality of life scores (from 86.6 to 82.3), but their body mass index and Hope scores remained more or less the same. For the children in ages 9–16 years, quality of life scores showed an increase (from 84.6 to 86.6) as did body mass index (from 14.1 to 14.8). Health sub-scores for quality of life saw the strongest increase. The Hope scale for this group of children also witnessed an increase.

3. The mortality rate for children living with HIV was higher than for all children in the program (4.6 percent versus 1 percent), with the mean age of death being 8.3 years for the children living with HIV. For the children affected by HIV, the mean age of death lay between 4.1 years (without an HIV test) and 6.4 years (tested HIV negative). Comparing these averages one could conclude that the life of children living with HIV has been prolonged by the program. This is supported by MIS trend analysis of CD4 counts, which showed an increase over time, averaging 88 points (standard deviation: 500) for children and 87 points (standard deviation: 289) for adults. The high value of standard deviations in these analyses indicates, however, that there are other children

and adults for whom the CD4 counts fell, which could be related to the mortality rate of this group. Of the 271 children living with HIV who died, only one third were on ART. Children without parents (double orphans) were more likely to have died than other children (2 percent versus 1 percent). The actual mortality might have been higher, as 9 percent of the children ever registered were LFU cases.

4. The most vulnerable children identified during the first round were the children living with HIV and those living with their grandparents. The latter group was also identified as being the most vulnerable in terms of adherence to regular CD4 testing and treatment. Together these findings suggest that the younger group of children living with HIV (0–8 years) is particularly vulnerable and that the program has not been able to improve their quality of life. The trend analysis of exposure time to the program versus quality of life scores shows, however, that when younger children are 42 months or longer in the program, their scores increase substantially (overall quality of life increased from 86.3 to 89.3 for 0–8 year olds). The highest sub-score increases were recorded for health and nutritional intake, the components on which Balasahyoga placed the greatest emphasis. A similar trend vis-à-vis exposure time was not seen for the children in the 9–16 year age group.

Hence, from a broader development perspective it may be too early to see the potential impact of the program. The transfer of specific strategies piloted by the program to the Government provides a unique opportunity to further explore their long-term impact on the quality of life of the target group. This could in turn inform the replication process in other states of India.

Key recommendations of the evaluation

The evaluation highlighted several key findings that contributed to the following recommendations:

1. Further support the current transitioning and mainstreaming process for the state of Andhra Pradesh, to build the capacity of ASHA and ANM as well as establish and strengthen the coordination mechanism

2. Identify the most vulnerable groups (double orphaned children, grandparent-headed households) and develop a specific sub-program to better serve their needs, with focus on service levels required for specific groups and a timeline for graduating to the next level of household resilience

3. Simplify the MIS for use by APSACS, as it is unique in providing follow-up data on individual households and monitoring the progress for CABA, and it can help in identifying key areas for programmatic level improvements

4. Identify existing tools and methods of importance for replication and develop a replication package

5. Extend the program's efforts toward enhancing its ability for replication and sustainability in a new state-level context. The technical assistance proposal of the consortium could serve this purpose, addressing both programmatic recommendations and assisting in expanding the knowledge base for replication.

Lessons, Challenges, Sustainability, and Transitioning

CHAPTER

9 Lessons, Challenges, Sustainability, and Transitioning

This chapter summarizes the major lessons that emerged from the implementation of the program, while also highlighting the challenges that informed the program's approach and implementation. Issues of sustainability and transitioning have also been discussed, addressing the need to sustain the processes and activities initiated by the program long after its culmination.

Lessons

Integrated approach

Balasahyoga has demonstrated the value of integrated comprehensive programs for children, unlike vertical programs that only address health and medical needs. Its comprehensive approach enabled the program to assess the multiple vulnerabilities of CABA and their families and facilitate provision of context-specific solutions that are valued and 'owned' by the participants.

Collaboration with Government

The program's strategy of working in tandem with Government departments and strengthening Government facilities and services has succeeded in establishing processes and systems that will sustain program activities. The coordination mechanisms established within Government structures have also demonstrated approaches that are feasible and can be replicated to reach out to a greater number of CABA.

Building partnerships

Balasahyoga has highlighted the strength of multi-partner programs in executing large, complex projects. Having a consortium to manage a large-scale program allows it to draw from each of the consortium partners' strengths and experience.

Enabling flexible approach

The flexibility and support provided by the donors in revising strategies proved crucial in fine-tuning project implementation and bringing it in sync with the changing circumstances and Government priorities as well as within the larger framework of national HIV programs.

Focus on social protection needs

The program highlighted the importance of addressing the social protection needs of a household through safety net and livelihood linkages, instead of focusing only on the child. Addressing this aspect builds the family's resilience and ensures its sustainability over time. For any continuum-of-care program to be complete, it must establish linkage with social welfare schemes based on the specific vulnerabilities of the family and the opportunities present in the local setting.

Information management and capacity building

Balasahyoga implemented an integrated and robust MIS, tracking and better targeting services to CABA

and their caregivers. Although collecting information and ensuring data quality proved challenging initially, the program was able to accomplish it through continuous training and mentoring and periodic data quality assessments.

Challenges

Managing partnerships and consortium

The program brought together partner organizations that were synergistic and with complementary strengths. The experience brought focus on the need for a joint vision and work plan but with clear division of roles and responsibilities to establish accountability and work toward crosscutting outcomes.

Operational challenges

The program faced several operational challenges in implementing its large-scale interventions to support CABA and their families. Some of these hindrances are briefly discussed below.

- Dispersed geography
  The vast geographical area and widely dispersed communities made it difficult to implement some components of the program. For example, there was difficulty in mobilizing children across a scattered geography to provide life skills education. Dispersed geography also made it difficult to calculate economies of scale and maintain cost effectiveness.

- Absence of estimates on CABA
  The absence of estimates and line lists made it difficult to reach CABA, as facilities did not screen individuals for their marital and child status.

- High numbers of orphans
  With 8 percent of the children being double orphans and 40 percent single orphans, the program needed to make additional efforts to retain them with their extended families.

- High levels of economic vulnerability
  Given their poor access to safety net services, the poverty-ridden households were extremely vulnerable to any change, such as loss of livelihood when the caregiver fell sick or died. High dependence on daily wage (70 percent) for livelihood and low literacy levels prevented them from pursuing alternate livelihood options.

"Now they are giving the safety net services only to few families. But if they give the services to all the families then it will be good."

— an FCM expresses the need for direct support to all vulnerable families

- Lack of outreach for follow up
  Due to lack of outreach staff across all domains, it was difficult to follow up on children for services, especially for non-HIV services, as facilitating access to these services involves coordination with various agencies.

- Difficulty in ensuring quality
  For any large-scale program, ensuring quality of service remains one of the biggest challenges. There were issues of out-of-stock drugs and reagents, sourced through Government agencies. It was also difficult to access specialized human resources to help with children's issues.

- Access to early infant diagnosis
  Despite being rolled out in all the districts of the state, making EID available for testing children in the age group of 0–18 months posed operational challenges at the field level. Results for those undergoing EID were also not made available in a timely manner, as the samples were sent to Chennai for testing. Further, if confirmed HIV positive, the families needed to travel with the infant every month to the ART center of excellence (COE) at Niloufer Hospital, Hyderabad, to access therapy. This restricted the number of HIV-positive infants (less than 18 months) on ART.

- Access to cotrimoxazole
  Provision of CTX prophylaxis happened in a very sporadic manner in most districts, due especially to long distances from ARTCs and poor knowledge

of national guidelines and prescription practices among key medical functionaries responsible for dispensing CTX. District-level advocacy by the program led to CTX being made available to TAPs for distribution by the FCM.

- Absence of child-centered counseling at ARTCs
  Although facility-based counselors have been oriented to provide child-centered counseling, some ARTCs have not been able to provide need-based counseling to children and lack skills in effectively communicating with children. Balasahyoga's consortium partners worked with NACO and APSACS to address this lacuna, but there is still scope for further improvement.

- Malnutrition
  High levels of malnourishment among children, combined with low food security of households, make them vulnerable to risk of SAM. Absence of treatment options for SAM within Government healthcare facilities impeded provision of appropriate care for the severely malnourished children and intensified the risk of child mortality.

- Stigma and discrimination
  The high level of stigma associated with HIV, at individual, family, and community levels, prevents disclosure and hinders CABA and their caregivers' access to available services. For example, it was difficult to mobilize girls in the age group of 15–18 years for HIV testing because of their parents' reluctance to get their daughters, who were approaching the marriageable age, tested for the stigmatized disease. Outreach and home-based counseling can help in overcoming stigma and discrimination and increase demand for testing and treatment services.

Sustainability and Transitioning

Sustainability and transitioning were built into the program's operational design and implementation, as it worked within existing structures and in close coordination with Government agencies at the national, state, and district levels to build capacities and ensure continuance of program activities.

"BSY has been well conceived, but the issues of sustainability and exclusiveness need to be addressed. The programs need to be integrated into regular programs."

— APSACS

The program hopes to identify key mechanisms and processes that worked well, such as the testing and treatment cascade and LFU tracking, which the Government can adopt and continue. These mechanisms and processes are linked to specific indicators that must be regularly monitored and updated to ensure effectiveness. The DAPCU would need to be strengthened to ensure smooth transition and adequate capacity. The transitioning aspect was built into the facilities strengthening component. Almost 90 percent of the program will be handed over to the Government once it comes to an end. The issue to consider is how many of the NGO partners can continue the program or its modified version after the program's culmination.

The Way Forward

An innovative, large-scale program, Balasahyoga aimed to address the testing, treatment, and care needs of CABA and their caregivers by using a comprehensive, family-focused approach and building linkages with the Government. The program gained credibility in the community by successfully demonstrating its strategy to reduce vulnerability and structural barriers to the access of high quality services. It increased coverage, strengthened health systems, improved service quality and delivery, and built linkages between communities, families, and facilities.

"This process (transitioning) *can result in important lessons regarding the potential replicability of the program approach in other states in India and a longer-term analysis of program impact on the quality of life of those targeted."*

— Balasahyoga Endline Evaluation

The way forward for this program would be to partner with state and national governments to adapt its continuum-of-care approach to other parts of the country. The consortium would share the tools and resources developed in the program and successfully pilot the CABA Scheme for scale-up to all high-prevalence districts of the country. This is an opportune time as NACO is planning and designing the fourth phase (NACP – IV) of its program, starting 2012. Balasahyoga hopes to demonstrate a cost-effective and replicable model for adoption and scale-up by the Government to other districts and states so that every affected and infected child receives appropriate care and support. Another important entry point is the convergence of health programs, as the national HIV programs are being integrated into NRHM. This development represents a step forward in the country's response to HIV and AIDS. Balasahyoga's demonstrated approaches and strategies can make a significant contribution here and emphasize the crucial role of family-focused community and facility systems to ensure better care of HIV-affected children.

"Balasahyoga scaled up continuum-of-care approaches, encompassing the needs of children across geography. For continuum of care to be complete, there is need for linkages to social protection schemes."

— Bitra George, Country Director, FHI 360/India; 2011

CABA Scheme

One of the key successes of the program at policy and implementation levels was the development of guidelines for implementing the CABA Scheme as well as demonstrating the model in one of the program districts. The key objectives of CABA Scheme are:

- Develop an integrated framework for the care, support, treatment, and protection of CABA
- Ensure provision of these comprehensive services to CABA at the community, block, district, and state levels through multi-sector coordination of NACO and other departments and organizations working for children

East Godavari was one of the districts where the CABA Scheme was piloted. The criteria for selecting the district were: ANC prevalence higher than 1 percent in the last three years, a functional DAPCU, and more than 500 persons registered for ART. The main thrust of the scheme was mainstreaming pediatric HIV/AIDS and establishing linkages between Government/public service delivery systems and CABA to facilitate their access to the following services: health/medical care, psychosocial support, nutrition support, education support, social protection/economic strengthening, legal support, and alternative care. The key expected outcomes were: (1) more affected children in the social safety net; (2) increased number of HIV-exposed children tested and the infected children receiving ART, OI prophylaxis, and related services; (3) establishment of multi-sector district coordination committees; and (4) development and placement of planning, monitoring, and training tools for the protection, care, and support of CABA.

The CABA Scheme focuses on coordination between different ministries/departments at national, state, and district levels to provide a comprehensive set of services to CABA and their families. In East Godavari, the district collector (DC) took leadership for the implementation of CABA Scheme and helped facilitate linkages between the various departments to accelerate decision-making. One of the DC's pioneering initiatives was the adoption of 90 double orphans by the District Government Officer's Association. As the ADMHO put it, *"Earlier it was routine work, now it has motivated us personally and professionally."* Being in close contact with the children and their families, usually grandparent-, widow-, or child-headed households, helped the Government officials better understand the problems and plight of these families, prompting them to fast-track linkages to Government services. For example, a cataract operation was facilitated for the grandmother of a child affected by HIV/AIDS and an ongoing legal issue was resolved by the intervention of the superintendent of police for a family of three orphan girls, whose uncles were trying to usurp their parental property.

"The Government officials have taken the issue of CABA seriously, because it's a sensitive children's issue. Children are innocent. They should inherit property, cash, and jewelry, not the disease."

– ADMHO, East Godavari district.

Even though the CABA scheme has worked well in the district, it has faced challenges from a limited budget and visioning for the future.

Annexures

Annexure 1: Brief profiles of consortium partners

Andhra Pradesh State AIDS Control Society (APSACS)

An autonomous and decentralized government body, APSACS steers HIV/AIDS prevention, treatment, education, sensitization, and control programs in the state of Andhra Pradesh. Established in 1998 by National AIDS Control Organisation (NACO), APSACS has the mandate to implement the National AIDS Control Programme in the state. While discharging this function the organization lays down guidelines and training modules for physicians, surgeons, laboratory technicians, healthcare workers, NGOs, and educators. It creates awareness among various risk groups, adolescents, and out-of-schoolchildren through a number of channels and special programs. Apart from this, APSACS conducts monitoring and evaluation of HIV/AIDS programs and surveillance of the infection among various population segments throughout the state. The Balasahyoga program was implemented in coordination with APSACS. Under the guidance of the Project Director, senior officials of APSACS facilitated the program's implementation through a data-sharing agreement and linkages with District AIDS Prevention and Control Units (DAPCUs) for overseeing service delivery. It also coordinated with heads of various line departments at district and block levels to improve access to HIV services.

FHI 360

FHI 360 is a global development organization with a rigorous, evidence-based approach aimed at improving lives by advancing integrated, locally driven solutions. The organization operates from 60 offices with 4,400 staff in the US and around the world. In India, FHI 360 brings a unique combination of strong management, financial, and technical capacity, expertise, and experience in public health programming and research. It manages a diverse portfolio of projects supported by a range of funders, including United States Agency for International Development (USAID), the Bill and Melinda Gates Foundation (BMGF), the Department of International Development (DFID), and the Children's Investment Fund Foundation (CIFF). FHI 360/India has demonstrated technical, management, and fiscal expertise in successfully managing large projects in India, and since 1995 it has worked with more than 150 local NGOs, government, and private partners in the country. FHI 360/India has a strong track record in providing high quality and effective technical assistance and research services in the areas of HIV prevention, care, and treatment; family planning and reproductive health; health systems strengthening; sexually transmitted infections; nutrition; education; and integrated development.

CARE

CARE is a leading humanitarian organization fighting global poverty. It works in 84 countries around the world, supporting 1,105 poverty-fighting projects to reach 122 million people, of which more than half are women. CARE has been working in India for over 60 years, focused on ending poverty through improvement in the lives and livelihoods of women from poor and marginalized communities. It does this through well-planned and comprehensive programs in health, education, livelihoods, and disaster response. CARE's health programs seek to promote essential newborn care and immunization, reduce malnutrition in children, decrease infant and maternal mortality rates, and protect those affected by or susceptible to HIV/AIDS and TB. It also works with local organizations to improve access to family planning, maternal, neonatal, and child health and nutrition through public sector programs, such as National Rural Health Mission (NRHM) and Integrated Child Development Services (ICDS), and private sector health services. Under the education portfolio, CARE works to help girls complete primary education and access formal schools, provides on site academic support to enhance the quality of teaching, and nurtures leadership skills among girls. Its livelihoods programs promote microfinance 'safety nets'; support small business, particularly those owned by women; and foster links between community and financial institutions.

Clinton Health Access Initiative (CHAI)

CHAI is saving lives in low- and middle-income countries by helping people gain access to essential medicines and health services. With offices in over 25 countries, the organization partners with governments on a wide range of issues, including HIV/AIDS, malaria, and maternal and child health, as well as strengthening in-country health systems, expanding human resources for health, and improving markets for medicines and efficiency of health resource allocation. CHAI does not implement stand-alone programs, nor does it build parallel health systems. It works at the invitation of governments to strengthen and sustain their own capacity to provide long-term healthcare to their citizens. Globally, CHAI negotiates price reductions for drugs and diagnostics while also working to enhance their quality. To date, more than 70 countries have access to lower priced drugs as a result of CHAI's work with pharmaceutical companies. Almost 3.9 million people — representing nearly 70 percent of those being treated for HIV/AIDS globally — have benefited from these reduced-price medicines.

Annexure 2: Details of lead and technical assistance partners by district

Lead Partner	Technical Assistance Partner	District
Social Educational and Economic Development Society (SEEDS)	Social Educational and Economic Development Society (SEEDS)	Guntur
	Society for Welfare of HIV Infected People (SHIP)	Guntur
	St. Xavier's Hospital	Guntur
	St. Paul's Trust	East Godavari
	PRAGATI	East Godavari
	Rural India Self Development Trust (RISDT)	East Godavari
Vasavya Mahila Mandali (VMM)	Damian Leprosy Centre (DLC)	West Godavari
	Association of Positive People for Living Excellence (APPLE)	West Godavari
	NATURE	Vizianagaram
Women's Development Trust (WDT)	Women's Development Trust (WDT)	Anantapur
	Vimala Women's Charitable Society (VWCS)	Kurnool
	Chaitanya Educational & Rural Development Society (CERDS)	Cudappah
	People's Action in Development (PAID)	Cudappah
	PASS	Chittoor
	RISE	Chittoor
Hyderabad Council for Human Welfare (HCHW)	Hyderabad Council for Human Welfare (HCHW)	Medak
	Asha Jyoti	Medak
	Adharna Positive Network (MAP+)	Mahbubnagar
	Rahul Medical and Health Services Society (RMHSS)	Mahbubnagar
	Adilabad Positive Network (ADP+)	Adilabad

AP State AIDS Control Society

BALASAHYOGA

THE CHILDREN'S INVESTMENT FUND FOUNDATION

Elton John AIDS Foundation

fhi360

CLINTON HEALTH ACCESS INITIATIVE

care