

A Study On Balasahyoga Programme- A Holistic Approach To Suuport Hiv Affected Children Families- A Critical Analysis

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Abstract: *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. A multipronged approach to improve the overall quality of life of children affected by AIDS and their families by facilitating access to superior services. In the need of hour a comprehensive package of services should address the needs in the areas of health, education, psychosocial support, nutrition, and safety nets. The efforts in ensuring a comprehensive package of services for Children affected by AIDS and their caregivers should bring significant changes in the lives in terms of their access to CTX drug, increased enrollment in school, access to double rations through anganwadi centers, received community based counseling, increased registrations to the PDS , receiving direct and indirect financial support from the government and nongovernmental organizations should help them to overcome food insecurity levels.*

I. Introduction

Despite India's impressive economic and social gains in the last few decades, its abysmal health record had 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. 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. 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. UNICEF estimates that India could be home to about 4 million children affected by AIDS, located mostly in the high HIV-prevalence 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. Balasahyoga program data shows the state's children affected by AIDS 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 children affected by AIDS have been given less priority.

In view of this critical need, a comprehensive care, support, and treatment program for Children and their families which was initiated in April 2007. Balasahyoga (active support to children), a 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 children affected by AIDS in 44,100 families spread across 11 districts of the state. It employed innovative family care management (FCM) approach, improving the quality of life of children affected by AIDS 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.

The study was undertaken with the objective of improving the quality of life of children affected by AIDS. The mode of improvement was in terms of improved accessed to continuous care of services for the children, by decreasing mortality, morbidity and number of children orphaned by AIDS. Further to develop a sustainable and replicable model of HIV care treatment and support services.

Coverage of the programme:

The target population for the program was 68,000 children affected by AIDS 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. The programme was launched in 11 of 23 districts of the state, namely, Guntur, West Godavari, East Godavari, Vizianagaram, Chittoor, Anantapur, kadapa, Kurnool, Medak, Mahbubnagar, and Adilabad.

Implementation of the Programme:

The programme 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 by the following indicators

- Cover 80 percent geographical area (districts and mandals) and saturate coverage of children affected by AIDS by establishing referral systems with facilities (HIV testing, care, and treatment) and community-based sources (PLHIV networks, other NGO-run programs, and support groups)
- Ensure access to testing and treatment services and minimize gap between the stages of HIV testing and treatment
- Ensure the target population’s access to superior quality of care in the areas of health, education, psychosocial support, nutrition, and safety net services
- Build capacities of HIV facilities to provide superior services to children affected by AIDS and their caregivers
- 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.

Services provided

The programme aimed to ensure that children affected by AIDS and their families have access to a comprehensive package of health, education, nutrition, psychosocial support, and safety net services. The services were provided in the following areas

a)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.

II. Prevention of parent-to-child transmission (PPTCT)

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. Also PPTCT services coupled with limited early infant diagnosis uptake contributes to high mortality among HIV exposed children.

As part of its family case management (FCM) approach, the programme focused on ensuring access to key PPTCT services for HIV-positive pregnant women. From 3rdYear onwards, the program placed special emphasis on services such as PPTCT counseling, antiretroviral therapy (ART) for eligible mothers, institutional deliveries, and nevirapine for mother-baby pair (MBpair). The exposed newborns were further followed up for EID, HIV confirmatory test, and antiretroviral therapy (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 1 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.

Table:1 Distribution of respondents according to year wise PPTCT Cascade

| | PPTCT Cascade | | | | | | | | | | | |
|---------------|-------------------------------|----|---------------------|-----|------------------------|----|------------------|----|------------------------|----|-----------------------------|----|
| | Pregnant women tested for HIV | | Provided counseling | | Registered for pre-ART | | Retained for ART | | Institutional delivery | | MB pair provided nevirapine | |
| | F | % | F | % | F | % | F | % | F | % | F | % |
| Year 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Year 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Year 3 | 469 | 95 | 428 | 97 | 330 | 75 | 79 | 91 | 274 | 91 | 259 | 86 |
| Year 4 | 876 | 98 | 722 | 88 | 754 | 92 | 194 | 90 | 516 | 94 | 499 | 91 |
| Year 5 | 1064 | 99 | 995 | 100 | 962 | 96 | 270 | 94 | 864 | 97 | 826 | 92 |

Based on their eligibility, the pregnant women and exposed newborns were followed up on for access to Cotrimoxazole (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.

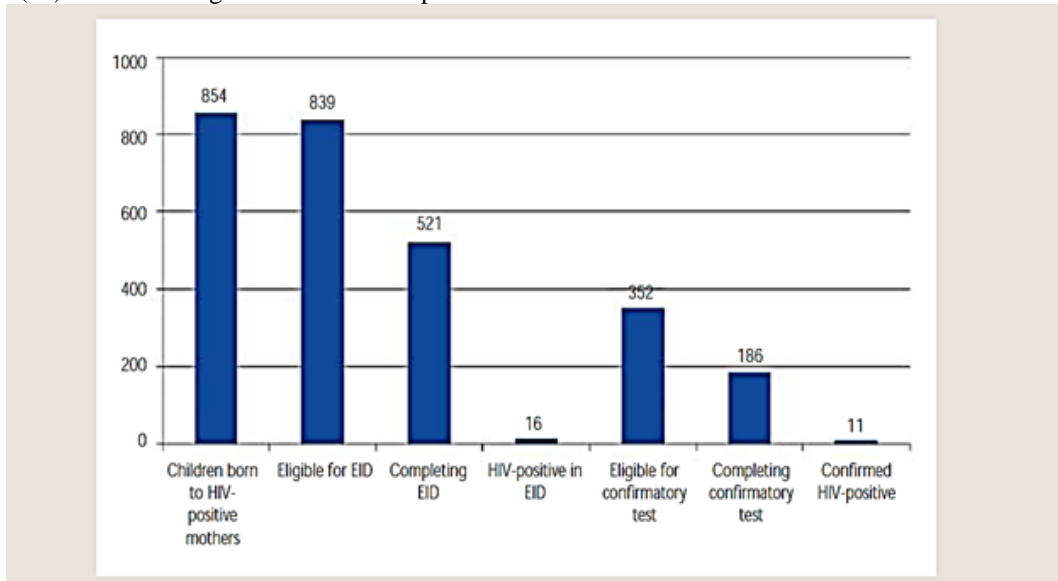


Figure 1: Testing of children born to HIV-positive mothers

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.

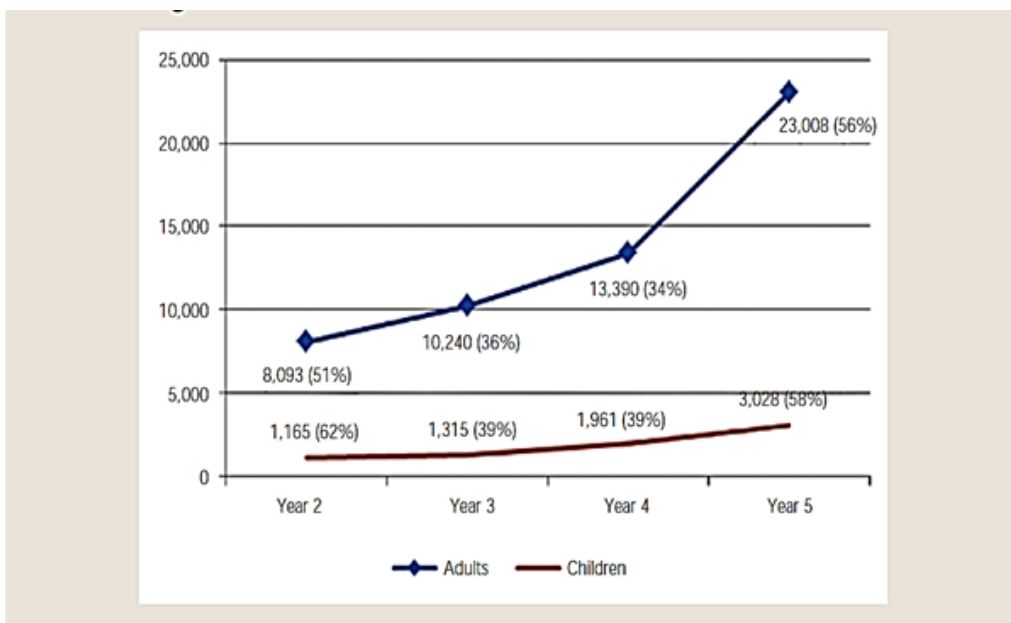


Figure 2: Access to CTX for infected children and adults

b) Education

Children affected with AIDS 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, 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.

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.

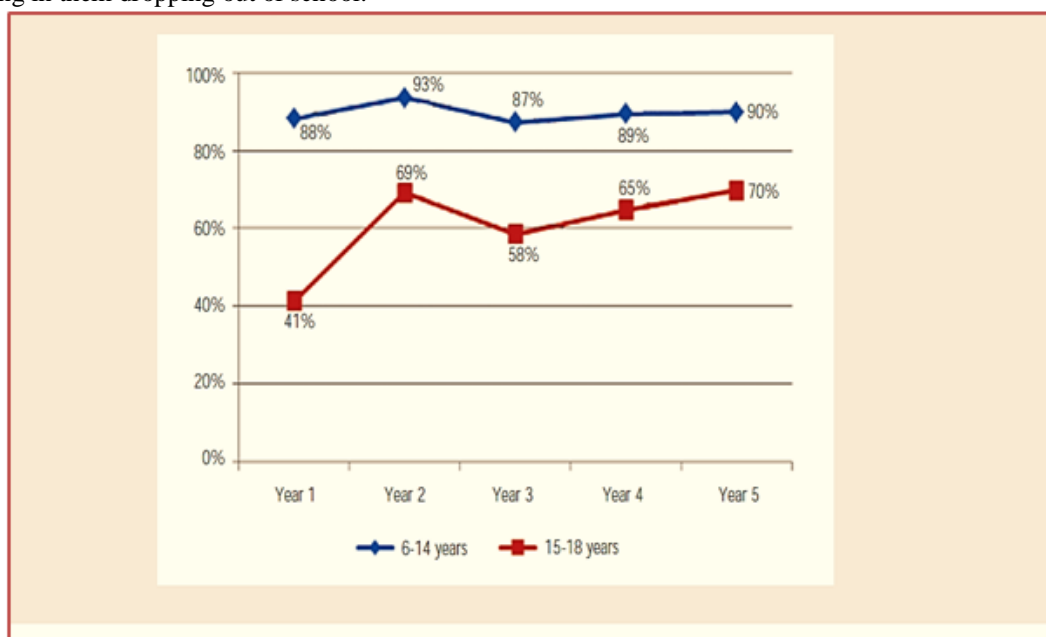


Figure 3: Children's enrolment in schools

c) 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 mal-absorption and altered metabolism.

Balasahyoga aimed to improve the nutritional status of Children affected with AIDS through supplementary food. It provided fortified blended food (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.

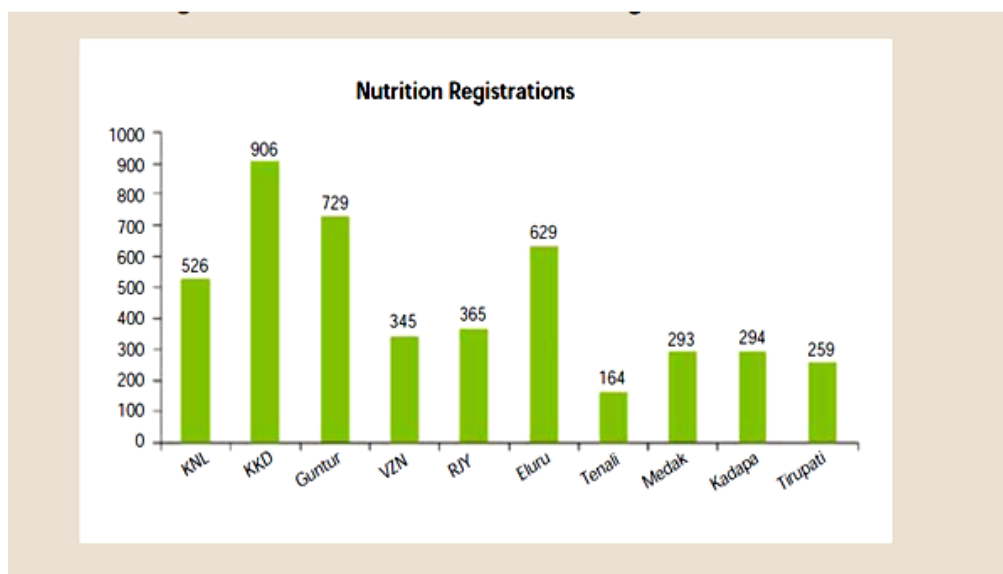


Figure 4: Infected children accessing FBF at ARTCs

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 Children affected with AIDS 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 Children affected with AIDS.

d) Life skills education

The challenges that Children affected with AIDS 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 Children affected with AIDS, 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 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.

e) 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.

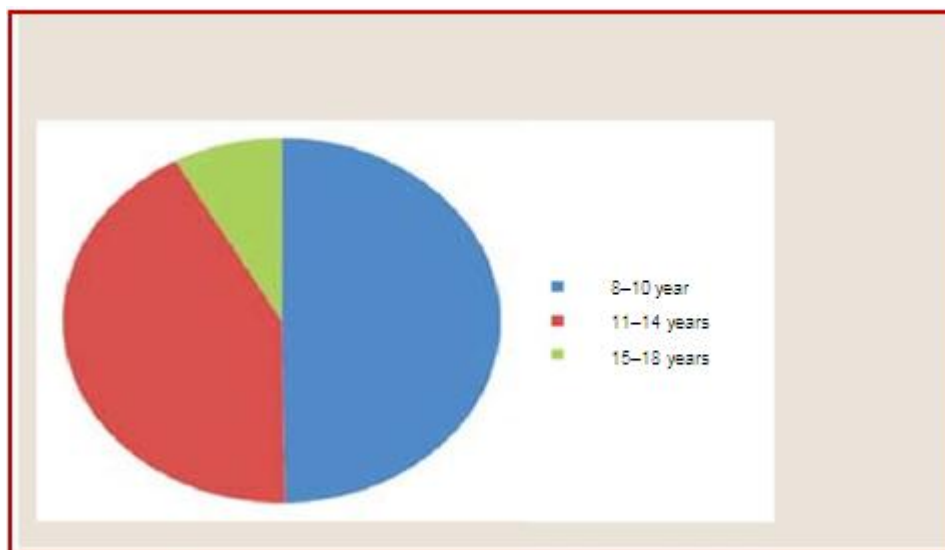


Figure 6: Age profile of children accessing LSE

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 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.

f) 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.

III. 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. 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.

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

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

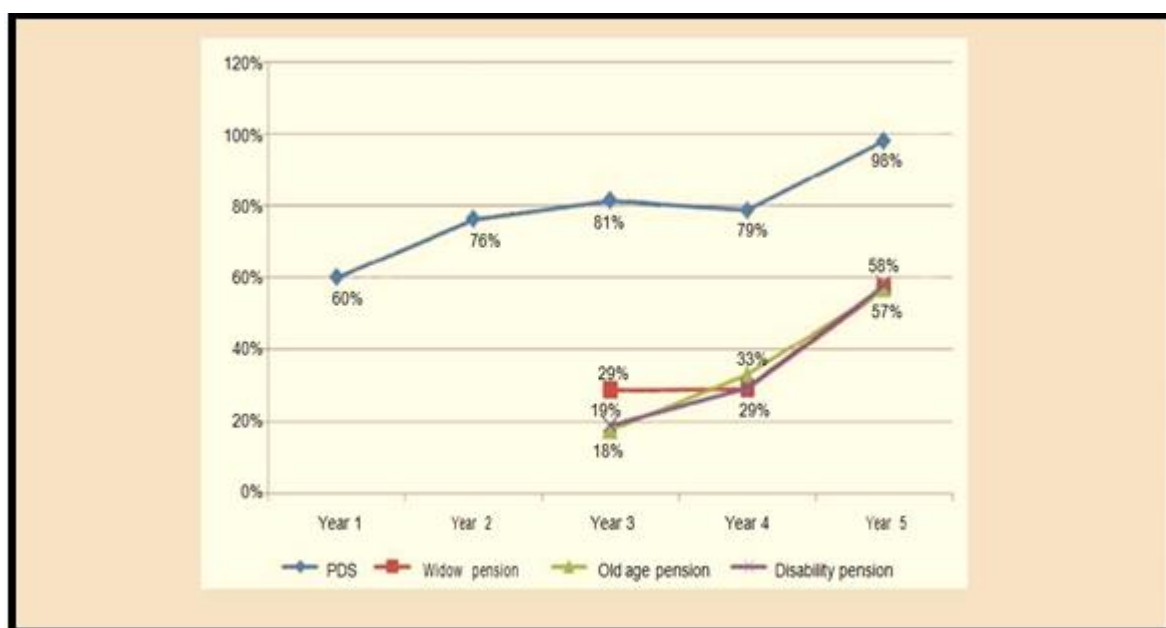


Figure 7 Access to PDS and pensions

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

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.

Table 2: 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% |

Table 3: 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% |

IV. Conclusion:

From the above study it could be concluded that Balasahyoga successfully took the issue of care beyond HIV testing and treatment. The program's efforts in ensuring a comprehensive package of services for children affected with AIDS and their caregivers brought forth significant changes in their lives in terms of their access to CTX drug, increased enrollment in school up to 71%, accessed to double rations through Anganwadi centers, received community based counseling by FCM teams, increased (38%) registrations to the PDS, receiving direct and indirect financial support from the programme helped them to overcome food insecurity levels.