DOCUMENTATION OF THREE PROGRAMS PROVIDING FAMILY-CENTERED SUPPORT TO MOST-AT-RISK POPULATIONS (MARP) AND THEIR CHILDREN: UKRAINE, VIET NAM, ZAMBIA

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Documentation of Three Programs Providing Family-Centered Support to Most-at-Risk Populations (MARP) and Their Children: Ukraine, Viet Nam, and Zambia

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<th>Acronym</th>
<th>Definition</th>
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<tbody>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral Medications</td>
</tr>
<tr>
<td>BMI</td>
<td>Body Mass Index</td>
</tr>
<tr>
<td>CDC</td>
<td>US Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CHBC</td>
<td>Community and Home-Based Care</td>
</tr>
<tr>
<td>FHI</td>
<td>Family Health International</td>
</tr>
<tr>
<td>HBC</td>
<td>Home-Based Care</td>
</tr>
<tr>
<td>IDU</td>
<td>Injection Drug User</td>
</tr>
<tr>
<td>IRF</td>
<td>International Renaissance Foundation</td>
</tr>
<tr>
<td>MARP</td>
<td>Most-at-Risk Population</td>
</tr>
<tr>
<td>MTCT</td>
<td>Mother to Child Transmission of HIV</td>
</tr>
<tr>
<td>MSM</td>
<td>Men Who Have Sex with Men</td>
</tr>
<tr>
<td>NASF</td>
<td>Zambian National AIDS Strategic Framework</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
</tr>
<tr>
<td>OI</td>
<td>Opportunistic Infection</td>
</tr>
<tr>
<td>OPC</td>
<td>Out-Patient Clinic</td>
</tr>
<tr>
<td>OSI</td>
<td>Open Society Institute</td>
</tr>
<tr>
<td>OVC</td>
<td>Orphans and Vulnerable Children</td>
</tr>
<tr>
<td>PLHIV</td>
<td>People Living with HIV/AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
</tr>
<tr>
<td>ST</td>
<td>Substitution Therapy</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
</tr>
<tr>
<td>SW</td>
<td>Sex Worker</td>
</tr>
<tr>
<td>UFPH</td>
<td>Ukrainian Foundation for Public Health</td>
</tr>
<tr>
<td>UTH</td>
<td>University Teaching Hospital, Zambia</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counseling and Testing</td>
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</table>
Executive Summary

Overview
In a 2010 literature review, researchers from the Boston University Center for Global Health and Development found little evidence describing the physical and mental health, educational achievement, specific vulnerabilities, and sources of resilience of children whose parents are most-at-risk for HIV infection (MARP) (1). Documentation and evaluation of programs and interventions that provide services to MARP and their children were also largely unavailable.

In an effort to address this gap and learn more about these families, we partnered with three organizations providing services to one or more most-at-risk populations and their children. Findings are presented from Tasintha (a grassroots organization in Zambia providing services to sex workers and their children), and from HealthRight International Ukraine and Family Health International, Viet Nam (both large international NGOs working with local partners to provide services to drug users and their children). This report documents the history of the programs, activities and services offered, implementation challenges, and promising practices.

Background
Viet Nam, Ukraine, and Zambia represent three very different HIV epidemics and three different adult risk group profiles. In Viet Nam and Ukraine, the epidemic has, for the most part, been limited to specific vulnerable groups. In Viet Nam, male intravenous drug users (IDU) and their female partners, male and female sex workers, and men who have sex with men (MSM) are especially vulnerable. In Ukraine, the epidemic is concentrated among male and female IDU, prisoners, sex workers, street youth, and MSM. In Zambia, HIV prevalence is much higher (13.5%), and, though concentrated within at-risk groups, is also widespread throughout the general population.

An overlooked, associated population that may be at considerable risk for HIV are the children of the adults who fall into one or more of these groups. Their risk for HIV can be biological through mother-to-child transmission or environmental, but HIV is not the only potential vulnerability they face. Few data are available on the number of children whose parents are MARP, and very little evidence (beyond anecdotal) is available describing their needs.

Methods
The three partner programs documented within this report were first identified as we conducted the literature review mentioned above. We contacted program staff at each of the three organizations through professional networks and posed preliminary questions about the needs and services being provided to vulnerable families. All three organizations were immediately responsive to our queries and agreed to partner with Boston University to share their knowledge and experience.

Program site visits were conducted at Tasintha, HealthRight International, and Family Health International. During these visits, we interviewed program staff as well as staff at partner organizations and donor agencies using a semi-structured in-depth interview guide developed in collaboration with USAID. The instrument asked questions about the genesis and changes over time of programming for children of MARP, about population needs and specific vulnerabilities and sources of resilience, services provided, successes, challenges, and future programming plans.
**Program Information and Child Needs**

**HealthRight International, Ukraine**
In 2008 MAMA+ for IDU was launched in Kyiv to focus on the special needs of HIV-positive female drug users who are pregnant or new mothers. The program operates on a comprehensive case management social work model, with a focus on the special needs of drug users for addiction counseling, rehabilitation services, and substitution therapy. The primary objectives of the program were: 1. early identification of HIV-positive, pregnant IDU; 2. provision of support, home visits, substitution therapy, and work with families; 3. referrals for additional medical and social assistance; 4. creation of peer support groups; 5. advocacy among state and private sector organizations to support the piloted approaches.

Respondents noted that children whose parents are active IDU are at greater risk for poor care, neglect, abuse, under-nutrition, and more. But they also stressed that there are some situations in which drug use does not negatively affect a child’s wellbeing. The consensus among program and partner staff seemed to be that stabilization on ART and substitution therapy or drug rehabilitation are the basic necessary conditions for a healthy parent-child relationship. Children are also often cared for by grandmothers and extended family, and these home situations can be positive or negative, depending on a number of other family dynamics. Alcoholism is common in many poor homes, pushing children, teenagers, and young adults to leave home, with the result that an estimated 30,000 to 150,000 live on the streets or in abandoned buildings or basements in the winter (2). Avoiding a future generation of children born to young, homeless mothers is the focus of much of the organization’s current work.

**Family Health International, Viet Nam**
In 2005, FHI began funding the provision of needed services to HIV-positive adults utilizing a continuum of prevention and care approach. This involved establishing HIV out-patient services embedded in district hospitals with linked community and home-based care teams and PLHIV (people living with HIV) support groups. Services were extended to children beginning in 2006. Currently, both populations are automatically served as soon as a family member is found to be HIV-positive at one of the participating outpatient clinics. This is done through a combination of clinic and home-based services including primarily voluntary counseling and testing, prevention of mother to child transmission, antiretroviral therapy, opportunistic infection treatment, palliative care, social support services, and adherence counseling.

The situation of families in which affected and infected children live varies, though poverty, often extreme poverty, is a consistent theme. Respondents reported that some degree of instability in the home is inevitable when the father is an active IDU. The most typical scenario is that he is frequently absent and the child is being raised by the mother, who is struggling to keep the family together and provide for basic needs. IDU are often incarcerated in rehabilitation centers, with stays ranging from two to five years. In the south, due to the large migrant population, many families lack adequate housing. Entire families may occupy one small room and be forced to move often. Aside from poverty and lack of adequate shelter, children also face other major vulnerabilities including stigma, food insecurity, psychosocial distress, and difficulty accessing health care.

**Tasintha Programme, Zambia**
Tasintha is a grassroots NGO started in Lusaka in 1992 to provide a variety of support services to female sex workers, with the overarching goal of providing women with the education and professional skills to find alternative means of income generation. Women are recruited into the program through street and
bar-based outreach. Once a woman has agreed to join Tasintha, she can receive skills training in a variety of areas that range from brick making and tailoring to auto mechanic and catering school. Other services include cash assistance, tuition support to enroll in further education, counseling, peer support groups, in-house health care for minor ailments and referrals for prevention of mother to child transmission, antiretroviral therapy, opportunistic infections, childhood immunizations, serious illnesses, etc. Over the last twenty years, more than 7,000 sex workers have participated in Tasintha programs.

Tasintha staff reported that the children of their clients can face special vulnerabilities including HIV, poverty, abuse, drug and alcohol use, dropping out of school, and taking up sex work at a young age. The primary assistance provided to children over the years has been educational support. Tasintha provides tuition and other assistance so that children can return to or remain in school, supporting them through primary, secondary, and in many cases tertiary education.

**Common Challenges Found in All Programs**

Though each of the three organizations with which we partnered is unique in terms of approach, assistance offered, and populations served, there are a number of common challenges with which they are confronted as they seek to provide services to MARP and their children:

**Funding:** While the programs vary in the degree to which they have enjoyed a stable and predictable funding source, all the programs are limited in what they can do for children due to financial constraints.

**Poverty:** The poverty that affects so many families, in addition to HIV infection, presents enormous challenges due to the complex web of issues that affect very poor client households. Program staff in all the programs mentioned the challenge of not being in a position to address the fundamental and enduring problem of experiencing HIV and other health issues in the face of extreme poverty. However, as we describe in the body of the report, program staff are often able to link clients with various government programs and services, which can play an important role in alleviating some of the worst poverty.

**HIV-related stigma and discrimination:** As highlighted above, stigma poses a major challenge in adequately and efficiently providing services to both adults and children. Fundamentally, the programs cannot remove stigma, but rather continually cope with it and try to overcome it as it relates to their clients.

**Serving MARP clients:** All the programs face inherent difficulties due to the high-risk behaviors of many of their clients. For the programs serving large numbers of IDU, the main challenge identified by staff is dealing with clients who in some cases have disabling addictions and/or priorities other than their own health needs and the needs of their children.

**Directions for Further Research**

This documentation project can be viewed as a critical first step in improving understanding of the needs of HIV-infected MARP adults and their children and the ways that different programs have been able to address these needs. Based on our findings and discussions with in-country collaborators, we recommend pursuing a number of relevant research questions that are applicable to numerous low- and middle-income countries with concentrated, mixed or generalized HIV epidemics. These are described below in two categories: evaluation research and exploratory/descriptive research.
A. Program evaluations

1. Evaluations of programs that aim to address the needs and vulnerabilities of children in order to improve our understanding of short-term and long-term impacts of these efforts. These should ideally encompass programs that serve children of different ages (<5 years, 6-11 year olds, adolescents, and teenagers) and genders. They might include rigorous quantitative studies that measure internationally recognized indicators of child well-being. They may also encompass in-depth qualitative explorations of different aspects of apparently successful programs, with a focus on collecting data from children and parents.

2. Research that examines elements of an apparently successful program, adapts and implements them in another setting, and evaluates the extent to which success can be replicated, along with reasons for success and failure. Such research can be particularly helpful in the efficient scale-up of interventions to address the vulnerabilities and needs of children affected and infected by HIV/AIDS.

3. Studies assessing program management and processes, including funding, personnel management, strategic goal-setting, and change adaptations.

4. Cost-outcome studies that help stakeholders at all levels better appreciate the resources needed to achieve improvements in child health and well-being.

B. Exploratory and descriptive studies

1. Research to shed light on the health and psychosocial needs of the children of MARP, including needs that may be related to the MARP behaviors and HIV status of the parent(s). Such efforts should focus on different ages and genders of children. This could be done using a rigorous quantitative analysis comparing children of MARP with other children, an in-depth qualitative research approach, or as a quantitative-qualitative mixed-methods study.

2. Research that involves digital archiving and qualitative analysis of detailed client social work and other narrative records. We have much to learn from small, long-running programs about the changes in the needs of MARP and their children over time (at the individual, cohort, and population level) and programming pitfalls and best practices from extant, detailed, fragile, paper-based program records.

3. Descriptive analysis of program cost—including sensitivity analysis to better understand those factors that affect total, fixed, and variable costs of program implementation.
Documentation of Three Programs Providing Family-Centered Support to Most-at-Risk Populations (MARP) and Their Children: Ukraine, Viet Nam, and Zambia

1 Overview

In a recent review of the published literature on the children of injection drug users (IDU) and sex workers (SW) in low and middle income countries, researchers from the Boston University Center for Global Health and Development found that little information has been published about children of adults most at risk for HIV (MARP) (1). We did, however, find several examples of programs providing services to these often fragile families. Staff implementing these support programs proved to be the most valuable source of information on the vulnerabilities these children face and the types of support they need. The interventions described here all began with a focus on adults but expanded their services as parents sought care for their children. This process was not automatic and took time and effort—perhaps because it can be difficult for donors to view MARP as parents, and to recognize the needs of these children as related to the vulnerabilities and behaviors their parents. The interventions may not completely meet the needs of vulnerable children but they appear to have made a positive difference in the lives of many of them.

Documentation of the initiation and scale up of these programs, the services they provide, the observed needs of children of MARP, and the challenges to service implementation proved to be minimal. Documenting existing services is a critical first step toward sharing information between programs and with a wider audience, assessing opportunities for program evaluation, developing and disseminating best practices, and scaling up and adapting successful programs to new contexts.

In an attempt to begin addressing this deficiency, Boston University partnered with three organizations that provide services to one or more most-at-risk populations and their children in three very different contexts. The specific objectives of the project were to document the history of programs (including initiation and scale up of services for both parents and children), program activities, implementation challenges, and promising practices.¹

This report presents findings from Tasintha (a grassroots organization in Zambia providing services to sex workers and their children), and from HealthRight International Ukraine and Family Health International Viet Nam (both large international NGOs working with local partners to provide services to drug users and their children). By documenting interventions implemented by organizations such as these three, we expect to be able to:

1. Draw attention to the unique needs of children of MARP in developing and middle-income countries with both concentrated and generalized HIV epidemics;

¹ This activity was requested by USAID following the literature review mentioned above. OVC CARE Project Objectives: In the last decade a global emergency response has been mobilized to assist the 145 million children orphaned or made vulnerable by HIV/AIDS. The US government, through the President’s Emergency Plan for AIDS Relief (PEPFAR), UNICEF, and UNAIDS have led the international response. As the emergency response begins to convert to a country-led, more sustainable approach focused on national capacity to continue to scale up services to reach as many children as possible, it is increasingly clear that there are significant gaps in our experience and knowledge. To fill these gaps, USAID has invested in applied, operations, evaluation, and economic research through the Orphans and Vulnerable Children Comprehensive Action Research (OVC-CARE) Project, implemented by Boston University’s Center for Global Health and Development.
2. Share experiences of program implementers with a global audience that includes other service providers, donors, and researchers;

3. Contribute to global knowledge on existing interventions providing family-centered services to MARP and their children.

4. Articulate study questions for future research with MARP parents and children.
2 Background

Ukraine, Viet Nam, and Zambia represent three very different HIV epidemics and three different adult risk group profiles (Table 1). In Viet Nam and Ukraine, which respectively have a prevalence of 0.4% and 1.33%, the epidemic is concentrated in key vulnerable groups, with considerable overlap between groups. In Viet Nam, male IDU and their female partners, male and female sex workers, and men who have sex with men (MSM) are especially vulnerable. In Ukraine, the key groups are both male and female IDU, prisoners, sex workers, street youth, and MSM. In Zambia, HIV prevalence is much higher (13.5%) and is generalized throughout the entire population as well as concentrated within risk groups. Female sex workers are the at-risk population that has received the most attention over the history of the epidemic in Zambia along with (to a lesser extent) truck drivers and miners, but researchers are now taking an interest in other most-at-risk populations, namely MSM, IDU, and prisoners.

Table 1: HIV Prevalence among MARP in VietNam, Ukraine, and Zambia

<table>
<thead>
<tr>
<th>Vulnerable Adult Populations</th>
<th>Viet Nam (3-5)</th>
<th>Ukraine (2,6)</th>
<th>Zambia (7-9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Prevalence</td>
<td>0.04%</td>
<td>1.33%</td>
<td>13.5%</td>
</tr>
<tr>
<td>Injection Drug Users</td>
<td>29.3%</td>
<td>32%</td>
<td>N/A</td>
</tr>
<tr>
<td>(56% in Quang Ninh and</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>48% in Ho Chi Minh City)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex Workers</td>
<td>6.6%</td>
<td>18%</td>
<td>68.7%</td>
</tr>
<tr>
<td>Men Who Have Sex with Men</td>
<td>17.0% in Hanoi;</td>
<td>14%</td>
<td>N/A</td>
</tr>
<tr>
<td>16.7% in Ho Chi Minh City</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prisoners</td>
<td>N/A</td>
<td>15%</td>
<td>27%</td>
</tr>
<tr>
<td>Street Youth</td>
<td>N/A</td>
<td>18.4%</td>
<td>N/A</td>
</tr>
</tbody>
</table>

An associated and often overlooked population potentially at considerable risk for HIV are the children of the adults who fall into one or more of these groups. Their risk for HIV can be biological (through mother-to-child transmission) or environmental, and HIV is not the only potential vulnerability they face. Depending on their parents’ health, financial and emotional stability, and social support network, they may or may not be at risk for stigma and discrimination, neglect, abandonment, abuse, under-nutrition, drug and alcohol use, generational sex work, sexual assault, and more. But these vulnerabilities are by no means a given. Stable emotional ties with present, loving, interested parents (no matter their addiction, sexual behavior, profession) or other adults can ameliorate vulnerability (10-21).

Few data are available on the number of children whose parents are MARP, and very little evidence (beyond anecdotal) is available describing physical and mental health, educational achievement, specific vulnerabilities, and sources of resilience. In this project, we set out to learn more about these families by tapping into the vast knowledge of the people working directly with most-at-risk parents and children. We started with this program-based research in order to learn more about these populations within specific contexts in order to both cultivate relationships with local experts and, in collaboration with them, begin to articulate the most appropriate research questions and study designs for future primary research with both parents and children.
3 Methods

Study Sites/Program Collaborators

The three partner programs were identified as we conducted the literature review described above. Program staff members were contacted through professional networks. The three organizations documented here were immediately responsive to our queries about the needs and services being provided to these vulnerable families and agreed to partner with Boston University to share their knowledge and experience. See Appendix 1 for a list of the organizations visited in the course of data collection.

Data Collection and Analysis

We designed a semi-structured questionnaire and conducted in-depth interviews with respondents. The instrument asked questions about: the genesis and changes over time of programming for children of MARP; population needs and specific vulnerabilities; sources of resilience; services provided; successes and challenges; and future programming plans. Interviews lasted approximately 1-2 hours each.

We visited each program for 5-7 days to interview program staff at Tasintha (Zambia), HealthRight International (Ukraine), and Family Health International (Viet Nam); staff at partner organizations; donors; and other relevant stakeholders. We also gathered program information from unpublished reports, grant applications, and other available sources.

The interview notes were analyzed using an approach borrowed from standard grounded theory in which we first identified themes and categories of information and then sought to understand and describe thematic characteristics, patterns, and relationships (22,23). As our themes developed, we explored and developed linkages between them and the data from interviews. We thus focused and reduced a large quantity of data through an iterative process of identifying, modifying, and grouping the primary themes. Thematic information was then summarized by program for each of the following categories:

- Population information
- Program information
- Broader need
- Success stories
- Challenges and limitations

Ethical Review

The project was granted a non-human subjects exemption from the Boston University Institutional Review Board.

Report Organization

Findings are reported by program in two sections: Program Overview and Key Themes. We have opted to report findings by program as this was a documentation project and program-specific sub-sections provide the space to tell the story of each program in uninterrupted detail.

Text boxes are used throughout to synthesize key themes that appeared across programs and contexts.
4 Study Limitations

This project was explicitly designed as an effort to document, not evaluate, the programs of the partner organizations. As such, we collected data solely from program staff through in-depth interviews, and supplemented these with interviews with other key informants and various written materials, with the aim to increase understanding of what these programs do, and how they operate, but not to rigorously assess how well they function or achieve their aims. This exploratory and descriptive focus was understood by our partners as we set out to collect a broad range of information from and with them. Thus, the first limitation we wish to make clear is that we do not present a critical analysis of service or program strengths and weaknesses, nor are we in a position to do so. Instead, given the bleak knowledge base regarding services that are available to the children of MARP PLHIV, we sought to shed light on three programs that provide services for this vulnerable population and learn from their deep experience about some of their clients’ most pressing needs.

Second, because we did not conduct evaluation research and we are unaware of evaluation research of the types of programs that are the focus of this project, we do not pretend to portray these programs as “best practices”. Rather, we describe these programs as “existing practices” and hope that the information we share may help inform the future design and implementation of programs for children.

Third, due to time and budget limitations, we were unable to conduct a comprehensive examination of each program. In each country, we spent approximately one week conducting interviews. Thus we can only describe here what we were able to glean from spending a limited amount of time with program staff, including implementing partners. For instance, in Viet Nam, FHI is providing services to the children of MARP PLHIV in over 20 sites, and thus it would be impossible to claim that we can adequately portray each and every facet of all the programs. That said, we were able to collect a large quantity of information that we believe makes an important contribution to a new body of literature focused on understanding the needs of MARP and their families and some of the programs attempting to fill those needs.

Fourth, identifying all the available resources for children of MARP in the three focus countries—from other organizations and government programs—was beyond the scope of this project. We inquired about linkages to other services and, where appropriate, asked interviewees about other services for children, but the information we gained was limited to interviewees’ knowledge. In relevant sections we have reported what we learned but recognize that it is in no way comprehensive.
5 Overview of Programs

5.1 HealthRight International, Ukraine

Program Overview
HealthRight International (formerly Doctors of the World, USA) provides care and support to strengthen families affected by HIV/AIDS in Russia, Ukraine, Kenya, and Viet Nam. In Russia and Ukraine, their focus populations are pregnant women, new mothers, former and active drug users, and street and other-at-risk children and youth. This report focuses on programming in Ukraine. The Prevention of Abandonment of Children Born to HIV-Positive Mothers Project (MAMA+) was developed first in Russia and Ukraine to help pregnant women with a new HIV diagnosis to stay or become healthy, access antenatal care, initiate ART, prevent HIV infection in their infants, and stay with their children. In 2008, MAMA+ for IDU was launched in Kyiv to focus on the special needs of HIV-positive female drug users who are pregnant or new mothers.

Program Approach
When MAMA+ started in Kyiv, Donetsk, and Crimea in 2005, HIV-positive pregnant women, in despair about a HIV-positive diagnosis and what seemed to be an unavoidably grim future, frequently abandoned their newborns at the maternity hospital. The mission of the project (funded in part by USAID) was to “build Ukrainian systems, capacity, and commitment to keep children born to HIV-positive mothers within their biological family environment” (24). Multi-disciplinary case management teams consisting of social workers, psychologists, doctors, nurses, and lawyers were formed with the support of community partners. These teams provided a referral network to identify HIV-positive mothers at risk of abandoning their children and offered comprehensive social, psychological, and medical assistance to them and their families. MAMA+ proved to be successful in helping ensure that 95% of women enrolled in the program (who had been at high risk of abandoning their babies) were able to keep their infants and raise them in a family environment. In 2007, MAMA+ services were turned over to the local partners providing the services.

Of the initial MAMA+ clients, 35% were injection drug users, and they had the highest failure rate within the program. With funding from the Open Society Foundations, MAMA+ for Drug Using Pregnant Women and New Mothers (MAMA+ for IDU) was piloted in Kyiv. The original MAMA+ multidisciplinary case management model is maintained, but with a new emphasis on drug and alcohol counseling. Addiction specialists work with women closely to identify the path to the best outcome for both mother and baby. Some women enter rehabilitation facilities in order to stop drug use completely; others deemed to be at risk for relapse are referred to opioid substitution therapy programs (ST). Peer support groups for current or former IDU pregnant women and new mothers were also established.

MAMA+ for IDU seeks to accomplish 5 primary objectives:
1. Early identification and enrollment of HIV-positive drug using pregnant women and young mothers living in Kyiv city
2. Provision of support, home visits, harm reduction counseling, and work with family members
3. Referrals and additional assistance in accessing health and social services
4. Establishing peer support groups focusing on the specific needs of project clients
5. Advocating for inclusion of piloted approaches for support to women IDU in the state and private sector of Ukraine
Links with Other Agencies
HealthRight International started the Ukrainian Foundation for Public Health (UFPH) in 2008 as a means to more seamlessly integrate their programming with government and non-government partners. Women and children receive services (including home visits, general health care, ART, psychological and drug counseling, referrals to rehabilitation and ST, peer support, and legal assistance) from a variety of community partners, including the Kyiv City AIDS Center, Kyiv City Hospital #5, Left Bank Center for HIV-Positive Children and Youth, Kyiv City Representative Office of the All Ukrainian Network of People Living with HIV, and a host of other organizations.

Box 1: Advocacy: A Key Program Approach

Ukraine: Advocacy is a primary goal of MAMA+ for IDU. Efforts are focused on building buy-in among state and private sector partners to expand programming. The Ukrainian Foundation of Public Health set out to educate health care experts and the general public about the vulnerabilities of drug users, particularly pregnant women and mothers, and how substitution therapy can help them achieve stability, regain their health, and care for their children. One of the most successful strategies was to produce a television documentary, "Returning Home," which was shown 4 times on national television with the State Substitution Therapy Hotline telephone number displayed throughout. Each screening yielded at least 100 phone calls from IDU or their family members. The film has since been distributed internationally. Over the two years of the MAMA+ for IDU program, ST enrollment use increased by 27%.

Viet Nam: FHI’s advocacy efforts exist on the local and national level. First, FHI developed a holistic Continuum of Prevention and Care service delivery model integrated within government health care and social welfare services. This approach focused on engaging and empowering PLHIV and MARP in service delivery and planning, integrating family-centered care within services for PLHIV and vulnerable children, and using a bio-psychosocial approach in service delivery that views the lives of people infected and affected by HIV/AIDS as more complex than their medical needs alone. This model of care has been accepted as a successful model to a certain extent within the PEPFAR program. At the national level, FHI has been a key partner in introducing social work reform, developing CHBC and palliative care guidelines for children and adults, and introducing and scaling up HIV care and treatment along with OST/methadone services for IDU.

Zambia: Tasintha has worked to raise awareness in the general public and with national and local governments to improve understanding about the factors pushing women and girls into sex work, their vulnerability, and the ways in which sex work is a symptom of a larger social epidemic rooted in poverty. They were one of several groups who worked with the National AIDS Council to integrate a gender perspective into the 2011-2015 National AIDS Strategic Framework (NASF), after stakeholders pointed out that the 2006-2010 NASF did not “cater for the different needs of women and men.”
5.2 Family Health International, Viet Nam

Program Overview
In 2005, FHI began funding the provision of needed services to HIV-positive adults utilizing a continuum of prevention and care approach. This involved the establishment of HIV out-patient services embedded in district hospitals with linked community and home-based care (CHBC) teams and PLHIV (people living with HIV) support groups. Services were extended to children beginning in 2006. Currently, both populations are automatically served as soon as a family member is found to be HIV-positive at one of the participating outpatient clinics (OPCs). This is done through a combination of services provided at the OPC (primarily voluntary counseling and testing, prevention of mother to child transmission, ART, opportunistic infection treatment, palliative care, social support services, and adherence counseling; methadone therapy for IDU was available at only one of the OPC sites visited—Thu Duc, in Ho Chi Minh City—though is expected to be scaled up in coming months and years) and through the OPC-based home-based care team.

The number of adult clients served in home-based care (HBC) programs ranges from 30-80% of the OPC population, with PLHIV in rural areas tending to be more interested in CHBC services. CHBC teams reach a range of 200 to over 600 adult clients, depending on the catchment area, and from 150 to over 300 children. Nationwide, FHI now helps fund services at 24 clinics, reaching 11,563 adult clients and 4,886 children. Including family members receiving care and support, a total of 31,163 individuals were reached with umbrella care services as of March 2011.

Program Approach
The programs aim to be comprehensive in nature and to provide services to adults and children in the key areas of: 1) care and shelter; 2) health care; 3) nutrition; 4) psychosocial well-being; 5) education; 6) legal protection; 7) economic strengthening. The degree to which programs can provide these services varies. An exception to the model is The Hien Quang Pagoda Club in Hanoi, which provides home-based care to adults and children and linkages to OPCs in nearby districts. Only the Van Don OPC offers mental health services, though these services are now being expanded to other FHI, USAID, and CDC supported OPCs. Program staff at the other OPCs visited described meeting psychosocial needs through counseling on topics such as care for HIV-positive individuals and adherence to ART. The CHBC teams in the two OPCs visited in the south of the country explained that it was difficult for them to address shelter needs due to the very tight supply of affordable housing for many migrant families.

In addition to being comprehensive in nature, the programs aspire to be multidimensional and to take into account the physical, emotional, social, and spiritual needs of all family members who live with someone who is HIV-positive. This comprehensive, family-oriented approach is rooted in the principle that if one family member is HIV-positive, every family member, and particularly every child, is likely to be affected in a variety of ways. This motivates the home-based care arm of the programs, with the effect of extending needed services to children.

Establishing these programs required considerable outreach to build trust within communities and among professionals who would be needed to provide services. Stigma was a major issue in the early 2000s, and many potential clients were reluctant to come forward to receive services, both for themselves and for their children. While stigma continues to be a barrier to service access, staff contend that the situation has improved noticeably, and each month, new families begin receiving services at each FHI-participating clinic and program.
Links with Other Agencies
FHI works closely with other agencies (international and national NGOs, hospitals, small self-help groups) and with the government at all levels (central government offices, health offices, provincial authorities, town, and commune offices) to ensure collaboration with key policy makers, to maximize capacity-building through cooperation and training programs, to mobilize resources, and to expand the reach of projects to the greatest extent possible. FHI staff provide capacity strengthening opportunities directly through a range of workshops with implementing partners. In doing so, they seem to have been responsive to suggestions and need for changes. Over time, responsibility for the direct operations of the OPCs has been turned over to local governments. Increasingly, FHI is thus supporting government health facilities and strengthening local capacity to manage OPCs. Likewise, FHI staff members are collaborating closely with the government social welfare system to develop its capacity to work with and protect vulnerable children.
5.3 Tasintha Programme, Zambia

Program Overview
Tasintha is a grassroots NGO started in Lusaka in 1992 to provide a variety of support services to female sex workers, with the overarching goal of providing women with the support, education and professional skills training they will need to find alternative means of income generation. Women are recruited into the program through street and bar-based outreach. Once a woman agrees to join Tasintha, she can receive skills training in a variety of areas. These range from brick making and tailoring to auto mechanic and catering school. Women also have access to temporary cash assistance, primary health care services for themselves and their children (including referrals for HIV and STI testing, treatment, contraception, prevention of mother to child transmission, immunization for children, etc.), drug and alcohol counseling, psychological counseling, and mentoring from both program staff and their peers, who have similar life experiences and have successfully left sex work behind. In addition to Lusaka, Tasintha now works with sex workers (usually in partnership with other organizations) in four rural and/or border towns: Chirundu, Kapiri Mposhi, Chipata, and Nakonde.

Program Approach
Over the last twenty years, more than 7,000 sex workers have participated in Tasintha programs. Tasintha’s primary emphasis is skills training and educational support for both women and their children. Their objective in providing skills training, education, and employment networking is to provide women with an alternative source of income. In providing education to women and children, they are also (on a person-by-person basis) attempting to reduce poverty and rebuild the Zambian economy. From its earliest days, Tasintha staff recognized that the children of their clients may be particularly vulnerable to HIV, poverty, abuse, drug and alcohol use, dropping out of school, and taking up sex work at a young age. Over the years, they have provided school fees nutritional support, counseling, and health care to the children of sex workers.

Links with Other Agencies
Tasintha works closely with University Teaching Hospital to ensure that women and children receive whatever health care services they are in need of by providing referrals and paying user fees. If a child who is affiliated with the program is orphaned, Tasintha staff work with the Department of Social Welfare to ensure that they are cared for and remain in school. Children may be reunited with family members after the environment is determined to be conducive to their wellbeing. They may also be placed in foster or residential care. Tasintha also partners with Chilengi Transit Home and Kasisi Orphanage to place children who cannot be placed in a family. Other partners include: Department of Education, Child in Need Network, the International Labor Organization, Serenity House (for women addicted to drugs and alcohol), and others. Of particular interest is the relationship they have developed with the police department over the last twenty years. Tasintha staff members have worked closely with the department to sensitize them to the vulnerabilities faced by sex workers. In doing so, they report they have observed a reduction in antagonistic and abusive behaviors towards the women on the part of the police.
Box 2: Focus on Stigma

Ukraine: At the Left Bank Center for HIV+ Children and Youth, case management teams include social workers who are themselves former clients, HIV-positive, and often in recovery: “90% of our success can be seen in our employment of HIV+ clients, which has helped break down other clients’ sense of stigma.” As noted by one such social worker: “Being able to provide them with my example of changing my life seems to make the possibility more real to them.”

Viet Nam: The program in Viet Nam has used a similar approach to the one in Ukraine where services are provided by PLHIV. PLHIV provide care through the out-patient clinic CHBC/OVC teams and the PLHIV support group. According to those interviewed, HIV-related stigma has declined substantially in the past five years but continues to affect both clients and program effectiveness. Stigma may prevent children from attending school along with other children, lead to social isolation in communities, exacerbate psychosocial vulnerabilities related to HIV infection in the family, and encourage some parents to refuse home-based care services out of fear of disclosure of HIV status. Even HIV-positive parents may refuse to allow their HIV-negative children to attend activities organized by programs for the children of HIV-positive adults. All programs include efforts to address stigma, but staff also asserted: “Children are often isolated. This is a problem we cannot solve.”

Zambia: Children of female sex workers can face stigma within the community because of their mother’s line of work. One staff member noted that women sometimes put off telling their children about their HIV infection and/or about their sex work. The children then find out about it through neighborhood or family gossip, which deepens their stigma. This lack of communication was also cited by another staff member as a source of bitterness for children who begin to resent their mothers.
6 Key Themes

6.1 HealthRight International, Ukraine

Population Information
Environment: Female IDU face numerous vulnerabilities. Research commissioned by the Open Society Foundations found that women tend to inject last in a group setting and need assistance with the needle, increasing their risk for infection (25). Unsafe injection practices are not, however, the only driver of HIV, as sexual transmission is increasing and routes of transmission in vulnerable groups are blurring (24). For instance, most sex workers are drug users and many drug users are becoming infected through sex, which is often exchanged for drugs. In recent years, 41% of new cases of HIV in Ukraine have been attributed to sexual transmission (25), and 34% have been attributed to injecting drugs (26). Frequent unprotected sex can also lead to unplanned pregnancy which, when combined with drug use and a new HIV diagnosis, can plunge a woman into depression and hopelessness.

Stigma and Other Barriers to Accessing HIV and Addiction Treatment: HealthRight International found in a small 2010 study of pregnant women’s experiences testing for HIV that only 20% of women were asked about their risk behaviors before testing and only 5% were asked about risk behaviors after testing (27). Pregnant women who are using drugs, influenced by a combination of denial and fear of discrimination, tend to avoid antenatal care. The fear of discrimination is legitimate as pregnant drug users have traditionally been counseled to abort and substitution therapy is still not widely available or understood by physicians (27). Reluctance to offer ST is often rooted in lack of ignorance about the effect it will have on the fetus. Mother to child transmission of HIV is still a challenge in Ukraine, and was the source of 16.5% of infections among women with a current or past drug addiction (28). Availability of ART to active drug users is an ongoing challenge, as they are perceived to be at high risk for non-adherence. As noted by a UFPH partner, this concern is not unfounded. Adults with an ongoing addiction struggle to adhere and are also less able to oversee their child’s adherence; as a result, physicians are reluctant to start therapy if a mother is not on ST or in recovery.

Drug rehabilitation services were designed for a male clientele, and in general cannot meet the specialized needs of pregnant, HIV-positive women or women with children. In particular, women cannot bring children with them and are often forced to choose between treatment and separation. In a worst-case scenario, this may mean turning the child over to the state. The focus on male drug users has also meant that rehabilitation and ST services rarely conduct outreach to women.

Substitution therapy became available in Ukraine in 2004, and is still to some extent misunderstood and stigmatized. While easily available in Kyiv, it can be more difficult and dangerous to access in other parts of the country. In 2010, two doctors providing ST were arrested and prosecuted for drug trafficking in Odesa and Ternopol. They were eventually released after several months of incarceration and the Prime Minister ordered the Ministry of Health to issue a statement supporting ST provision and scale up (29). While an estimated 26% of IDU in Ukraine are women, only 20% are accessing ST (30).

Women and Children: When MAMA+ started in 2005, 20% of the infants born to HIV-positive mothers were abandoned at maternity hospitals (31). Factors contributing to this decision are the mothers’ relatively young age (50% age 18-26), unplanned pregnancy, learning HIV status while pregnant (44%), lack of support from the baby’s father (42%), criminal history (44%), and active drug use (35%) (31). The young women tended to come from single parent, poor families with little understanding of HIV
treatment, prevention of mother to child transmission, or substitution therapy. Pressure to abort or turn their infants over to state care comes from families, already stretched too thin, who have little understanding that the child can, with PMTCT, be HIV negative and (no matter their serostatus) have a full, healthy, and productive life. Likewise, physicians and other health care providers also pressure HIV-positive and drug using pregnant women to abort or give up their infants immediately after birth.

Staff from partner community service organization had the following to say about the special vulnerabilities faced by children of drug users: “Children whose parents are active IDU are at greater risk for poor care, neglect, abuse, under-nutrition, etc.” However, the consensus among all informants was that stabilization on ART and substitution therapy or drug rehabilitation had the potential to contribute to a healthy family environment for children.

Households and Homelessness: In Ukraine, multigenerational families tend to live in small apartments with little space, privacy, or resources. Many children grow up only knowing one of their parents (usually their mother). Alcoholism is common in many poor homes, pushing children, teenagers, and young adults to leave home, with the destination of an estimated 30,000 to 150,000 being the streets, abandoned buildings, and basements in the winter (2).

Ukraine is also grappling with a legacy of child institutionalization, a remnant of the Soviet system (32). Abandoned children, runaways, and children removed from family homes due to unsafe conditions can spend years in orphanages and boarding schools. Just over a quarter of street youth surveyed in a multicity survey by HealthRight International in collaboration with the US Centers for Disease Control reported having lived in such an institution (2). Youth living on the streets are themselves vulnerable to alcoholism, drug use (particularly glue), transactional sex, unprotected sex, and unintended pregnancy. Avoiding a future generation of children born to young, homeless mothers is the focus of much of UFPH’s and their partners’ current work. HealthRight International has been supporting street children through the creation of drop-in centers in Chernihiv in 2006, Donetsk in 2009, and Kyiv in 2010. In these drop-in centers homeless youth can take refuge from the cold, bathe, wash their clothes, receive counseling and skills training, get referrals for health care, and interact with their peers in a safe, clean environment.

Program Information
Multidisciplinary Case Management: Client support services operate on the multidisciplinary case management model. Social workers are particularly important to this process as they work to gain patient trust, and then act as intermediaries who report to the case management team comprised of medical, mental health, drug and alcohol, and legal specialists who review each case regularly in order to better understand patient needs and devise individualized responses. Home visitation is central to case management for vulnerable women and their children. Because women usually live with many other people in small apartments, these visits can be tricky if the client has not disclosed her HIV status: As a program staff person explained: “We sometimes have to lie or be evasive with family members about why we are there. In some instances I have had to call ahead and meet the client in the stairwell.”

Peer Support Groups: Although PLHIV, IDU, and other marginalized at-risk populations live in close proximity to extended family and peers, many new clients are lonely and suffer from self-stigmatization. Staff at all the partner organizations visited discussed the centrality of peer support groups which help individuals begin to break out of their emotional isolation. Active groups exist for PLHIV more generally as well as for women, pregnant women/mothers, men, youth, IDU, ST support, parents of children infected by HIV or who are IDU. Infected and affected children meet and interact with other children in
play rooms and groups and special educational sessions organized by partner organizations. Hope and Salvage is an example of partner organization that is a peer support and advocacy group for parents of IDU. A primary focus is on helping parents to support IDU children in need of or already receiving substitution therapy. They educate and support one another, and also have organized to educate health care providers, government, and the general community about the benefits of ST.

**Drug Counseling:** Individual mental health and addiction counseling are key components of the case management model. The decision about whether to enter residential rehabilitation, join a 12-step, program, and/or use substitution therapy are highly personal decisions dependent on many variables in a woman’s life. All of the service providers interviewed readily acknowledged the vital importance of ST to women not yet ready to stop drug-use altogether. But they also noted that it too is a dependency that continues to chain women and families to one place and a daily ritual involving direct observation at ST clinics.

Pregnancy and children can be important motivating forces for a mother to get healthy, start and adhere to ST and ART. But, these vulnerable mothers do not arrive at this realization easily. As one provider noted, “a mother usually needs to work intensively with our social workers in order to arrive at this place.” An important element of case management for highly vulnerable and drug-using mothers is teaching them how to care for their children: “they don’t learn to become good mothers in one day. They do not know what to do with a baby or how to care for it.” One social worker noted the special attention young and addicted mothers need in order to help them be good parents: “Rehabilitation and learning to be a good mother should be parallel programs. In the current system, the mother is separated from the child.” Rehabilitation psychologists do not focus on children when counseling a parent: “They do not use them as motivation to stop using drugs and successfully rehabilitate.”

**Residential Rehabilitation Programs:** In extreme cases and using personal connections, organizations like the Left Bank Center can occasionally influence residential rehabilitation programs to allow a child to accompany the mother. The respondents were clear that this form of case management by exception is untenable and needs to be a focus for future years: “We need a set amount of space set aside to accommodate parents with children. This is especially true for mothers with young babies.” Rehabilitation for mothers with school age children would also, they noted, need to figure out a way to help a child avoid dropping out of school altogether if she or he were to accompany their mother.

**Broader Need**

There are many female IDU in Ukraine who are not accessing substitution therapy, drug rehabilitation facilities, PMTCT, or HIV treatment. Youth living on the streets are extremely vulnerable to drug use, abuse, unwanted pregnancy, HIV and other sexually transmitted infections. Their needs are only beginning to be understood and addressed. These are both areas in which HealthRight International is conducting research and designing programs to meet key needs. UFPH programs are time and geography-limited pilot interventions funded for the most part by international donors. But their model of implementing promising programs in conjunction with city and non-governmental partners and then advocating for state funding to continue programming with proven success is a business model that inherently acknowledges the limitations of what they can achieve on their own.

**Challenges and Limitations**

UFPH and partner programs are a response to challenges and limitations within the current health care system. They tackle these challenges head on and, as noted above, have made some important headway. But the following problems remain:
• Only 20% drug users accessing ST are women (30);
• HIV-positive women who use drugs have limited access to PMTCT and ART;
• Rehabilitation facilities do not allow children, forcing women to choose between getting clean and family separation;
• 47% of street youth report unprotected sex, and 18.5% are HIV-positive (2);
• Substitution therapy is legal in Ukraine, but still faces some controversy. It is currently paid for with Global Fund money, but may be vulnerable to conservative, pro-Russian political and social forces if international funding ends.
6.2 Family Health International, Viet Nam

Population Information
Most at Risk Adult Populations: All five FHI-supported programs that we visited provide services to IDU, SW, MSM, and their partners. IDU are the largest single client group and comprise the majority of adult clients in the northern clinics (60-80%), and at least 40% of clients in the two HCMC programs. Nearly all IDU are men, while nearly all sex workers are women. However, the majority of women in the north are the partners or spouses of IDU men and not sex workers. The Thu Duc and Binh Thanh programs also provide services to many migrants who come to HCMC to find work in the bustling factories that are a key feature of the area’s rapid economic growth. Most adults (60-80%) live with their children.

Infection and Orphan Status of Children: The proportion of HIV-positive children is 8-10% in most of the OPC sites, which generally serve between 200 and 400 children total, including those receiving ART at an OPC but not being reached in HBC programs. (Receiving visits from a CHBC team is voluntary and some families refuse visits from the CHBC team due to fear of stigma.) A lower proportion is HIV-positive at the Pagoda Club program (4 out of 154 children). The orphan status of children is more variable. In most programs, double orphans (children who have lost both parents) represent 2-5% of all children, and single orphans (children who have lost one parent) represent another 7-12%, with the majority of children living with both parents. However, in Cam Pha, an estimated 60% of children have lost one parent, usually the IDU father, while in Thu Duc, only 30% live with both parents. Here, about one-half of with grandparents or other relatives, though in some cases children have a parent who is living and/or working elsewhere. In addition, even where both parents are alive, when the father is an IDU, he may not be physically present much of the time, effectively leaving the child(ren) in the family to be raised by the mother alone. Incarceration or placement in a mandatory drug rehabilitation center is the most common reason that IDU fathers are absent from the home.

Family Setting: The situation of MARP families varies, though poverty, often extreme, is a consistent theme. In the north, most families own their homes, though some rent. If the child has an active IDU father, some degree of instability in the home is inevitable. The most typical scenario is that the father is frequently absent and the child is being raised by the mother, who is struggling to keep the family together and provide for basic needs. The father may be a hindrance in this, as it is not uncommon for IDU to sell the family’s furniture and other assets, and take any cash aid on hand, in order to buy heroin. In the south, due to the large migrant population, many families lack adequate housing. Entire families may occupy one small room and be forced to move often.

Aside from poverty and lack of adequate shelter, children of at-risk parents also face other major vulnerabilities:

Schooling: Stigma has declined considerably in the past five years, so most children can attend school, but sometimes they must do so separately from other children (attend only in the morning, sit in separate rooms, etc.). Teachers typically understand that allowing HIV-positive children to be with other children does not pose undue risks of transmission, but many parents still do not. Parents help fund schools through a variety of fees, so teachers and school administrators often face pressure from parents to not permit HIV-positive children to attend school with other children. When they do, HIV-positive children are frequently stigmatized, made to sit alone, and excluded from activities. It is in these school settings that children known to be infected or affected by HIV/AIDS are not accepted by others. A
Pagoda Club staff member: “Some children go to school, but the teacher and other kids keep a distance from them. This must be hard and the project can’t help with this. The children are isolated socially.”

Food insecurity: Insufficient food intake, which results in poor nutrition status, is a persistent vulnerability that stems directly from the dire economic environment in which most orphans and vulnerable children (OVC) live. As a staff member in Cam Pha noted: “they worry about food at every meal.”

Psychosocial Issues: These issues were named by all the programs as a major impact of HIV/AIDS for the children they serve. Most children were described by program staff as not seriously depressed or anxious; on initial enrollment into a program, they are frequently shy, fearful, self-isolated and lacking in basic trust. Staff described the ways in which they approach children in the home during home visits and build trust. However, it should be recognized that understanding of mental health issues among children is limited in Viet Nam and it is possible that staff are not always identifying those at risk.

Health care: Vulnerable children, like their parents, need health care services, which may be difficult to access due to poverty, poor knowledge of where and how to obtain services, and self-stigma or lack of care by parents. Of particular importance is the provision of ART and symptom management to children.

Disclosure of HIV Status: One of the most difficult topics HIV-affected families face in Viet Nam is the disclosure of an adult’s or a child’s HIV infection to others in the family, particularly the children. Parents fear the stigma they believe will be directed toward themselves and their children once HIV is known to affect a household. They also fear the loss of children’s confidence once disclosure happens. There is little information available to guide parents on this sensitive issue. As a result, they often avoid discussing it with their children. Children may find out they are HIV-infected or that their parents are from a doctor or nurse at an OPC and not until they are teenagers. The CHBC team is trained to raise disclosure planning with parents and FHI Viet Nam is in the process of publishing a care guide for children living with and affected by HIV, including guiding parents in how to disclose. Qualitative research conducted by FHI in Cam Pha and Van Don found that among parents who have disclosed their HIV status to their children, the majority expressed relief at having done so (28).

Program Information
All the programs in Viet Nam utilize a comprehensive approach to service provision. Once an HIV-positive adult or child is registered at an OPC, services are automatically available to all family members. Key services provided to children are:

Health Care Services: Children attending the OPC programs (with the exception of the Pagoda Club, which provides care and basic medications for mild infections, referrals to OPCs and hospitals, and adherence counseling, but no other direct clinical services) all have access to the usual range of clinic services, including VCT, ART, OI treatment, and adherence counseling. Children under six years of age are also enrolled in the free primary care scheme provided by Viet Nam’s Ministry of Health.

Educational Support: All programs provided support in the form of school fees, uniforms, and books, if needed. In addition, the legal support provided—including obtaining birth certificates, local registration card, etc.—is generally oriented toward school attendance. Community outreach with school authorities and others to address stigma also has the result of helping ensure school attendance by the children of PLHIV.
Nutritional Support: To address food insecurity, all children under sixteen are screened and assessed routinely for food insecurity and moderate and severe malnutrition. All clients receive nutrition education and diet counseling. When malnutrition is identified based on BMI and food insecurity criteria, children receive supplementary food monthly via food baskets. The baskets are formulated based on essential nutrients and are limited to a certain number of children in each CHBC program (generally 30) with the worst status. Children may only receive food baskets for a period of 3 months which may be expanded 6 months. In extreme cases, however, program staff may extend this period and also refer children to the OPC for assessment and further assistance.

Psychosocial Support: All the programs aim to address psychosocial issues, though in most programs, such support is limited to counseling related to health care, adherence, and coping with whatever troubles the family. This is often referred to as “spiritual support” and includes organizing events at temples and/or churches (in the south). Specifically for children, program staff members organize “Play and Learn Groups,” outings to nearby sites, and parties to celebrate special events throughout the year. They give gifts to the children on special occasions. When they encounter children who seem distressed, they try to find ways to help the children be happier and more sociable. Only the Van Don OPC currently provides formal mental health services. This includes screening adults and children and then providing a combination of counseling, medications, and meditation/Thai Chi therapy, depending on the severity of the problem. For those with less serious issues, meditation/Thai Chi only is provided; those with the most serious issues are offered both counseling and medications.

Legal Protection: Typically, this focuses on ensuring school attendance, including obtaining birth certificates and local registration cards. Child abuse is described as rare and usually related to child labor, as when parents both die and a child needs to help support a household headed by aged grandparents. In such instances, program staff will work with the family to find a way for the child to go to school. Only rarely do government agencies become involved.

Care and Shelter: Programs in the north (Hanoi and Quang Ninh) try to help families find adequate shelter when necessary, but these services are often limited. The programs in HCMC do not generally aim to address shelter needs due to the challenge this poses—housing can be extremely tight given the influx of migrants—and their focus on other basic needs. However, in the case of orphans who have no chance to live in an extended family, staff at Thu Doc in HCMC help them to access shelter in children’s homes to ensure that they have a safe and healthy living environment.

Economic Strengthening: All the programs try to provide job-seeking advice and links to potential employers and to DOLISA (Department of Labor, Invalids, and Social Affairs). Some provide job training. Many staff members mentioned the need to do more to enable clients to find jobs. They also noted that some clients were not healthy enough to work or did not actually want to find employment.

CHBC teams utilize an approach that is distinguished by several key features, including:

- Active identification of potential clients;
- Respect for clients’ confidentiality and privacy, which leads team staff to only make home visits after Receiving permission;
- Flexibility in when and how they visit families to reduce the risk of unwanted disclosure of HIV status;
- A determined effort to address the full needs of all family members, guided by thorough training and job aids;
- Home-based care kits that can address mild-moderate pain and other common symptoms;
• A policy of visiting clients in pairs, generally comprised of one medical person and one PLHIV peer educator or community outreach person.

In addition, program staff members—in the OPCs, in non-OPC programs (e.g. the Pagoda Club), and the HBC teams—all display a remarkable combination of dedication, skills, and compassion. Employing hard-working and competent staff is an important element in program implementation.

Programs have been developed with a clear recognition of gender issues and addressing the unique needs of men and women. Staff members mentioned the need to ensure the provision of all services to women and men, girl children and boy children, despite the preference parents will often give to their boys relative to their girls.

**Identification of New Clients:** New clients at OPCs are generally identified once an individual tests positive for HIV. At this point, the family is registered with the CHBC team at the OPC, and if the adults in the family agree, home visits commence. At the first home visit, an assessment is made of the needs of each family member, covering physical health, psychosocial health, spiritual health, nutrition, education, shelter, and legal protection.

Additional ways of identifying new clients are through referrals from commune health centers, community self-help groups, and current clients. CHBC teams mentioned attempting to contact a household if they heard that someone in the home was HIV-positive but not accessing nearby services.

**Views of Program Impact**
FHI’s programs are not without gaps. However, the program staff we interviewed are confident that services are playing an important role in addressing the needs of adult and child clients. Staff members described in detail having saved lives by linking HIV-infected individuals with ART and other clinic-based care and treatment. The programs provide urgently needed food to children, and help ensure that children attend school. Staff explained that they believe the programs’ special activities and attention serve to encourage the children and their parents. They also expressed confidence that program counseling and training play a meaningful part in helping all family members cope with the daily stresses of chronic family illness. In Van Don, program staff were certain that the formal mental health services offered at the OPC improved the quality of life for clients.

However, program staff openly discussed their views of the fundamental obstacles that limit these impacts. These obstacles include persistent poverty, continued HIV-related stigma, and the instability that accompanies living with or as a heroin addict. Many program staff welcomed the anticipated scale-up of methadone therapy for IDU throughout Viet Nam, noting that, where available, methadone has helped IDU to live more stable lives. In addition, staff at each program site acknowledged that some families in need of their services were failing to access them. This appears to be primarily due to the continued stigma related to HIV that inhibits some individuals from being willing to come forward and accept services. It is possible that some affected families are unaware of these services, but given the length of time these services have been provided, it is likely that continued lack of access is due to the deliberate actions of potential clients rather than ignorance of services.

**Broader Need**
FHI’s programs in Viet Nam appear to have reached most potential clients. This is likely due to a focus on outreach to identify new clients, advocacy, a positive track record with existing clients, and close ties with PLHIV and a wide range of other agencies. However, program staff at each of the five visited sites
acknowledged that, undoubtedly, some families were failing to access their services. Primarily, this appears due to the continued stigma related to HIV that inhibits some individuals from being willing to come forward and accept services. It is possible that some affected families are unaware of these services, but given the length of time these services have been provided, it is likely that continued lack of access is due to the deliberate actions of potential clients rather than ignorance of services.

**Challenges and Limitations**

FHI’s programs face a number of substantial challenges. First, all the programs are limited in what they can do because of funding constraints. While program staff asserted that they are able to meet the main needs of families and children, they also discussed the ways in which limited resources directly constrain program capacity to provide nutritional support and activities for children, and to address families’ shelter and employment needs. Tight budgets also prevent programs from hiring more staff and paying higher salaries, thereby putting pressure on existing human resources. Program staff mentioned having to care for large numbers of clients, often at considerable distances, which leads to long working hours and hurts morale over the long term.

Continued HIV-related stigma also poses a major challenge (see Box 2). Program staff note that some adults refuse to access home-based services due to fear that neighbors will discover the HIV status of a household member. Stigmatization of HIV among school children is also a particularly frustrating challenge. Fundamentally, the programs cannot remove stigma, but rather continually help their clients cope with it and try to overcome it.

In addition, program staff consistently mentioned challenges related to providing services to IDU clients, particularly those who were active users. Issues that were frequently noted included: ART adherence, adequate care of children, admission into mandatory rehabilitation centers (‘06 centers’), and joblessness. Some also mentioned that they felt that visiting IDU clients in their homes could be risky due to the somewhat unstable mental state of these clients.

Lastly, the grinding poverty that affects so many families, in addition to HIV infection, presents challenges due to the complex web of issues that affect very poor client households. Program staff are able to provide treatment for specific ailments, and to cheer up children for a day with a special outing, but are not in a position to truly solve the underlying problem of being ill in the face of extreme poverty.
6.3  Tasintha Programme, Zambia

Population Information

Sex Work Environment: Very few sex workers in Zambia work for pimps or in brothels. In Lusaka, they tend to work on the streets in front of hotels and guesthouses, in bars, and from car parks. One Tasintha staff member noted that small guesthouses attached to bars where women can entertain clients have become common over the last few years. Sex workers may live in groups of other sex workers under a “queen mother” who collects earnings from each girl and then pays them from the pool of funds. Women do not usually bring men to their homes, so the queen mother housing arrangement is not a brothel. Some women may also start out living in one large room together, but then move out on their own as they earn money.

Women and Children: Approximately 60% of the women supported by Tasintha are HIV positive; 40% are on ART, and the other 20% are newly diagnosed or have CD4 counts over 350. Staff estimate that, during the first 10 years of the program, 20 women died from AIDS-related causes per year. Of the first cohort of recruits, only 10 are still alive. Now, they usually only have 1 death per year among clients and very few clients’ babies are born HIV-positive.

Tasintha staff estimate that 80% of the women in their program have 1 to 5 children, with most having 3 or fewer children. One staff member noted that most tended to have 5 or 6 children in the early days of the program. Most of the children are under age 3. Among the 20% who do not have children, staff note that these women view sex work as a career and understand that having a child might be detrimental to business. Those who do have children do so for a variety of reasons, including what staff describe as a strong desire to be a mother.

Because sex workers tend to not entertain clients in their home, their children are arguably less vulnerable to molestation by clients. But they are vulnerable in other ways, especially when their mothers live on their own or with only one other woman. Sex worker households with fewer than three adults increase the likelihood that small children will be left alone while their mothers are working. Sex workers who are isolated have also been known to leave infants in drainages ditches or with shopkeepers while they work.

Socioeconomic Factors: Tasintha staff stress that poverty and unemployment are the primary factors pushing women and girls into sex work. Over 70% of Zambians are living in poverty, which is most extreme in rural areas at 83% and less so but still pervasively the daily reality of over half of the urban population (56%) (33). Sex work can not only help provide much needed cash to pay rent and buy food and other necessities, it also pays at a much higher level than most other jobs, thereby providing not just disposable income, but also luxury goods and the associated status that comes with nice clothes, the latest mobile phone, etc. Thus, while poverty may be the push factor driving women into the business, once they experience life with a substantial income, it may be difficult for them to see other jobs as an appealing alternative. Though sex work may provide high incomes, Tasintha staff note that the women they recruit have rarely saved or invested their income. Most who decide to leave sex work need to adapt to a significantly lower income even if they receive skills training and are able to work in their chosen field.
The women recruited by Tasintha and their partners in Chirundu, Kapiri Mposhi, Chipata, and Nakonde tend to be highly mobile agricultural workers who come into town one or two days a week to sell sex to truck drivers and train travellers passing through town.

All of the staff members agreed that the children of sex workers are more vulnerable than other children, noting that many of the women in the program have little confidence in their ability to be a good mother: “We try to empower them to be good mothers. Many think they can’t. They come from bad home situations and don’t know how to be mothers. Most girls look for their children to have better lives, want them to not be sex workers and to have good homes.”

Other vulnerabilities noted by staff include: not knowing their fathers, mother’s absence, mother’s drug and alcohol abuse, malnourishment leading to stunting, and compromised education and social development. The slum environment was also perceived as a having great potential to push girl children into taking up sex work themselves: “If we had the funding we would send older girls to boarding school to get them out of the environment.”

Program Information

Assistance to Women Who Want to Leave Sex Work: Each year, approximately 200 women are recruited by peers who are Tasintha clients and program staff in groups of 50-60. Women typically stay in the program for 1-2 years and then are phased out as they begin to be able to support themselves and their children. Women who join the program accept that the goal is to receive training and assistance that will enable them to make a choice other than sex work, if they so choose. The mission of Tasintha is to give women a choice about what type of work they do.

During their time in the program, women who decide to stop selling sex receive monthly cash assistance to replace some of the income they are losing. The objective of this temporary conditional cash assistance, which decreases over time, is to wean women off of their former income expectations while simultaneously giving them time away from the sex work environment to develop new professional skills, find jobs, and establish themselves in a new situation and with new work acquaintances.

Education and Skills Training for Women: The sex worker demographic and education needs have shifted over the years that Tasintha has been operating. When Tasintha first started, the women had little education and were often illiterate; they were eager to learn sewing, tie-dying, and crafts and to sell them at markets. Now, most of the women in the program have completed both primary and secondary school. As the program coordinator noted, “We need to reassess. Girls don’t want tailoring. They want training in computers and other information technology, catering, hotel management, chicken and piggery management, and auto mechanics.” Markets are flooded with hand-made goods, so it is also harder for women to sell their wares than it once was. Zambia’s economy has been growing at real annual rates above 6% since 2005, though unemployment remains high (>10% according to recent figures) (33), so things are changing rapidly both in terms of job opportunities and in terms of competition for those opportunities. In Nakonde (on the Tanzania border), women have less interest in learning a specific skill and, instead, want assistance in getting involved in trading.

Educational Assistance for Children: The primary assistance provided to children over the years, constituting the largest consistent investment, has been educational assistance. Tasintha provides tuition and other assistance so that children can return to or remain in school, supporting them through primary, secondary, and in many cases tertiary, education. Although women are generally phased out of the program after two years, their children can receive educational assistance until they have finished
secondary school or tertiary education if the program staff believe that the child is at risk of withdrawing from school due to household financial insecurity. Over the years, they have provided educational support to over 600 children and youth attending primary, secondary, and tertiary education.

**Health Care:** Tasintha has a basic primary health care clinic on the premises which is available to women in the program and their children. It is staffed five days a week by a nurse, and several days a week by two physicians affiliated with the University Teaching Hospital (UTH). They are able to provide contraception services, and screen for and treat sexually transmitted infections, influenza, malaria, diarrhea, and other ailments. They also partner with other service providers to facilitate access to voluntary counseling and HIV testing days to women on site, PMTCT, and disclosure counseling. Currently, they are not equipped to provide a full range of primary care or services for mothers and children. However, they provide referrals and transport to UTH and Coptic Hospital and pay user fees. Women who join the program when they are pregnant or who become pregnant receive antenatal care services through both the on-site clinic and through referrals to UTH. Every Thursday, the UTH physicians hold discussions on health-related topics ranging from HIV to drug and alcohol abuse to nutrition and common seasonal ailments.

The program physician and management are currently working with the Board to look into building a fully functioning, registered clinic which would provide a full range of primary care services including:

- Family planning and reproductive health
- Antenatal/post-natal/under-five care
- STI screening and treatment
- HIV testing on demand/ART
- Home-based care

Their plan is to open the clinic to the local community and charge user fees on a sliding scale which would subsidize free treatment for Tasintha clients and their children.

**Community-Capacity Strengthening:** In 2007, Tasintha partnered with the International Labour Organization to provide educational support and community economic development and income-generating activities within the poorest communities in Lusaka. The primary goal of this work was to create options within poor communities for vulnerable women and children so that they would have choices for earning money outside of taking up sex work. Income-generating activities included textile design and printing, tailoring and sewing, knitting, block making, and poultry management. Fifty vulnerable families participated in income-generating activities; 300 children from poor HIV/AIDS-affected families were supported with school fees and supplies; and 300 children were removed from child labor and integrated back into their communities and schools.

**Family Reintegration and Follow-Up:** Tasintha also assists women who desire to mend rifts with their families to re-open communication by providing counseling to both women and family members with the ultimate goal of reintegration. Extended follow-up with women after they leave the program is something Tasintha staff would like to do more of, but systematic follow-up and home visitation have been limited by lack of financial and human resources. Many of the women develop a bond with Tasintha staff and other women in the program, and often visit or call to check in and give updates on how their lives are going. They also turn to Tasintha staff in times of distress. Children who have been supported over the years by the program also tend to keep in touch even after they have grown into adults. Staff mentioned one young man who now has his MBBS who visits frequently and helps out with
program activities when he can. While the staff regret that their own capability to do follow-up with women and children is limited; they are grateful that so many former clients and children keep in touch.

**Psychosocial and Peer Support:** Women in the program are encouraged to talk about their experiences in sex work openly with one another as a means of reducing their self-isolation and feelings of stigma. There is a trained counselor/social worker on staff who meets with the women individually and in group sessions. According to program staff, most Tasinha clients have experienced some form of gender-based violence, which is a frequent topic of discussion in group sessions. As women gain confidence in talking about their experiences they are encouraged to speak out about their lives in order to educate the general public. Over the years, a number of clients have appeared on television and radio to educate the general population about the vulnerabilities faced by sex workers, gender-based violence, addiction, and HIV. Tasinha assists women with alcohol and drug addiction to access rehabilitation assistance at Serenity House.

**Broader Need**
Tasintha leadership has a strong sense of the unmet need faced by young women for education, skills training, and economic opportunities that will give them feasible money-making opportunities beyond sex work. As they state in their 2009 Annual Report: “Currently, Tasinha Programme is overwhelmed by the large number of practicing sex workers who would want to participate in our empowerment and training programmes but due to limited funds, we can only take limited numbers (approximately 200 per year).”

**Challenges and Limitations**
**Funding:** Tasinha’s annual budget is approximately $250,000 USD. They operate on a combination of small grants from a variety of donors; therefore, continuous funding for key programs is an ongoing challenge. Program staff write multiple small grant proposals each year for tied funding to support skill training for set numbers of women. While they have achieved important, long-term partnerships with their key donors, their programs are still at the mercy of changing donor priorities. For instance, the Global Fund for Children (not affiliated with the Global Fund for Tuberculosis, AIDS, and Malaria) began supporting education and nutritional supplements for Tasinha children in 2002, but recently discontinued their funding. For this reason, nutrition assistance is not currently provided to children. Tasinha staff noted that in their experience donors are not interested in providing comprehensive nutrition assistance for either children or women; therefore, they cited the nutritional assistance as one of the biggest challenges they face. They are currently approaching potential private sector partners seeking long-term commitments to assist with key program areas such as nutrition or day care for children. Staff noted that the Zambian government tends not to provide financial support to civil society organizations; therefore, they do not foresee government assistance as a potential source of support.

The current Tasinha facility is not a full drop-in center in the broader meaning of that term. Women can receive some health care, counseling, referrals, skills training, and one another’s company at the center, but they cannot bring their young children when they come for training as there are no day care facilities. Program leadership and staff spoke eloquently about their frustration at these gaps in their programming and about future plans to make support services for both women and children more comprehensive. If they can secure funding, they plan to build a room where children can come after school to use computers, do their homework, receive assistance with homework, etc.

Despite these challenges, Tasinha staff have been extremely resourceful about creating a sustainable funding stream to support their initiatives. Several years ago, the Norwegian Agency for Development
Corporation helped them to buy the large industrial compound in which their offices are located (formerly Zambia Steel). They rent space in the compound to artists and to a variety of manufacturing companies, including a wig factory and construction companies. The rent paid by these tenants constitutes 40% of their operating budget, helping to pay staff salaries, education fees for children (particularly for tertiary education), and cash assistance to women as they transition out of sex work. They have subsequently invested in another property on the outskirts of Lusaka that they collect rents from and eventually plan to move to so that they can expand their income generating activities, which at a larger scale can be used to further support services.

*Program Record Stability and Data Archiving and Management:* For the last 20 years, Tasintha has kept extensive files on the women and children receiving their support. For the most part, this rich resource (which fills a small locked room) is paper-based and at the mercy of mildew, termites, water damage, fire, etc. Digitizing program client records would improve information security and also allow senior management to use the data for evaluation and future grant-writing purposes. The records could also be used to understand the needs of sex workers and their children in Zambia over time. They currently have funding from the Nike Foundation to document success stories and improve their monitoring and evaluation system. Securing these records and rich institutional history is a project that will take time and human resources that are far beyond their current capacity.
Helping sex worker mothers build skills and find work in Zambia: One of the women currently enrolled in Tasintha had been selling sex for approximately a year in order to pay her sons school fees. When she was recruited by Tasintha, they immediately started paying his fees and she enrolled in an income generation project. When she later found out she was pregnant, she was given leave and some financial support when the baby was born. She has been associated with the program for 3 years.

Supporting education of a child through tertiary education: Even though Tasintha only supports women enrolled in its programs for a couple of years, they continue to assist with school fees for children as long as they are needed for the child to stay in school, and they do their best to also provide youth with professional, tertiary training. Some examples of this advanced, long terms support helping young people to enter professional careers include: A young man finishing the fourth year of his MBBS and volunteering at the Tasintha offices on a regular basis; 2 currently working as medical officers; 1 studying nutrition at the University of Zambia; 1 working in hotel catering in Lusaka.

Impact of substitution therapy on parenting in Ukraine: Despite the limitations inherent in continuing addiction to a drug, there is no question that substitution therapy can help adults be more responsible parents. A social worker explained her own ambivalence about the benefits and limitations of ST: “A client comes here every day with her baby to take her ST. It sometimes makes me feel sad to see that she is still chained to a drug. But I also regularly see her shopping for fresh fruit at the market on the corner, and I am happy to know that the [ST] is what allows her to be healthy and a good mother.”

Intervening creatively in Ukraine: Social workers at the Left Bank Center can occasionally influence residential rehabilitation programs to allow a child to accompany the mother: “Many rehabilitation centers will not accommodate children who may end up with a family member or in an institution or on the street. One of our clients was very successful staying clean for 2 years, but then she started using again. She couldn’t find a place where she could go with her child and he almost ended up on the street. We intervened and she was able to bring him with her.”

Successful ART in Quang Ninh, Viet Nam: There are a total of 22 children on ART at the Van Don OPC. All are healthy and none have died. However, a number of children have arrived at the clinic in dire need of ART, with ultimate survival far from certain. One case involved a child who was brought to the clinic when she was 9 months old and weighed only 4.5 kilos. A program staff person explained: “This child had been referred to the Central Pediatric Hospital in Hanoi, but there was nothing there for her. She was brought here [to the Van Don clinic], given ART, and is now thriving.”

Another case involved an HIV-positive child whose parents had both died: “He lived with his grandparents for some time, but after the grandfather died, the boy became aggressive. He came to the OPC and was able to receive help with school fees to allow him to stay in school. We (the HBC team) visited him at home to provide him with ART. The child now is more open and happy, attends school, and is a regular OPC client.”

Attending school in Hanoi, Viet Nam: Staff at the Pagoda Club came across a family in which there was a 14-year-old child who was working and not in school. “We intervened and talked to the parents, persuading them to let the child go to school the next year. This worked because we focus on the child-adult relationship. We organized a small group of families and talked about the importance of caring for each other and maintaining strong relationships. It was successful and the families really liked it.”

Overcoming stigma in Van Don, Viet Nam: A 15 year-old girl had lost both parents and was living with her aunt. The aunt had psychosocial issues that affected the child. When Van Don HBC staff encountered the child, they saw she was very sad: “When we tried to talk to her, she wouldn’t respond. We persisted and discovered that her friends wouldn’t play with her. So the doctors at the OPC met with her school principal and teachers and we organized a community event to explain HIV transmission. Teachers were invited to a training course offered by a private health clinic. The OPC also invited the child to share her experiences at some public events. People began to understand and help her. DOLISA also gave her 300,000 VN Dong every month. Now she is doing well and in school.”
Programs in the three countries face both common and unique challenges. Here we highlight challenges experienced by all the programs:

**Funding:** While the programs vary in the degree to which they have enjoyed a stable and predictable funding source, all the programs are limited in what they can do for children due to financial constraints. In **Zambia**, Tasintha is not currently able to provide nutritional support for children because of changes in donor priorities. Tasintha also lacks resources with which to visit clients' homes, so are not able to follow up with women and children as systematically as they would like.

In **Viet Nam**, FHI's funding constraints appear to most directly limit nutritional support, gifts and activities for children, and help addressing shelter and job needs. Tight budgets also prevent programs from hiring more staff and paying higher salaries, thereby putting pressure on existing human resources. Program staff typically care for large numbers of clients, often over remote distances, leading to long working hours. Over time, this hurts staff morale.

In **Ukraine**, a comprehensive case management and harm reduction program for sex workers, implemented by AIDS Foundation East-West (a HealthRight International partner) has been running successfully for the last three years in three cities. Trained social workers assist sex workers to “resocialize,” by helping them to get legal documents, learn vocational skills, find housing, and fill other basic needs. The apparently successful program closed its doors in April 2011 as the donor, the Swedish International Development Agency, has identified new priorities and redirected funding.

**Poverty:** The grinding poverty that affects so many families, in addition to HIV infection, presents enormous challenges due to the complex web of issues that affect very poor client households. Program staff in all the programs mentioned being able to provide treatment for specific ailments, and to help cheer up children for a day with something special such as an outing, a meal, or a gift, but not being in a position to address the fundamental and enduring problem of experiencing HIV and other health issues in the face of extreme poverty.

**HIV-related stigma:** As highlighted above, stigma poses a major challenge in adequately and efficiently providing services to both adults and children. Fundamentally, the programs cannot remove stigma, but rather continually cope with it and try to overcome it as it relates to their clients.

**Serving MARP clients:** All the programs face inherent difficulties due to the high risk behaviors and vulnerabilities of so many of their clients. For the programs serving large numbers of IDU, the main challenge is dealing with clients who often have priorities other than their own health needs and the many needs of their children. While some clients are on substitution therapy or are high functioning as an active IDU, others focus on obtaining and using drugs, often with little attention to their children or even actively disrupting family life. As a program staff member noted in Viet Nam: “IDU are special clients with many problems.” For Tasintha in Zambia, a major challenge is finding ways of reducing the appeal of highly-paid sex work. Once a woman is earning the relatively large income commercial sex provides, she may have a hard time deciding to stop sex work for good (no matter how much she may want to). Unfortunately, they rarely save or invest their income in ways that can help make them more financially stable over the long term.
7 Lessons Learned

While this project was not an evaluation of programs, and we are not in a position to assess program strengths and weaknesses, we do believe that there are several messages that emerge from this documentation of programs that serve the children of MARP. We hope the following are of use to other organizations currently or contemplating providing services to these children.

1. Children of MARP typically live in complicated situations and often have a variety of unmet basic needs, among them: food security, access to education, appropriate care and shelter, health care, psychosocial health, and legal protection. We recommend that existing programs providing services to adult MARP try to learn about the most urgent needs of the children of their MARP clients and, to the degree possible, add to their programs to help meet these needs.

2. The “continuum of prevention and care” approach that FHI is implementing, involving a combination of out-patient services and home-based care services, seems to work well in large part because it treats HIV not as an individual infection but as a family and community challenge which requires a multi-dimensional approach to tackle. It also accepts that no child or household will be identical and require the same set of services. Likewise, HealthRight International’s comprehensive case management approach focuses on the specialized needs of individuals and their families while simultaneously attempting to reduce vulnerability a the population-level through provision services and ongoing advocacy. Although there may be no perfect or ideal way to cope with the challenges faced by the children of MARP and their parents, an approach that recognizes the complexity of these situations and the need for a comprehensive approach seems appropriate.

3. The psychosocial issues faced by children of MARP are poorly understood. The stigma and isolation they often confront, exacerbated by the effects of poverty and possibly ill physical health, suggest that there is a major need for greater knowledge of these needs and the design and implementation of services to help address them. While this calls for more research on this topic, existing programs need not wait for more evidence to begin to take action. First, they can begin to offer counseling for children-in groups or individually-where possible. Second, they can play an important role in attracting attention to this issue by raising it with donors and experts and seeking help to understand the psychosocial needs of children they are or plan to assist.

4. Stigma emerged as one of the foremost barriers to successful programming—both for clients who receive services and for potential adult clients who shy away from services out of fear that they and/or their children will be stigmatized. We recommend that programs serving MARP, regardless of whether they also offer services for children, actively seek to reduce stigma in the communities in which they work through more outreach and education designed to help community members understand HIV, routes of transmission, and the services available to prevent and treat HIV/AIDS. The more that adult MARP are comfortable coming forward to take advantage of those services that are available, the more their children will benefit in direct and indirect ways.

5. The available evidence suggests that opioid substitution therapy can help IDU live more stable and productive lives. In addition, our findings (in Ukraine and Viet Nam in particular) underscore the benefits that extend to children of IDU when their parents are able to access methadone therapy. While scaling up access to ST is a major task for large organizations and governments, programs that provide services to MARP should be able to provide information about methadone services to their clients and encourage them to access them.
6. While the three programs documented here all provide critical health and social services to MARP and their families, they are also each in their own way vocal advocates for HIV prevention, stigma reduction, human rights, and family-centered care and support and policy change to protect vulnerable populations at local and national levels.

7. The limitations faced by each program are inextricably tied to context-specific social, economic, and political challenges including high levels of poverty of clients, gender-based violence, stigma and discrimination toward both PLHIV and MARP, and (in the case of Ukraine and Viet Nam) legacies of institutionalization as a form of social control, and (in Zambia) lack of government funding for civil society organizations.
8 Directions for Future Research

In this exploratory program-based research project, we focused on three different intervention models in clearly different social contexts and HIV epidemics to shed light on the special needs of MARP individuals and their children. Through our data collection, we gained valuable insights into the environments of MARP program clients and their children, the needs and vulnerabilities of affected children, the services the three programs are providing, and the challenges they face as they seek to ameliorate the negative impacts on children of HIV infection within families. We found commonalities in the issues that affect children and the limits in what programs can achieve. We also uncovered notable differences in programmatic approaches and emphasis on service areas. This suggests that a variety of strategies may be employed to make a substantial difference in the well-being of children of at-risk parents. We hope these findings will be useful to other programs interested in addressing the needs of children affected and infected by HIV.

This effort can be viewed as a critical first step in improving understanding of the needs of HIV-infected MARP adults and their children and the ways that different programs have been able to address these needs. Based on our findings and discussions with in-country collaborators, we recommend pursuing a number of relevant research questions that are applicable to numerous low- and middle-income countries (e.g. Ghana, Russia, and India) with concentrated, mixed or generalized HIV epidemics. These are described briefly below in two categories: evaluation research and exploratory/descriptive research.

A. Program evaluations

1. Evaluations of programs that aim to address the needs and vulnerabilities of children in order to improve our understanding of short-term and long-term impacts of these efforts. These should ideally encompass programs that serve children of different ages (<5 years, 6-11 year olds, and adolescents and teenagers) and genders. They might include rigorous quantitative studies that measure internationally recognized indicators of child well-being, in such areas as nutrition, emotional health, social well-being, school attendance, educational performance, and child labor. They may also encompass in-depth qualitative explorations of different aspects of apparently successful programs, with a focus on collecting data from children and parents. These evaluations should include government programs as well as those provided by NGOs and could include cash transfer projects, educational support programs, etc.

2. Research that examines elements of an apparently successful program, adapts and implements them in another setting, and evaluates the extent to which success can be replicated, along with reasons for success and failure. Such research can be particularly helpful in the efficient scale-up of interventions to address the vulnerabilities and needs of children affected and infected by HIV/AIDS.

3. Studies assessing program management and processes, including funding, personnel management, strategic goal-setting, and change adaptations.

4. Cost-outcome studies that help stakeholders at all levels better appreciate the resources needed to achieve improvements in child health and well-being. These would be relevant at any or all of the three programs included in the present study, though other programs addressing the needs of children would be target participants as well.
B. **Exploratory and descriptive studies**

1. Research to shed light on the health and psychosocial needs of the children of MARP, including needs that may be related to the MARP behaviors and HIV status of the parent(s). Such efforts should focus on different ages and genders of children. This could be done using a rigorous quantitative analysis comparing children of MARP with other children, an in-depth qualitative research approach, or as a quantitative-qualitative mixed-methods study.

2. Research that involves digital archiving and qualitative analysis of detailed client social work and other narrative records. We have much to learn from small, long-running grassroots programs about the changes in the needs of MARP and their children over time (at the individual, cohort, and population level) and programming pitfalls and best practices from extant, detailed, fragile, paper-based program records.

3. Descriptive analysis of program cost—including sensitivity analysis to better understand those factors that affect total, fixed, and variable costs of program implementation.
Works Cited


10 Appendix 1: Field Sites Visited

Findings synthesized from interviews with staff at the following organizations and partner sites:

**Tasintha (Zambia)**
- Lusaka Headquarters
- Child in Need Network (CHIN)
- Chilengi Transit Home
- University Teaching Hospital
- Archdiocese of Lusaka

**HealthRight International (Ukraine)**
- Kyiv Country Office
- All Ukrainian Network of PLWHA
- Community Center for PLWHA
- Kyiv City AIDS Center
- AIDS Foundation East-West
- International Renaissance Foundation (Open Society Institute)
- Center for Women and Girls
- Kyiv City Center for Social Services
- Convictus
- Kyiv City Crisis Center
- International HIV/AIDS Alliance
- Hope and Salvage

**Family Health International (Viet Nam)**
- Hanoi City Offices
- Pagoda Club, Hanoi,
- Van Don OPC and HBC, Quang Ninh
- Cam Pha OPC and HBC, Quang Ninh
- Thu Duc Preventive Health Center, OPC, and Community Home Based Care (CHBC) Team, Ho Chi Minh City
- Binh Thanh OPC and CHBC Team, Ho Chi Minh City