India's HIV Orphans and Vulnerable Children

Generating Evidence for Policy and Practice

January 2012

Foreword

The United States Agency for International Development (USAID) supports India's vision for reducing HIV/AIDS transmission and improving the lives of children infected and affected by the disease. The prevalence of HIV infection in India is relatively low compared to many of the most severely affected countries in the world, but the scope of the challenge due to HIV is enormous. Because of the size of India's population, India has the third largest number of people living with HIV, with an estimated 2.3 million and 115,000 children infected.

USAID, through the President's Emergency Fund for AIDS Relief (PEPFAR) has supported the Government of India's policies by providing assistance to local NGOs, which deliver direct services to orphans and vulnerable children (OVC). This builds on more than a decade of previous USAID work supporting OVC.

In order to move forward in supporting the Government of India's OVC agenda, evidence-based assessments and evaluations of existing programs are essential to inform future policy and programming. To address this need, USAID engaged with Boston University (BU), through the OVC-Comprehensive Action Research Project, to conduct a set of evaluation studies to generate key lessons about the experience, impact and effectiveness of different program approaches and strategies across the USAID-funded OVC programs. BU's scientific documentation is an important first step in creating a rigorously developed India-specific OVC evidence base.

The following compilation of BU's work not only showcases important lessons learned, but it highlights new knowledge that will feed into the current national dialogue on OVC programming as it evolves into the Government of India's next five-year National AIDS Control Program (NACP IV). The ability to achieve an AIDS-free generation is possible with all of us working together to reach the collective vision of zero new HIV infections, zero discrimination and zero AIDS-related deaths. USAID hopes that the attached document will provide useful inputs in the process.

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Boston University Center for Global Health & Development

The Center for Global Health & Development (CGHD) at Boston University is a multidisciplinary research center that engages faculty from across the University to help solve the critical global health and social development challenges of our time. The mission of the Center is not only to conduct high-quality applied research, but also to advocate for the use of this research to improve the health of underserved populations around the world. Through our collaborative work with scientists worldwide, we also seek to strengthen individual and institutional capacity to conduct and utilize research.

OVC-CARE Project

The USAID | Project SEARCH, Orphans and Vulnerable Children Comprehensive Action Research (OVC-CARE) Task Order, is funded by the U.S. Agency for International Development under Contract No. GHH-I-00-07-00023-00. It was awarded to Boston University's CGHD in August 2008. The India OVC project, comprised of six program evaluation studies, was initiated in October 2010. The objective is to improve the coverage and quality of OVC program services in developing countries through OVC program based research. The Project uses outcome evaluation, impact assessment, and cost-outcome analyses to answer high priority research questions at the level of service delivery to inform policy, planning, and programming.

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Acknowledgements

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Children Affected by AIDS Pilot Scheme: Organizational Network Analysis in Five Districts	Jenny Ruducha (PI) Carlyn Mann Keith Provan Priya Kumar Robin Lemaire	FHI 360 – Delhi & AP India HIV/AIDS Alliance KHPT WAG…CHELSEA VMM
The Effectiveness of an Integrated Care Model Drop-in Center (DIC) in Improving Access to Services and Selected Social and Health Outcomes of OVC in Maharashtra	Jenny Ruducha (PI) Carlyn Mann Keith Provan Priya Kumar Robin Lemaire	Avert Society Nagpur Drop-in-Center Satara Drop-in-Center Thane Drop-in-Center
Karnataka Cash Transfer Program	Candace Miller (PI) Lora Sabin (Co-PI) Jenny Ruducha (Co-PI)	KHPT
Committed Communities Development Trust: Integrating Home Based and Residential Care and Support in Mumbai	Jennifer Beard (PI) Ashok Patwari (Co-PI) Priya Kumar CarmenLeah Ascensio	CCDT Avert Society

Introduction to AIDS in India

India's first reported HIV case was among the sex workers in Chennai, Tamil Nadu in 1986.[1] Given the rapid spread of HIV/AIDS in the late 1980's, India launched the first National AIDS Control Program (1992-1999) to coordinate national efforts covering surveillance, blood screening, and health education[2] where the National AIDS Control Organization (NACO) was to oversee the implementation of this program.[3] Despite these national efforts, the spread of this virus continued and became more prominent among the general population previously seen as 'low-risk'. During this time there was an emergence of community-based organizations (CBOs) that provided services to people infected and affected by HIV based on observed need. With the free antiretroviral treatment (ART) initiative laid out by the Government of India in 2004[4], the battle against HIV/AIDS shifted from mostly providing a safe haven for those that were dying to providing the care, treatment, and support that people infected and affected with HIV need in order to live healthier lives.

The emergence of India as a world economic power places a special responsibility to address the needs of the country's most vulnerable citizens, including AIDS orphans and a broader group of children affected by HIV/AIDS. Currently, India has the third largest number of people in the world living with HIV/AIDS, totaling 2.3 million adults and 115,000 children. In most recent reports, the National AIDS Control Organization (NACO) estimates that

Source: Avert Society (2011). 'Overview of HIV and AIDS in India'. http://www.avert.org/aidsindia.htm

57,000 children are infected each year with HIV/AIDS but has not finalized total estimates; however 64,000 children living with HIV/AIDS are registered[5] and 22,837 are on antiretroviral therapy.[6] The high prevalence states are concentrated in the South, namely Tamil Nadu, Andhra Pradesh, Karnataka, Maharashtra and the northeastern states of Nagaland and Manipur.

The Government of India has displayed a commitment to preventing HIV-infections and mitigating the medical impact of the virus on the

lives of those already infected. It has provided a detailed vision of how it proposes to do so in the National AIDS Control Program 2007–2012 (NACP III) along with a separate "Policy Framework for Children and AIDS" released in 2007. The first priority, as articulated in the policy is to prevent HIV infection, in order to "ensure an AIDS-free generation".[7] Subsequently, prompt diagnosis and treatment of parents and children became a vital component to survival and protection of family cohesiveness. Since the roll-out of free ART in 2004, there has been a steady decline in HIV prevalence (0.41% in 2000 to 0.31% in 2009), especially among the southern states, and in AIDS-related deaths (172,000 or 1.72 lakh deaths in 2009 compared to 200,000 or 2 lakhs in 2006).[8] There has been a further focus to ensure that affected children and families are not excluded from the same services and opportunities as others in their communities. To reduce stigma and discrimination, 839,000 (8.39 lakhs) front line workers and personnel from various government departments, civil society organizations, and the corporate sector have been trained.[9]

As part of the policy framework, government departments working at all levels are encouraged and expected to coordinate and collaborate on a myriad of potentially available services to orphans and vulnerable children (OVC). The Government also recognizes the central importance of civil society groups, NGOs and the private sector in the coordination functions with government structures at the district level as well as the linkage with service delivery mechanisms to reach and serve children affected by AIDS.

Over the last five years, four United States Agency for International Development (USAID) programs containing innovative OVC components have been implemented to support and complement the Government of India's initiatives: Samarth in NE Delhi, APAC in Tamil Nadu, Avert in Maharashtra and Samastha in Karnataka. Additionally, USAID has been leading OVC care and support policy and advocacy efforts nationally in collaboration with NACO, MWCD, UNICEF, FHI 360, Clinton Foundation and the India HIV/AIDS Alliance. The six studies contained in this report were developed collaboratively with USAID-India and their grantees at the end of their program period to assess and understand different dimensions of organizational development as well as measures of program effectiveness to better inform future OVC policy and programming.

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Abbreviations

AIDS	Acquired Immune Deficiency Syndrome	DCPS	Department of Child Protection Services
Alliance	India HIV/AIDS Alliance	DE	Delhi
ANM	Auxillary Nurse Midwives	DHFW	Department of Health and Family Welfare
AP	Andhra Pradesh	DHMO	District Health and Medical Officer
APAC	AIDS Prevention and Control Project	DHS	District Health Society
ART	Antiretroviral Therapy	DIC	Drop-In Center
ASHA	Accredited Social Health Activist	DOE	Department of Education
AWW	Anganwadi Worker	DRDA	Department of Rural Development
BCFC	Backward Caste Finance Corporation	DSACS	Delhi State AIDS Control Society
BMGF	Bill and Melinda Gates Foundation	DSJE	Department of Social Justice
BMI	Body Mass Index	DSPU	District Social Protection Unit
BPL	Below Poverty Line	DSW	Department of Social Welfare
BU	Boston University	DWCD	Department of Women and Child Development
CABA	Children Affected by HIV/AIDS		
CBO	Community Based Organization	FBO	Faith Based Organization
CCC	Community Care Centre	FHI	Family Health International
CCDT	Committed Communities Development Trust	GFATM	Global Fund to Fight AIDS, Tuberculosis, and Malaria
CCW	Comprehensive Child Welfare	GHC	Government Housing Corporation
CDPO	Child Development Program Officer	GP	Gram Panchayat
CGHD	Center for Global Health and Development	HBC	Home-Based Care
		HIV	Human Immuno-deficiency Virus
CHAHA	Children Affected by HIV/AIDS Project	ICD	Integrated Community Development
CHC	Community Health Center	ICDS	Integrated Child Development Service
CHES	Community Health Education Society	ICM	Integrated Care Model
CIC	Crisis Intervention Centers	ICTC	Integrated Counseling and Testing Center
COTR	Contracting Officer Technical Representative	IRB	Institutional Review Board
CSI	Child Status Index	ICPS	Integrated Child Protection Scheme
CWC	Child Welfare Committee	ICTC	Integrated Counseling and Testing Center
DAPCU	District AIDS Prevention Control Unit		
DCAA	District Coordination Action Agency	KSAPS	Karnataka State Prevention Society
DCO	District Collector's Office	KHPT	Karnataka Health Promotion Trust

M&E	Monitoring and Evaluation		SDQ	Strengths and Difficulties Questionnaire
MHRD	Ministry of Human Resource Development		SHG	Self-Help Group
MPH	Municipal Public Health Department		SIHFW	State Institute for Health and Family Welfare
MSACS	Maharashtra State AIDS Control Society		SocP	Social Protection Unit
MS	Mandal Samakya		SSA	Sarva Shiksha Abhiyan
MOH	Ministry of Health		STFC	Scheduled Tribe Finance Corporation
MOST	Management and Organizational Sustainability Tool		TB	Tuberculosis
			TN	Tamil Nadu
MWCD	Ministry of Women and Child Development		TNSAC	Tamil Nadu State AIDS Control Society
			TOT	Training of Trainers
NACO	National AIDS Control Organization		TSA	Task Force Agency
NACP	National AIDS Control Program		UN	United Nations
NGO	Non-Governmental Organization		UHC/IH	Urban Health Center/Urban Health Post
NPP	Network of Positive People		UNCRC	United Nations Convention on the Rights of the Child
NRHM	National Rural Health Mission			
OBC	Other Backwards Caste		UNICEF	United Nations Children's Fund
OI	Opportunistic Infection		USAID	United States Agency for International Development
ONA	Organization Network Analysis			
OVC	Orphans and Vulnerable Children		VHC	Village Health Committees
OVC-CARE	Orphans and Vulnerable Children Comprehensive Action Research		VHS	Voluntary Health Society
			VHSC	Village Health and Sanitation Committee
PHC	Primary Health Center			
PLHIV	People Living with HIV/AIDS		WAG...CHELSEA	Women's Action Group: Children, Health, Education, Ladies, Senior Citizens, Environment and Awareness
PPTCT	Prevention of Parent to Child Transmission			
PRI	Panchayat Raj Institution		WCD	Women and Child Development
RNTCP	Revised National TB Control Program		WHO	World Health Organization
RevD	Revenue Department		WIP	Women in Prostitution
RKS	Rogi Kalyan Samiti		WMM	Vasavya Mahila Mandali NGO
SACS	State AIDS Control Society		WoN	Women's Network
SCFC	Scheduled Caste Finance Corporation		YWCA	Young Women's Christian Association
SCT	Sneha Charitable Trust		ZP	Zilla Parishad

Evaluating the Organizational Capacity of 3 NGOs

Background

Government of India policy recognizes the central importance of civil society groups, NGOs and the private sector, in coordination with government structures, to serve children affected by AIDS. USAID/India has been a catalyst, advocate, and supporter of the Government of India's vision and policies. They have provided innovative OVC program funding to strengthen NGOs, work directly with National AIDS Control Organization (NACO), and forge new public-private partnerships. As funding of the current USAID portfolio of projects draws to a close, there is a "graduation" of supported local NGOs to independent funding and "sustainability". However, there are gaps in the knowledge base to determine when an organization is ready to graduate or achieve sustainability.

We set out to create an internally validated instrument that will enable a quantifiable and replicable assessment of an organization's state of development, and associate this with the health and service delivery outcomes for children served by the organization. In order to do this we selected three civil society organizations that have been working on HIV care, support and treatment since NACP I.

GAPS IN KNOWLEDGE TO DETERMINE GRADUATION/SUSTAINABILITY

- Factors associated with institutional performance are generally measured subjectively and not objectively;

- Stages of organizational development are not consistently defined;

- Rigorous evaluations of capacity building efforts have not been conducted;

- Measurable associations between organizational capacity and the ability to produce health outcomes have not been clearly laid out; and,

- Consistent predictors of an organization's capacity for sustainability (and thus readiness for graduation) have not been described.

The characteristics of these organizations are laid out in Table 1.

NGO	FOUNDED	LOCATION	SERVICES PROVIDED	POPULATION SERVED	MAJOR DONORS (PAST & PRESENT)
Women's Action Group CHELSEA	1992	North East Delhi, India	• Community Home Based Care • Training	• HIV affected children and families • Female Sex Workers	• USAID • Clinton Foundation • BMGF
Community Health Education Society	1995 (activities started in 1993-'94)	Chennai, India	• Community Home Based care • Residential care • PPTCT follow up	• HIV affected children and families • Vulnerable children	• USAID • GFATM
Sneha Charitable Trust	2002 (activities started in 1997)	Bangalore, India (multi-state presence)	• Residential care and education • Medical services and palliative care	• HIV+ children • HIV+ adults	• USAID • Catholic Health Association India • GFATM

T1 CHARACTERISTICS OF THE 3 NGOS

Methods

The evaluation had three objectives:

1. Construct an organizational history;

2. Conduct an organizational development assessment; and,

3. Assess the health outcomes from program activities over the last 3 – 5 years.

Organizational History

Historical interviews were conducted to assess how each organization was created as well as key events and challenges in the NGOs growth and development. Data was coded using NVivo 9 ™ and analyzed to identify key themes and historical timelines.

Organizational Development

A new organizational assessment tool was developed using the Management and Organizational Sustainability Tool (MOST), developed by Management Sciences for Health, and adapted to the Indian context. Fourteen organizational domains were defined (Table 2).

T2 ORGANIZATIONAL DOMAINS

1   Mission

2   Values

3   Organizational Structure

4   Organizational Strategic Planning

5   Market Analysis/Business Planning

6   Operational Planning

7   Links to Beneficiaries

8   Financial Management

9   Management of People

10   Management of Information

11   Quality of Service Delivery

12   Management of Drugs and Supplies

13   Leadership and Governance

14   Organizational Networking

Each domain was divided into several sub-domains, which in turn were measured through clearly defined indicators, which are specific and replicable See Figure 1.

Data was collected using three sources: 1) Key informant interviews with management staff, 2) A survey was administered to all staff (except those who completed the key informant questionnaires), and 3) A thorough review of organizational documentation and records was conducted for each organization.

Health Outcomes

Outcomes were measured using a retrospective review of demographic, health, and nutritional records at each NGO. Qualitative data was collected through case studies conducted with caseworkers for ten children at each organization to assess: 1) how a child developed physically and psychosocially from time of entry into the program until the present day, and 2) the services the NGO provided to the child and family.

F1 **ORGANIZATIONAL DEVELOPMENT TOOL**

Domain ---> Sub-domain ---> Indicator

A. Mission

1. Statement of mission
- A written mission statement exists
- A document (presentation, brochure, etc) exists that reflects the mission

2. Use of mission statement
- The mission is displayed where staff or clients gather
- The percentage of times in the last year that the mission has been used in written marketing materials or proposals
- The mission is displayed on website

3. Staff awareness of mission
- Percentage of staff who know the organization has a mission
- Percentage of staff who can quote at least one element of the organization's mission

4. Mission reviewed to reflect changes
- The mission statement has been updated within the last two years

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Results

Organizational History

Interviews were conducted with the founder, program staff and relevant stakeholders at each NGO. This allowed for an analysis of the organization's history to identify factors influencing the success, survival, and growth of an NGO over time as well as setbacks and challenges that affected the growth and development of the NGO. Such an analysis contributes to understanding the current status of the organization and may be used to anticipate how an NGO may react to similar challenges in the future.

We learned…

the strength of our organization comes from our volunteers and supporters. Even twenty years into this organization, if tomorrow there's any funding crisis, we'll have the support from our volunteers and supporters.

CHES

There was never enough money, there were never funds. I was a treasurer for years and I know there was no money and at times we all pitched in…to pay for rent, traveling, transportation, basic things and you know it was very hard.

CHELSEA

Each NGO was created in response to an identified need, which is a contributing factor to their current success. Table 3 shows the key factors that contribute to the success and survival of CHES, CHELSEA and SCT. Notably, SCT and CHES have had success in building capacity and using their expertise to develop policies for OVC and HIV care, support and treatment at the state level and to contribute to national level discussions – making these NGOs visible, furthering their growth and sustainability.

T3 FACTORS OF SUCCESS AND SURVIVAL FOR CHES, CHELSEA, AND SCT

1 Determination of leaders
2 Program development in response to community needs
3 Development of expertise on HIV care, support and treatment in the early stages of the epidemic in India
4 Continuation of work despite HIV stigma and discrimination
5 Ability to set up the organization with little, or no funding
6 Ability to deal with variable and unpredictable funding during operation
7 Ability to navigate a bureaucratic registration process
8 Development of staff team from volunteers
9 Relationships and connections with key people and institutions
10 Contributions to policy discussions at state and national level

Some of the patients [in Snehadaan, run by SCT] died and their children were left orphans, so nobody was there to take care of such HIV infected children who don't have parents at all. Slowly it actually became a kind of health need for us to start a program for HIV infected children also, that was the reason in 2000, we started our Snehasadan program with children, but then there was no medication and nobody knew as to what to do with HIV infected children…slowly medication improved and everyone knew that these children would live longer…we need to have a separate program for HIV infected children with proper foundation and proper plan.

SCT

CHES, CHELSEA and SCT all began their work during India's first National AIDS Control Program and were pioneer NGOs in India's HIV/AIDS sector. Figure 2 shows an extended timeline for each organization and their relationship to the National AIDS Control Program.

EXTENDED TIMELINE FOR NGOS IN INDIA

1994 CHELSEA registered

1997 Snehadaan (SCT) established

2000 Project Thooli initiated

CHES registered

2002 SCT registered

2006 USAID Samarth and Samastha projects initiated

| 1986 | 1988 | **1990** | 1992 | 1994 | 1996 | 1998 | **2000** | 2002 | 2004 | 2006 | 2008 | **2010** | 2012 | 2014 |

1994 First case of HIV in India

1992 NACO established

Tamil Nadu SACS established

1998 Delhi SACS established

2004 Roll-out of free ART

2006 Roll-out of free pediatric ART

NACP I [1992-99]   NACP II [1999-2006]   NACP II [2006-11]

Organizational Development

Each indicator was measured and translated into a potential score of 10 points. The points were aggregated at the sub-domain and domain levels, which are then expressed as percentages. As seen in Figure 3, the three organizations are at very different overall stages of development, which is consistent with the organizational history and development of the three NGOs. The high scores for mission, management of finances, and management of drugs are possibly reflective of the focus from support organizations and USAID for accountability. The same almost certainly applies to the failure of each organization to perform in the area of strategic planning (not a major donor focus). The strong performance of SCT for values reflects the fact that SCT is a faith-based organization and strongly value driven. The remaining organizations, while highly ethical, are not value driven in the same way. The results show that CHES consistently performs as well as, or better than, the other two organizations, while CHELSEA consistently performs less well. While it is difficult to attribute all aspects of the individual organizations level of development to USAID funding, we hypothesize that the capacity building efforts of FHI 360 with CHELSEA through the Samarth Project were less effective than those of either KHPT through the Samastha Project and VHS through the APAC Project. VHS' efforts appear to be the most effective, which is corroborated from key informant and historical interviews.

ORGANIZATIONAL PERFORMANCE BY DOMAIN

CHELSEA
SCT
CHES

0% 20% 40% 60% 80% 100% 120%

Mission
Values
Organizational Structure
Organizational Strategic Plan
Market Analysis/Business
Operational Planning
Links to Beneficiaries
Financial Management/Budget
Management of People
Management of Info
Quality of Service
Management of Drugs/Supplies
Leadership/Governance
Organizational Networking
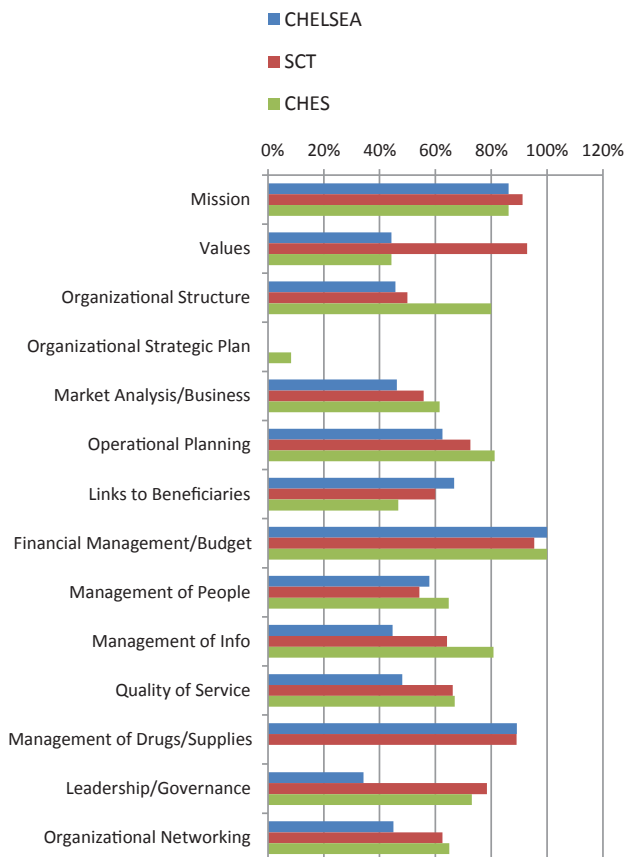
Weighting Data and Setting Priorities

There is no agreement in the organizational development literature on which domains of organizational capacity are more important to organizational functioning than others, with the result that priority setting for capacity building interventions is not guided by logical or rational arguments. To address this, we divided the 14 domains into four categories based on their relative importance for organizational development, and assigned weights accordingly (see Table 4). Based on these weights, it is then possible to ascertain the relative importance of each domain in a "healthy" organization and compare the individual NGO's performance against this standard. This is represented in Figure 4.

T4 WEIGHTS OF EACH DOMAIN

WEIGHT 3	WEIGHT 2.5	WEIGHT 2	WEIGHT 1
Mission Leadership/governance Financial management Human resources	Service quality Information management Management of drugs Organizational planning	Values Strategic planning Market analysis	Links to beneficiaries Organizational networking Structure

DEVIATIONS FROM THE NORM AFTER WEIGHTING THE DOMAINS   F4
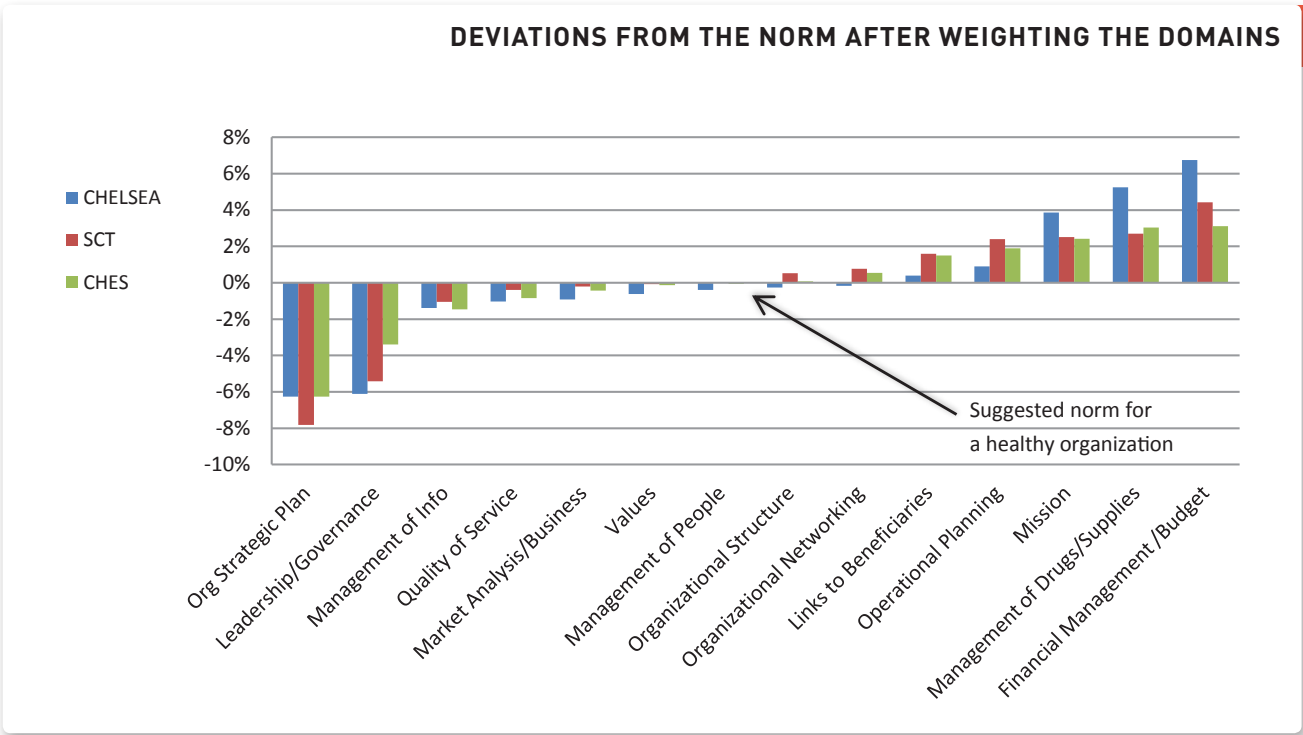
Overall, CHES is the most balanced and well-developed organization with a symmetrical curve, while both CHELSEA and SCT's overall capacity is relatively unbalanced. SCT's curve is skewed to the right, with more domains being over-developed, while CHELSEA is skewed to the left, with more domains being under-developed. Most importantly, Figure 4 provides a guide for each organization to set priorities. All three organizations have significant deficits in their capacity to develop strategic plans and require additional focus on building leadership and governance structures. Next in terms of priorities comes managing information and improving quality of services. Ideally, after providing capacity building in these areas, the tool should be reapplied and new priorities set.

Health Outcomes

Basic demographic and health data of the children receiving services from the three organizations are included in Table 5. Overall there are significant differences across the children registered at these organizations, mostly due to geographic and programmatic differences in the populations served. Since program data was collected during the retrospective review there is a considerable amount of missing data and thus, denominators change for each variable. Height and weight measurements were recently collected at each organization between March and July 2011. Using the WHO standardized calculations and categorization, BMI-for-age z-scores were calculated for all children 5-19 years of age. The majority of children at all three sites were in the normal BMI-for-age range, but there were significant differences across these organizations except between CHELSEA and SCT. Notably, 88.7% of children at CHELSEA were in the normal range, with only 2% of children in the severe thinness range. By contrast, only 0.5% of HIV+ children are classified as severely thin at CHELSEA.

T5 DEMOGRAPHIC AND HEALTH CHARACTERISTICS OF OVCs AT 3 NGOs IN INDIA

	CHES n=371	CHELSEA n=652	SCT n=84	p-value for trend
Age n (%)	367	592	82	
0-4	12 (3.3)	63 (10.6)	0 (0.0)	0.09
5-10	152 (41.4)	194 (32.8)	59 (72.0)	0.06
11-17	180 (49.0)	256 (43.2)	23 (28.0)	0.001
>=18	23 (6.3)	79 (13.3)	0 (0.0)	0.39
Median age (years)	11.0 (8.0 to 15.0)	11.0 (8.0 to 15.0)	9.0 (7.0 to 11.0)	<0.01
Male n (%)	366	610	84	
Male	189 (51.6)	332 (54.4)	51 (60.7)	0.17
Orphan status n (%)	153	582	–	
Double	55 (36.0)	216 (37.1)	n/a	<0.01
Single	70 (45.8)	50 (8.6)	n/a	
Non-orphan	28 (18.3)	316 (54.3)	n/a	
Registration date n (%)	99	625	80	
<2007	26 (26.3)*	375 (60.0)+	–	
2008	25 (25.3)	80 (12.8)	17 (23.3)	
2009	23 (23.3)	82 (13.1)	33 (41.3)	
2010	25 (25.3)	88 (14.1)	30 (37.5)	
Positive HIV status n (%)	365	618	84	
HIV+	156 (42.7)	114 (18.4)	84 (100.0)	0.02
CD4 count n (%)	151	91	83	
2010	128 (84.8)	22 (24.2)	5 (6.0)	<0.01
2011	23 (15.2)	62 (68.1)	78 (94.0)	<0.01
Median CD4 count (IQR)	1002 (743 to 1325)	651.0 (470.0 to 978.0)	846.0 (489.0 to 1162.0)	<0.01
Children on ART n (%)	153	92	84	
Children on ART	100 (64.4)	39 (42.4)	33 (39.3)	<0.01
BMI-for-age n (%)	81	204	79	
Obese (> +2 SD)	1 (1.2)	6 (2.9)	0 (0.0)	
Overweight (> +1 SD)	8 (9.9)	3 (1.5)	0 (0.0))	
Normal	57 (70.4)	181 (88.7)	64 (81.0)	
Thinness (-2 SD)	5 (6.2)	10 (4.9)	14 (17.7)	
Severe Thinness (-3 SD)	10 (12.4)	4 (2.0)	1 (1.3)	
Median (BMI-for-age) (IQR)	-0.7 (-1.70 to 0.18)	-0.2 (-0.94 to 0.26)	-1.30 (-1.90 to -0.69)	

Notes: * 1997-2007   + 2006-2007

At CHES, 12.4% of children were in the severe thinness range, where 11% consisted of HIV+ children. Additionally, 42.7% of children registered at this organization are HIV infected with 65.4% of them on antiretroviral therapy (ART). By comparing the two home-based care (HBC) programs, it is evident that children at CHELSEA are significantly healthier by measure of BMI-for-age compared to children at CHES – this is especially true among the HIV+ children. Although both CHES and CHELSEA provide nutritional support, CHELSEA has placed a significant focus on the nutritional status of HIV+ children. At SCT, a majority of children were in the normal BMI-for-age range with only 1.3% categorized as severely thin. Additionally, there are fewer children on ART compared to CHES and CHELSEA (42.4%) and the median age is 2 years younger than for both of these organizations.

Policy Implications

This study highlights several significant challenges for capacity building, which lead us to the following observations and recommendations:

1. **Importance of the Role of NGOs.** Our observations make it clear that NGO staff from all three organizations play pivotal roles in establishing and maintaining linkages between community, government departments, and the private sector. This reinforces the framework laid out by the Government of India in NACP III and the "Policy Framework for Children and AIDS".

2. **Measuring Capacity Building.** Different approaches to capacity building result in different capacities being developed. Organizations providing capacity building assistance should be held accountable for their efforts in the same way that organizations providing services are held accountable. This has not been possible because no validated assessment tool exists. The organizational assessment tool presents an internally validated instrument that can be used to measure baseline organizational status and note incremental improvements in response to assistance or capacity building. Although the tool requires further testing it provides promise as a way to formally evaluate capacity building.

3. **Donor Agendas Artificially Shape Organizations.** Our analysis shows that the principal drivers of capacity development are those of the donor. Financial accountability, management of fungible items such as drugs, and developing a clear mission are highly developed in all three NGOs, while strategic planning and marketing are poorly developed. Thus donors need to be mindful that in ensuring their own needs, they do not promote organizations to be developed in a way that is contrary to achieving sustainability.

4. **Use of Data.** Monitoring and evaluation systems in each organization were unable to meet organizational needs. Even where the management of information was competently carried out, the type of data collected did not bear on the decisions the organizations needed to make for day-to-day management. The data was limited, poor quality, and often incomplete. Data collection cannot be donor driven. In future, information demanded by donors has to be linked to the data management needs of the organization.

5. **Vertical Programs versus Capacity Building for Rapid Results.** The weakest organization in terms of its overall capacity, development, and sustainability, was the highest performing in terms of improving child nutrition. This is in line with the long-standing tradition of providing vertical program assistance to a population through an institution. Regardless of the degree of organizational development, it is possible to see significant changes in specific outcomes if the problem is directly targeted and enough resources are directed at it. However, without investing in capacity building while providing a vertical program, the organization is unable to continue to provide similar assistance after external support ends.

2

Disclosure of Children's HIV Status in Four High Prevalence States in India

Background

Telling a child they are HIV positive, answering their questions about medicines, visits to the hospital and their future is a challenging and sensitive issue for parents, health care workers and HIV counseling and testing centers. This study responds to the scarcity of research and programmatic knowledge on disclosure of HIV status to children in India. The study was conducted with four NGOs which have developed resources, models and expertise to facilitate disclosure to OVC and their families in Bangalore, Chennai, Delhi and Mumbai. The aims of this study were:

1. To better understand factors which influence disclosure and the challenges of disclosing to children;

2. To describe psychosocial well-being among disclosed children in these NGO programs;

3. To document approaches used by four NGOs in India to facilitate disclosure of HIV status to a child and disclosure of the HIV status of family members to the child.

The study was framed and guided by an extensive literature review on studies examining the disclosure of HIV status to children. The following findings are salient:

- Disclosure to children has shown to be associated with positive familial relationships, better psychosocial adjustment and increased adherence to treatment.[1-7] Children who know their HIV status have been shown to have higher self-esteem and better relationships with their caregivers than those who are unaware of their status.[8,9] Likewise, the disclosure of a mother's HIV status to her child has also been associated with improved health outcomes for both mother and child. [8,10,11]

- Most reports strongly suggest disclosure should be addressed within a family context, led and initiated by caregivers instead of healthcare providers; [9,12-14] and thus, serves to strengthen the parent-child relationship, facilitates communication, and promotes a child's and mother's ability to cope.[15,16]

- There are common challenges caregivers face that act as barriers to disclosure; including stigma, being emotionally unprepared, and a lack of knowledge and skills to communicate disclosure.[1,13,17-20] Many parents fail to disclose to their children due to guilt and fear.[8,12,16,18,21-23]

As of 2011, only two journal articles and one report had been published on disclosure to children in India. Both articles examined disclosure to children in North India and the report commissioned by AIDS Alliance looked at facilitating HIV testing and disclosure in Andhra Pradesh.[1,20,24] We failed to identify any published work on disclosure in Tamil Nadu and Karnataka; states which have high HIV prevalence rates.

T1 STUDY SITES AND DATA COLLECTION

NGO	LOCATION	PROGRAMS	NUMBER OF INTERVIEWS (Primary Language)
Women's Action Group...Children Health Education Ladies Senior Citizens Environment Awareness (CHELSEA)	North-East Delhi	• Community home-based care	4 (Hindi)
Community Health Education Society (CHES)	Chennai	• Community home-based care • Residential care	5 (Tamil)
Committed Communities Development Trust (CCDT)	Mumbai	• Community home-based care • Residential care	5 (English)
Sneha Charitable Trust (SCT)	Bangalore	• Residential care	4 (English)

Research Design

Both qualitative and quantitative methods were used to better understand disclosure. Eighteen in-depth interviews with counselors, social workers and program managers working in each NGO were conducted between March and July 2011. Interviews were conducted in Hindi, Tamil and English, recorded, translated and transcribed. In addition to interviews, training modules, visual resources and other tools used by NGO staff to facilitate disclosure were examined. Quantitative data was extracted from routine program monitoring information (demographic, health, psychosocial, and nutritional data) on children and their families from CHELSEA and CHES .

Key Qualitative Findings

Factors Influencing Disclosure

Findings showed that there are multiple factors influencing disclosure (Figure 1). Children often receive their first source of information about HIV/AIDS from the media (radio, posters, and television), peers, education curriculum in schools, and through awareness programs in the community. However, HIV/AIDS is not typically discussed in the household and children rarely receive their first source of information on HIV/AIDS directly from a parent or a family member who later may be involved in disclosure to a child.

FACTORS INFLUENCING DISCLOSURE **F1**

10
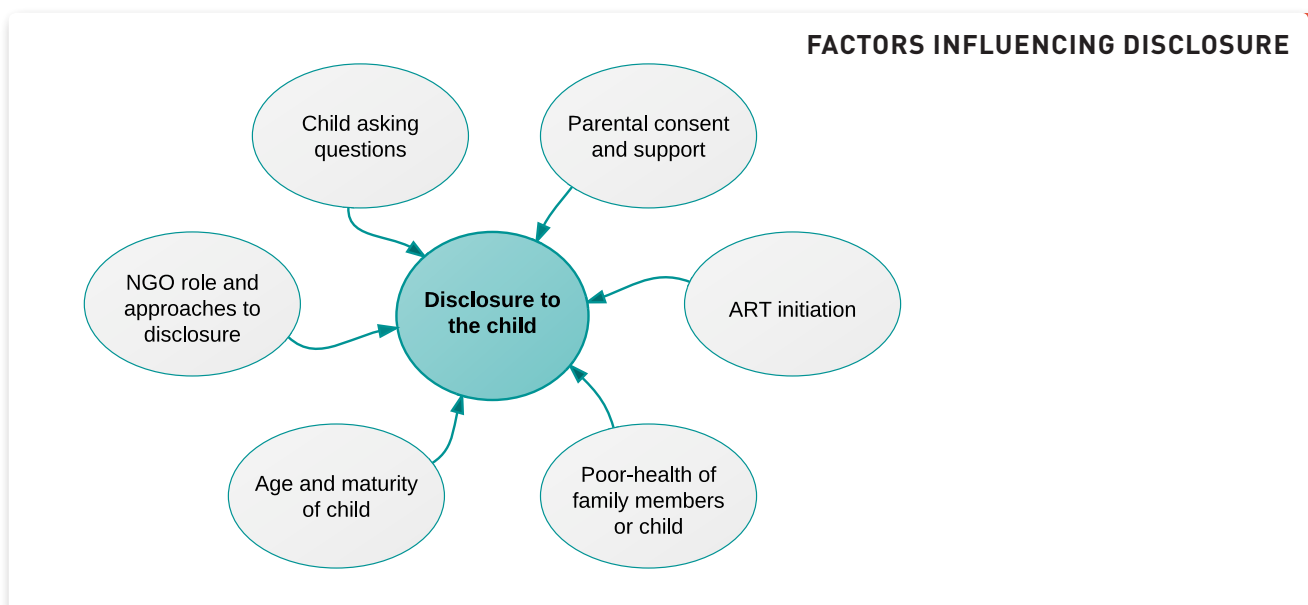
Child asking questions: NGO staff agreed on both the importance of using a child's questions to assess readiness for disclosure and advising parents to disclose when the child begins to ask questions. Typically, these questions are about ART, why the child is being taken to the hospital, why their parents are falling sick, and why the lives of their siblings (if relevant) are different to theirs.

- *"Because the child is eating medicines he has questions in the mind...why it is so, why is he so ill, we tell his parents to tell him his status"* **(CHELSEA)**

- *"It is always better it is disclosed when child is asking such questions. When the child is curious to know the reason, it is always better to tell them"* **(CHES)**

Parental consent and support: While all NGO staff felt it was the right of a child to know their HIV status, most felt parents had the right to decide whether the child should, or should not, be told their own HIV status. There was agreement on the importance and necessity of parental consent for HIV testing, pre and post-test counseling and disclosure and that, in practice, parents are more likely to deny disclosure than to be predisposed to it.

- *"Children should know their status but it is a practice that parents deny. And without parents' consent we cannot do anything"* **(CCDT)**

One respondent explained that, although parents may deny disclosure, it is the NGOs role to encourage parents to disclose, explore their concerns and facilitate the disclosure process.

- *"We will respect that decision but it's our job to slowly-slowly try to convince the parents. Here the child is not a problem...we have to focus more on parents than child"* **(CHES)**

In residential care, seeking parental consent is more complex since contact with parents or caregivers can be intermittent. In CCDT, the residential care program is structured with the aim of reintegrating children with their families after one year, and therefore, parents are involved in the disclosure process, wherever possible. In the residential programs in SCT and CHES, all children are single or double orphans and the organization has only intermittent contact with parents. SCT staff described the challenges in engaging parents who live across the state of Karnataka in the disclosure process.

NGO staff felt that single parents were more likely to disclose to the child and had differing opinions about the role education levels of parents and caregivers played in influencing disclosure. The quantitative data appears to associate more parental education with a higher likelihood of child disclosure. There was agreement in both the qualitative and quantitative data that mothers were the lead actors in the disclosure process. In some cases, written consent was taken from parents before disclosure, especially in CHELSEA where staff often disclose directly to the child.

ART initiation: Watching a parent take ART, visiting the ART Center, reading posters about HIV and starting ART were said to be a key factors that influences disclosure. Previous studies have also shown that access to treatment is often the turning point for a parent to begin thinking about disclosure to a child.[25,26] The quantitative data shows that a child is more likely to know their HIV status if they are on ART or if a parent is on ART.

- *"Any child who has been taking ART knows somehow or the other that they are positive"* **(CCDT)**

This statement was in the context of ART group meetings in residential care programs of CCDT as children who are part of this group invariably come to know the status of other children.

Poor-health of family members or child: If parents fall sick frequently, or if the child is sick, the child begins to ask questions. NGO staff also described their role in counseling parents, who were falling sick frequently, to disclose to the child in order to better prepare them for their future.

Age and maturity of child: As expected, both the qualitative and quantitative data suggests older

children and children involved with the NGOs for a longer time are more likely to know their status. This is both related to the sexual maturity of the child (onset of puberty is reported to be a triggering factor for disclosure) and the growth and increasing maturity in cognition (older children being reportedly more able to understand HIV and their HIV status). As children absorb information, begin to access treatment, overhear conversations and observe family interactions, 'partial disclosure' often occurs even though the child may not have engaged in a direct conversation about HIV:

- *"Partial disclosure would occur on its own… she would start thinking why she has to take medicines, why CD4 has to be conducted …*

every 6 months, she has to give blood…so, partial disclosure will be made during this process" **(CHELSEA)**

Similarly, NGO staff described cases where children were already aware of their status and their parent's status when disclosure occurred.

- *"There are also children who know their status, but their parents think that their child does not know it. Children are very fast to understand– they are on medication, going to hospital, getting sick, so they come to know by all this, but do not ask parents and hence parents think that their child does not know"* **(CHES)**

NGO Role and Approaches to Disclosure

There has been an emergence of NGO programming to support and facilitate disclosure to children. NGO staff identified that little support was provided to parents and caregivers from Integrated Counseling and Testing Centers (ICTC) and ART centers on how to disclose to their children. Furthermore, respondents were rarely able to identify examples of pre and post-test counseling for children in government centers; ART counseling for children was also infrequent. This highlights the importance of both NGOs and parents in disclosure to children. CHES initiated work on disclosure in 2000 when 'nobody talked to the children' and CHELSEA several years later, in 2004. CCDT placed a focus on disclosure in 2007 following the introduction of free pediatric ART in India. While NGOs shared an ethos of how and when to disclose, each NGO had developed innovative interventions, resources and tools to support and facilitate the disclosure process.

In varying ways, the NGOs follow a similar six-step process (Figure 2) in conducting their disclosure activities. Though it appears linear and sequential graphically, many of the steps occur simultaneously.

A. Initial assessment and enrollment

Although many families and children have accessed

HIV testing and/or ART services prior to enrollment in the NGOs program, it is rare for a child to know their HIV status. In most cases, counselors and social workers spoke to parents to determine how much a child had been told about his/her status and also asked a child open questions about health and sickness to understand how much the child knew. Whether a child had been disclosed to or not was rarely documented in NGO records/registers at enrollment. Once children and families were enrolled into the program and an initial assessment of needs was conducted, monthly home visits would begin (CHELSEA, CHES, CCDT) in the case of the community-based programs, or the child would live in the residential care facility and attend the school run by the NGO (CHES and SCT) or enroll in Government, Government aided or Private schools (CCDT). Additionally, CCDT linked families to support group meetings for people living with HIV. If a child was not tested for HIV at the time of enrollment, the child was then referred for testing based on the parents' HIV reports; and staff at CCDT, CHES, and CHELSEA would seek parental consent for pre and post-test counseling. This was often done without telling the child their HIV status. However, the residential care program in CCDT directly linked disclosure to HIV testing.

| A.
Initial assessment and enrolment | → | B.
Build rapport with the family | → | C.
Assess whether the child is ready to learn about HIV status | → | D.
Encourage and prepare parents to disclose | → | E.
Disclosure | → | F.
Follow up (short and long-term) with children and parents |
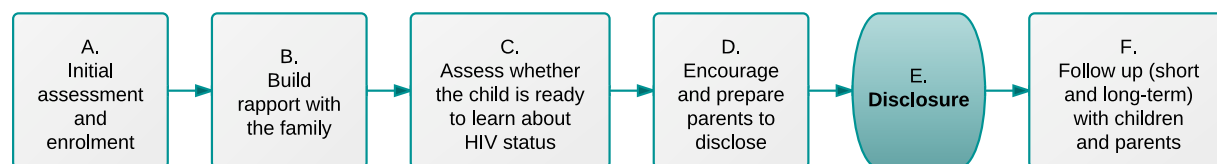
B. Building rapport

NGO staff agreed that without building a rapport with the child and family, it was not possible to discuss disclosure. Games, stories, the use of art and listening to the child were cited as strategies to build rapport; and counselors highlighted the importance of 'breaking the hierarchy between the adult and the child' (CCDT). Building rapport in order to broach the subject of disclosure was facilitated by accompanying families and children to the ART Center, gaining their trust, and showing parents that the NGO is committed to providing support.

C. Assess whether a child is ready to learn about their HIV status

Counselors and social workers assessed how much a child knew about HIV during home visits, or during initial counseling sessions in residential care. SCT conducted interviews with children to assess their knowledge of HIV, ART and blood tests for CD4 prior to initiating disclosure and documented these interviews in order to better understand how a child's knowledge of HIV changed through the disclosure process.

D. Encourage parents to disclosure

NGO staff play a crucial role in initiating a discussion on disclosure with parents (if relevant) and in supporting parents and caregivers to disclose. This can take from several weeks to a year in some cases as NGO staff will not disclose to children without parental consent. Parents were shown the benefits of disclosure and disclosure was framed as a powerful step in equipping a child to deal with the

future, take care of themselves, and cope with the loss of parents. CCDT runs groups for parents as well as three-day family camps where parents are able to share concerns and discuss strategies for disclosure. Role plays and visual resources are also used to encourage and prepare parents to disclose.

E. Disclosure

In all four NGOs, children are given age and maturity-specific information. Three of the four modes of transmission are introduced initially and the fourth, sexual transmission, is typically explained after the child has reached puberty or after 18 years. HIV is described as a 'worm' or 'germ' in the blood and stories and visual images are used to explain the effect of ART and good nutrition on 'fighting the germ'. NGO staff also provides education on nutrition, ART adherence, CD4 count and hygiene and these themes, in addition to life skills education, are used to develop a child's understanding of HIV. In CHELSEA, staff highlighted how they would share developments in HIV care with young people.

F. Follow-up

Follow up visits were felt to be essential to understand the reactions of the child post-disclosure and to assess whether the child had absorbed and understood the information provided about how HIV was transmitted, how to take care of themselves and the importance of ART. Often NGO staff would supplement the information given to the child by the parents, deal with additional questions about puberty and marriage, and discuss the implications of disclosing to a friend or a partner.

COMPARISON OF DISCLOSURE PROGRAMMING IN FOUR NGOS   F3

E. Disclosure

Method		NGO - Community-based	NGO - Residential care
Mother → Child		CHES, CHELSEA, CCDT	-
Mother + NGO → Child		CHELSEA, CCDT	CCDT
NGO → Child		CHELSEA	SCT, CHES, CCDT

Each NGO had a component of peer support and organized groups for children who were aware of their HIV status. CHES developed a training manual for counselors facilitating this group, which was finalized after input from children, and focuses on building resilience.

There was agreement that disclosure was a process instead of a one-off session; however, most respondents suggested a point at which they considered disclosure to be complete:

- *When child is completely aware of transmission of disease and learnt that he has got HIV and his parents have the same and he is known to have learnt that he would have to take medicines regularly to be better and disclosure becomes complete there.* **(CHES)**

Comparison of Approaches to Disclosure

A key difference between the approaches to disclosure across in the NGOs was their engagement with mothers and caregivers, especially in the context of community home-based care (Figure 3). All three NGOs providing community home-based care placed a focus on preparing mothers (or caregivers) to disclose. CHELSEA and CCDT counselors would disclose to children with mothers and caregivers and the counselors in CHELSEA would also disclose to the child without the parents, after seeking their consent.

Caregiver Concerns

T2   CAREGIVER CONCERNS ABOUT DISCLOSING TO CHILDREN

- The child will live in fear, be anxious, and disclosure will have a negative impact on their education.

- The children will blame them, especially the fathers, and family relationships will change. NGO staff discussed that fathers were usually more reluctant to disclose.

- Belief that the child will find out later and therefore there is no need to tell the child now.

- Perceptions that HIV is only transmitted through sexual intercourse.

- Fear that a child may tell others in the family, community or in their school. They are worried about stigma in the community and that broader disclosure may lead to eviction from their home and greater discrimination of the family and child.

- Belief the child is too young to know their status; however, there were cases where parents would express this concern for post-pubescent children as well.

Highlights of Quantitative Outcomes of Disclosure

For this part of the study, two research questions were assessed with retrospectively collected, routine program quantitative data from two NGOs, CHELSEA and CHES:

- What are the characteristics of families who disclosed the child's HIV status or the parent's HIV status to the child?

- Are disclosed children psychosocially healthier as measured by a standardized psychometric tool, the Strengths and Difficulties Questionnaire (SDQ), than children who did not receive HIV status disclosure?

It is not possible to infer statistical differences between these two organizations due to differences in data collection and measurement.

What are the characteristics of families which disclose HIV status to the child, including child and parent status? At CHELSEA, 64.6% (53/82) of children were disclosed to about their own status and 37.1% (127/342) were aware of their parent's HIV status. Of the HIV+ children at CHES, 25.2% (39/155) of them were disclosed of their HIV status; and where information about parental disclosure was available, 24% (36/150) knew their parents' status. Table 3 highlights the predicting variables for both CHELSEA and CHES on disclosure of child and parent HIV status to the child.

The data demonstrates the differences between these two organizations when it comes to disclosing a child's or parent's HIV status to the child. However, for both organizations children are more likely to be disclosed of their own status if on ART. CHELSEA beneficiaries were younger (pre-pubescent) males on average; in contrast, CHES beneficiaries were

T3 PREDICTING VARIABLES FOR DISCLOSURE

PREDICTING VARIABLES	CHELSEA		CHES
	Child Disclosure	Parent Disclosure	Child/Parent Disclosure
House type (proxy for income)	-	Disclosed families more likely to be living in kaccha style homes compared to those living in semi-pucca and pucca homes	Disclosed families more likely to be living in kaccha style homes compared to those living in semi-pucca and pucca homes
Gender	More males disclosed to than females	More males disclosed to than females	More females disclosed to than males
Average age	11 years	10 years	14 years
Orphan status	-	-	More double orphans disclosed to than single orphans or children with both parents alive
Child on ART	If child is on ART, 13 times more likely to be disclosed to	-	If child is on ART, 8 times more likely to be disclosed to
Parent on ART	-	Disclosure to child 3 times more likely if parent is on ART	-
Time with organization	-	Disclosed children have been in program 1 year longer	-

more likely to be female and post-pubescent. These differences appear to be driven by programmatic choices. Children aware of their parent's status are more likely to have higher educated parents (data not shown), to be HIV infected themselves, disclosed to about their own status and have a parent on ART. When examining parental disclosure with multivariate regression models, parents with higher education, and have a child who is also HIV+, are more likely to disclose their HIV status to a child.

Are disclosed children psychosocially healthier as measured by SDQ scores? Both CHELSEA and CHES administered the Strengths and Difficulties Questionnaire (SDQ), a standardized psychometric tool. This questionnaire has 25-scored questions encompassing 5 sub-categories: emotional symptoms, conduct problems, hypersensitivity, peer problems, and prosocial behavior. A total difficulties score is calculated using the sub-scores from the first four mentioned categories. Prosocial behavior, a separate indicator, assesses how well a child socially integrates within the community.

A total of 63 HIV-infected and affected children from CHELSEA were administered the SDQ. Overall, there was no significant difference between the total difficulties score outcomes for children who disclosed of their own status and/ or of their parents' status. However, children that were disclosed of their parents' status had higher borderline/abnormal prosocial scores – indicating that these children are having a more difficult time socially compared to those that are not aware of their parents' status.

At CHES, there were a total of 124 infected and affected children that were administered the SDQ. At this organization, children who are single orphans are more likely to have borderline/abnormal total difficulties scores compared to double orphans. There were only 4 out of 124 children that have a borderline/abnormal prosocial score. Given the small sample, statistical significance could not be determined.

Future Directions for Disclosure Programming

In 2006, the National AIDS Control Program introduced free pediatric antiretroviral in India, increasing the number of HIV positive children surviving into adulthood.[8,9] As HIV positive children reach adolescence, the public health significance of disclosure increases as young people begin to take a more active role in decisions about their own health, often become caregivers for their ill parents or siblings, and increasingly become sexually active and risk spreading the disease to their sexual partners.[12,25,27]

1. **Build and/or strengthen state institutional capacity, particularly the ART centers, to improve the provision of care and support to mothers/caregivers and children in the disclosure process:** ART Centers can integrate a much stronger focus on child counseling, which includes stronger collaboration with, and support for, parents/ caregivers, in the training of counselors. Monitoring the quality of counseling is essential.

2. **Build and/or strengthen NGO capacity to support or undertake disclosure activities:** NGOs should continue to facilitate linkages with hard-to-reach populations and be prepared and trained to provide disclosure counseling services to families that cannot or will not access services through the state institutional settings. These services should be based on clear organizational guidelines and policies with child-centered care plans. NGOs need to provide ongoing support and mentoring to counselors and social workers who work with children and families.

3. **Develop national guidelines, informed by the global experience, on pediatric disclosure and a toolkit on disclosure to children:** These guidelines need to be created in consultation with key stakeholders – State AIDS Control Society (SACS), NGOs, and other institutions that have an expertise in child psychology and HIV. These guidelines could include, good practices, clarification on questions around disclosure, and child-friendly resources (stories, games, visuals) for discussing HIV with children and disclosing their own or family members' status.

4. **Based upon the national guidelines, develop training modules and resources on disclosure:** These materials need to be differentiated to meet the needs of ART center personnel, NGO staff and caregivers. Training modules should be available in local languages.

5. **Develop a robust monitoring and evaluation process:** Develop and maintain a child-centered routine information system of the counseling and disclosure process. The identification of appropriate outcome measures of the well-being of children and families is essential to conduct impact evaluation studies. Using well collected routine program data will allow for evaluation research to measure outcomes and impacts over time as the programs develop. Improved documentation will ensure institutional memory, continuity of service delivery in case of staff turnover and may allow the quality of services provided to be monitored and improved.

Children Affected by AIDS Pilot Scheme: Organizational Network Analysis in Five Districts

Background

The National Aids Control Organization (NACO) of the Government of India launched the Children Affected by AIDS (CABA) Pilot Scheme, in May 2010 to "ensure that all children exposed to and affected by HIV/AIDS are identified and linked to early diagnosis and treatment services, along with development, protection and welfare services on a need basis."[1]   The strategies and operational guidelines were developed through a Task Force Agency (TSA) comprising of NACO, Ministry of Women and Child Development (MWCD), UNICEF, USAID, FHI360, India HIV/AIDS Alliance and the Clinton Foundation.   These organizations were assigned to 10 different districts to provide support to the CABA roll-out and implementation. The District AIDS Prevention and Control Unit (DAPCU) is the coordinating body under each State AIDS Control Society (SACS) with two additional staff funded for CABA implementation: Project Coordinator and Mainstreaming/Training Officer.   Support is provided through local non-governmental organizations (NGOs) designated as District Coordination Action Agencies (DCAA) under the mentorship of the CABA TSAs. USAID, as a member of the CABA TSA, requested BU CGHD to conduct an analysis of the CABA Pilot Scheme to: "Identify the good and promising programmatic practices that are sustainable, replicable and enhance the integration approach of service delivery for orphans and vulnerable children programming."[2] Utilizing the methodology of Organizational Network Analysis (ONA), the research team set out to identify and understand the most effective pathways for coordination and linkages of multi-sectoral government departments and non-governmental organizations resulting in needed services for CABA. This study was conduced in 5 districts with the support of the accompanying DCAAs: Karnataka (Karnataka Health Promotion Trust – KHPT) in Belgaum and Bagalkot; Andhra Pradesh: Krishna (India HIV AIDS Alliance and Vasavya Mahila Mandali - VMM) and East Godavari (FHI 360); and North East Delhi (FHI 360 and WAG...CHELSEA).

Methods

The BU CGHD research team contacted the DCAAs designated to support the CABA Pilot Scheme implementation and visited each of the districts. Working with the partner NGOs and designated DCAAs, a comprehensive list of all government departments and NGOs involved in HIV/AIDS work in each district was established. Two talukas or mandals per district were also selected for the

study. Partner organizations at the district level were asked to identify one high performing taluka or mandal and one weaker taluka or mandal for inclusion. A fixed sampling methodology was chosen because it allowed for confirmation of relationships between different departments.

A draft questionnaire was finalized through pre-testing in the field and feedback from mock interviews. It was translated into Hindi, Kannada and Telugu. After a three-day training, state level teams from Sigma Research and Consulting Group conducted the district and taluka/mandal level interviews. Revisits were made at least twice to ensure a high response rate. Additionally, if potential respondents on the lists were not available or had been transferred, other respondents were identified for the interview. Upon completion of the interviews, the responses were double entered

into a CS Pro database, cleaned and sent to BU CGHD for analysis. UCINet[3] was used to analyze and develop the network measures and Net Draw created the plots.

Descriptive Statistics

CABA Characteristics

Overall the response rate for this study is fairly high ranging from 77.1% (Belgaum) to 92.3% for NE Delhi. Patterns were detected among district level responses, within the diversity of organizations interviewed. HIV-related organizations reported the highest levels of both knowledge of CABA and involvement. Non-health organizations were second highest while very few health institutions had a high degree of knowledge about CABA, except in

T1 DESCRIPTIVE STATISTICS BY TYPE OF DEPARTMENT WITHIN THE 5 DISTRICTS*						
KEY DESCRIPTIVE VARIABLES	Types of Organizations	KARNATAKA		ANDHRA PRADESH		DELHI
		Belgaum (%) N=37	Bagalkot (%) N=33	Krishna (%) N=34	East Godavari (%) N=36	NE Delhi (%) N=24
CABA knowledge (Moderate/A lot)	Non-Health Health HIV/AIDS	30.0 27.3 81.2	18.2 40.0 75.0	57.1 28.6 69.2	26.7 16.7 60.0	33.3 25.0 70.0
CABA involvement (Moderate/A lot)	Non-Health Health HIV/AIDS	20.0 18.2 68.8	18.2 20.0 83.3	42.9 28.6 69.2	40.0 33.3 60.0	0.0 37.5 70.0
Enough funds to serve OVC+ (yes)	Non-Health Health HIV/AIDS	66.7 14.3 28.6	27.3 30.0 0.0	7.1 0.0 23.1	13.3 0.0 35.7	33.3 0.0 20.0
Enough funds to serve OVC+ (don't know)	Non-Health Health HIV/AIDS	0.0 28.6 21.4	54.6 20.0 25.0	85.7 100 38.5	80.0 83.3 35.7	66.7 75.0 50.0

* For each district, the reported percentages are based on the total number of organizations by type of organization (non-health, health, and HIV) and are not based on the total number of organizations in the district.

+ For Belgaum, there were a significant number of organizations that did not respond to this question and therefore have a lower denominator for the non-health, health, and HIV organizations compared to the other descriptive variables.

Bagalkot where 40% of the health organizations had a moderate to a lot of knowledge about the CABA Pilot Scheme. Interestingly, in both Andhra Pradesh (AP) districts (Krishna and East Godavari) there is almost twice the level of involvement for the non-health organizations compared to the other three districts.

Less than 50% of all three types of organizations, non-health, health, and HIV/AIDS, claimed there were enough funds to serve CABA; though, Belgaum was an exception as 66.7% of its non-health organizations maintained they had enough funds. A majority of non-health and health organizations reported that they did not know if their department had enough funds to provide services and benefits to CABA and their families.

ONA Results

The effects of the CABA Pilot Scheme is analyzed by applying ONA methods to assess inter-organizational relationships before the CABA Pilot Scheme was implemented (Period 1) and one-year after implementation (Period 2) in the 5 identified districts. In order to do this, we compare the density measures (the % of confirmed relationships out of the total possible relationships) in Periods 1 and 2 as well as key players within these 2 time periods (Table 2). NE Delhi is a unique case as its total possible ties is about half of the other districts because its an urban location and does not contain lower administrative units as compared to other districts in Karnataka and Andhra Pradesh.

T2   COMPARISON OF DENSITIES BETWEEN PERIOD 1 AND PERIOD 2

STATE	District	Total Possible Ties*	Period 1 Density (%)	Period 2 Density (%)	Key Players in Period 1	Key Players in Period 2
KARNATAKA	Belgaum	1056	40.5	49.0	District hospital, DWCD, DAPCU	DHMO, DWCD, District hospital, DAPCU
	Bagalkot	1332	35.3	33.9	DHMO, DAPCU, ICTC, NRHM	DAPCU, ICTC, DHMO, NRHM
ANDHRA PRADESH	Krishna	1122	23.6	25.0	DAPCU, DRDA, DWCD	DAPCU, DRDA, ICTC, DCAA, DWCD
	East Godavari	1260	21.9	21.9	DHMO, DAPCU, DCO	DHMO, DAPCU, DCO
DELHI	NE Delhi	552	16.8	24.3	DSACS, DAPCU, DHMO	DAPCU, NRHM, DHMO, DSACS

* The total possible ties between Period 1 and Period 2 are slightly, but not significantly, different due to respondents who were new employees (working with an organization for less than one year) and did not know the relationships with other organizations in Period 1.

+ The formula for density calculation is: $X/(n*(n-1))$ where; X = sum of total confirmed ties; n = the number of organizations; and $n*(n-1)$ = total number of possible confirmed ties.

Whole Network Density and Key Players

Overall Belgaum has the highest densities for both time periods, as 40.5% of all possible ties were confirmed in Period 1 and 49% in Period 2, demonstrating that this district is a highly connected network. East Godavari and NE Delhi have the lowest densities, with 21.9% of all possible confirmed ties in Periods 1 and 2 for the former and 16.8% in Period 1 and 24.3% in Period 2 for the latter. However, the districts in Karnataka had fewer non-health respondents and thus, may have had lower densities if more non-health organizations were interviewed. As for the key players within each network, there was little change between Periods 1 and 2. Both DAPCU and DHMO are consistently the key players across all districts. They garner a high level of direct relationships as well as link organizations at the periphery to the broader network. Both of these organizations, especially DAPCU, are essential in connecting non-health clusters of government departments with the health/HIV organizations contributing to the formation of a more functional cohesive network.

NETWORK DEFINITIONS

- **Multiplexity:** multiple relationships among the same set of organizations.

- **Intensity:** level of interaction between different organizations or nodes (no interaction; at least once a year; quarterly, at least 3-4 times a year and monthly or more frequently).

- **Density:** sum of the ties divided by the number of possible ties.

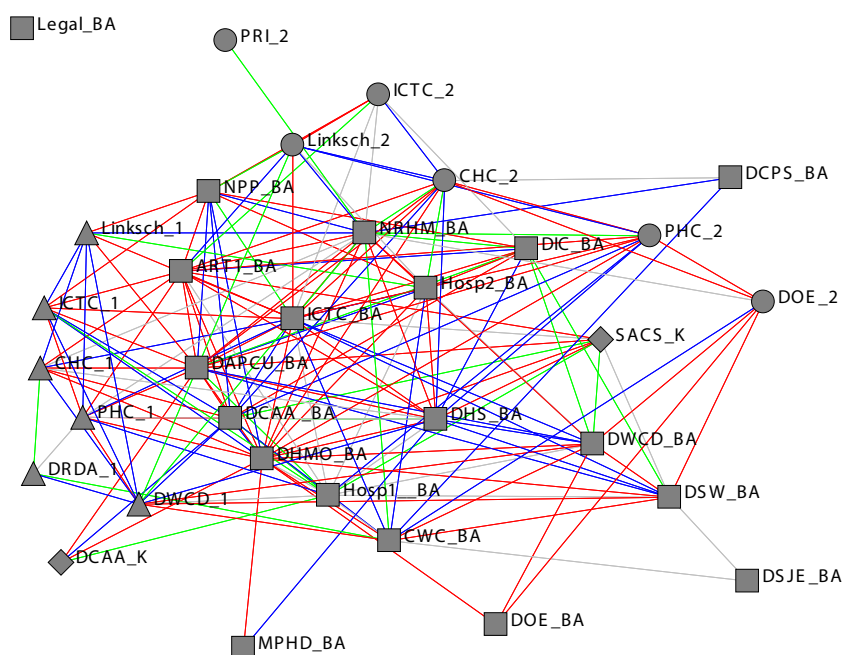**F1** **ROBUST MULTIPLEX NETWORK (BAGALKOT)**

PLOT GUIDE

Departments are organized by:

State: Dept. followed by K (for Karnataka; SACS_K)

District: Dept. followed by BA (for Baglakot; NRHM_BA)

Talukas/mandals: Dept. followed by BA_1 or BA_2 (for Bagalkot Taluka1; ICTC_1 or Bagalkot Taluka 2; ICTC_2)

Red = 4 activities
Blue = 3 activities
Green = 2 activities
Grey = 1 activity

Multiplexity

A robust organizational network will consist of multiplex relationships. This study requested departments to report on 4 key activities that informed the CABA Pilot Scheme implementation: joint planning, sharing information, referrals, and training. Figure 1 illustrates a highly robust multiplex network (Bagalkot). The majority of the ties are in "red" and "blue" which represents participation in all 4 and 3 activities, respectively. This creates a resilient network structure reducing the risk to fragmentation or cessation of relationships. If one activity is terminated, departments are still connected and engaged through 2-3 other activities. On the network development continuum, Krishna exhibits an emerging network structure (Figure 2). The majority of connections are across only 2 activities within the health and HIV clusters, while most of the non-health organizations are connected only by one activity. As relationships mature, different types of working relationships are likely to develop.

Network Activities

Looking more closely at each activity network, it is evident that organizations are more connected through some of these activities as compared to others. According to the reported densities in Table 3, information sharing is the densest network for all 5 districts. This activity is considered to be a gateway for interaction and relationship development that may lead to active engagement in other activities. On the other hand, training is the lowest density activity for all 5 districts; and this alone may affect the CABA Pilot Scheme implementation. Overall, the absolute density percentages are also rather low for all districts except Belgaum.
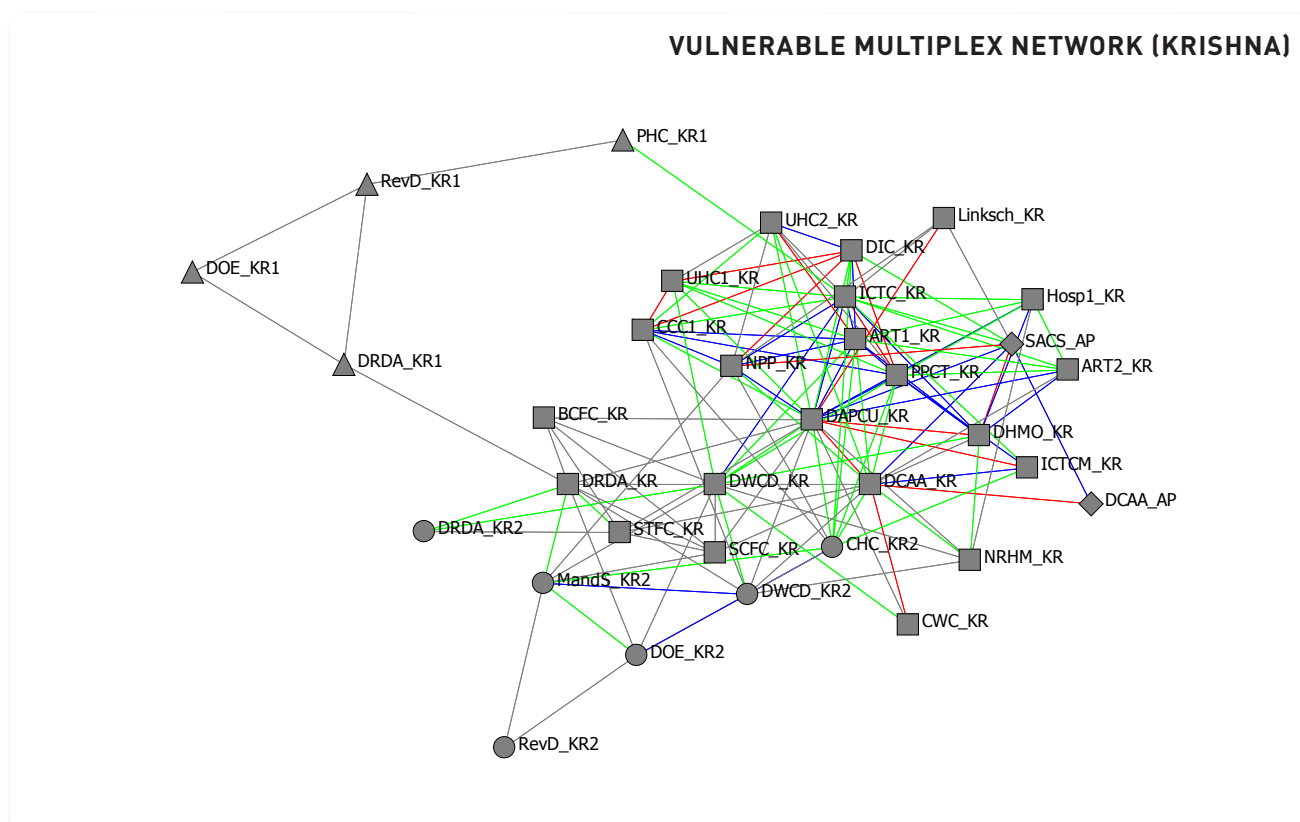
VULNERABLE MULTIPLEX NETWORK (KRISHNA)   F2

T3 DENSITIES OF THE 4 NETWORK ACTIVITIES

DISTRICTS	Joint Planning (%)	Information Sharing (%)	Referrals (%)	Training (%)
Belgaum	48.5	48.8	47.9	46.4
Bagalkot	25.1	33.5	26.1	17.0
Krishna	8.7	21.9	15.3	3.6
East Godavari	7.2	20.4	17.6	6.9
NE Delhi	13.4	23.2	9.4	3.6

F3 REFERRAL NETWORK (EAST GODAVARI)

Red = 4 activities
Blue = 3 activities
Green = 2 activities
Grey = 1 activity
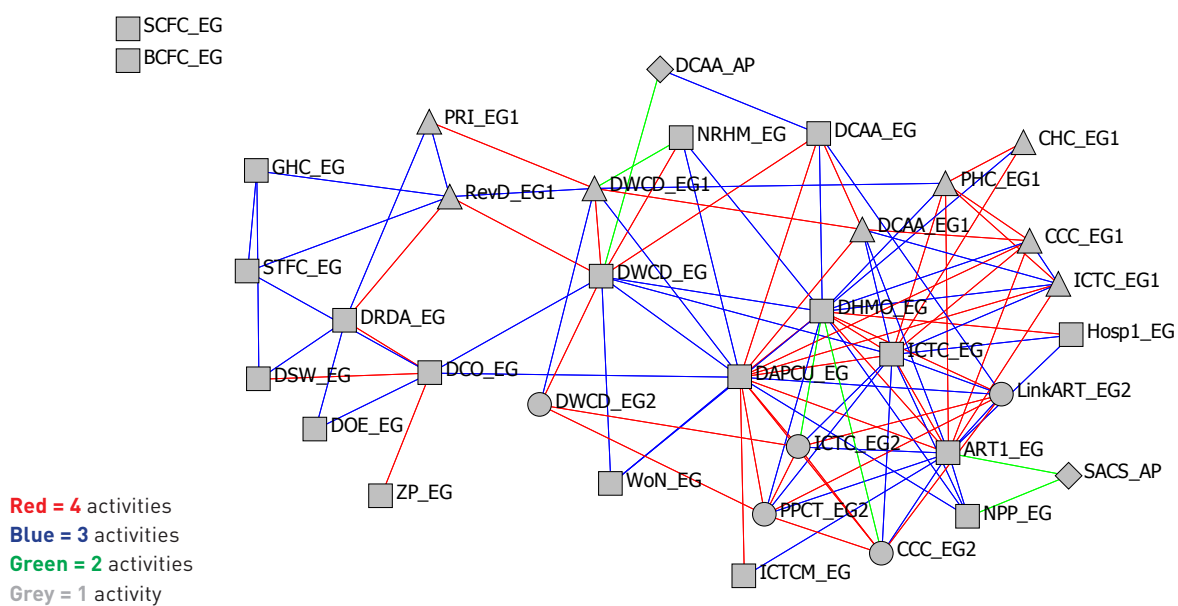
Although the referral network is the second densest network among these activities, with the exception for NE Delhi, there are very few referrals being made or received across non-health and health/HIV organizations.

As depicted in Figure 3, it is evident that the referral system in East Godavari is rather strong between health and HIV-related organizations, with a heavy dependence upon key players (DAPCU, DCO, and DWCD) to connect non-health organizations with health/HIV departments for this activity. Despite the referral network having a relatively higher density compared to the other two activities (joint planning and training), the reliance on key players reduces direct communication between departments impeding transmission of referrals and the feedback loop to monitor outcomes of referrals.

Policy Considerations

1. **Institutionalize coordination of schemes and services for CABA.** The CABA Pilot Scheme has brought attention to the needs of CABA in the districts. Moving forward, it is essential to identify existing key players within each district and leverage their role to facilitate the coordination of departments for the benefit of children and families affected by AIDS, while continuing to work with DAPCU.

2. **Improve collaboration across HIV/AIDS departments, health departments and social service departments.** The three types of departments work mainly within their own clusters, with a lot of dynamic relationships within HIV organizations. The coordination across other departments is limited. The social sector departments are particularly disconnected and often have minimal relationships even within their own cluster of organizations.

3. **Create mechanisms for sharing summary beneficiary information and use of resources across all departments for planning and accountability.** Many departments did not know the levels of funding required to meet the health and social service needs of children affected by AIDS. Development of a planning process and equitable distribution of resources is a necessary first step in addressing the needs of orphans and vulnerable children in the district.

4. **Build and strengthen the referral system.** The referral systems are reliant on key organizations to transmit referrals, reducing the number of direct referrals across organizations. Children are not getting linked to services and schemes, and organizations and departments do not have a system for sharing and receiving confirmation of whether the referral took place and whether the child or family received the service or scheme. Increasing the coordination of referrals by working within the district, talukas/mandals and across different types of departments can lead to improvement in realized access to social schemes and a range of services.

5. **Create and improve training programs.** There are very few training relationships among departments, limiting the implementation and possible impact of the CABA Pilot Scheme. Expansion of training sessions by involving more departments at the district and taluka/mandal levels to facilitate learning about different programs can generate the development of mechanisms to improve services to children and their families.

The Effectiveness of an Integrated Care Model Drop-in Center (DIC) in Improving Access to Services and Selected Social and Health Outcomes of Orphans and Vulnerable Children in Maharashtra*

Background

The Eleventh Five Year Plan of the Government of India places emphasis on the process of inclusion as the foundation for development in India. Following this principle, the National AIDS Control Program (NACP III), has developed a Drop-In Center (DIC) concept of service provision to people living with HIV/AIDS (PLHIV) to be managed by PLHIV networks. The vision of the DIC, as articulated in the Revised Operational Guidelines for DIC by NACP III, is: "Provision of community managed healthy and friendly supportive spaces to PLHIV and their families to improve the quality of life and effectively reduce their vulnerability to HIV, opportunistic infections, stigma and discrimination, isolation, stress and lack of access to vital rights like dignity, livelihood, education, health, etc."

The Avert Society, operating in Maharashtra in a partnership with the Maharashtra State AIDS Control Society (MSACS) and USAID, began supporting the implementation of the Drop-in Center concept in 7 districts through 7 different community-based organizations (CBO) in 2003. In April 2009, they added an Integrated Care Model (ICM) approach to increase coverage and expand linkages with schemes and services with a major focus on care and support for OVC. The goal of this study, is to: (a) understand the network structure of organizations and departments at the district level and assess the mechanisms for linking children to schemes and services, and (b) to determine the effect of the ICM approach on selected DIC service delivery and referral indicators as well as available health outcome information.

* New information was received from the DICs and Avert Society at the time of printing. This will be further assessed and may be incorporated into the final report as appropriate.

Methods

Organizational Network Analysis

Together with the Avert Society, the research team established a comprehensive list of all government departments and NGOs involved in HIV/AIDS work in the districts of Nagpur, Thane and Satara to establish relationship characteristics among a fixed set of departments and organizations. The same method of data collection, as described in the Children Affected by AIDS ONA study, was administered. For the interviews conducted in Maharashtra, an extra section was added to the end of the interview, which asked respondents their knowledge and involvement with the DIC-ICM. Overall the response rate was high among the three districts with 86% for Nagpur, 90.7 % for Thane, and 91.1% for Satara.

Drop-in-Center Data Collection

The research team visited each of Avert Society's DIC-ICM in Nagpur, Thane and Satara. After reviewing the information flow at each DIC and the existing Master Register (in Excel) that was developed by the Avert Society for the ICM program, a lot of gaps and missing information were identified. The information on type of contact and content of service provision with the child and family in the program was also captured through approximately 20 hand-written registers[i], where the same information was duplicated in multiple places.

In order to gain access to this information, a system was created for a designated staff member to abstract the child specific data and enter it into the electronic child line list. The electronic database was maintained but additional categories were added to ensure that key information was retrieved. Selected staff at the DICs was trained in data abstraction by a team consisting of one BU staff member and one Avert Society staff member. Upon completion of the training, the DIC staff reviewed all of the data sources and manually recorded for each child, the dates of counseling sessions, referrals made, dates of home visits and socio-demographic characteristics. This data was then entered into the electronic child line list. Due to staff turnover and vacancy of the positions, this process was unable to be completed in Satara.

Using the updated child line list, the DIC staff member spent time at the ART Center in the District Hospitals reviewing all the white cards (record kept on each patient) for children in their district. While at the ART Center, the number of visits to ART Center, date of visit to ART center, ART status, height and weight were electronically entered. Once the data abstraction process was complete, the final line listings were sent to BU CGHD for analysis.

Results

The first part of this study employs ONA methods to assess the role of the DIC in the district network structure one year before the DIC-ICM was implemented (Period 1) and one year after implementation (Period 2). We can gain an understanding of the level of existing relationships in Nagpur, Satara, and Thane by comparing the densities (the % of confirmed relationships out of the total possible relationships) and key payers between Period 1 and Period 2.

Whole Network Density and Key Players

The density measure of confirmed relationships among the departments and organizations in Satara and Thane were low in Period 1, 7.5% and 8.9%, respectively. Nagpur is the exception, with a density of approximately three times higher compared to Satara and Thane, with 22.8% of all possible confirmed ties in Period 1 and 24.6% in Period 2. It is important to note that Nagpur is also a participating district in the CABA Pilot Scheme, with this scheme's implementation coinciding

DISTRICT	TOTAL POSSIBLE TIES*	PERIOD 1 DENSITY (%)	PERIOD 2 DENSITY (%)	KEY PLAYERS IN PERIOD 1	KEY PLAYERS IN PERIOD 2
Nagpur	1482	22.8	24.6	NRHM, DHFW, DAPCU, CCC1	NRHM, DHFW, DAPCU, CCC1
Satara	1892	7.5	10.8	DWCD, ICTC, DAPCU	DWCD, DAPCU, ICTC
Thane	1640	8.9	11.7	District Hospital 1, WoN, DHMO, Taluka 2 Orgs	DAPCU, District Hospital 1, DHMO, WoN, Taluka 2 Orgs

* The total possible ties between period 1 and period 2 are slightly, but not significantly, different due to respondents who were new employees (working with an organization for less than one year) and did not know the relationships with other organizations in period 1.

+ The formula for density calculation is: $X/(n*(n-1))$ where; X = sum of total confirmed ties; n = the number of organizations; and $n*(n-1)$ = total number of possible confirmed ties.

with the roll-out of the DIC-ICM. Overall, there was a slight increase in densities for all of the districts – illustrating an increase in the number of connections within these networks after the implementation of the DIC-ICM scheme.

As for the key players within each network, there was little difference between Period 1 and 2. However, each district had different departments taking on the leadership role in the district: (a) Nagpur: NRHM, DHFW and DAPCU; (b) Satara: DWCD, ICTC and DAPCU; and (c) Thane: District Hospital, DHMO and Women's Network. However, DAPCU maintains a consistently important role in Nagpur and Satara in both Period 1 and 2, and emerged as a key player for Thane in Period 2.

Overall, these departments possess a high level of direct relationships and link organizations at the periphery to the broader network solidifying their influence in the districts.

DIC Densities

The DIC did not emerge as a key player in the districts. In order to understand the DIC's position with the district level organizations, a further assessment was conducted. Table 2 reports the densities for the DIC in Period 1 and in Period 2 across the three districts. Between these two periods there was an increase in relationships for the DICs, an exception is Nagpur where the number of ties remained the same despite the

T2 COMPARISON OF DIC DENSITIES BETWEEN PERIOD 1 AND PERIOD 2			
DISTRICT	TOTAL POSSIBLE TIES	PERIOD 1 DENSITY (%)	PERIOD 2 DENSITY (%)
Nagpur	39	45.9	43.6
Satara	44	12.8	15.9
Thane	41	0.0	9.8

T3 DENSITIES OF THE 4 NETWORK ACTIVITIES				
DISTRICT	**JOINT PLANNING** (%)	**INFORMATION SHARING** (%)	**REFERRALS** (%)	**TRAINING** (%)
Nagpur	23.9	22.4	21.5	15.8
Satara	7.2	9.8	8.5	1.5
Thane	8.6	10.6	9.4	3.5

lower reported density in Period 2[ii]. Despite this increase in number of ties for the DICs, there are very few direct relationships with other departments even though it was expected for the DICs in all three districts to play a more prominent role in establishing referrals to health, HIV, and non-health organizations to better serve OVCs.

Network Activities

Looking more closely at each activity network, it is evident that some of these networks are more integrated compared to others. According to the reported densities in Table 3, information sharing is the densest network for both Thane and Satara. This activity is usually the first type of relationship that organizations develop, paving the way to building stronger ties in other domains that require additional commitment and reciprocity. In the case for Nagpur, joint planning is a slightly denser network compared to information sharing. This illustrates that Nagpur is becoming a more mature network by working in closer collaboration with other organizations. This may translate into having a higher number of joint committee project meetings or meetings specifically about coordinating services and schemes for OVCs. The training network has the lowest density for all three districts, confirming that departments are not conducting training sessions together.

Intensity of Referrals Network

As stated in the operational guidelines, the DIC-ICM will "provide a one-stop-shop for basic counseling and support services and to establish links with existing community support groups and/or services provided by departmental social workers, welfare organizations, or other specialist service providers where more comprehensive services can be provided"[1]. The following 3 figures indicate that this mission is not being fully implemented as the referral system is stronger among health and HIV-related organizations, compared to non-health organizations with a heavy dependence on key players. Although the referrals network is the second densest among the 4 activities, the absolute level of connections with other departments for referrals is very low, 8.5% and 9.4% for Satara and Thane, respectively. Nagpur has almost three times as many referral relationships (21.5%) as compared to the other 2 districts.

Figure 1 illustrates the frequency of referrals across Satara. Each tie is color-coded which corresponds to how often organizations are sending and/or receiving referrals. Since Satara has the least dense referral network there are a significant number of organizations that are isolates (with no confirmed connection to any other department). Referring to Figure 1, non-health organizations (left-hand side) are heavily reliant on the DWCD to connect them with the rest of the network. Additionally, the DIC is located along the periphery of the network with very few connections – providing evidence that this organization is a not very active participant for sending/receiving referrals.

In Thane, the DIC follows a similar pattern (Figure 2). This network is fragmented into 5 separate structures with the non-health organizations not connected to the rest of the network (however there

F1 SATARA'S INTENSITY OF REFERRAL SYSTEM

PLOT GUIDE

Departments organized by:

State:
diamond shape
District:
square shape
Talukas:
triangle shape for taluka 1
and circle shape for taluka 2
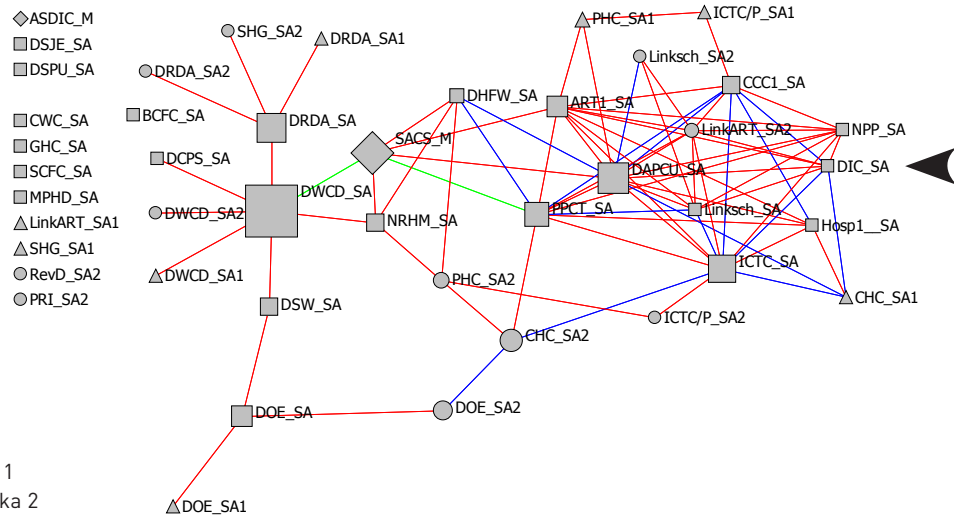
F2 THANE'S INTENSITY OF REFERRAL SYSTEM

Red = Monthly or more frequently, either weekly or daily
Blue = Quarterly, at least 3-4 times per year
Green = At least once a year
Grey = Relationship but unsure of interaction level (for new respondents)
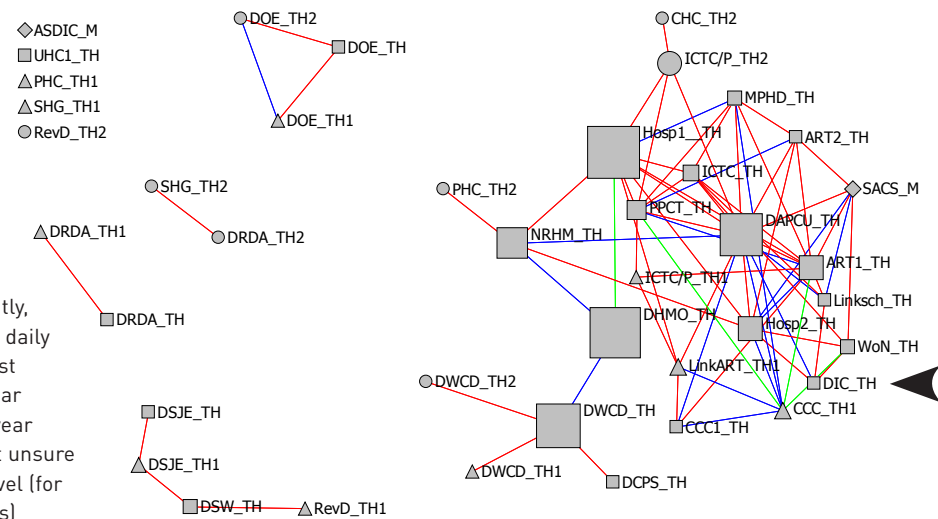
are fewer isolates than Satara). The position of the DIC continues to remain along the periphery of the network without any direct connections to social service departments and agencies.

Figure 3 displays the referral network for Nagpur. There are many "red" ties indicating a high level of interaction among the HIV/AIDS organizations and the district hospital. However, the non-health organizations are still not incorporated into the network, with a majority as isolates. Additionally, although the DIC has more relationships (compared to Satara and Thane) it continues to remain along the periphery of the network – while DAPCU is a key player in connecting a majority of these organizations. The CHC's in both talukas have an important role to play in connecting their taluka level departments to the Nagpur district network.
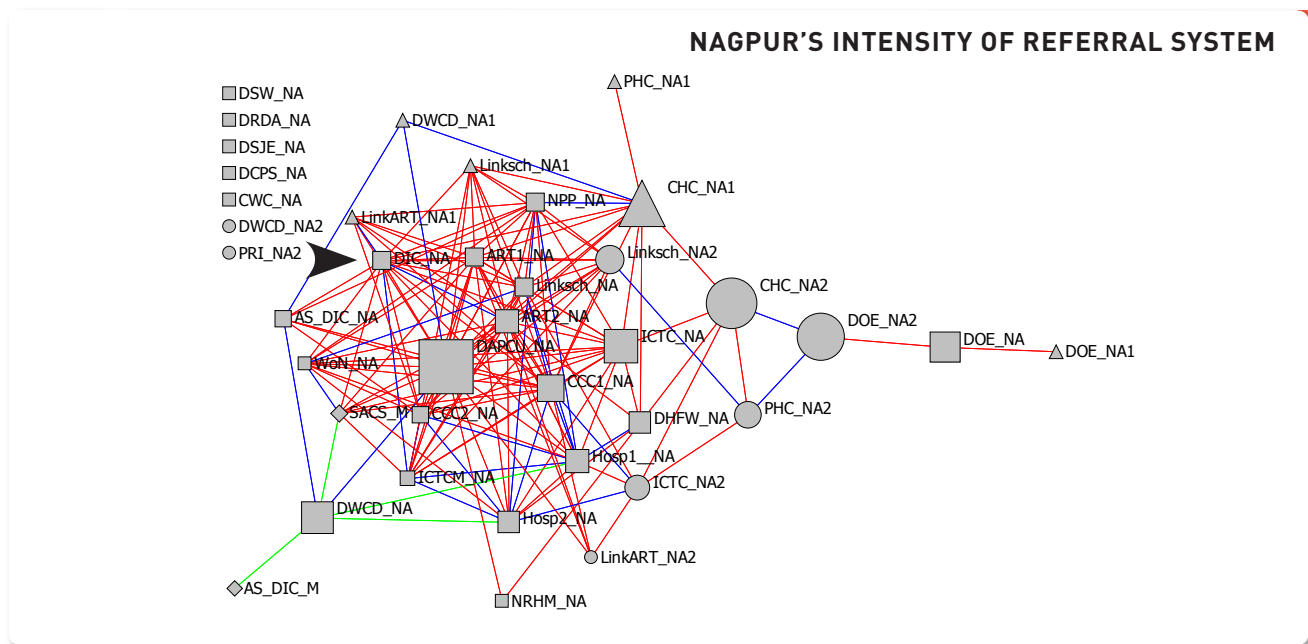
NAGPUR'S INTENSITY OF REFERRAL SYSTEM **F3**

Drop-in-Center: Pre and Post Integrated Care Model

Sociodemographic Characteristics

The mean age of children in Nagpur was 6.7 years as opposed to 9.2 years in Thane. In Nagpur, almost 41% of the children were single orphans, 46% had both parents and 13% were double orphans. In Thane, 85% of the information on orphan status was missing. The enrollment statistics revealed that 121, or 40%, of the children in Nagpur were enrolled after the DIC-ICM model was adopted; while this was the case for only 50, or 22%, of the children in Thane.

DIC Services and Referrals for Schemes and Other Services

The distribution of DIC services delivered and referrals made is presented in Figures 4 and 5, respectively. Contrary to the goals of the enhanced DIC-ICM, home visits by the DIC outreach workers and counseling services provided at the DIC decreased significantly (p<0.001) by approximately 50% in all categories in both districts. In Nagpur, 18.5% of children received a home visit 1 year prior to the DIC-ICM implementation, which decreased to 8.8% after implementation of this model. The counseling visits decreased from 42.9% in Period 1 to 24.9% in Period 2. Thane had a similar pattern.
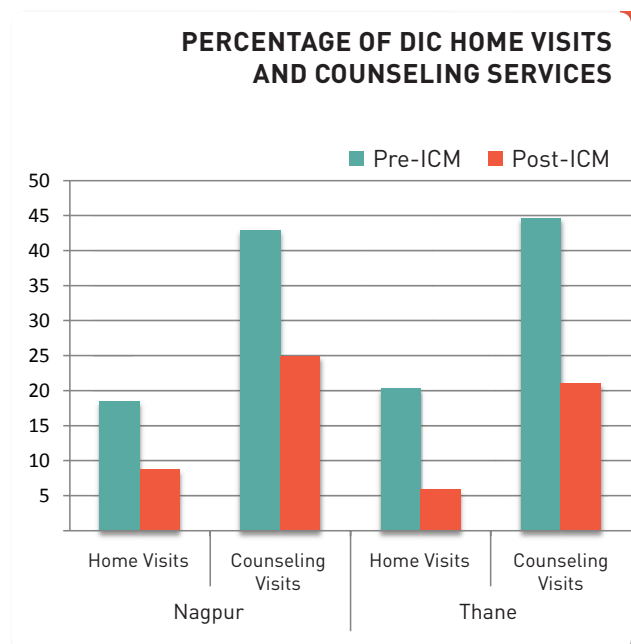
PERCENTAGE OF DIC HOME VISITS AND COUNSELING SERVICES **F4**

PERCENTAGE DISTRIBUTION OF DIC REFERRALS FOR SCHEMES AND SERVICES

T4 HEALTH INDICATORS OF CHILDREN ENROLLED IN DIC

HEALTH INDICATOR	NAGPUR	THANE
WEIGHT FOR AGE	N=96 (%)	N=16 (%)
Normal+	55 (57.3)	7 (43.8)
Moderately underweight	20 (20.8)	1 (6.2)
Severely underweight	21 (21.9)	8 (50.0)
ART STATUS (if reported)	N=304	N=229
On ART	165 (54.3)	69 (30.1)
Not on ART	139 (45.7)	149 (65.1)
Don't Know	1 (0.03)	11 (4.8)
TB SCREENED	N=294	N=233
Yes	154 (50.5)	14 (6.0)
No	112 (36.7)	40 (17.2)
Don't Know	39 (12.8)	179 (76.8)
TB RESULT	N=154	N=14
Positive	27 (17.5)	8 (57.1)
Negative	107 (69.5)	5 (35.7)
Don't Know	20 (13)	1 (7.2)

Children's Health Indicators

Available weight-for-age data for 96 children in Nagpur revealed 21% were moderately underweight (< 2 SD, using the WHO criteria) and 22% were severely underweight (< 3 SD). Data was only available for 16 children in Thane and therefore is unreliable in establishing any trends; however, half of the children were severely underweight. ART status revealed that 54% of children were on ART in Nagpur as opposed to 30% in Thane. If receiving ART, 94.2% of the children in Nagpur visited the ART Center at least once in Period 1 and it increased to 98.5% in Period 2 (suggestive of a statistical significance at p=0.08). In Thane, where 49 of 69 children had data for ART status and visiting the ART Center, only 16% of the children had at least one visit in Period 1 and it did not change significantly in Period 2 (18.8%).

Screening for health risks in HIV positive children is an important preventative health activity. In Nagpur, 50% of the children in the program were screened for TB and 17.5% were positive. In Thane only 6% (14/233) of children were screened for TB and 57.1% (8 children) were positive.

Policy Considerations

1. **Review and realign the mission and functions of the Drop-in-Center.** The DICs pre and post ICM are performing at a very low level of service delivery consisting of home visits and counseling and the referrals to schemes and services to departments outside the DIC. The high expectations coupled with a low level of resources and limited capacity building have detracted the DICs from achieving their goals.

2. **Improve the level of connectivity between different departments both within sectors and across the HIV/AIDS, health and social service departments through leveraging key players in each district.**

3. **Establish an effective referral system with an interactive process to monitor the status and outcome of applications for schemes and results from health consultations.**

4. **Improve the efficiency of record keeping and data management systems.** Reduce duplication of effort by abandoning the use of multiple registers. Together with the DIC staff, develop one system and keep it updated.

5. **Address the severe nutritional deficiencies in children affected by AIDS by collaborating with the DWCD and enrolling children in the double ration program and other nutrition support services.**

5

The Karnataka Cash Transfer Program

Background

Karnataka is one of the five states in India most affected by HIV. In 2009, HIV prevalence was 1-1.9% across the 30 districts.[1] In Karnataka, most orphans and vulnerable children (OVC) do not receive support, despite their needs. In communities, stigma and discrimination of people living with HIV//AIDS and their family members is still a serious issue that undermines efforts to care and support this population. To respond to this need, the Karnataka State Government approved a 1 crore cash scheme in March 2010 to provide targeted monetary support to OVCs through the Department of Women and Child Development (DWCD). In order to target the limited support to the neediest beneficiaries, a family assessment tool was developed by the USAID supported Samastha project implemented by the Karnataka Health Promotion Trust (KHPT) with technical support from EngenderHealth. Anganwadi Workers (AWWs), Accredited Social Health Activists (ASHAs) and Auxillary Nurse Midwives (ANMs) are being trained to implement the family assessment tool to identify beneficiaries. Applications for assistance are validated and approved by the Village Health Sanitation Committee (VHSC). In the program's first round, 700 villages put forward proposals yielding approvals for 5,000 children. To expand the program, KHPT has been providing technical support to the State Institute for Health and Family Welfare (SIHFW) to roll out the Training of Trainers (TOT) for the State's remaining AWWs and ASHAs. The transfers average 500 Rupees (Rs.) per month, with a maximum benefit of Rs. 800 per month or Rs. 9,600 per year. The Cash Transfer money can be used for basic necessities including food, educational support, foster care, and medical care.

Program Questions

In the Karnataka Cash Transfer studies, our goal is to answer the following questions:

Phase 1 What are the components of the Karnataka Scheme?

Phase 2 Given the Cash Transfer targeting strategy in Karnataka, which children are included and excluded and what are their comparative needs?

Phase 3 How do Cash Transfer beneficiaries and non-beneficiaries compare with regards to child health, wellness and development?

This report will present the results of Phase 1.

Methods

In July 2011, Dr. Candace Miller conducted interviews for two weeks in order to document the key aspects of the Karnataka Cash Transfer Scheme. The research activities included key informant interviews and focus group discussions with stakeholders at the national, district, and village levels. Dr. Miller met with representatives from KHPT, the Directorate at the DWCD, District Executive Officers and Deputy Directors of DWCDs, Child Development Program Officers, Gram Panchayats, workers from Voluntary Counseling Centers, Village Health and Sanitation Committees (VHC or VHSC), AWWs, ASHAs, ANMs and their

supervisors and KHPT link workers. Key informant Interviews and Focus Group Discussions took place in Bangalore, Mysore, Hubli/Dharwad and Bagalkot. The interview questions included: program design, implementation activities, the targeting strategy, delivery mechanisms, frequency and level of benefits, scale up plans, sustainability, linkages to other programs, and other implementation issues. Findings will be used to assess program quality, sustainability and provide information for further scale up.

Design and Targeting

The Karnataka Cash Transfer provides cash to families to support OVCs that are infected or affected by HIV. The program compliments the Integrated Child Development Service (ICDS) developed by the Ministry of Women and Child Development (MWCD). With the cash scheme, ART clinic lists are used to identify eligible children (other programs rely on people seeking out benefits).

Community level front line workers conduct Family Health Assessments. Once families are identified and assessed, Village Health Committees (VHC), Gram Panchayats, Child Development Program Officer (CDPO), DWCD, and finally, the Executive Officer approve the households. Next, funds are released to Districts by the WCD Directorate at the State, and transferred to CDPOs and VHCs to be deposited in recipients' accounts.

The Karnataka Cash Transfer is targeted to households with children aged 0 to 18 years who are infected or affected by HIV/AIDS. Additionally, the child and family must be in need of cash support. Families do not have to show a "Below Poverty Line" (BPL) certificate because it is often a difficult and lengthy process to obtain these certificates. Households will be re-assessed annually to determine ongoing need. However, in order to be considered during the first Family Health Assessment, the family must have been registered with an ART clinic. Families must consent to home visits and allow the community worker to do the

assessment. If a child is affected by AIDS, but not registered with the ART clinic, they will not be assessed.

Benefits

The cash benefit of the Karnataka Cash Transfer was set in 2009. Families may receive up to Rs. 800 per month per child. The Foster care benefit, which is cash to a household caring for a non-biological orphan, is Rs. 750. The Sponsorship benefit, which is cash to a household caring for their own child (such as by the biological mother or father or grandparent) is Rs. 650. Families may also receive cash for nutrition, education, and housing. However, the per child total benefit may not exceed Rs. 800 per month per child. The AWW, ASHA or ANM worker determines the amount of money during the Family Health Assessment process.

Implementation

The implementation of the Cash Transfer Scheme includes the following activities: 1) Ongoing sensitization of District and Community officers (Executive Officer, District Officials, etc.) 2) Training of ASHA, AWW, ANM, CDPO, Village Health Committees and Gram Panchayat (GP)) 3) ART Centers provide family names to WCD 4) AWW, ASHA and ANM complete family health assessments; build rapport with families; link to other services 5) CDPO, GP, DWCD, and Executive Officer sign off on assessments 6) Money transferred to districts 7) Households receive cash in accounts and 8) Regular auditing of district accounts.

Current Operations

While many districts and talukas have completed the Family Health Assessments, by July 2011, the funds only began to reach the first set of beneficiaries in September. Money had been delayed at the DWCD level as CDPOs waited for official directions on how to disburse funds. The scale up of the Cash Transfer Scheme could also be hampered when ART centers are hesitant to give client lists to government. The ART centers worry that it would be a breach

STAKEHOLDER	CONCERNS
State Government	One major advocate involved from beginning; without Deputy Director WCD, program is at risk
Executive Officers and District Officials	Responsible for 30-60+ other programs; if not sensitized, will not support
Zilla and Gram Panchayat	Supportive of program; could possibly take on financing in future if impact is positive; sensitization needed in new Talukas, Districts
CDPO	Concerns about releasing cash; Not sure how to monitor program
Village Health Committee	(Often same as Gram Panchayat); Have many programs; this is relatively small; Also not clear how to monitor program
AWW, ASHA, ANM	Have other responsibilities; low pay, need ongoing sensitization;
KHPT	Provided ongoing Technical Assistance but USAID funded Samastha Project has ended, leaving major gap in implementation technical expertise

of confidentiality to give client lists to the DWCD department, despite the fact that families would receive benefits.

Ongoing Activities

The need for sensitization of EOs, Gram Panchayats, CDPO, Village Health Committees, AWW, ASHA, and families is ongoing given the election cycle and employee turnover. Again, sensitization action plans have been developed for some talukas. Still, capacity building and technical assistance was universally requested by the DWCD in order for them to fully and effectively implement the scheme.

Scale up of Cash Transfer

If the Karnataka Cash Transfer is to be scaled up throughout Karnataka, NGO technical assistance is required throughout the 14 districts where the program has been launched and more especially in the 16 outstanding districts. Stakeholders universally agree that there will be an important gap without KHPT providing technical assistance and support. Specifically to scale up throughout Karnataka, the Cash Transfer must be expanded to include 30 Districts, which contain 27 Zilla Panchayats, 175 Taluka Panchayats, and 5,659 Gram Panchayats.

Additionally, several problems must be overcome, such as Cash Transfers being delayed in some districts because some District Officers are still unsure of the program, the EO or Deputy Director WCD is still requesting a letter from the WCD Directorate at the state level to proceed, and CDPOs must be instructed to release funds. Nevertheless, funding for the Cash Transfer is available through state government so hopefully the implementation and scale up challenges will be overcome.

Monitoring and Evaluation

During the interview period in July 2011, the program had just been launched and there were no monitoring and evaluation activities under way, nor had an M&E plan been developed. The Districts do ¼ to ½ year financial audits, but these do not encompass program or beneficiary monitoring. Ideally, a monitoring system will be articulated where activities and beneficiaries are frequently monitored, and problems are flagged so that they can be addressed swiftly and early. An adequate monitoring system can ensure that program activities are implemented and impacts are achieved. Implementers can 'course correct' before the Cash Transfer Scheme gets far off

track. At the community level, AWW, ASHA, ANM and VHC members are willing to monitor, however with low capacity for monitoring and using data to course correct, training and technical assistance is essential.

Technical assistance and capacity development are essential to help build an M&E system for the Karnataka Cash Transfer Scheme: (a) to train all AWW, ASHA, ANM, VHC, District WCD officers, and (b) to manage and utilize monitoring data.

Impacts

It is still unclear what the program impacts will be given that the program has just been launched and only recently have children and families been receiving the funding. In Mysore, where families have begun to receive cash, there are anecdotal reports of families enjoying improved nutrition (including high quality proteins and dairy), improved ability to send children to school, improved health, confidence that they will have a "good life", and concerns over confidentiality and disclosure of the child or family members HIV status.

SWOT Analysis

Strengths

The Karnataka Cash Transfer Scheme has many important strengths including the following: First, the Karnataka Government wants this scheme to continue. There is a nearly universal perception that fraud and corruption are unlikely because of many bureaucratic layers. The policy option is child-friendly whereby children remain at home without any sibling separation. Stakeholders believe the program design will help maintain the dignity of the child and family because the HIV status does not have to be disclosed at the community level and families do not have to beg for assistance. Community workers identify families within villages who often do not come forward on their own. Moreover, the scheme has been community driven with a bottom up design and ongoing

community consultations. Finally, the Karnataka Scheme is evidence based, drawing upon cash transfer literature. Stakeholders explored policy alternatives and then designed this program and made adjustments to the design as needed.

Weaknesses

The Karnataka Cash Transfer Scheme also has weaknesses that must be addressed. Still, despite ongoing efforts, there is a high level of sensitization required for community workers, elected officials, and district officers. The Karnataka Cash Transfer Scheme may lead to HIV disclosure, stigma, and discrimination if information is not handled confidentially. Also, there are many layers of approvals necessary, which may reduce corruption, but could also cause bureaucratic delays. Additionally, the community workers (AWW, ASHA, and ANM) have limited education, low pay, and many competing responsibilities so their ability to prioritize or simply carry out activities for this program, without incentives, may be limited. Moreover, the children from families that are not registered as ART center clients may be overlooked despite their needs. Another issue is that the Karnataka Cash Transfer Scheme is implemented slightly differently across districts, which may yield differences in the quality of implementation. The Scheme may soon need updating as the Family Assessments were completed and the transfer value set in 2009 without subsequent updates despite the evolving situation of families.

Opportunities

Once the Karnataka Cash Transfer Scheme is operating effectively, it could be expanded to include all OVC and all children in need. Every AWW, ASHA, ANM and VHC member knows of additional children in community needing a transfer too; however if children do not meet the program guidelines they are not currently included. Still, in the future, this program could link well with all other programs to ensure comprehensive support to all children in need, while avoiding duplication and exclusion. The Scheme utilizes a well-designed assessment

procedure with community input so this process can be replicated and utilized for other coordinated programs. Additionally, if implemented well, it could reduce HIV stigma.

Threats

The threats to the Karnataka Cash Transfer Scheme include the fact that stigma and fear of disclosure may keep families from joining the scheme. One suggestion is to broaden the scheme for all orphans (OVC implies HIV) to reduce HIV stigma. Of course, framing the transfer for "all orphans" means more children and families will be eligible, creating budgetary implications and possibly concerns about the program size. Another threat is that if AWW, ASHA, ANM are not well trained, they will not utilize the program. Finally, if lack of awareness and sensitization of program persists, the risk of abandonment is real.

Research and Evaluation Questions

Several research and evaluation questions should be answered as the program is launched and scaled up. For example, 1) Will all eligible children be identified? What are the errors of inclusion and exclusion? 2) How much money will reach families? 3) How will families use money? 4) What are short and long term impacts of cash within families and communities?

Committed Communities Development Trust: Integrating Home-Based and Residential Care and Support in Mumbai

Background

Maharashtra is one of the Indian states hit hardest by the HIV/AIDS epidemic, with NACO estimating prevalence at 0.50% among pregnant women and 18% among women in prostitution (WIP). There are no official national or state estimates of the number of children orphaned by HIV or the number of children infected or affected; however, UNICEF has estimated that 4 million children in the country (concentrated in high burden states) are affected by HIV. And a 2008 study estimates that 40% of HIV-positive children in Mumbai are orphans. In response to this crisis, Committed Communities Development Trust (CCDT) has been providing care and support to families and children affected by or at risk for HIV/AIDS in Mumbai since 1995. Their approach is multi-faceted and community-based: focused in equal parts on filling health and social services gaps, stigma reduction, community development, and advocacy within some of Mumbai's most vulnerable communities. This study set out to document the care provided to vulnerable children living in CCDT's 4 residential crisis intervention centers (CICs): Ashray, Aakaar, Ankur-Asmita, and Umang.

Overarching Objective

Describe the needs of children, the care they receive, and the evolution of CCDT's care and support services over the last twenty years. The analysis looks at factors contributing to successes, challenges, and the organization's strategic vision. It will also recommend next steps for evaluating program effectiveness and cost in order to establish evidence-based best practices.

Methods

Our approach to documenting CCDT's residential care is a hybrid process evaluation and narrative analysis. It is a process evaluation to the extent that it sets out to answer the questions: What is done? When? By whom? To whom? And it is a narrative analysis in that it weaves together disparate sources, anecdotes, perspectives and personal histories to tell the story of this organization's strategic vision and programming over the last fifteen years and their current and future objectives.

Data Collection

Three types of primary data were collected and analyzed: 1) qualitative data from in-depth interviews with CCDT staff conducted in February and June 2011; 2) de-identified child case management records, 3) de-identified child health care files. The key limitation of the study is that we did not speak to children and parents; thus, we are not able to assess effectiveness. Rather, this analysis provides a foundation upon which to design an impact evaluation strategy.

Site Visits

We designed a semi-structured questionnaire and conducted in-depth interviews with CCDT program staff working in the four CICs, integrated community development projects, and headquarters. The instrument asked questions about: the genesis and changes over time of programming for vulnerable children and families; services provided; successes and challenges; strategic vision and plans for future programming.

Record Review

Case records[i] were reviewed for 25 children associated with the 4 residential crisis centers for at least 3 years. Documents[ii] related to health care services at Ashray were also reviewed.

Literature Review

We also reviewed best practice and minimum standards guidelines for children living in residential and other alternative care in multiple contexts.
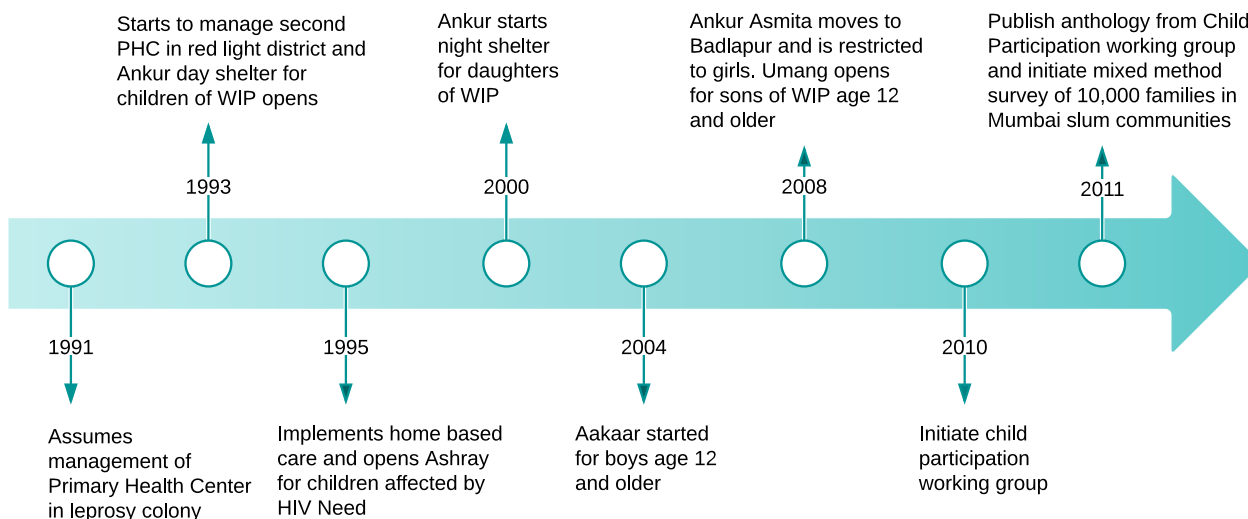
Committed Communities Development Trust: History and Mission

Ashray, CCDT's first residential care center, was initiated in 1995 as an extension of the organization's home-based care (HBC) programming. HBC staff providing care and support in the community quickly began to see that HIV was pushing already-vulnerable families into extreme crisis, causing them to spiral into further poverty and marginalization. The objective of Ashray and Aakaar (initiated in 2004 as an extension of Ashray for older boys) is to provide temporary residential care to children infected and affected by HIV/AIDS living in highly vulnerable situations (parents dying or recently dead, homelessness, child illness, etc). Two other CICs, Ankur-Asmita and Umang, provide residential care to children of women in prostitution (WIP). The children and youth in the CICs sometimes have HIV in their family, but HIV is not always the reason for their vulnerability. They are identified as in crisis by community outreach workers or partner organizations working in the red-light district. A brief overview of CCDT's history is presented in the timeline below, Figure 1.

F1 **CCDT HISTORICAL TIMELINE**

1993	Starts to manage second PHC in red light district and Ankur day shelter for children of WIP opens
2000	Ankur starts night shelter for daughters of WIP
2008	Ankur Asmita moves to Badlapur and is restricted to girls. Umang opens for sons of WIP age 12 and older
2011	Publish anthology from Child Participation working group and initiate mixed method survey of 10,000 families in Mumbai slum communities

1991	Assumes management of Primary Health Center in leprosy colony
1995	Implements home based care and opens Ashray for children affected by HIV Need
2004	Aakaar started for boys age 12 and older
2010	Initiate child participation working group

Crisis Intervention Centers/Residential Care

This section describes the pathways from crisis to residential care taken by the children living in CCDT's crisis intervention centers.

Children Infected and Affected by HIV/AIDS (Ashray and Aakaar)

In the 16 years since it started, Ashray has provided care to over 160 children, including girls up to age 18 and boys up to age 12. By law, boys age 12 or older cannot live in an institution with younger children or girls of the same age. Therefore, Aakaar was designed as a residence for HIV-infected and affected older boys living in Ashray. According to CCDT staff, Ashray and Aakaar remain the only residential care facilities in Maharashtra that accept both HIV-infected and affected children and youth.

From CCDT's perspective, residential CICs are a necessary, temporary safety net for the families enrolled in their home-based care programs. As articulated by one staff member:

HBC and residential care go hand-in-hand. Residential care is a necessary option for some families in extreme crisis, especially as their vulnerabilities are compounded by HIV, other illness, parent death, inability to work, etc.

The goal of the organization is to help fragile families stabilize after a crisis and to reintegrate every child back into the community as soon as it is in the child's best interest. For each child taken into care at any CCDT residential center, the organization works with the family to develop a plan and objectives for the child's care and a timeline for reintegration. These plans are revisited periodically and objectives and timelines are adjusted based on the family's situation, the child's needs, and whether or not the crisis has been resolved. CCDT collaborates with the Child Welfare Committee during the admission and reintegration processes. Those children who are double orphans and have no extended family willing to take them may remain in CCDT's care until early adulthood, with CCDT

To be in CCDT, you are working directly with the children. My great work is to be with the children. Some of these children when they arrive have forgotten how to smile. We cannot have 100% outcomes, but to help 3 or 4 children reunite with their families and become healthy and happy is a reward. I see no difference between the children here and my own son. He is the same age as many of them, and has grown up knowing them.

designated as their official guardian. This is the case for many of the older girls at Ashray and many of the boys at Aakaar.

Children of Women in Prostitution (Ankur-Asmita and Umang)

The objective of CCDT's work in Kamathipura, the largest red-light district in Mumbai, is to reduce vulnerability faced by children due to their mother's profession and the high-risk brothel environment in which they live. From 1999 to 2011, CCDT also ran the Roshni Drop-In Center for WIP, which provided health care referrals, food assistance, group support, peer education, and more. Children were referred to Ankur and Umang through the Roshni project prior to its closing. Now they are referred through partner organizations working in the community (including law enforcement), and a CCDT outreach worker who is in the community several times a week.

As with Ashray and Aakaar, staff at Ankur and Umang strive to reintegrate youth into the community but only when the situation is stable and their mother is no longer living in Kamathipura. Children whose mothers remain in Kamathipura, are sometimes placed with willing extended family living in stable households outside of the red-light district. Because family reintegration is often contingent on a mother leaving the brothel, the youth at Ankur and Umang tend to stay longer, often until they are 18.

Care Provided: Priorities and Processes

Child care within CCDT's crisis intervention residential centers is structured around case management, with social workers playing the central role in understanding the child's needs, planning objectives for their time in residential care, and organizing other necessary services in conjunction with housemothers, program officers, and senior management. Health care and education are particular priorities. Many children enter Ashray in poor health and significant resources are directed at helping them to achieve physical, nutritional, and emotional stability. Likewise, education is a primary emphasis as it is seen to be fundamental to each child's ability to develop a profession, earn a living, and live independently. Therefore a great deal of energy and staff time is devoted to getting children into the most appropriate schools, overseeing academic achievement, assisting children in their studies, and helping adolescents to think about appealing, feasible professions and planning a course of study accordingly. CCDT's approach to care is individualized to each child's needs, while simultaneously being structured around the organization's key child care priorities.

T1 KEY CHILD CARE PRIORITIES
• Restoring emotional and physical stability
• Health care
• Nutrition
• Education
• Life skills education
• Case management
• Family and community reintegration
• Assistance to young adults entering the work force and community life after growing up in residential care.

Strategic Vision and Advocacy

While home-based care and crisis intervention residential care are central to CCDT's mission, care and support are only one piece of the organization's scope of activity and long-term vision. CCDT's human-rights-based agenda includes the following priorities and activities: (1) Integrated community development; (2) Advocacy at the local, state, and national level; (4) Research to better understand population needs, and (5) Training of staff, government, and other relevant stakeholders.
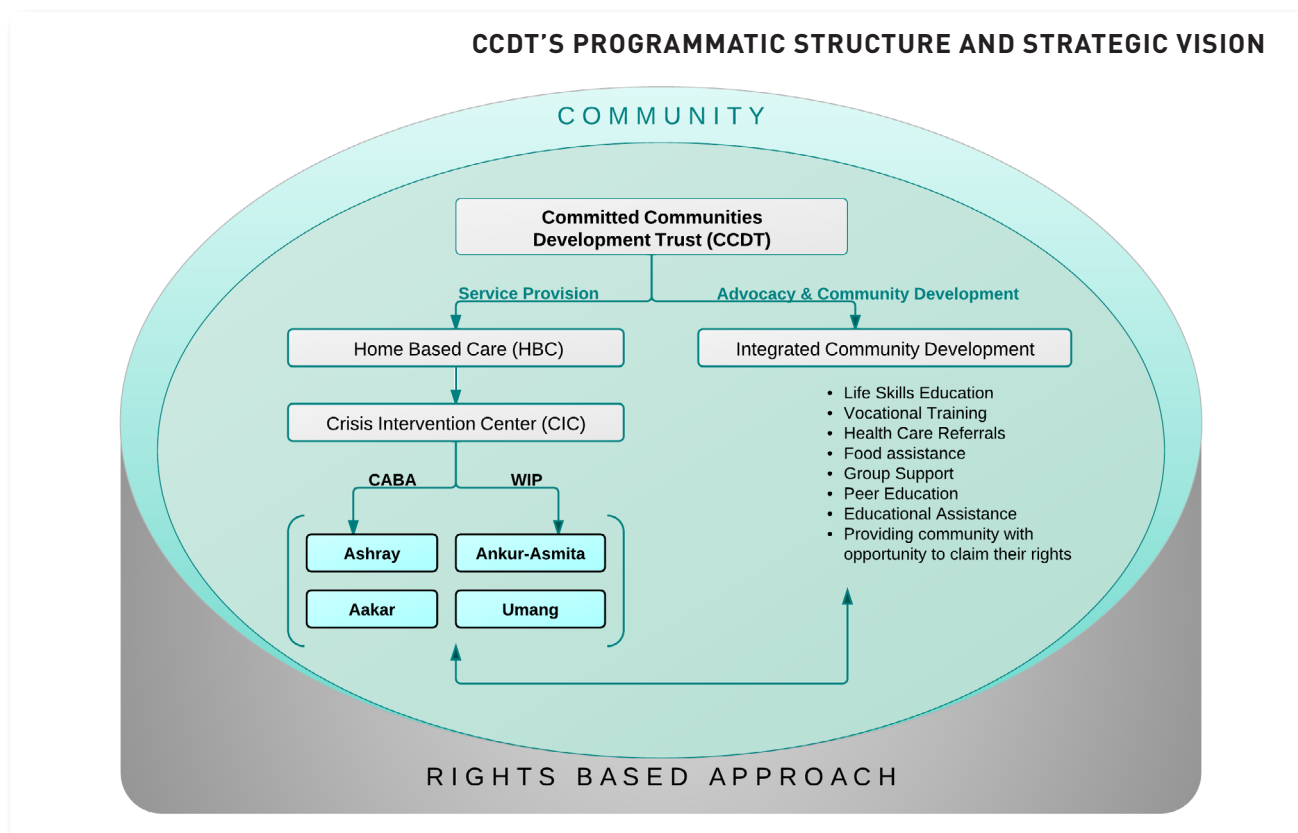
> **CCDT'S vision:**
> *A world where every child is ensured of her or his rights, and lives in dignity.*

Human Rights Approach

CCDT's mission has been focused from its earliest days on helping marginalized children, adults, and communities to improve their health and economic situation, understand and demand their rights, and participate in civil society and governance. Throughout, their commitment has been in equal parts to service provision, family and community strengthening, and rights-based advocacy. This advocacy has taken many forms: caring for both HIV-positive and negative children at Ashray and Aakaar (rather than isolating children based on their serostatus); addressing stigma with service providers and within the community; demanding better public care and support services for OVC and HIV-impacted families; helping children grow into adults equipped with the skills and knowledge to demand their rights.

Care and support have been happening in parallel with the organization's integrated community development work but not necessarily in tandem. The organization's strategic challenge and goal is, therefore, to more fully integrate their care, support, and advocacy for individual children and families within their broader objective to strengthen

CCDT'S PROGRAMMATIC STRUCTURE AND STRATEGIC VISION F2

COMMUNITY

Committed Communities
Development Trust (CCDT)

Service Provision   Advocacy & Community Development

Home Based Care (HBC)   Integrated Community Development

Crisis Intervention Center (CIC)

- Life Skills Education
- Vocational Training
- Health Care Referrals
- Food assistance
- Group Support
- Peer Education
- Educational Assistance
- Providing community with
  opportunity to claim their rights

CABA   WIP

Ashray   Ankur-Asmita

Aakar   Umang

RIGHTS BASED APPROACH

civil society capacity within the community. They acknowledge that the sheer size of the population in need in the communities where they work is much larger than their capacity to provide care and support. As illustrated in Figure 2, the service provision arm of CCDT's programming exists on a parallel track with their community development work. The arrow at the bottom depicts their current focus on integrating the two into a cohesive effort. The figure also illustrates CCDT's integration within the larger community and how their entire model is grounded in their rights-based approach.

Integrated Community Development and Advocacy

CCDT will continue to fill the need where they can and offer residential care for the children who come their way who are in the greatest need. However, their objective is now equally focused on strengthening community support systems, facilitating an environment where families and the broader community can better protect the rights of children. While the ultimate goal is to reduce and even remove the need for residential care, the more immediate critical need is to build capacity

within civil society to advocate for government to provide for the needs and rights of children and families. CCDT is also advocating for government to guarantee the right to education, acknowledge the right to health, improve basic housing and sanitation, and ultimately provide care and support to those families and children with the greatest need.

CCDT engages in advocacy through:

- Participating in multiple policy forums focused on HIV/AIDS, the right to education, patient rights, street children's health, child exploitation, child labor, and monitoring of special homes for vulnerable children;

- Collaborating with other service providers and government to develop and implement policy and programming in a number of areas including after care/group homes and child participation;

- Reducing stigma and discrimination among health care and other service providers and within the community

Research

CCDT is engaged in population-based research as a form of advocacy. For instance, in 2011 they initiated a mixed methods survey of 10,000 families in slum communities where they work to gather baseline data against which to measure the effectiveness of their programming and to support advocacy efforts calling for policy change.

Training

CCDT provides continuous training and professional development for organization staff as well as training for government, service providers, and community members on stigma, child participation, and other topics.

Challenges to Providing Residential and Community-based Care to Children Affected by HIV/AIDS

Key social challenges cited by CCDT staff to achieving service and community development objectives include:

- Complexity of reintegration for children into families;

- Difficulties faced by young adults in transitioning into independent community life after growing up in residential care;

- Barriers to finding appropriate schooling due to frequent sub-standard quality of education in the public school system and stigma within private schools barring entrance for HIV-positive children;

- Lack of government entitlements to health and food security;

- Lack of a government sponsored foster care system;

- Few residential vocational placements for slow learners who are HIV-positive;

- Few suitable residential placements for boys age 12 and over;

- Need for greater government attention to and funding for care and support programming for families and children affected by HIV/AIDS;

- Unsubsidized second-line ART for HIV+ children.

The HIV+ older children are asking questions about getting married and having children. These are nice questions. We tell them that these things are possible but that they must do certain things first. They need to tell their partner about their status before having sex and they need to be prepared for that person's reaction to the information. Then before they start thinking about marriage they need to finish school, start working, and start saving money to buy a small place to live.

Analysis of Organization Strengths and Limitations

How does CCDT measure up against established best practices for providing "alternative care" and residential care for children in crisis, supporting extremely vulnerable families and helping them to stabilize, and reintegrating children into their families and the community? Due to the limitations of process evaluation and program documentation, we cannot yet answer this question either quantitatively based on measurement of inputs and outcomes or qualitatively based on interviews with children and parents. We believe that the findings from this study provide a necessary foundation for a rigorous mixed-methods program evaluation as a next step. Below we look at the findings from the staff interviews and record review through the lens of India-specific and international guidelines for providing residential care:

- **Standardizing the Minimum Standards of Care for Children Orphaned by AIDS, Under Institutional Care (2010):** Based on meetings organized by the Community Health Education Society and UNICEF, is comprised of recommendations from 14 heads of organizations running homes for orphaned children in India. Aside from CCDT's own publications, it is the only India-specific guidance we were able to find on residential care for children affected by HIV/AIDS.

- **United Nations Convention on the Rights of the Child (1989).**

- **United Nations Guidelines for the Alternative Care of Children (2010):** Fills gaps in the UN Convention on the Rights of the Child (UNCRC), which recognizes that some children are in need of permanent or temporary alternative care outside of their family environment but does not offer clear guidelines for such care.

Strengths and Limitations

Long before the India-specific minimum standards cited above and the UN Guidelines for Alternative Care, multiple internal and external program documents articulate CCDT's commitment to rights-based family-centered care. CCDT started in the era of the Convention of the Rights of the Child and has, throughout its history, sought to provide care and support to vulnerable children and families in line with the rights outlined there. Evidence of their organizational philosophy is detailed in Positive Caring Involves a Balance of Heart and Mind, a 2007 charter outlining the components of care provided at Ashray and Aakaar. (See Table 2 for excerpts.) The language of these self-imposed terms of service is closely aligned with that found in the UNCRC and the UN Guidelines on Alternative Care.

In general, the India-specific minimum standards are focused on the necessary functions, facilities, staffing, and training within residential centers for children affected by HIV/AIDS. Of note, these guidelines describe the quality of residential care for children affected by AIDS in India as broadly falling into one of three categories:

1. Those that violate the rules, neglect or abuse the children, and have no right to exist.

2. Those that are not fully reaching all the standards of an ideal home, but where the children are being taken care of, and some standards are being maintained.

T2 EXCERPTS FROM CCDT'S POSITIVE CARING INVOLVES A BALANCE OF HEART AND MIND

- Will be given privacy and assured confidentiality when receiving counseling, personal care, and treatment. His/her status will not be disclosed unless in the best interests of the child concerned;

- Will be given medical care in accordance with the minimum standards of care stipulated by WHO and guidelines of the State Department of Women and Child Development;

- Will be given explanations in simple non-threatening and easily understood terms on why he/she is being placed in the centre. This will ensure the that the child/children being admitted to not feel abandoned or rejected;

- Will be given space to express his/her own individuality: i.e, to be alone/private when in the mood to be away from the group but never having to feel 'alone' and 'left out';

- Will be encouraged and supported in the rights to give a child's views on decisions at the centre that affect quality of life. Weekly meetings of staff with children will provide a platform for this;

- Will involve the child (depending on age and understanding) together with the living parent in making long-term rehabilitation plans;

- Will not suppress the children in the false notion that absolute obedience and silence denote good behavior. This will only result in an oppressive atmosphere in the centre.

3. Those that are being maintained in an ideal fashion. These homes can serve as models for others who are trying to run homes for children. The people running these homes can also train others who are running homes.

> *When you work with children, you need to be able to catch subtle cues that each child gives about what he needs and wants, and whether he is happy and feeling healthy.*

Based on the information we collected from staff, child records, and other program documents, we see CCDT as falling squarely into the third category. This is not to say that their programming does not have limitations; indeed it does. But the primary limitations we found were not related to the quality of care and support provided to children and families. Rather, the following recommendations are focused on gaps in record keeping and cost assessment that CCDT will need to fill in order to develop a clearly documented model of family-centered, rights-based care and support for vulnerable families and children to share with government and other stakeholders as a potential model for best practices.

Next Steps for Evaluation and Further Documentation

1. **Undertake mixed methods program evaluation measuring program inputs and short and long-term impacts of children and families.** The survey of 10,000 families living in CCDT's catchment communities will provide a useful baseline to understand the needs of the communities against which they can attempt to measure the impacts of their integrated community development programming. But, in order to measure outcomes, CCDT can also design indicators of interest for their care and support programming and begin to collect routine data from the families and children receiving their home-based and residential care at intake and then periodically while they are receiving services.

2. **Revise routine case management data collection to more uniformly document each child's strengths, perspective, and the process by which care decisions are made.** The limitation of the current system is that scattered anecdotes are buried in a great deal of repetitive information about the child's particular challenges or misbehavior. These gems, combined with the in-depth staff interviews, lead us to believe that the child-focused, strengths-based care being provided

to children is not being recorded adequately. The gaps in the individual records point to a process that likely relies heavily on the memories of staff and their intimate knowledge of families (only a small amount of which is recorded). The challenge of acting on this recommendation will be to create a record keeping system that is strengths-based and more comprehensive but feasible and, ideally, easier to maintain than the current one.

3. **Analyze program cost to better understand those factors that affect total, fixed, and variable costs of program implementation.**

4. **Undertake cost-outcome evaluation to help stakeholders at all levels better appreciate the resources needed to achieve improvements in child health and well-being.**

5. **In collaboration with other NGOs and government, define specific and measurable best practices/minimum standards for use by public and private OVC residential crisis intervention centers to inform programming and against which to assess service quality.**

Notes

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4. The Effectiveness of an Integrated Care Model Drop-in Center (DIC) in Improving Access to Services and Selected Social and Health Outcomes of Orphans and Vulnerable Children (OVC) in Maharashtra

i   Most specific to our study needs were: DIC line listing, master register, counseling register, referral register, home visit register, self-help group register, death register, and outreach worker daily diary.

ii There is this slight discrepancy because the total possible ties between period 1 and period 2 are slightly, but not significantly, different due to respondents being new employees (working with an organization for less than one year) and not knowing the relationships with other organizations in period 1. Since the number of relationships remained the same, while the denominator increased, it appears that there was a decrease in ties in period 2 for Nagpur which is not the reality.

6. Committed Communities Development Trust: Integrating Home-Based and Residential Care and Support in Mumbai

i   Case records document individual children's intake, history, medical status, school performance, and observations from social workers, counselors, and housemothers.

ii This includes medicine stock register, ART book, ART register, Ashray Children's Medical register, Ashray Children's Record, hospital visit register, lab register, nutrition support file, bed wetting counseling file, individual counseling file and group counseling and ART group sessions file.

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"Children are living beings - more living than grown-up people who have built shells of habit around themselves. Therefore it is absolutely necessary for their mental health and development that they should not have mere schools for their lessons, but a world whose guiding spirit is personal love."

- Rabindranath Tagore

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