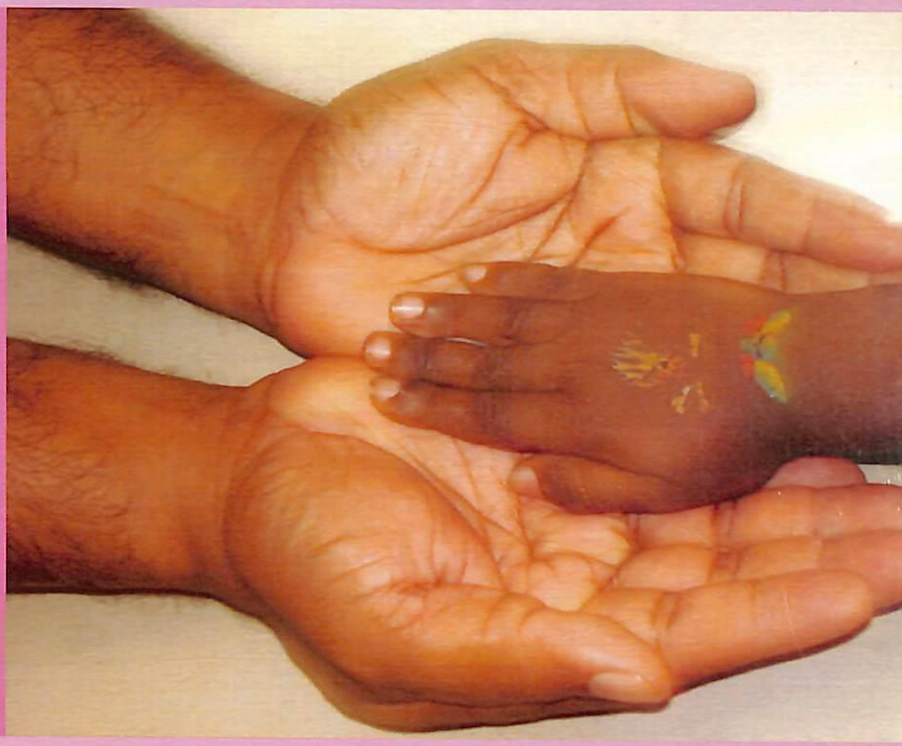
Successful Practice Documentation

Program for Children Living with HIV/AIDS (CLHA)



APAC-VHS

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COMMUNITY HEALTH EDUCATION SOCIETY
PREVENT AIDS

AIDS Prevention And Control (APAC) Project
Voluntary Health Services (VHS)

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Foreword

NACP III has currently gone past its mid way and we have a long way to catch up with the goals set by this plan. It may not be an exaggeration to state that we are running short of time.

Care, Support and Treatment seeks to implement the principle of a continuum of care. In this document we have tried to record one of our best care project in Chennai that provides care continuum for the children infected and affected by HIV.

Through experience we know that the Community Care Centres bridge between the patient and the ART centres and provide psycho-social support, counselling through strong outreach services, referrals and palliative care. Home based care is an integral part of this strategy. Care, support and treatment services will include management of opportunistic infections including control of TB in PLHA, anti-retroviral treatment (ART), safety measures, positive prevention and impact mitigation.

Going with the NACP III goal, APAC makes every effort to address the needs of persons infected and affected by HIV, especially children. The CHES experience is a classic example of this effort and we hope that this document will share the key learning points and execute systems that have already been proved successful.

APAC is grateful to the SAATHII-SAMARTH team for documenting this project. I personally take this opportunity to thank Dr.P.Manorama and her dedicated staff who bring delightful smiles on the face of many children who wouldn't have seen the light of a brighter day in this world. I would like to appreciate Dr.T.Ilanchezhian, Director (Program Operations), APAC and his team for coordinating this initiative. I also wish more partners would join hands with CHES to make this the country's best service model to learn on child care and support.

Best Wishes,
Dr Bimal Charles
Project Director-APAC

Acronyms

APAC	AIDS Prevention and Control Project
ART	Anti Retroviral Treatment
CAA	Children Affected by AIDS
CABA	Children Affected by AIDS
CHBC	Community and Home based care
CHES	Community Health Education Society
CIA	Children Infected by AIDS
CLHA	Children Living with HIV AIDS
FHI	Family Health International
HBC	Home-Based Care
HRLN	Human Rights and Legal Network
ICTC	Integrated Counseling and Testing Center
LSE	Life Skills Education
NACP III	National AIDS Control Program Phase III
ORW	Outreach Worker
OVC	Orphan and Vulnerable Children
PEPFAR	President's Emergency Plan for AIDS Relief
PLHA	People Living with HIV and AIDS
SAATHII	Solidarity and Action Against the HIV infection in India
USAID	United States Agency for International Development
VHS	Voluntary Health Services
WHO	World Health Organization

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Executive Summary

Among the estimated 2.5 million people in India living with HIV/AIDS, 70,000 are children under 15 years old (UNAIDS 2007). Every year about 21,000 children are infected through mother to child transmission and thousands of children are affected because their parents are HIV positive. In Tamil Nadu 7,000 children are registered with the ART Centres and more than 2,000 children are on ART.

In 2007, the Indian Government under the Ministry of State for Women and Child Development launched the first comprehensive National Policy on Children and AIDS in India. According to the NACP III, only a multi-pronged approach involving NGOs and private sector hospitals can provide better service to the children infected and affected by HIV in this country.

USAID implements HIV/AIDS prevention, care and treatment as part of the President's Emergency Plan for AIDS Relief (PEPFAR), a U.S. Government-wide effort. India is a priority country under the plan, one of the largest health care initiatives of its kind. PEPFAR efforts include HIV prevention in high prevalence states and among high risk groups; work to ease the suffering of children affected by or infected with the disease; care and support to those affected; and involving the private sector to help stem the spread of HIV/AIDS on a broader scale.

The AIDS Prevention and Control Project (APAC) administered by the Voluntary Health Services (VHS), a 50-year-old service organization in Chennai, India works through various partners including NGOs, private sector partners and the government health care facilities. CHES (Community Health Education Society), one of the long term USAID implementing NGO, first through FHI's IMPACT program and later through APAC-VHS, has been in the forefront of advocating for the rights and services to the children infected and affected by HIV in this country.

This document narrates various approaches by CHES in carrying out its mission, which are aligned to the National AIDS Control Program Phase III (NACP-III) and the PEPFAR goals for the children infected and affected by HIV AIDS (CLHA).

The documentation process was carried out through a systematic data gathering methodology which involved desk review of existing literature, interviews with key stakeholders including staff, beneficiaries, partners, collaborators and children, and through several focus group discussions.

The program's success has been attributed to a four-pronged approach in service delivery to CLHA and their families. They are: Hope Club, Home-based Care through Outreach Work, School sensitization program and Documentation. All the four approaches are synergistic

and complementary to achieve the goal of providing the best care that the children could get within the existing limited resources in the country.

The salient features of the success of this program are commitment of its staff headed by leading paediatrician Dr. Manorama Pinagapany, networking and linkages with the government and other NGOs providing various services, close monitoring of case history of individual child and their family members, and the neighbourhood community support and encouragement.

The document narrates many case studies of individual children, staff and community leaders who participated in the success of this model in service delivery. It also points out the learning points where attention is further required in the future, where expertise such as paediatric counselling is required especially for status disclosure to children, and where family's cooperation is necessary for a holistic home-based care to be established for the children.

As one of the long standing care centers for HIV infected and affected children in Chennai, India, it is our hope that the CHES model could be replicated in other parts of the country where children are suffering due to their age and environment.

PART I: Background

Programs funded by the U.S. Government's President's Emergency Plan for AIDS Relief (PEPFAR) have made substantial impact on HIV prevention, care and support activities in many countries, including India. Among these programs are those that provide services for children infected and affected by HIV/AIDS.

The USAID-funded project SAMARTH, initiated in 2006, includes in its mandate promoting visibility of PEPFAR-funded programs in India by identifying, documenting, and disseminating practices, models and strategies that have demonstrated positive impact.

In 2009, SAATHII, a consortium partner in SAMARTH, undertook the task of documenting successful practices of the Community Health Education Society (CHES), a Chennai-based NGO supported by USAID partner AIDS Prevention and Control Project (APAC-VHS). CHES offers community, home-based and institutional care to children infected and affected by HIV. CHES was selected for documentation after consultations with SAMARTH's lead partner Family Health International (FHI), and APAC-VHS. CHES is a pioneer in pediatric HIV and has a successful track record of 15 years in providing high quality services to children infected and affected by the HIV epidemic.

Introduction to CHES' programs for CLHA

Community Health Education Society (CHES) established the first HIV care home for HIV infected orphans in India in 1994. Under the leadership of an eminent Chennai-based pediatrician Dr. Manorama Pinagapany, CHES has been in the forefront of HIV prevention and care programs since its inception. It has initiated several model projects such as the orphan care project, counseling services to children affected by HIV/AIDS and the tsunami, foster care program for AIDS orphans, prevention programs among women in prostitution, male sex workers and transgenders, women in self-help groups, and programs for ante-natal, post-natal and lactating women. Dr. Manorama Pinagapany also serves as the Chair of the Tamil Nadu Government's Child Welfare Committee, a position that enables her to advocate as an 'insider' for government policies related to children and their rights.

In the year 2000, through the IMPACT Project of FHI, CHES started receiving USAID support for HIV-infected and affected children.

Since 2005, CHES has been one of the prime NGO implementing partners of the Tamil Nadu Family Care Continuum Program, an innovative Government-NGO collaboration that links clinical, community and home-based services in order to ensure comprehensive care, reduce orphaning, and improve quality of life among children and families affected by AIDS.

CHES has also been involved in several research studies on children infected/affected by HIV/AIDS and other vulnerable children. Some of these include:

i. Ante-natal care and infant feeding practices in Tamil Nadu, in partnership with MBC University of Australia, and Dr. MGR Medical University
ii. Needs assessment study among 500 children and their families affected by AIDS at Chennai city in 2006 with technical support from USAID – FHI.
iii. A vulnerability study among tsunami-affected children in 5 districts in Tamil Nadu in partnership with Save the Children UK, 2006
iv. Impact assessment of children affected by AIDS in Tamil Nadu (2002, 2005)

Actively involved in training and policy, CHES has developed training manuals and curricula on pediatric HIV care, counseling and treatment for diverse audiences including caregivers, medical practitioners, and counselors. It has trained more than 600 caregivers, 150 health care providers, and 40 counselors so far. CHES has also contributed to the formulation of policies for care of HIV/AIDS-affected children nationally and at state level.

Since 2006, CHES has been supported by APAC-VHS-USAID for Project Thooli, a community and home-based care (CHBC) program for Children Living with HIV/AIDS (CLHA). Thooli focuses on six PEPFAR core areas: 1) clinical care, 2) psychosocial care, 3) nutrition, 4) protection, 5) shelter, and 6) education.

CHES addresses these core areas through a minimum package of services offered to all families in CHES' follow-up, as listed in the box below.

Minimum Package of Services

- Need assessment
- Home visit at least once a month for all infected children
- Customized Care plan for each child
- Home Care Kit provision and Health Education
- Psychosocial support
- Life Skill Education (LSE)
- ART linkages
- TB screening
- HIV testing for those who have not been tested
- Patient tracking for medical and non -medical aspects of child's health using a comprehensive case file system
- Caregivers training
- Referral Service

Under the current APAC-funded phase, CHES has evolved a minimum package of service concept that ensures uniform access to essential services to every family accessing the organization. This program follows the PEPFAR guidelines, and provides these services directly, or through referrals to other local organizations. The team under this program comprises a project director, a project coordinator, three outreach workers, a part-time nurse, a part-time doctor and a part-time accountant. Besides, CHES office provides a training room, a medical clinic and administrative office space.

At the time of writing this report, there were 105 infected children receiving home-based care (HBC) under the APAC-CHES initiative. In addition, about 400-500 HIV-affected children (but tested negative for HIV), whose parents are positive, currently receive care and support through the project.

Objectives of the documentation exercise

The key objective of this documentation exercise is to identify successful models and practices of the CHES' CLHA program from October 2006 to May 2009. These practices were selected after consultation with APAC-VHS, the CHES management and the field team of the Thooli project. Selection criteria included evidence of positive outcomes and relevance to national scale up of programming for care and support of HIV-infected children.

Specific areas include Hope Club, home-based care, school sensitization, and its programmatic documentation. The findings may be used as a learning tool for other organizations in developing their own CLHA programs, and to support ongoing national efforts to standardize, *operationalize and mainstream CLHA* programming in NACP-III.

Methodology of Data Collection

An initial discussion among FHI, APAC-VHS, and SAATHII, held at APAC-VHS office on October 17, 2008, identified the CLHA program funded by USAID/APAC-VHS as a site to document successful practices. The documentation team met the CHES team on April 6, 2009 to brief the team on the scope of work and assist them in short-listing activities they considered to be noteworthy using criteria of evidence and scalability. Following receipt of a preliminary listing of practices, the documentation team held a second meeting with the team on April 18, 2009. It reviewed available documents, and collected data from respondents from April 26 and June 5, 2009. After analysis and writing, a first draft was submitted to CHES and APAC on June 8, 2009 for their review.

1. Focus Group Discussions (FGD) and Methodology interviews with families receiving HBC services, outreach workers, other staff and involved community members.

2. Review and analysis of individual case files, monthly reports and annual reports to gain qualitative and quantitative data with respect to efficacy, impact and reach of those merited practices/programs/innovations identified by CHES.

3. Observing group activities organized by CHES to have informal conversations and interactions with beneficiaries.

Log of Documentation Activities

Activity	References	Date	Purpose
Hope Club FGD with 8 CABA Mothers	042609-FGD-1	April 26, 2009	Learn about benefits of Hope Club activities and HBC
Hope Club FGD with 11 CHES children	042609-FGD-2	April 26, 2009	Learn about Outlook Camp and benefits of CLHA life-skills education
Hope Club FGD with 9 parents of CLHA	052409-FGD-3	May 24, 2009	Learn about benefits of Hope Club activities and HBC
Interview with Dr.Santhosh, Medical Officer at CHES	042709-KII-1	April 27, 2009	Learn about medical services provided to CHES beneficiaries.
Interview with Ms.Padma (alias) and Mr. Vijay (alias), CHES Beneficiary	043009-IDI-1	April 30, 2009	Learn about HBC and Vocational Training Sponsorship
Interview with Mr.Narasimhan (alias), CHES Beneficiary	043009-IDI-2	April 30, 2009	Learn about his experience as a CHES beneficiary for more than 10 years.
Interview with Mrs. Chandra Paati (alias), CHES Beneficiary	050409-IDI-3	May 4, 2009	Learn about Grannies Club
Interview with Dr.Manorama, CHES Director	052709-KII-2 0629M002-KII-7	May 27, 2009 June 29, 2009	Learn about the origin and growth of CHES' programs, partnership of CHES with USAID and APAC.
Interview with Mr. A.Srinivasan, Counselor at VCTC TB Hospital in Otteri.	060309-KII-3	June 3, 2009	To learn about CHES' network; both CHES and this counselor refer clients to each other.
Interview with Mr.V.Jeyaraj, Community Health Coordinator at World Vision	060309-KII-4	June 3, 2009	To learn about CHES' referral network; both CHES and WV refer clients to each other
Interview with Ms.Stella Mary, senior Outreach Worker at CHES	061009-KII-5	June 10, 2009	To learn about her experience as an ORW and her relationship with the families under her follow-up.
Interview with Mr.Kalyanasuntharam, Headmaster of Pathippaga Chemmal K.Ganapathy Government Higher Secondary School, Kodambakkam.	0629M001-KII-6	June 29, 2009	To learn about school sensitization program
Interview with three Hope Club attendees	0627M001-children-nutrition	June 27, 2009	To obtain testimonies on the benefits of nutrition support

Review of Documents:

The following documents have been consulted for this exercise. A full citation is located at the end of the report.

- CLHA Case Sheets, CHES
- Hope Club Minutes, CHES
- Hope Club Register, CHES
- Children's General Register, CHES
- Hospital OP and Medical Drugs Register, CHES
- Service Delivery Register, CHES
- Nutritional Supplement Log, CHES
- Life Skills Education Record, CHES
- TNFCC Hospital NGO Monthly Technical Reports
- "Protocol for Child Counseling on HIV Testing, Disclosure and Support," Family Health International (FHI)
- "Living well with HIV/AIDS: A manual on nutritional care and support for people living with HIV/AIDS," Food and Agriculture Organization (FAO)

Project Thooli: Beneficiaries

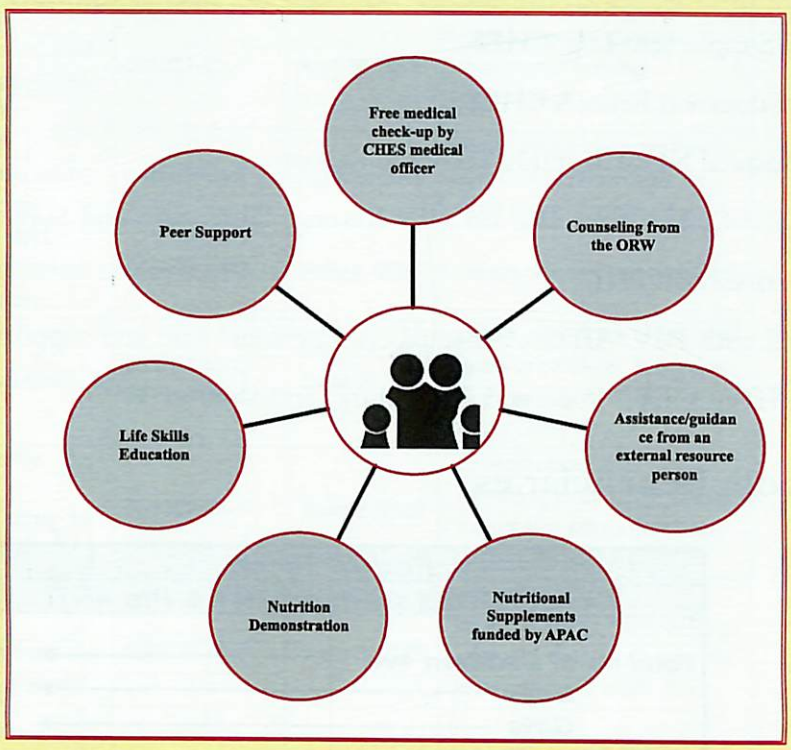
Project Thooli	
Consolidated sheet on ART & Pre ART	
Total no of Children +ve	105
Boys	54
Girls	51
Total No. of Children on ART	68
Boys	38
Girls	30
Total no. of Children on Pre ART	37
Boys	16
Girls	21

All CLHA program activities fall under CHES' Community and Home Based Care (HBC) component is described as follows:

Activity 1: The Hope Club

The Hope Club was initially supported by USAID/FHI from 2000 to 2006. USAID/APAC-VHS has been supporting the forum since 2006. The club brings together infected and affected families in a common forum for peer support on the fourth Sunday of every month. During a Hope Club meeting, the CHES team conducts medical check-up for the families that attend; provides nutritional supplements to about 25 children malnourished according to a WHO metric; teaches to use macro-nutritional supplements creatively; offers life skills classes for children; and organizes legal services on will-writing, property and inheritance, stigma/discrimination and insurance. The forum also teaches proper usage of nutritional supplements, health literacy, and has helped both children and adults to be more confident by reducing levels of self-stigma.

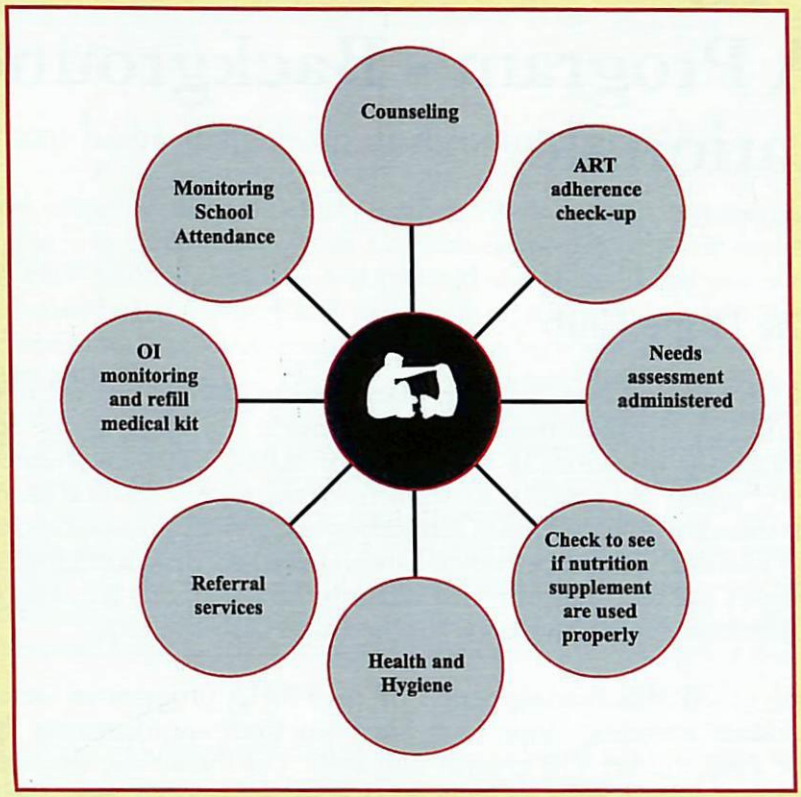
The Hope Club services are depicted in the following diagram.



Activity 2: Home-Based Care

Home-Based Care was initially supported by USAID/FHI from 2000 to 2006. Support has since been continued by USAID/APAC-VHS from 2006 to the present. Monthly home visit is the cornerstone of this activity, where outreach workers provide education on health-seeking behavior and nutrition, psychosocial support to children and referral monitoring.

Every CLHA and his/her family under CHES' follow-up receive the following services:



Activity 3: School Sensitization

As a part of the community outreach component of the CABA program, CHES continues to conduct school sensitization activity to promote health, sex and sexuality education in government schools. Three schools have been involved in this program, one in each of the following Chennai localities: Vadapalani, Saidapet and Kodambakkam. The program also motivates the headmasters (principals) and teachers to provide education to infected and affected children without stigma and discrimination.

Activity 4: Documentation

With the assistance of APAC, CHES developed a comprehensive system of maintaining records and files of the entire program which has proven instrumental in tracking clients and their families, and the progress of program components.

PART II:
CLHA Program - Background and Rationale

Activity 1: The Hope Club

When the Hope Club was first started by Dr. Manorama in 1997, it was intended to be a support group for PLHA and their families, and to provide free medical care for an early detection of opportunistic infection. In the period of APAC-VHS' involvement, CHES introduced a series of additional activities to supplement the routine medical check-ups and counseling sessions already within the Hope Club framework, giving importance to the specific needs of CLHA. In addition to primary medical care and essential drug administration (upon availability), the Hope Club meetings provided referrals, legal support, life skills education, nutrition support, nutrition demos, and lunch for the Hope Club attendees.

Since the beginning of APAC's funding period of the CLHA program in October 2006, the number of children attending Hope Club has risen from approximately 70 children at the beginning of 2007 to over 110 towards mid 2008. On the whole, attendance of an individual Hope Club session was more when CHES invited external legal facilitators or positive speakers. In the last months of 2008, attendance stabilized at approximately 80 to 90 children; no external resource persons provided their services and children were on holiday from school (Hope Club Register and Hope Club Minutes, CHES.)

Initially having only five families in attendance in 1997, Hope Club has grown to have over 70 families at each Hope Club meeting who availed themselves of medical check-ups, life skills education (LSE) courses, nutrition demonstrations and guest speaker activities. For adults, CHES arranged legal advice from Human Rights Legal Network (HRLN) that helped PLHA plan for the future. Topics included information on health insurance, maintaining property, and government schemes for which PLHA are eligible.

Selvi receives Legal Support

Selvi (name changed) worked at a shoe factory from 2006 to 2008 as a tailor, during which she discovered she was HIV positive and subsequently registered with CHES. She then resigned from her post at the factory, but was denied her Provident Fund and Employee Safe Insurance amount to which she was rightfully entitled. Upon attending a legal session facilitated by HRLN during her usual visit to Hope Club in August of 2008, Ms. Selvi was advised to furnish her employer details, pay slip and experience certificate to the advocate. HRLN is currently pursuing the case and in the process arranging for settlement out of court. (Legal Record, CHES)

Positive speakers and nutritionists also facilitate sessions for parents and grandparents on positive living to increase levels of confidence and to educate them on how to lead healthy and balanced lives within the family, emphasizing the importance of diet, play and education for their children. Mr. Narasimhan (name changed) first came to CHES in 1997. He says that being with CHES has given him hope and confidence to live, especially for the sake of his children. (043009-IDI-2)

Narasimhan: hope for a long and meaningful life.

Mr. Narasimhan found out about his HIV status in 1998 after getting a medical examination in Singapore. He was deported back to Chennai immediately. After another blood test confirming his HIV positive status, he was referred to CHES. "I had just gotten married at that time and I didn't have children so I would ask myself why I should (live). I called Dr. Manorama several times and I was worried a lot, I was very scared. I would ask Madam how long would I live with this disease." Dr. Manorama then told him to come to the Hope Club meetings every month, and he became a regular visitor. Although given many opportunities to talk on living positively, he felt uncomfortable and shied away. However, a few years later, after seeing the number of people who came to Hope Club, interacting with them and hearing their stories, he gained confidence in his own situation. In 2005 he introduced his wife and children to CHES. His children regularly participate in activities held during Hope club. "I live for my children and my wife. If Dr. Manorama hadn't told me that I can beat this, I would have committed suicide a long time back." He said that coming to the Hope Club regularly has indeed given him hope to live a long and meaningful life. (043009-IDI-2, Valavan, pers. comm.)

CHES holds Life Skills Education (LSE) sessions for children who are infected or affected by HIV/AIDS. The sessions are based on the "Life Skills Education Toolkit for OVC in India," a resource developed by FHI, USAID and other NGO partners in India. CHES translated the modules into Tamil and adapted them to local needs. More details on LSE are given in a subsequent section.

Early this year, CHES introduced a Valentine's Day activity in 2009 where each child described their interpretation of 'love' and then spoke about a parent, sibling, grandparent or friend whom they loved. During that day, CHES also organized a science fair, a drawing competition and other games to further engage the children who came to the Hope Club.

Nutritional Support

Nutrition demonstrations provided during the Hope Club meetings have promoted healthy dietary practices along with suggestions on managing simple Opportunistic Infections (OI). This has contributed to the improvement of overall health of CLHA (Dr. Manorama, interview). CHES beneficiaries who need ART are linked to an ART center in a government facility, where they receive ART as well as one kilogram macro-nutritional supplements (satthumavu) to promote good health while taking ART. Satthumavu is a mixture of fortified flours, which is normally consumed as porridge every day. As the porridge is bland in taste, many people, especially children, refuse to consume it regularly, thus failing to achieve the objectives of the nutrient supplementation and causing wastage.

Due to the heavy case load at the government facilities, the staff or counselors at these centers fail to follow-up with clients to insist on eating satthumavu regularly. The children when initially introduced to the CHES' programs are found moderately or completely malnourished because their parents are health illiterate and/or they do not have the economic means to provide food of sufficient quantity or nutritional content for the family. Children, especially those who are HIV positive, often bear the brunt of these situations.

One of the ways CHES promotes child nutrition is to assist parents in making the macro-nutritional supplement tasty. While the ART center in the Government Hospital of Thoracic Medicine (GHTM) provides samples of creative satthumavu preparations for example, only CHES performs a live demonstration allowing CLHA care-givers to participate. This also allows the children to get excited and taste the new recipes made of Satthumavu (043009-B-1). Every Hope Club day, social workers bring a stove and ingredients to prepare appealing alternatives to porridge, like pakoda, adai, chapatti, and so forth, incorporating satthumavu in the preparation. About 30 mothers and fathers attend these cooking classes, ask questions and actively participate in clarifying recipes and tasting the final product. Employing new techniques of incorporating macro-nutritional supplements into daily foods encourages families to be intentional about foods they consume (pers. obs.).

"It's very difficult to get my son to drink porridge, but it is easy to make satthumavu pakoda and adai which he eats. The mavu won't go waste and it will make him stronger. The entire family eats it too." (A mother, interview)

"I even come up with my own different ways of preparing satthumavu since I stay at home, and I can come to CHES and share these recipes with the other mothers." (Ref. 052409-FGD-3)

The CHES team meticulously tracks the nutrition status of children and provides additional nutritional support if needed based on a comprehensive nutritional assessment as per WHO guidelines, in addition to a structured growth monitoring chart (designed by Dr. P. Manorama specifically for children in South India) instituted in July 2008.

Initially, HIV positive children who are in the bottom 60% for weight in their age group were given additional nutritional support funded by APAC. (Nutrition Support Register, CHES) (Age+3/2.2 Formula) Starting in August 2008, the cutoff was raised to 70% since very few children fell below 60% (Amudha, interview). ORWs check to see if this supplement is being given appropriately to the child during their home visits. The CHES medical officer tracks weight and height gain for subsequent months. For other children who may not qualify for this nutrition supplement, ORWs make referrals to the World Vision health project office, where provisions are distributed to all HIV infected or affected families free of charge (Referral Register, CHES).

Nutrition Package	
Contents	Quantity
Rice	2 Kg
Thoor Dhal	500g
Sugar	1Kg
Vermicelli	450g
Manna Mix	500g
Wheat Flour	1Kg
Maida Flour	1Kg
Milk Biscuits	4Packs

Since APAC started providing supplements for around 25 malnourished children, there has been an overall upward trend in their height and weight, as shown in Table 1

Table 1: Weight Change in Twenty HIV Positive Children after Taking Nutrition Supplements from October 2008 to March 2009.

Weight Shown in Kilograms (Kg)						
Age/Sex	**Oct 08**	**Nov 08**	**Dec 08**	**Jan 09**	**Feb 09**	**Mar 09**
3/M	10	10	10	10	10	11
5/M	12	12	14	16	16	16
5/M	12	12	12	13	13	13
5/M	13	14	15	15	14	15
5/M	10	10	11	12	12	12
6/M	13	13	14	14	14	14
9/M	14	15	15	16	16	17
10/M	16	16	17	17	17	17
10/M	18	19	20	20	20	20
12/M	22	24	25	25	25	24
14/M	25	25	25	25	26	26
15/M	24	25	26	26	26	26
3/F	9	10	10	11	12	12
4/F	9	11	12	12	12	13
4/F	10	12	12	11	11	12
6/F	13	12	14	14	14	14
9/F	20	22	22	23	23	23
9/F	15	15	16	16	17	18
14/F	24	23	24	24	25	25

The names of the children have been removed to protect confidentiality. Due to the success of this program, in the next phase of programming starting July 2009, APAC has raised the amount of money allotted for providing support to malnourished children from 25 children to 30 children. (Data of children with their real names is in the Nutrition Support register.)

Life Skills Education (LSE)

Life skills education helps children who are infected or affected by HIV in improving their skills in communication and problem-solving, developing self-confidence and coping skills, in addition to gaining sexual health education and support from peers. Every month CHES organizes two LSE sessions of the same module, adapted from the FHI/USAID LSE Toolkit, one for children whose HIV status is not disclosed and another for those whose HIV status has been disclosed. The ORWs refer children between the ages of nine and 15 for the LSE (Nelson, pers. comm.)

Life Skills Education helps resolve family conflict

Divya's family joined CHES during FHI's IMPACT phase in 2004. In 2007 when Divya was 14, her parents disclosed about their HIV status. Already knowing about HIV, Divya assumed that her father had an extramarital affair with a sex worker and refused to talk to him. She became disrespectful and resentful toward her father; this behavior interfered with her studies and other relationships at home. Divya's mother then referred her to CHES' LSE course. From the other children, Divya was able to develop coping and communication skills, and learned that HIV can be acquired through means other than sexual contact. She continues to attend the LSE courses; she fares well in school and has a good relationship with her father. (Nelson, interview)

Life Skills Education motivates Pooja to return to school

Pooja (name changed) was orphaned at an early age; both parents died of AIDS leaving her under the care of her grandmother. Pooja dropped out of school upon finding out she was HIV positive; a CHES ORW motivated her to attend to the LSE class. During these classes she noticed other children attending school as normal students. Her interaction with other children and listening to their experiences, she too decided to go to school. She rejoined school in July 2007 as a fifth-grader. She continues to attend LSE courses to help her in school and to cope with her HIV status. (Nelson, interview)

Outlook Camps

In addition to the LSE offered during the Hope Club sessions, CHES has also organized three Outlook Camps; each camp is a two-day excursion with children and staff. LSE modules are incorporated into the Outlook Camp curriculum, and the CHES children learn about first aid, sexual harassment, and acquire soft skills interpersonal relations. The camp offers cultural activities, arts/crafts and games. From these activities, the children learn to interact with each other, share experiences and play with one another while learning.

A few of the children who have attended the CHES' Outlook Camp, spoke to the SAATHII documentation team about their knowledge on first-aid, life skills and basics of safety. They could also articulate ideas and opinions clearly and thoughtfully. They were able to recall the phone numbers for the child abuse hotline and how to perform first aid. During this interaction, a few of the children who had experienced their parents getting sick, presumably due to OI, discussed amongst themselves on what they would do this situation. The children shared their experiences, explained to each other how to use a first aid kit and knew that the CHES social worker would help them get assistance in case of an emergency. (042609-FGD-12, pers. obs.)

Key Lessons:

This section seeks to articulate the **key lessons** from the Hope Club so that other organizations working with children infected and affected by HIV may use these models, methods and systems to formulate a successful intervention for children, similar to that of CHES.

1. For families affected by HIV, a monthly support group with opportunities for medical check-ups and speaking to legal and nutrition professionals encourages families affected by HIV to be mindful of their own health and livelihood, as shown in the increased attendance of Hope Club during these specialized presentations. Coupled with home-based care, Hope Club is instrumental in promoting adherence to ART, preventing loss to follow up, and increasing self-esteem and confidence of both the parents and their children, ultimately contributing to the well-being of the children in these families.

2. Monitoring a child's nutrition using WHO standards and providing supplements when they are malnourished can help ensure that positive children who are on ART are healthy and may help in preventing the onset of opportunistic infections, muscle wasting and progression of the infection according to the Food and Agriculture Organization manual on nutrition, care and support for people living with HIV (FAO, 2002). Furthermore, even if children are not clinically malnourished, referring families to other organizations that provide provisions free of cost can contribute to the overall good health of the children within these families, especially if the use of these provisions is monitored by the ORW during home-visits.

3. Incorporating a LSE component into any CLHA intervention is an important part of guiding children to overcome hardships associated with being infected or affected by HIV, as shown in the two case studies presented in this section. Furthermore, adapting the Life Skills Education Toolkit to the needs of the children in the appropriate language assists in keeping their attention and contributes to consistent attendance.

Recommendations:

Operational guidelines for Hope Club activities, if developed, will help in replication of this model in other settings.

Activity 2: Home-Based Care

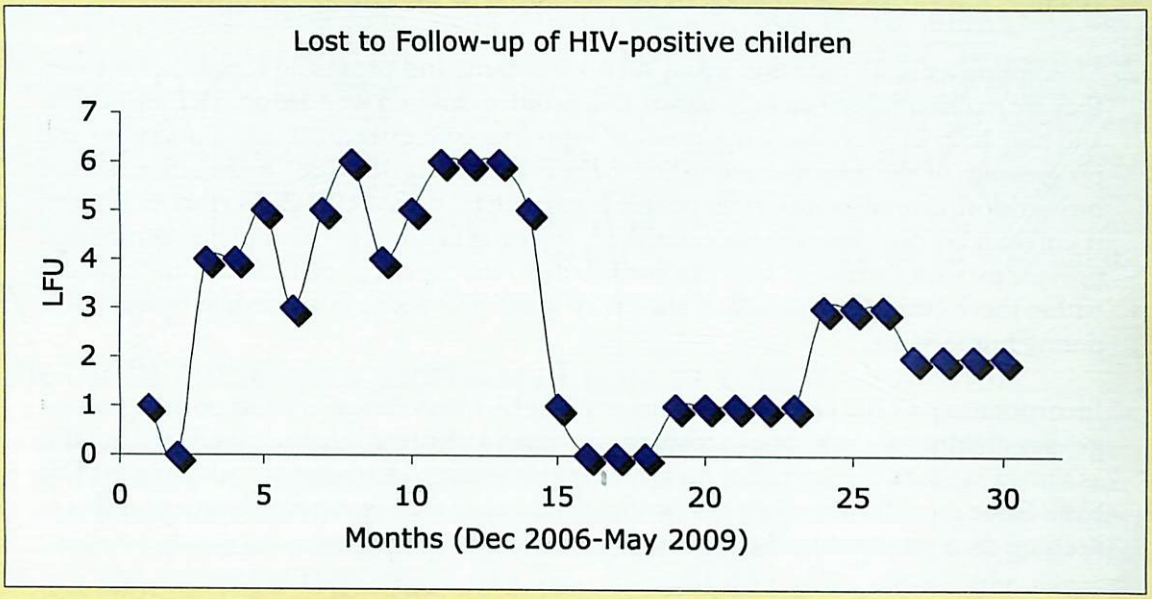
Home-Based Care was initially supported by USAID/FHI from 2000 to 2006. Support was then continued by USAID/APAC-VHS from 2006 to the present. The primary services offered in HBC are client follow-up during monthly home visits, education on health-seeking behavior and nutrition, psychosocial support to children, monitoring child growth and adherence to medication, and networking to leverage supplementary services for clients.

CHES has three ORW on staff who each have a client load of thirty infected children in their given coverage area. At the beginning of each month, the outreach workers go through case files and determine priorities for that month for each of the infected children under their supervision. These priorities include, nutrition, education, OI monitoring, ART adherence and the like. For these children and their families, the outreach worker makes at least one visit home to speak with the parents, ensure that ART and macronutrients are consumed appropriately and develop a rapport with the extended family of that child. The ORW will then write the result of that visit in his or her daily diary and use it to follow up on requests

made by the families. The ORW will then update the case file and touch base with the family when they come for Hope Club. At the end of each month, the findings and results of follow-up will be documented in monthly reports and internal records.

Client Follow-Up and Holistic Care

During the interviews with HBC beneficiaries (as detailed in the table in the 'Methodology' section) and it was found that the program has been instrumental in monitoring adherence to ART and detecting opportunistic infections early. Home-visits require a great deal of commitment from the ORW staff and due to frequent follow-up from ORW in the HBC component, every positive child under CHES' care is linked to an ART center and have consistently gone each month to the center with which they are linked.



During the project period, the lost-to-follow up has been maintained at a low level. Dedicated ORW staff members who are in constant touch with their clients have achieved this. It was observed by the documentation team that clients immensely trust CHES to provide utmost care and support. Children and parents alike are comfortable calling their ORW day or night with queries and clarifications regarding not only medical issues but also non-medical issues.

Check-list for home visit

What to ask	What to look	What to tell	What to do
1. General enquiry about family 2. Enquire about children in specific 3. Ask about school education 4. Enquire about problems which they said last time 5. Ask about visit to ART 6. Ask about missing ART 7. Ask about support services provided if any 8. Food intake 9. Ask about CD4 count 10. Ask about ask for any illness 11. Ask about any treatment since last visit 12. Ask about referrals made 13. Ask for any support 14. Discordant couple – ask about condom use and need	1. General appearance of children 2. Look for obvious weight loss 3. Look for general cleanness - head to foot look 4. Environment cleanliness – mosquito net 5. Count ART tablets 6. Check nutritional packs 7. Skin changes, lymph nodes, weight loss, dehydration, fever 8. Look if external environment is safe to girl child or both 9. Any stigma 10. Assess the need for psychosocial support 11. Caregivers kit if used 12. Look out for boiled water 13. Nutrition closed 14. Check ART notebook for drug collection, CD4 counts	1. Personnel hygiene 2. Environmental hygiene 3. Nutrition 4. ART adherence and visit to ART center 5. Discuss stigma issues 6. Discuss on future plans for children 7. Discuss on property inheritance & WILL writing and Savings 8. Children being sent to LSE class 9. Discuss on waste handling (menstrual) 10. Referral to PLHA network or other needs including medical 11. Invite for caregivers training 12. Motivate for HIV testing 13. Motivate to school if dropped 14. Discuss about disclosure	1. Organize medical records 2. If sick prepare kanji and give needed tablets 3. Nursing if needed 4. Bathe if sick 5. Clean wound 6. Nutritional demo 7. Referrals internal 8. Referrals external 9. Help children in education 10. 10.Use of caregiver kit 11. 11.Tablets segregation or labeling 12. 12. Take them to health center 13. 13.Pay school or vocational classes fees 14. Play, teach children

Case Study - Outreach Worker

Ms. Stella Mary became an Outreach Worker at CHES in 2004. Married to an auto-driver when she was 18 years old, she found out her husband HIV positive when he got into a traffic accident in 2003; he was 28 years old. At the time she was a school teacher and decided to quit her job due to stress at home. Because neither she nor her husband was working, they were unable to provide for their eight year old son. Her husband passed away and she was devastated; she did not know anything about the disease that killed her husband she did not leave her home and even attempted suicide.

A CHES outreach worker then visited her home and offered her a job at CHES. "There was a vacancy for an ORW position and they said that it would be a good way for me to start working again." She says that it is solely because of her personal experience with HIV that she is able to connect with other HIV affected families.

"I remember how ignorant I was about the disease, scared, and always at home. Only after CHES came to my house did I realize that there are so many others who are affected and they need help. My heart is satisfied doing this work. I do not go to a home and just do my job. I sit with them, I cook for them, I eat with them, I play with their children. I speak kind words to them which would show my care and understanding for what they are experiencing."
In her sixth year as an ORW, Ms. Stella has under her follow-up 45 families whom she is required to visit at least once a month, but she says she visits each family at least two to three times. "I want to give them the support that would have been helpful to me. Sometimes, I am their only family." (Stella, interview)

Further evidence of the success of HBC component of CHES' CLHA program is that of the 57 children who have been registered in the after the beginning of the APAC funding in October of 2006 and have been identified as positive, only one child has died. Both parents of this child were positive and after being registered at CHES in April 2008, the family transferred elsewhere and the child was no longer under CHES' follow-up. The remaining children are under active follow-up to ensure they remain pre-ART for as long as possible and if they are already on ART, the ORW seek to ensure that these children remain adherent and healthy (Children's General Register, CHES).

Mr. Srinivasan, a counselor for 10 years at the TB Hospital in Otteri said CHES' ORW staff are among the most dedicated he had seen in ensuring tracking and meeting the needs of all clients. "I see about 15 children a year from CHES. A child with HIV is the most complicated situation." CHES ORW, Mr.Srinivasan said, are skilled in identifying children who are in need of counseling as well as in motivating the family to seek counseling (060309-KII-3).

Other examples of services ORW provide outside the medical realm are arranging for collection of ration cards, integrating children into school, referring families to government schemes and providing emotional support in times of crisis. It is apparent that the CLHA team recognizes that the well-being of parents assists in ensuring the well-being of children. This support is made possible due to the close relationship between the ORW and the beneficiary family. In this way, CHES takes a more holistic approach to HIV care and support, which the government facilities and services are insufficient due to the massive client load at government hospitals and ART centers. As the CHES medical officer explains, "CHES functions as a middle-man" and is able to supplement government HIV efforts to ensure that families not only get the medical attention they require, but also the psychosocial and livelihood support as well (042709-KII-1).

In this way, CHES has successfully framed "child issues" in terms of promoting supportive families and communities; CHES equips families with skills that contribute to the overall development and well-being of the child.

CHES helps raise Padma's economic status

Ms. Padma (name changed) has been a beneficiary of HBC for the past two years. Her husband died of AIDS and she is HIV positive. She supports her two children, both of whom are not infected with HIV. A CHES ORW visits her home more than once a month and in addition to making sure she is adherent to ART and her other medical needs are met, CHES also provides economic support for education and vocational training for Ms. Padma's children. CHES funded her son's course in computer graphics and other applications and at present, he is the breadwinner for the family as graphic designer with a local photography studio. CHES referred her to World Vision of India, and from them she was able to get a sewing machine. Ms. Padma is now able to generate some income for her family working from home. Her daughter participates in the LSE programs at CHES, is in the top three ranks in her class at school and she hopes to compete in a dance competition on television. (043009-IDI-1)

Leveraging and Networking

Leveraging with the other NGO and government partners has contributed to a comprehensive provision of care, support and treatment of all families in CHES' follow-up. While CHES provides some nutritional and medical services, along with supporting a few income generation programs and education for the children, the organization has developed a strong relationship with the NGO community and health care providers in the area for which CLHA needs may be met more holistically.

Specifically, CHES is able to provide free medical check-ups and referrals; nutrition supplements for malnourished CLHA, home-based care, limited education support and vocational support, in addition to life skills education for OVC and a forum for adult peer support. CHES does not have the resources to provide education and nutrition support to all needy families. Only 25 malnourished CLHA qualify to receive such nutrition support. Education support is also provided on a case-by-case basis. For more substantive nutrition support, rent support, and income generation program for all families under CHES' follow-up, ORW refer families to World Vision of India.

CHES has successfully leveraged support from World Vision's health program to supplement CHES' efforts to address CLHA, especially in areas of education and livelihood support. Many families who come to CHES for their medical and nutritional needs also avail of services from World Vision with the help of Mr. Jayaraj, Community Health Coordinator of South Chennai's Grace Programme. This programme aims to provide care and support services to mainly women and children who are infected and affected by HIV. Starting in 2007, Mr. Jayaraj sends a letter to Dr. Manorama yearly with the details of each child who came to WVI, South Chennai branch on CHES referrals or that calendar year. From 2008 to 2009, WVI provided services to 25 children who were referred to the Grace Programme from CHES (NGO Contribution File, CHES). Data were not available for WVI's other branches although CHES does indeed work with them as well.

Ms. Divya (name changed), 18 year old has been coming to CHES since 1995, following after her father's death. Her mother passed away in 1991. She was diagnosed with HIV at the age of four. She also suffers from multiple neurofibromatous lesions. Her grand-mother is the care taker. When asked about nutrition support she gets while visiting CHES, she said, "I get grocery items such as rice, dates, white flour, pulses, nutrition powder, and biscuits. I eat two dates a day and my 'Aaya' (grandmother) prepares Vadai, Aappam, Ada, Bonda, and

Puttu out of the nutrition powder that we get from CHES and hospital. I like to eat nutrition powder when it is prepared in different ways. I do not get fever but I get leg pain often. I used to be short and now I am tall and have put on weight. Doctor meets us, asks us about our health and gives us medicine. I like to come to CHES because I get to play with my friends and learn a lot about good behavior.

"Many families come to WV's Grace Program from CHES and we are so happy to be able to provide provisions, money for the education of their children and (rental fees for their homes) and the like. World Vision of India does not have medical service and so we direct them to CHES," says Mr. Jayaraj (060309-KII-4). A close relationship has been forged by the CHES CLHA program staff where affected families are able to receive holistic care and support through the services that both World Vision and CHES provide. (pers.obs.)

CHES also collects free drug samples from neighborhood doctors that would otherwise be disposed; these drugs are then prescribed and distributed by the CHES medical officer. The value of the donated drugs ranges from 5,000 to 10,000 Rs/- per month (NGO Contribution file, CHES).

Similarly, Dr. Manorama, who has established herself as a respected authority on child health, is able to network with government programs as well. She has been part of many bodies that address child welfare and health at both the state and national level. Furthermore, Dr. Manorama said that because of CHES' association with USAID, they are able to leverage international funding from sources such as the United Postal Service (UPS), a private American postal company, and Emirates Foundation, in addition to good media coverage which has been highly beneficial to their other programs (052709-KII-2)

Key Lessons:

This section seeks to articulate the key lessons from Home-Based Care so that other organizations working with children infected and affected by HIV may use these models, methods and systems to formulate a successful intervention for children, similar to that of CHES.

1. Comprehensive care involves clinical, community and home-based care components, and the CHES experience has demonstrated that networking with local NGOs is a cost effective way of offering a diverse suite of services that meet the needs of CLHA and their families.

2. A dedicated corps of ORW is instrumental in monitoring the medical and non-medical needs of CLHA families. From the CHES experience, it is apparent that the ORWs, having established themselves as trusted friends of the families in the CHES follow-up, are privy to the personal situations of the children and their families, and are subsequently able to assess and facilitate their immediate and long-term needs. The ORW is the prime link between families and the services they need, therefore this is an extremely effective component of this HIV care and support intervention.

Recommendations:

This section seeks to offer recommendations, based on observations made in the course of documenting the successful practices of HBC.

The study recommends that operational guidelines for HBC be made available which will help in replication and scale up of this successful model.
It also recommends that a professional child psychologist be hired to oversee the psycho-social health of every child in CHES' follow-up, to ensure high quality support, especially since this is one of the primary PEPFAR areas addressed by this program.

In child-centric programs such as the CHES CLHA program, providing psychosocial support for children is an essential feature of the continuum of care. CHES has provided counseling training to the CLHA ORW team, however training alone does not equip them to address the psychological stress that accompanies being infected or affected by HIV, especially to the unique needs of children. (Please refer to the case study in the Annexure.)

In a conversation with members of the CLHA counselors team, they expressed (1) inadequacy in providing appropriate counseling to the children even though they had attended training sessions arranged by CHES; and (2) lack of time to sufficiently attend to the psychosocial needs of all the children under their follow-up. Because the ORWs do not have the official qualification and/or designation of "counselor", they are often unable to gain the trust of the parents to access and counsel the child separately. Furthermore, they are unable to offer consistent follow-up to specifically monitor the child's psychological needs due to their other responsibilities (pers. interview)

To address this, the "Protocol for Child Counseling and HIV Testing, Disclosure and Support" a publication supported by FHI/USAID, suggests that "the professional counselor orients and provides ongoing support to the lay counselors." (FHI/USAID, 2007) In this case, the lay counselors are the ORW who are currently responsible for home-visits, documentation and referral management.

If a child psychologist were on the CHES staff, he or she could be responsible for overseeing the psychosocial condition of each CLHA under CHES' follow-up, make home-visit specifically for this purpose; organize individual and family counseling sessions; and coordinate the LSE component of the CLHA program. Each child's progress would periodically be reported to the ORW to use when determining an overall treatment plan for the child. This model has been employed by other care and support programs for children including the Tamil Nadu Family Care Continuum program – a project focusing on preventing HIV infected children from being orphaned which was funded by the Children's International Investment Fund from 2005 to 2009.

Referrals to external organizations for child counseling may be a feasible alternative: however, the CLHA staff said that (1) suitable child counseling facilities are not available/easily accessible in Chennai and (2) motivating the children/families to go for multiple counseling sessions will be more difficult than having a counselor as part of the HBC staff at CHES.

Activity 3: School Sensitization

As part of the community outreach component of the CABA program, CHES conducts schools sensitization activity to promote health, sex and sexuality education in government schools at Chennai.

Introducing sex and sexuality education in government schools has faced criticism at both the local and national level in India. To address this need, CHES started a pilot program in the second phase of APAC funding to sensitize headmasters and teachers to the necessity of teaching health and sexuality in the classroom. At present, three schools have been involved in this program namely Corporation Higher Secondary School, Trust Puram, Vadapalani; Valluvar Gurukulam Special school for gypsy community, Saidapet; and Pathippaga Chemmal K. Ganapathy Government Higher Secondary School, Kodambakkam. CHES outreach workers have held several sessions in each school on issues of health and hygiene and sex/sexuality by having separate capacity building sessions for teachers and students. In both groups, the facilitators asked for the participants to submit their questions on slips of paper so they could be answered anonymously.

During the review of the questions asked during the sex and sexuality education, it was found that overall knowledge on sex and sexuality was minimal, as illustrated in the following box (translated from Tamil):

1. Do people who have leprosy also have HIV? (11th Standard)
2. How does the uterus form? (8th Standard)
3. If I masturbate, will my kidneys fail? (9th/10th Standard)
4. Did I do something wrong (lying or stealing) when I was younger that I have irregular periods? (9th/10th Standard)
5. During my menstrual cycle, I have heavy bleeding for two days, which is brown. Is all the bad blood leaving my body? (9th/10th Standard)

CHES has used communication methods such as puppet show, presentations, awareness programs through which all the students who are studying in Grade 9 and above were reached. Awareness classes are taken separately for girls and boys in order to make them feel comfortable to clarify their questions or personal nature.

During an interview with Mr. Kalyanasuntharam, Headmaster (Principal) of Pathippaga Chemmal K. Ganapathy Government Higher Secondary School, Kodambakkam, he expressed the important role CHES plays by educating his school children on health and hygiene, sex and sexuality. CHES staff are able to talk about sensitive subjects that his staff teachers felt shy to discuss. The headmaster felt that such topics were essential for adolescent students, given *the short age gap between puberty and marriage.* In his words, "This cannot be addressed by me but by people [like you], because the students may feel difficult to accept this information from a teacher."

The headmaster is aware that CHES has admitted HIV positive children in his school but does not know who they are, nor is he particularly interested in knowing their status. He is convinced if all the children in his school are given education on HIV/AIDS no one needs to bother *who is infected and who is not.*

He is convinced even if other parents come to know about such children studying in the school, and if those parents put pressure on him to remove the infected children from the school, he would not acquiesce. He says, "They may take out their children from the school,

but can they take away their children from the society? Some of their neighbors could be infected with HIV."

CHES has successfully sensitized headmasters, teachers, and students in the three schools and hopes to scale up this program to include more schools and more frequent visits to schools once the curriculum is finalized and funds are available.

Activity 4: Documentation

CHES has developed a detailed and comprehensive system of internal documentation even before APAC started supporting this project. During the initial stages APAC technical experts provided guidance in maintaining records of all CLHA program components since 2006. A list of the key documents currently maintained are as follows:

1. **Case Sheets:** CHES emphasizes patient documentation, which the normal government facilities seldom prioritize due to their caseload. CHES has a comprehensive system of patient tracking, with each individual having his or her own case sheet number. This number links a child or an adult to the rest of his/her family members. This way the physician or nurse can examine the medical history of an entire family. These clinical case sheets have a record of every prescription provided by CHES; a growth chart from 2006 tracking height and weight; and a systems record (digestive, abdominal, nervous etc.). In addition, each child gets a comprehensive nutritional assessment as per WHO guidelines, in addition to a structured growth monitoring chart started in July 2008. This assists the CHES team to meticulously track the nutrition status of children and provide additional nutritional support if needed.

   Besides using the medical history, an additional sheet is maintained by the ORWs to record psycho-social needs/results after they make home-visits (this information extracted from their daily diary and incorporated into the patient case sheet). Recording this information in the case sheet helps the medical officer contextualize particular complaints of patients during consultation. According to Dr. Santhosh, the medical officer of CHES, "a detailed documentation of every patient visit by ORW is so vital that a new doctor or a nurse on staff will understand the reason for the present and previous complaints (042709-KII-1).

2. **Hope Club Minutes:** Each Hope Club meeting since 2006 has maintained a record of the minutes, activities and an attendance register. This record is kept by the ORW after approval from the director of the CHES and the CLHA program manager.

3. **Hope Club Register:** This register shows the number of male and female children who attended Hope Club each month.

4. **Children's General Register:** This spreadsheet serves as a reference table for children and their families with information on age, education status, ART status, HIV status of the parents, if they are under CHES follow-up and other related information. This register contains information from 1997.

5. **Hospital OP and Medical Drugs Register:** A part time nurse records the number of children who are brought into CHES' medical facility during non-Hope Club hours. In the same register details of drugs distributed at the CHES medical facility, along with patient's name and the dosage of medicine.

6. **Service Delivery Register:** ORWs keep record of the educational, nutritional, legal, medical and vocational services that CHES provides to the children in their follow-up and it is updated based on the changing needs of CHES children and their families.

7. **Nutritional Supplement Log:** This log maintains the names of children who received additional nutritional supplement in a particular month along with what was distributed This data is again entered into their case file so that the ORW may enquire the use of those supplements during their home-visit.

8. **Life Skills Education Record:** The ORW in charge of the LSE course takes note of attendance and lessons given in each session, including names and ages of children in attendance, activities, modules covered and any other salient information pertaining to LSE.

Documentation Contribution of CHES:

- Operations Guidelines for the Orphan Trust which was released recently by the Tamil Nadu AIDS Control Society (TANSACS), Chennai

- National Guidelines for Orphans and Vulnerable Children (OVC) for the National AIDS Control Organization (NACO) for the National AIDS Control Program Phase III (NACP-III)

Key Lessons

This section seeks to articulate the key lessons from CHES' documentation methods so that other organizations working with children infected and affected by HIV may use these models, methods and systems to formulate a successful intervention for children, similar to that of CHES.

1. Having a comprehensive documentation system that shows disaggregated data on HIV status, gender, nutrition status/progress and the like, is extremely helpful in not only tracking each client, but also for improving the quality of the programs based on the data analysis. It is a good monitoring tool for sponsoring agencies and external evaluators.

2. Including both medical and non-medical issues in each individual's case file allows medical staff and ORWs to get a comprehensive idea of each child's progress. Factors like family situations which may have an impact on the child's health status can easily be detected because it is mentioned in the case file along with the medical information.

3. The clinical case sheet provides a relatively comprehensive medical case history and data of each patient which enables the physician to give appropriate advice and prescription. This elaborate case history records are not normally given importance in other clinical settings in this country. CHES physicians rely on individual case analysis for providing better medical care.

PART III:
Discussion and Way Forward

In formulating a program specifically for children, the child must be at the center of all programming. To meet this goal, CHES strives to ensure that the HIV infected and affected children under CHES' care are supported and taken care of through the programs described in the previous sections of this report. Under APAC, CHES' CLHA program specifically focuses on the needs of HIV infected children. However assessing the impact of CHES' services for infected children will not be justified unless the child's family members become part of the services offered by APAC through CHES.

For example, provisions such as oil, sugar and flour given to infected malnourished children along with the nutritional supplements may be consumed by the child's family members too. Because of this, SAATHII has viewed this program through a wider lens, to assess overall quality of life of the infected children, in addition to a few quantitative indicators like weight gain and LFU.

From the activities that have been discussed in the previous sections, it is apparent that all three individual components are ultimately linked and are critical pieces that lead to the overall impact of the CLHA program. With input from APAC, CHES has put in place a detail oriented documentation system that allows the CLHA program to offer personalized care and support to families through client tracking and follow-up. These services are extended in large part by referrals and counseling during home-visits and medical check-ups during the Hope Club meetings. A child therefore is tracked by a medical officer, a nurse and an outreach worker, often multiple times a month; the frequency of follow-up offered far exceeds that of government facilities. This is possible because of the dedication of the ORW staff. In this way, CHES is able to provide infected children and their families with sufficient attention while supplementing government provided HIV services.

CHES' CLHA program under APAC depends heavily on referrals and linkages to other government and non-government players in HIV Care such as World Vision of India and the Integrated Counseling and Testing Center (ICTC) services offered by the government hospitals. By maintaining this network, CHES is able to provide a wide range of services to each infected child under its follow-up. Considering the limited resources available to CHES, this referral model is more sustainable than providing all the services in-house. The quality of service is compromised in two ways: (1) Outside services may not be supervised as per CHES' desired standard and (2) it is possible that the overall number of infected children receiving HIV care and support in CHES is relatively small, as the same families seek services from many places within the CLHA NGO network. More resources are needed to fund CHES-like programs such that more HIV infected children can have access to care and support services.

Bibliography

Family Health International (FHI), "Protocol for Child Counseling on HIV Testing, Disclosure and Support." Funded by USAID, 2007

Food and Agriculture Organization (FAO), "Living well with HIV/AIDS: A manual on nutritional care and support for people living with HIV/AIDS," 2002

PART IV: Appendix

Appendix 1

Table 1 and Figure 1: Change in Weight of Malnourished Children After Taking APAC's Nutritional Supplements. Five children have taken these supplements for the duration of this program from August 2008 to March 2009. Weight is shown in kilograms and graphically shown in the line graph following the table.

Age	Aug 08	Sept 08	Oct 08	Nov 08	Dec 08	Jan 09	Feb 09	Mar 09
5	11	12	13	14	15	15	15	15
15	24	24	25	25	26	26	26	28
5	12	12	12	12	13	13	13	14
13	20	22	22	23	23	23	23	23
10	24	24	24	23	24	24	24	25

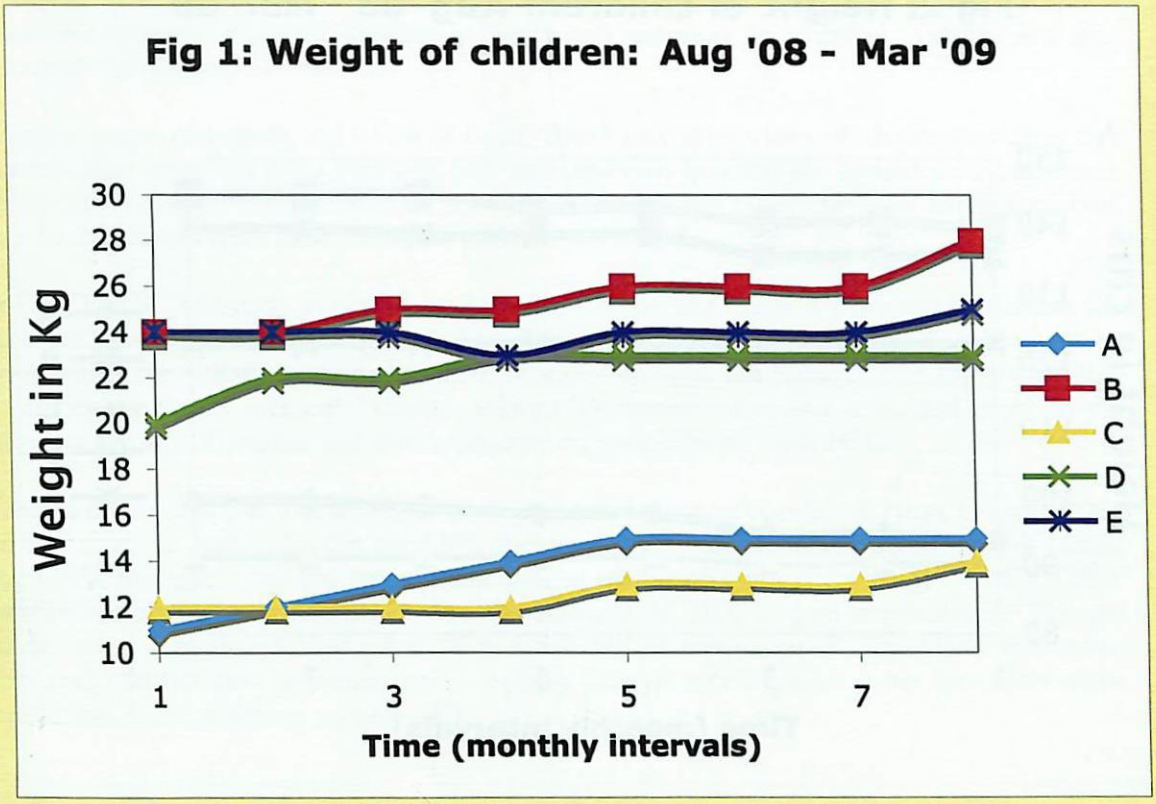
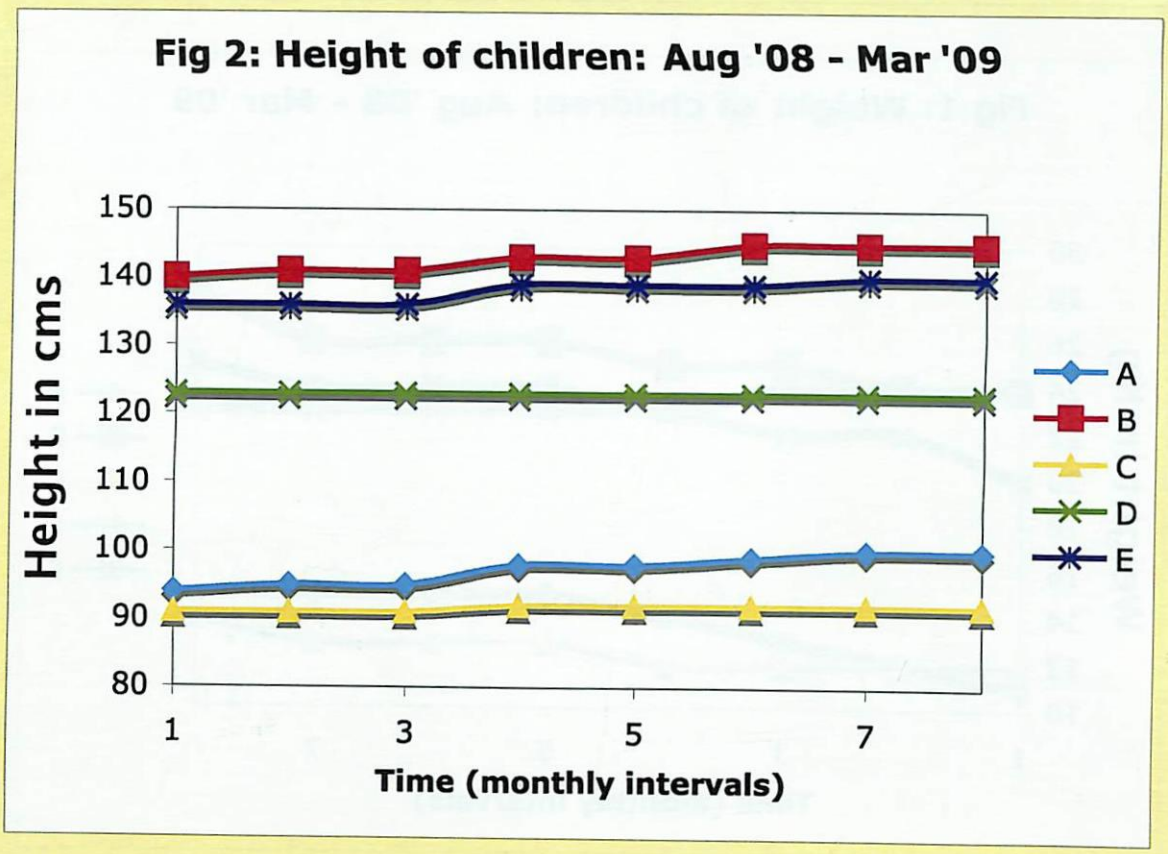


Table 2 and Figure 2: Change in Height of Malnourished Children After Taking APAC's Nutritional Supplements. Five children have taken these supplements for the duration of this program from August 2008 to March 2009. Height is shown in centimeters and graphically shown in the line graph following the table.

Age	Aug 08	Sept 08	Oct 08	Nov 08	Dec 08	Jan 09	Feb 09	Mar 09
5	94	95	95	98	98	99	100	100
15	140	141	141	143	143	145	145	145
5	91	91	91	92	92	92	92	92
13	123	123	123	123	123	123	123	123
10	136	136	136	139	139	139	140	140



Appendix 2

Case Study
Home-Based Care Helps HIV-status disclosure and reduces stigma in HIV-infected Orphans.

Challenge

People living with HIV in India face a significant amount of stigma and discrimination from their families and communities. Many are thrown out of their homes without access to food, shelter or medical attention. Children, particularly orphans, infected and affected by HIV are confronted with not only being rejected from their extended family, but also face a host of additional challenges. One such challenge is that of disclosure: children often do not know that they are HIV positive until their adolescence, and disclosing such information is a delicate matter for parents and counselors. Once a child finds out that he or she is HIV+, proper counseling and family support is required to help deal with the shock and overwhelming psychological stress the child may face. Until such specialized counseling services for children become available in the public health system, proper home-based care (HBC) and support is an essential need.

Initiative

The Community Health and Education Society (CHES) started the Home-Based Care (HBC) program, which was initially supported by USAID via Family Health International from 2000 to 2006. Support was then continued from 2006 to the present by USAID and AIDS Prevention and Control project (APAC)/Voluntary Health Services (VHS), located in Chennai. Monthly home visits are the cornerstone of this activity, where outreach workers provide education on health-seeking behavior and nutrition, in addition to counseling and psychosocial support to children.

Geetha (name changed), a 14-year-old girl, developed symptoms of depression after her parents died from AIDS six year ago. She was extremely worried about who would take care of her and her elder brother because she was rejected by her other extended family members due to the stigma associated with HIV/AIDS.

A CHES-HBC outreach worker visited the girl's home and made it a priority to address the relatives' reasons for alienating her. Through multiple sessions of home-visits and group counseling, the ORW developed a close relationship with the family. The ORW was able to clarify the family members' doubts about HIV transmission and sensitized them on the negative impact of stigma and discrimination on people living with HIV.

Geetha then fell ill and was admitted to the hospital in critical condition. Her CD4 count was so low that she had to be put on ART immediately. After consulting with Geetha's family, the ORW thought it was the appropriate time to tell Geetha that she was HIV+. The ORW performed a small role-play to explain the concept of HIV and its implications. The girl understood immediately and asked, "Am I infected by this disease?" The ORW confirmed this and told her that treatment and a healthy lifestyle would prolong her life. After some hesitation, Geetha agreed to take ART.

Results

Geetha has been taking ART with the support from CHES for six years now. The ORW continues to work with the family to help them be supportive and keep a positive attitude. Now they have whole-heartedly accepted her, despite her HIV+ status. She now participates in religious festivals, home functions, and other celebrations.

Through the effective and systematic counseling CHES provides, Geetha is knowledgeable about HIV and is growing up to be confident and courageous. This support has been made possible mainly due to the close relationship between the ORW and the beneficiary family.

As a result of CHES' counseling and support, children like Geetha are able to think about their future plans and goals; something they may not have been able to do prior to their relationship with CHES. Through USAID's mentorship and financial assistance, CHES has been able to take a more holistic approach to HIV care and support, through professional child counseling and building relationships between the community and the organization.

Notes

Notes

APAC-VHS

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COMMUNITY HEALTH EDUCATION SOCIETY
PREVENT AIDS

AIDS Prevention And Control (APAC) Project
Voluntary Health Services (VHS)

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