CRS
CATHOLIC RELIEF SERVICES

Home-Based Care Assessment

GIVING HOPE TO A WORLD IN NEED

2008

Since 1943, Catholic Relief Services (CRS) has held the privilege of serving the poor and disadvantaged overseas. Without regard to race, creed or nationality, CRS provides emergency relief in the wake of natural and man-made disasters. Through development projects in fields such as education, peace and justice, agriculture, microfinance, health, HIV and AIDS, CRS works to uphold human dignity and promote better standards of living. CRS also works throughout the United States to expand the knowledge and action of Catholics and others interested in issues of international peace and justice. Our programs and resources respond to the U.S. Bishops' call to live in solidarity - as one human family - across borders, over oceans, and through differences in language, culture and economic condition.

Important Note: The photographs in this publication are used for illustrative purposes only; they do not imply any particular health status (such as HIV or AIDS) on the part of any person who appears in the photographs.

Acronyms

AIDS   Acquired Immunodeficiency Syndrome
ART   Antiretroviral Therapy
ARVs   Antiretrovirals
CRS   Catholic Relief Services
HBC   Home-based Care
HIV   Human Immunodeficiency Virus
IGAs   Income Generating Activities
M&E   Monitoring & Evaluation
NGO   Non-Governmental Organization
OVC   Orphans and Vulnerable Children
PEPFAR   President's Emergency Plan for AIDS Relief
PLHIV   People Living with HIV
PQSD   Program Quality and Support Department
UN   United Nations
UNAIDS   Joint United Nations Programme on HIV/AIDS
USAID   United States Agency for International Development
USD   United States Dollar

Introduction

The World Health Organization defines home care as "the provision of health services by formal and informal caregivers in the home. Such care includes physical, psychosocial, palliative and spiritual activities." WHO goes on to say that the goal of home-based care "is to provide hope through high-quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life," (Foundation for Hospices in Sub-Saharan Africa, 2008). According to AIDSmap, "…home-based care, which in many resource-limited settings is the only way to deliver care to the patient. It has been estimated that 50% to 60% of people with HIV/AIDS worldwide have no access to professional healthcare workers to address their medical needs," (2003). Often distance to health centers and the lack of finances and resources for medical care, make HBC the most effective way to care for those that are ill. Health care facilities often lack trained personnel and basic medical supplies and medications. "Palliative care programs that focus attention on integrated community- and home-based care (HBC) are thus the most efficient and cost-effective approach to healthcare delivery," (AIDSmap, 2003).

Providing support to Home-based Care (HBC) programming has evolved into a significant aspect of the Catholic Relief Services (CRS) response to the HIV epidemic worldwide. This support takes the form of financial resources and technical assistance to partners, and in some cases, direct engagement in implementation of care and support to people living with HIV (PLHIV). The HBC model, the methodology applied, specific services provided and implementation philosophy vary (sometimes dramatically) from one country to the next, providing a plethora of experiences and learning to draw from. An assessment of CRS' HBC programs was undertaken to look for trends, similarities, differences and promising practices among HBC programs throughout the world. The observations recorded in this document will provide insight into future HBC programs, as well as making generalized recommendations for HBC programming.

Methodology

In June and July of 2007, two consultants were contracted by CRS to interview staff and partners in an effort to examine a range of issues related to their HBC programs. The development of the questionnaire was a collaborative effort by CRS Program Quality Support Department, HIV and AIDS Unit and the consultants. It consisted of 24 questions on themes ranging from how the program identifies clients from within the population and what the typical client's disease stage is when they enter the programs, to what indicators are used and what are the greatest challenges in monitoring the program.

A total of 21 interviews were conducted with individuals who volunteered to contribute to this study, representing 26 CRS projects from 19 countries. Most interviews were conducted by phone, and lasted (on

average) 2-3 hours. Supporting documentation and photos were also collected, and in many cases, email follow-up elicited further detail. Most interviews were conducted in English, but where participants were more comfortable in French, Spanish or Portuguese, a range of methods were used, including the use of a third-party translator, exchange of written responses for translation[1] and recording of interviews (to allow for more careful transcription). Respondents were drawn from many levels of HBC service, and included CRS field staff with direct line authority for the project, representatives from partner agencies involved in implementation, CRS staff in Chief-of-Party positions, and a CRS Regional Advisor[2].

This report briefly examines some of the trends that emerged in comparing and contrasting the various programs. It also points to promising practices that potentially warrant further investigation, with the goal of sharing learning across countries and HBC models.

Through interviews conducted with CRS country programs and partners, information was gathered from the following HBC programs:

1. **Benin**: SEDEKON ("The Spirit of God Watches Over the Patients")
2. **Brazil**: Igreja Construindo Solidariedade na Luta Contra a AIDS (The Church Constructing Solidarity in the Fight against AIDS)
3. **Cambodia**: Little Sprouts, Seedling of Hope, and AHEAD/Cambodia
4. **Cambodia**: HIV Integrated Livelihoods
5. **Chad**: Home-based Care
6. **China**: HIV/AIDS Outreach Program (Liaoning Province); Light of Hope Program for Care and Support for PLWHA and Prevention and Awareness (Hebei Province); HIV/AIDS and Health Outreach (Jilin Province)
7. **Congo**: AMITIE ('Aid impact initiative to amass care and support for OVC and PLHIV')
8. **Eritrea**: HBC Program
9. **Ethiopia**: Mekelle and Enderta HIV/AIDS Prevention, Care and Support Project
10. **Gambia**: CRS Catholic Church HIV/AIDS Care and Support Project
11. **Ghana**: Community Collaborative Care and Support Project (COMCESUP)
12. **Guatemala**: Proyecto Vida (PV), or Project Life
13. **India**: Vasavya (VMM) HCBCS (Home and Community Based HIV/AIDS Care & Support Program)
14. **Kenya**: APHIA II Rift Valley
15. **Malawi**: Dedza Integrated HIV and Food Security Project
16. **South Africa**: Diocese of Tzaneen HIV/AIDS Response
17. **Togo**: Love/Hope
18. **Vietnam**: Hoc Mon Program
19. **Zambia**: RAPIDS
20. **Zambia**: Scaling Up Community Care to Enhance Social Safety Nets – Return to Life (SUCCESS-RTL)
21. **Zimbabwe**: HIV Partners Project (Diocese of Mutare Community Care Project [DOMCC] and Chinhoyi Health Care Commission [CHCC])

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[1] The questionnaire was translated to French to encourage engagement of Francophone programs (see Appendix A and B).
[2] A complete list of respondents is attached at the end of this report (Appendix C).

Following the completion of the survey, the data were analyzed using the STATA statistical software package (version 9) and the Nvivo qualitative data software package (version 7). In the case of one of the Cambodia surveys (i.e., Little Sprouts, Seedling of Hope, and AHEAD/Cambodia) and the China survey, it was necessary to treat each program within the survey as a separate entity for the quantitative analyses, even though they had been combined into one document. This is due to the fact that in some cases, answers to the questions differed between the programs that were listed in the same survey. This is the reason that in many instances, n>21.

Project Description

> **"With a multi-level approach, we are not working in isolation – each part of the strategy informs the others, with information flowing in all directions. We don't become disconnected. We're more powerful"**
>
> *– Respondent, Zambia*

The programs that were represented during the course of the assessment show a wide diversity in programming. One of the clearest findings to emerge from this assessment is that there is no "set formula" for HBC programming. In fact, two of the programs represented (Brazil and the Cambodia Integrated Livelihoods program) overtly stated that they were not even HBC programs in the technical sense, but they did offer HBC-related services. HBC models reflect the communities they serve and the needs of their clients. As such, some programs relied on volunteer caregivers, while others relied on paid staff; some were actually facility-based, while others were community-based, and others were truly home-based; some were highly interconnected with the local Church units, others were not. Many programs deliberately recruit PLHIV as HBC providers. The clear message is that HBC can and should be tailored to local needs and resources.

Likewise, the stated goals of the programs varied as well. Among them were: to build community capacity, to contribute to the national response to AIDS, to reduce HIV-related stigma, to meet the needs of orphans and vulnerable children (OVC), to integrate HIV programming with other services, to foster solidarity, to increase the lifespan of PLHIV, to improve livelihoods, to foster the dignity of clients, and to help people make better decisions.

In light of the above, it might be tempting to think that HBC is so context-specific, that it is impossible to generalize the experience of any given HBC program to another. However, there were some useful themes and data that emerged across programs that will be outlined in this paper.

Funding

The average grant amount for the HBC programs surveyed was 1,180,801 USD, although this figure is somewhat misleading. Indeed, the average grant amount in areas with a concentrated epidemic was only 402,850 USD, whereas in countries with a generalized epidemic, it was 1,958,752 USD-- a difference of 1,555,901 USD. Unsurprisingly, the size of the grant was a significant predictor of the number of clients served by the project: for each additional 100,000 USD on the grant, an average of 244 clients more were served ($p<0.001$).

Funds for the projects came from a variety of sources (Figure 1). By far, the most common donor was CRS, through private funds. The two bilateral organizations that were represented as donors were USAID and PEPFAR. It is notable that not a single program had funds from the UN or other international agencies. However, it was very common to have multiple donors for any given project. On average, the programs had 2 different types of donors for their programs (SD=1).

Project Clients

Most of the programs only served patients who had tested positive for HIV. This does not necessarily mean, however, that the clients must present with HIV-related symptoms in order to be included in the HBC program. The percentage of clients who were symptomatic varied widely across the programs. A small number of programs only admitted those who were symptomatic, but most had a mix of symptomatic and asymptomatic clients. Furthermore, some programs served not only PLHIV, but also people with other chronic illnesses.

Figure 1: Program Donors (% of Programs)

It is worth noting that all three of the programs that reported using active recruiting methods (such as outreach to specific groups) were located in areas with a concentrated epidemic (i.e., low-prevalence areas). This fact may be important to those designing such programs in low-prevalence countries, as in some cases, the most effective way of locating clients is by actively recruiting rather than waiting for referrals or self-referrals.

Services Offered

Respondents were presented with a menu of 13 types of services and asked to select those that were provided through their HBC program. The most commonly provided services are summarized in Figure 2. Those that were less-commonly provided are summarized in Figure 3.
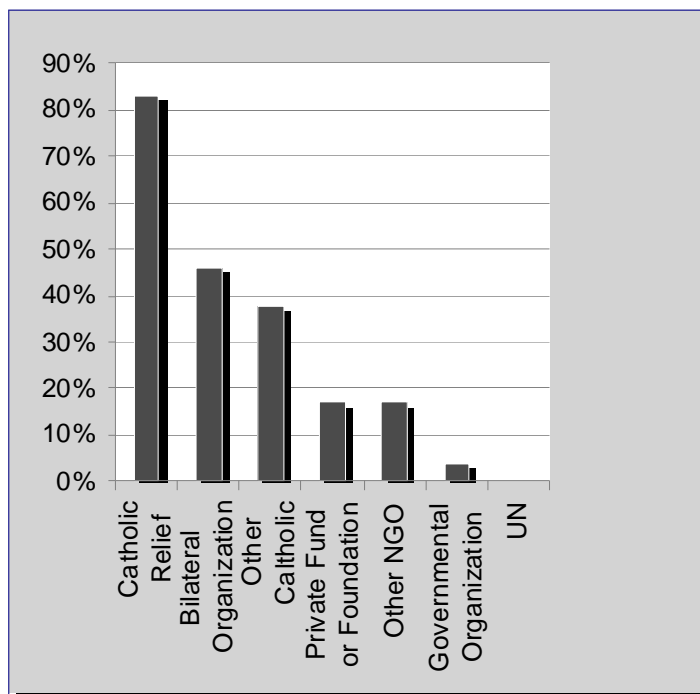
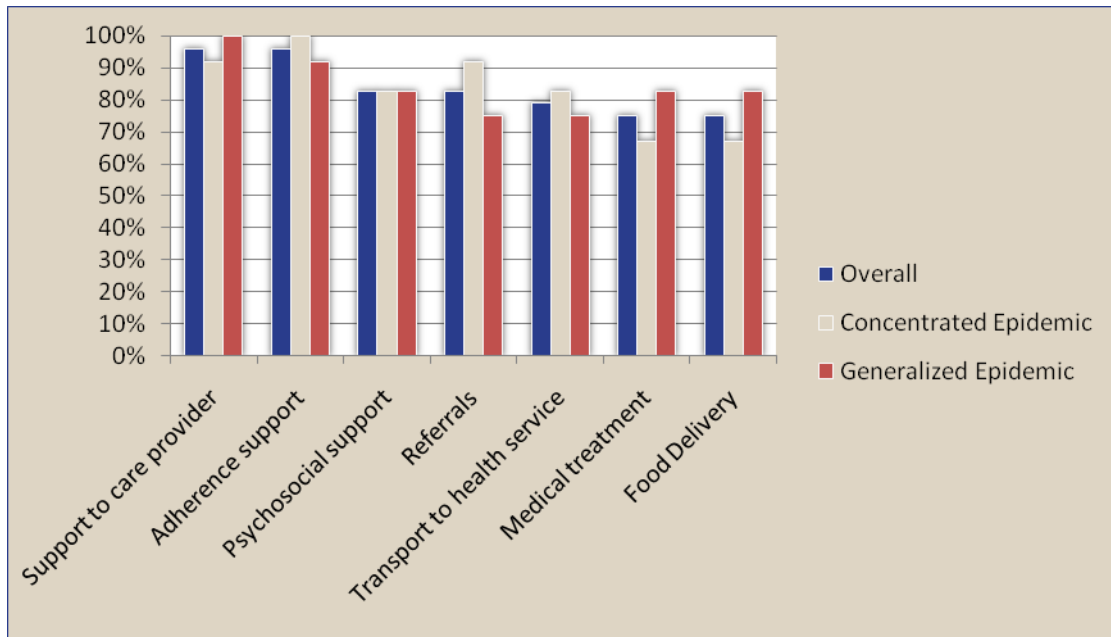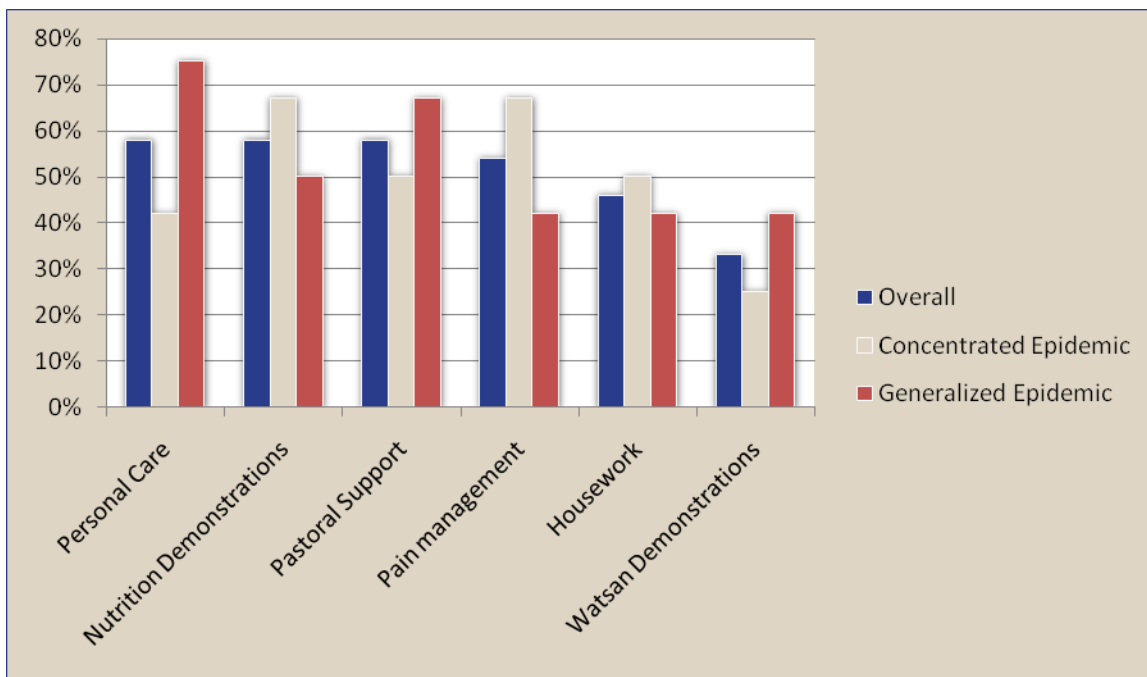**Figure 2: Most Common Services Offered (% of Programs)**

Figure 3: Less Common Services Offered (% of Programs)

It should be noted that neither the grant size, nor the type of epidemic, nor the percentages of caregivers who are volunteers were statistically significant predictors of the total range of services offered. Even for some of the more common services, there were some creative ways of making them appropriate for the local situation. For instance, one program promoted referrals and linkages by working with the volunteers to map each of the services in the community, which they then printed and distributed to clients. Another program did not feel that providing food through the project was sustainable or fair to other poor not living with HIV. However, recognizing the need for nutritional support for PLHIV, they decided to collect food from the community, which is then provided to the neediest.

One interesting contrast in views was the issue of providing personal services to the clients (such as cleaning or grooming). One program provided haircuts and grooming as it was felt that it accomplished the larger goal of promoting the self-esteem of the clients. On the flip side, one program discouraged providing services (such as cleaning the house) for clients because they did not want family members to start to rely on caregivers for such services; it was felt that this was not the best use of the caregivers' time.

Table 1: Other Services Provided

Beyond the HBC services that were specifically included in the survey, there were a number of additional services provided by the various programs. These are listed in Table 1.

• Advocacy for rights of PLHIV	• IGAs
• Agriculture planning	• Massage therapy
• Community prevention campaigns	• Microcredit
• Educational materials	• OVC-specific services
• Environmental hygiene	• Rural livelihoods
• Family gardens	• Self-care
• HBC kits	• Socialization
	• Stigma reduction

Around 70% of programs stated that they not only supported the individual client, but also the family of the client. This took many different forms, the most common of which were income generating activities (IGAs) (7 programs), training for family members (5 programs), and nutritional support (3 programs). The provision of psychosocial support and microcredit were other—albeit less commonly listed—ways of providing support to the families. Likewise, 67% stated that they provided some form of nutritional support to clients.

Caregiver Workload

The mean number of clients per week that each caregiver saw ranged from 3 to 24, with a mean number of clients per week of 11 (SD=5.0). In addition to actual differences in caregiver workload, the wide range in distribution can in part be accounted for by two facts: 1) these figures were often—as overtly stated—conjectures on the part of program managers, and a few simply had no idea; and 2) the fact that some caregivers worked full-time, while others had jobs, and thus had more limited time for

caregiving activities. The fact that some program managers did not know the specifics of the workload of their caregivers may indicate a lack of a tracking system on the part of the caregivers, which may be an area for improvement. On average, programs with volunteer caregivers saw 9 patients per week. Programs staffed with paid caregivers, on the other hand, saw an average of 17 patients per week. This difference is statistically significant (p=0.003).

Caregiver Retention

The issue of caregiver retention proved to be very interesting and complex. In the words of one program manager, "attraction of [a] good salary is not the only motivation" for caregivers. The outcomes, approaches, and opinions on the issue were as varied as any in the analysis. Eight of the programs mentioned specifically that they had no problems with retention, whereas others stated that it was a real issue in their program. Although a few respondents offered actual caregiver retention rates, they were not specifically asked to report on them. For future evaluations, it would be highly useful to gather actual retention rates. If programs are not already currently collecting such data, it should become part of standard monitoring and evaluation practice of CRS HBC programming. This information can help determine for future programs what types of incentives really affect retention rates, thus helping provide more sound guidance to country programs on the types of incentives they should consider offering. Furthermore, it would be interesting to do a study among HBC caregivers as to what they relate as their motives for continued service.
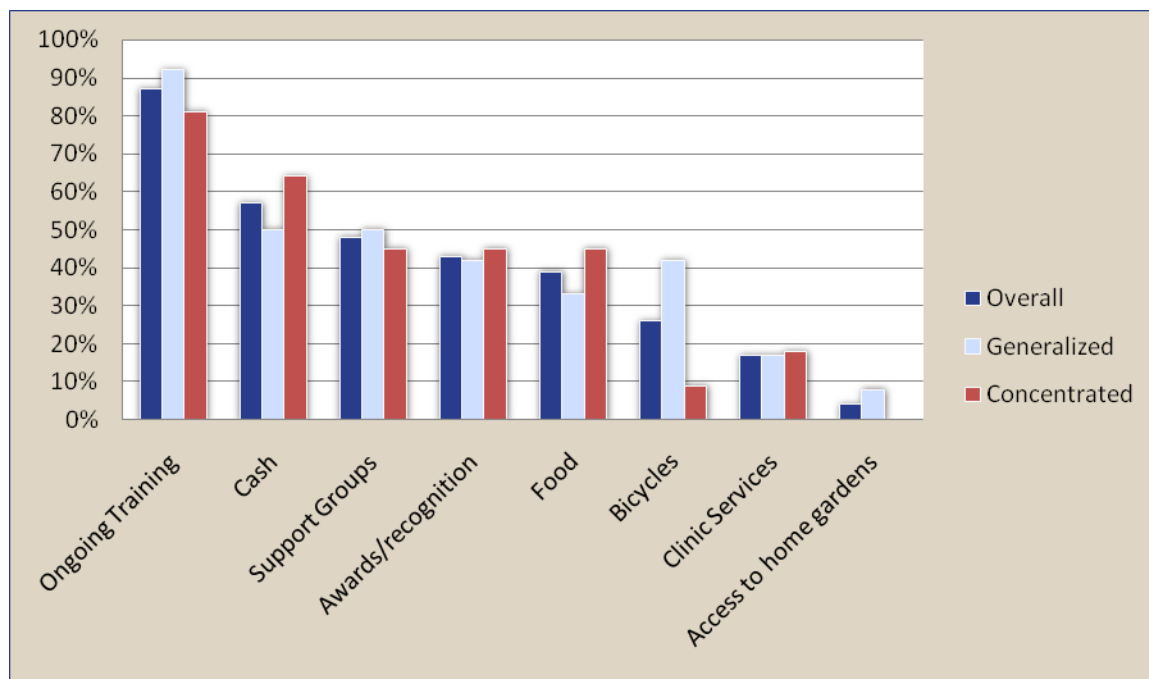
Strongly intertwined with retention is the issue of incentives, which, as one respondent put it, "is contentious because of the need to harmonize with other CRS resources." In the field, "there is a lot of politics around 'incentives' between NGOs [as well as] between NGOs and the government, with fear about sustainability and a growing interest in trying to harmonize." In response, some programs refuse to provide any form of incentive to caregivers. Others simply provide what one program called "Tools for Work", (in that case, umbrellas, bags, T-shirts), which they did not feel were true incentives. Some programs felt strongly that the volunteers' needs should be addressed just as much as their clients'. However, others felt just the opposite: that volunteering in and of itself was fulfilling a need, and thus, in the words of one respondent "[we] need to direct [our] services to the beneficiary, not more towards the volunteers."

In a similar vein, one respondent felt that incentives actually had little to do with caregiver retention. Rather, it was "the careful selection process [that] contributed to the retention success. When the program began looking for volunteers in each village, they engaged local authorities and representatives from various community structures-- such as village health volunteers, village health committees, health center management committees and traditional birth attendants-- in their search." In other words, steps can be taken during selection to ensure that people that are less likely to drop out of the program are used as caregivers.

As with the program services question, respondents were presented with a list of incentives and asked which were provided for caregivers (Figure 4). There was no statistically significant difference between the types of

incentives offered to caregivers between those in areas with a concentrated epidemic and those in areas with a generalized epidemic; it is, however, interesting to note that caregivers in areas with a generalized epidemic were far more likely to have been provided with a bicycle than those elsewhere (42% vs. 9%, respectively). The difference was of borderline statistical significance (chi-squared p=0.076). This may be due to the fact that in areas with concentrated epidemics, the distance between clients is potentially greater than in countries with generalized epidemics. The most commonly provided incentive across the board was ongoing training, followed by cash—whether as a salary or to reimburse for transportation and other incidental costs (Figure 4). In addition to the incentives in Figure 4, some programs also offered psychosocial support, such as self-managed support group meetings (23% of programs), facilitated support group meetings (36% of programs), and regular contact with a supervisor or mentor (73% of programs).

Figure 4: Percent of Programs Offering Select Caregiver Incentives

In the Era of ART

All of the programs that were interviewed stated that they had clients that were on antiretroviral therapy (ART). ART is a relatively new part of the equation in the response to HIV and AIDS. Most respondents felt that it had fundamentally changed the nature of their HIV programming. ART has placed some additional demands on program staff and caregivers, but a few were quick to point out that in spite of this, ART has had a very positive impact on their clients. As one respondent put it, "all projects notice a more optimistic outlook among staff, volunteers and clients…and the physical care and palliative care are not in high demand. Much more time [is] spent on long term adherence issues and economic self-sufficiency." Another respondent felt that the additional demands, although grueling, contributed to the "professionalization" of the organization and made them more attractive to donors.

Some respondents also noted that ART has required that volunteers be re-trained and in some cases, budgets need realignment. The rush to build sufficient capacity to absorb HIV/ART funding was mentioned among respondents several times. Training and mentoring partners to be financially compliant with rigorous US government requirements was both positive and negative: staff complain about the extra workload but acknowledge the benefits of the training on their skill-set.
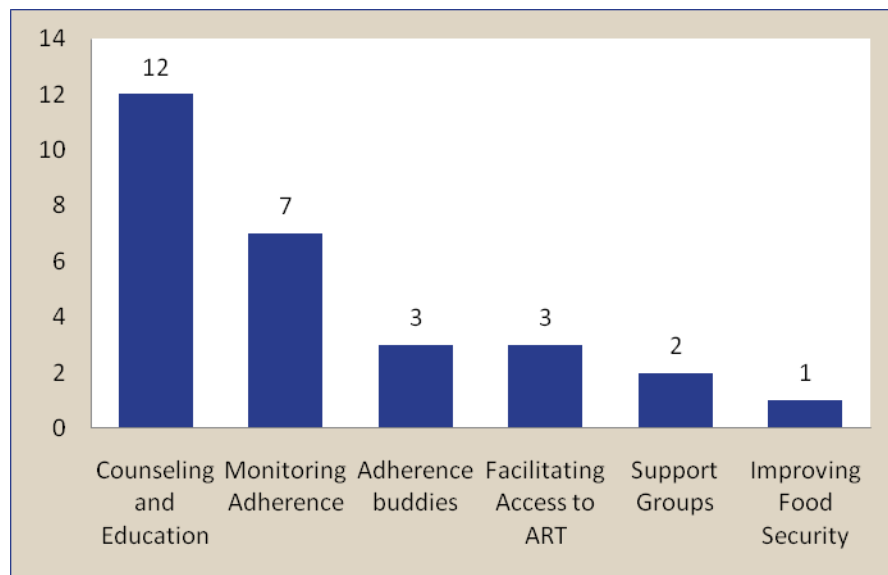
ART Support

Because every program had clients on ART, it is unsurprising that a significant majority of the programs (n=17) stated that they provided ART adherence support to their clients. Two programs made compliance to or participation in adherence support activities mandatory for all clients receiving ART through the program. Even among some of the programs that specifically stated that they do not

"First, patients receive two weeks of adherence training. They undergo this training before they are provided with ART so that they know what drugs they are taking, understand the importance of adhering to their treatment for life, and what to do if they experience side effects."

—*Respondent, South Africa*

provide adherence support, it was mentioned that they do counsel their patients to adhere. This indicates that the term "adherence support" may not be fully clear to program managers. In some cases, respondents indicated they provide adherence support, but failed to elaborate on how that was accomplished. As shown in Figure 5, adherence support took on a number of forms, although counseling and education were the most common forms.

Figure 5: Forms of Adherence Support

Monitoring adherence was accomplished in a variety of interesting ways. One innovative approach to monitoring adherence was by providing volunteer caregivers with cell phones, and having them call or send text messages to remind clients to take their antiretrovirals (ARVs). Other programs had caregivers create and maintain a calendar for their clients or had the caregivers be responsible for ensuring the medication was taken in their presence.

Respondents were asked to comment on their efforts vis-à-vis Positive Prevention and Positive Living programming. As with the term "adherence support", there was some confusion over what exactly this entailed. Three programs specifically mentioned that they do Positive Prevention, but they do not call it by that term. The majority of programs (n=18) had Positive Prevention programming in some form or another. As ART has become more available in low-resource settings, clients have begun to take a more active role in their health care decisions and maintaining wellness. Some respondents described their clients as more mobile, moving around freely so that they were difficult and expensive to locate and track and self-identifying to the project office in order to gain access to specific services. Client's expressed needs changed and programs are identifying increased need for transportation money and cell phones. As clients become more active and ART becomes more widely available, prevention with positives is a key component in providing the still much-needed support to PLHIV and curbing the HIV epidemic in these areas.

> **"The volunteers want to work to do the work, not to prove to the donors that they do the work. Convincing them that it is important to show their progress, not just for the donors but to improve their work is a challenge."**
>
> *—Respondent, Brazil*

Monitoring and Evaluation

Many of the programs used PEPFAR and/or UNAIDS indicators for monitoring in order to comply with donor mandates. However, some programs devised program-specific indicators.

The projects were at various stages of the project lifecycle. Some had already been completed, some had undergone evaluations, but were still ongoing, some were approaching their midterm evaluations, and one (Vietnam) even had yet to start.

Monitoring presented a number of challenges to respondents. These are listed in Table 2. Most of these challenges can be mitigated during the program development and implementation phases. For example, four respondents mentioned updating monitoring technology. This refers to only having a paper-based system available, thus increasing the amount of time needed to monitor. The program can budget for a computer and appropriate software in the proposal development phase to help avoid this challenge.
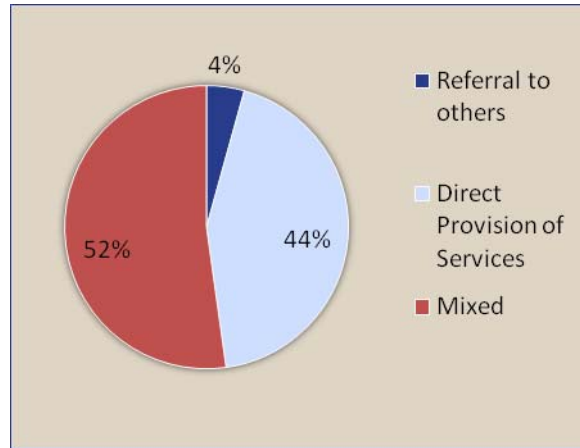
Table 2: Monitoring challenges

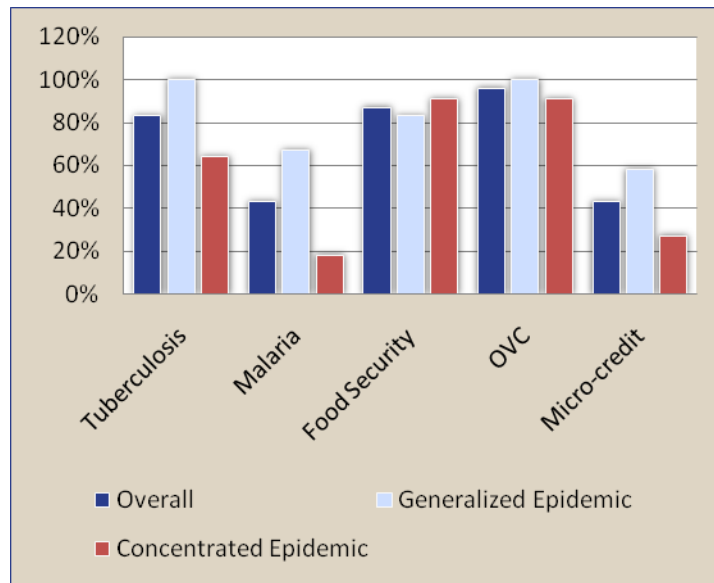| Challenge	Number of respondents
Ensuring the quality of monitoring data	6
Low motivation of staff to participate in monitoring	5
Conforming to donor monitoring standards	5
Updating monitoring technology	4
Measuring quality of life	3
Ensuring conformity of staff to monitoring plan	3
Geographic distances between sites	3
Low education level of volunteers	3
Stigmatization during monitoring activities	1
Standardization of process across sites	1
Dissemination of findings	1
Increasing the number of follow-ups	1

Referrals, Linkages, and Integration

Referral systems made up an important part of CRS HBC programs. When asked to determine whether the focus of their programs was referral to others or direct service provision, 56% said that referrals were an integral part of their programs. Even among those who stated that they focused on the direct provision of services; linkages were made with an average of 2.7 different types of services (compared to fewer than 4 types of services for those who reported a mixed focus and 5 for those focused on referral to others). Just over half of the programs reported that their referral systems were formalized (e.g. through forms, and/or institutionalized mechanisms, etc.). Two-thirds of the programs stated that they kept track of the number of referrals made.

Figure 6: Stated Program Focus

Programs in countries with a concentrated were less likely on all counts (other than food security) to form linkages with other programs. In some cases, such as with malaria, it is likely due to the differing overall epidemiological profile (i.e. many of the countries with concentrated epidemics happen to lie outside of malarial zones).

Figure 7: Linkages with Other Types of Programming (% of Programs)

Overall Program Successes and Challenges

Each program had specific features that they felt were particularly remarkable or "promising practices." These features were broad in scope, as each program had its unique experience with HBC. All felt that they were making a difference in their clients' lives, and sometimes even positively impacting the community as a

whole. One point that came up on a number of occasions was the commitment and dedication of the volunteers and staff of the project. Many of the program managers felt inspired by the caregivers' work.

Each program also identified various areas where improvement was needed. These are listed in Table 3. The most common challenges may be overcome with adequate training and a sound M&E plan. Other challenges directly involve a lack of resources, which may be impacted by increased or diversified funding.

Table 3: Identified Needed Improvements

Improvement Need	Number of Respondents
Inadequate skills of staff	7
Number of services offered	6
Monitoring	6
Information sharing (learning)	5
Service delivery	3
OVC component	3
Human resources	3
Access to ART	2
Needs assessments	2
Referral mechanism	2
Scale up	2
Targeting	2
Advocacy	1
Community mobilization	1
Increased church involvement	1
Number of male caregivers	1
Keeping up with changing environment	1
Inadequate caregiver incentives	1
Psychosocial support	1

Several respondents also mentioned that in addition to the benefits to the clients, one of the important outcomes of the projects was the increased visibility, respect for, and cooperation of CRS and the church in the communities they served.

Overall Program Recommendations

1. **Assess community needs -** It is evident by this assessment that there is not a set formula for HBC, as programs should be tailored to the local needs and resources. The needs of the community will impact the types of services provided; culture will impact what is appropriate in the context of HBC. The type of epidemic will impact how caregivers and beneficiaries are recruited and what types of HBC services are provided. CRS HBC program goals varied greatly, based on the type of program being implemented. HBC programs can serve many different purposes from OVC to stigma reduction to community capacity building or a combination of these.

2. **Diversify funding base -** There is a clear need for CRS country programs to diversify the existing donor base. While programs have two funders on average, there are limited funding sources with the majority of programs currently receiving funding from PEPFAR, USAID and private funds. While these are all valid sources of funding, the country programs should seek additional funding from alternate sources to maximize program long-term potential and sustainability.

3. **Increase funding -** For each additional 100,000 USD, an average of 244 more clients were served. Increasing funding widens the impact of the program both in services provided and those served. Evidence from the assessment shows that areas with generalized epidemics on average, obtain more funding for HBC than those with concentrated epidemics. The type of epidemic may also affect the variety and amount of funding available in that particular area. By diversifying the funding base, the opportunity for increased funding may be more feasible.

4. **Client selection and recruitment -** Clients should be selected based on need and the parameters identified by the program. The services provided may be appropriate for symptomatic, asymptomatic clients or both. Programs should create guidelines for the type of client to be served by the program. The assessment indicated that client recruitment is often based on the type of epidemic in the community. A community with a concentrated epidemic required more active recruitment for the program, whereas in a generalized epidemic clients were typically more self-referred.

5. **Services provided -** Individual program goals and resources play a role in the services provided to clients, especially pertaining to nutritional support and personal care. Some programs view these services as important parts of HBC, while others think that they create dependence. The development of program goals prior to implementation will help prioritize the services provided by the program. The type of beneficiaries also plays a role in service provision. If many of the PLHIV in the catchment area are on ART, there will be less need for care of the chronically ill and more resources will be required to put towards transportation and adherence support.

6. **Identify generalized versus concentrated epidemic -** The type of epidemic in the community being served will determine the need for certain types of services, the number of clients that can be served, the geographic areas of the community to be served and whether or not the client will be more likely to self-refer or need to be recruited. The type of epidemic in the area may also dictate the program goals and the type of funding obtained.

7. **Consider direct and indirect benefits to the client's family -** Families may benefit indirectly by nutritional support provided to clients. Other direct benefits to families, such as IGAs and microcredit may help reduce the time commitment of caregivers to a specific client/family and create increased stability for families. Programs may consider implementing some interventions to address psychosocial support among families to help them remain physically and emotionally supportive to the sick family member.

8. **Track caregiver retention and workload -** Monitoring the patterns of caregivers will help the program develop a balanced budget and also determine the number of caregivers (paid versus volunteer) to reach the target community. Tracking retention may help the program identify caregiver needs and develop ways to increase caregiver retention, if it is a problem. Use of incentives is an independent program decision, where many programs differ in opinion. Tracking caregiver retention may help a program analyze whether or not incentives play a role in overall retention.

9. **Assess the impact of ART -** All CRS HBC programs assessed were serving clients on ART. ART impacts the type of client being served and their needs. When clients receive ART, they are often more mobile and difficult to track. It may impact the frequency of home visits required, the type of services provided to clients, the type of resources provided to clients and the materials and training required by caregivers.

10. **Provide caregiver training -** Training for paid and volunteer caregivers may increase ownership in their role in the program and also benefit clients. All programs assessed had an ART component, which can be a new area for many HBC programs. Additionally some grant regulations have stringent training qualifications that must be followed. Increased training may also help professionalize the role of caregivers and program commitment.

11. **Increase referral base and know local referrals -** Assessing local resources and programs is important in helping to maximize a HBC program. Knowing referral sources will allow the HBC program to target their funding in their area of expertise and not create parallel systems. Widening the referral base will also allow for partnerships and other potential programmatic and funding opportunities.

12. **Improve/Develop Monitoring & Evaluation systems -** There is a clear need to put M&E in the program budget. M&E training should be part of the M&E portion of the program. Having appropriate monitoring capability, such as a computer and appropriate software should be part of the program budget to make M&E a feasible time and personnel investment. A strong M&E component will help programs evaluate and improve their programming related to caregiver retention, program effectiveness, service provision and impact on client's health and their families.

References

Smart, Theo (2003, November). Palliative care and home based care for HIV. *HATIP #18.* Retrieved September 4, 2008, from, http://www.aidsmap.com/en/docs/A5A87EC4-00E2-4F7F-9459-14C308AE908C.asp#0efd8f1c-c49e-4df6-88e0-74c44940d867

Foundation for Hospices in Sub-Saharan Africa's Hospice, Palliative Care and Home-based Care in Africa. (n.d.). Retrieved September 4, 2008 from, http://www.fhssa.org/i4a/pages/index.cfm?pageid=3286

Children participate in reviewing the program through paintings and drawings, CRS India

Appendices

Appendix A: Questionnaire (English)

DRAFT Interview Guide for HBC Documentation	
Background Information	
Country Program	
Person Interviewed Position Contact information	
Thumbnail sketch of HIV situation:	Prevalence rate: Generalized /concentrated epidemic (if focused, where?): Caliber/quality of response (govt, donor, civil society):
Name of Project	
Location of Project (geographic scope in country)	
Length/Size of Project	Runs from _____ to _____ Grant amount _____
Donor	
Implementing partner(s)	
Project Description	
1. Describe your HBC model.	
2. How many clients are cared for?	Disaggregate as much as possible: gender, age
3. What would a typical client look like? How do they come to be in the program? Are they found in the general population or in an epidemic sub-group?	Mix of illness/wellness What %age is presumed to be HIV+?
4. What services do the clients receive?	____1. HBC visits to monitor/support/train care provider at home ____2. Personal care of ill patient (feeding, bathing) ____3. Treatment with medications/dressings ____4. Pain management ____5. Adherence support ____6. Housework (cleaning, cooking, etc) ____7. Accompaniment to health service ____8. Delivery of food or other requirements ____9. Psychosocial support to pt and family ____10. Referral to other sectors (non-health) ____11. Nutrition demonstrations ____12. Watsan demonstrations ____13. Pastoral/spiritual support

5. Who provides the home-based care?	What proportion of those listed?	____1. Trained volunteers ____2. Paid healthcare workers ____3. Men ____4. Women ____5. Youth
6. Can you give an indication of the caregiver workload?	# clients/day or week/case load Distance traveled? length of visit? how tracked?	
7. How do you retain the care providers in the program?	What do you know about actual retention rates? Do you have formula for calculating retention?	If incentives are used, which ones: ____1. Cash ____2. Food ____3. Bicycles ____4. Radios ____5. Access to home gardens/inputs ____6. Award/recognition systems ____7. Clinic service privileges ____8. Support groups ____9. Further/ongoing training
8. What kind of support is provided to care providers (both volunteer and family)?	____1. Self-managed support group meetings ____2. Facilitated support group meetings ____3. Regular contact with a supervisor/mentor	
9. If the program provides PSS, what form does this take? (i.e. support groups, etc.) To what extent is this considered pastoral/spiritual ?	Who provides the support ? Trained lay people ? Trained social workers ? Psychologists ? Separate programs for age groups, gender?	
10. How do caregivers/volunteers interact with clinics and clinical health care providers? How are they supervised?		
11. How long do clients stay in the program? Is there an exit/graduation strategy?		
Referrals, Linkages and Integration		
12. Does the program link with any government (or non-government) programs (health-related, other)?	How does this linkage occur? Are referral mechanisms structured formally or informally? Are they funded? Does your program report on # of referrals made?	List ministries, agencies, programs:

	In general, would you say that your program focuses on 1) direct service provision or 2) referral to other existing services and programs (CRS or other)?	
13. Specifically, does the program link to: a) TB programs? b) Provision of bed nets or any malaria programming? c) Food Security, d) OVC e) Micro-credit	If so, who runs the TB programs and how does the integration happen? Are clients on DOTS? Do our caregivers play a role in this, if so? If so, who runs these programs and how does the integration occur?	
14. Does the program have a focus on supporting the family of the client? (i.e. through livelihood interventions.)	If so, how does this work?	
15. Does the program provide nutritional support (food)?	If so, what types and where does it come from (i.e. USG, WFP, local purchase, etc.)? What about other nutritional support (ie. nutrition education, nutritional assessment and counseling)?	
In the Era of ART		
16. Are the clients receiving ART (either through the program or through another service)?	Where does the ART come from, when did it arrive and how does it link in with the project?	
17. Has the advent of ART had any effect on your HBC program?	What activities did it add (or subtract) to HBC staff? Have staff and volunteers experienced a shift in their roles? How have they adapted? Have they needed retraining/re-orientation?	
18. If ART is available: Does the program provide adherence support? Does the program provide Positive Prevention programming?	What form does this support take? (i.e. adherence buddies, DOTS, etc.) How is Positive Prevention delivered? Are the PSS activities different now than pre-ART ?	
19. Did the advent of ART influence the kinds of resources required for HBC programming?	Has it influenced your ability to access resources for HBC?	
Monitoring and Evaluation		
20. How is the program monitored?	Can you list the primary indicators used (or send M&E plan) – at both individual level and program level? Are there any specific challenges you would like to mention re: monitoring of your program?	
21. Has the program ever been evaluated?	If so, when, by whom, and whether we can get a copy of the evaluation. If not, please ask if any evaluations are planned. And photographs, please?	
22. What is the most impressive feature of the	Why do you consider this feature to be important?	

program?	
23. What area of the program needs the most improvement?	Why do you consider this area of improvement important?
24. Do you see any other changes in HBC programming over the last several yrs?	What are those changes and why are they taking place? How can your program respond to those changes? Is it responding in this way?

Appendix B: Questionnaire (French)

DRAFT Interview Guide for HBC Documentation	
Information d'arrière-plan	
Pays	
Votre Nom Votre Position Vos Coordonnées (Information de Contacte)	
Bref introduction sur la situation du VIH dans le pays	Prévalence du VIH: Est-ce que l'épidémie est concentrée ou généralisée (si c'est concentrée, dans quels groupes ou endroits)? Qualité de la réponse (i.e. gouvernement, donations, la société civile):
Nom du Projet	
L'emplacement du Projet (scope géographique)	
Durée/Montant du Projet	Dates du projet : De _____ jusqu'à _____ Montant de la bourse/des fonds : _____
Bailleur(s) de Fonds	
Partenaire(s) pour la mise en œuvre	
Description du Projet	
1. Décrivez votre modèle de Prise en Charge à Domicile	
2. Combien de clients avez-vous?	Dégroupez autant que possible (par sexe ou âge, par exemple)
3. Décrivez le client typique. Comment est-ce les clients sont recrutés pour la participation dans le projet? Est-ce qu'ils sont de la population générale, ou d'un groupe spécifique?	Quel pourcent des clients sont présumés d'être VIH+?
4. Quels services reçoivent-ils les clients?	__1. Visites à domicile pour suivre/soutenir/former les fournisseurs de soin de la maison __2. Soin personnel d'un client malade – alimentation, baignade __3. Traitement avec des médicaments / pansements __4. Gestion de la douleur __5. Soutien pour l'adhésion __6. Ménage (nettoyage, la cuisine, etc) __7. Accompagnement aux services de santé __8. Livraisons de la nourriture ou d'autres biens __9. Soutien psychosocial au client et/ou leur famille

	__10. Orientations aux autres secteurs __11. Démonstrations alimentaires __12. Démonstrations sur l'eau et l'assainissement __13. Soutien pastorale/spirituel	
5. Qui est-ce qui fournit les soins à domicile?	Indiquez les proportions à droite.	__1. Volontaires formés __2. Travailleurs médicaux payées (soignants professionnels) __3. Hommes __4. Femmes __5. Jeunes
6. Décrivez la charge de travail des fournisseurs de soin.	Nombre de clients servis par jour ou semaine Moyenne distance voyagée par jour Moyenne durée de visite Comment suivez-vous ces données ?	
7. Comment retenez-vous les fournisseurs de soins dans le programme ?	Que savez-vous a propos des taux de rétention actuels? Avez-vous une formule pour calculer la rétention des fournisseurs de soins ?	Laquelle ou lesquelles de ces primes offrez-vous aux fournisseurs de soin (si aucune, ne marquez rien): __1. De l'argent __2. De la nourriture __3. Des bicyclettes __4. Des radios __5. De l'accès au, et/ou des ressources pour, des jardins domestiques __6. Des remises des prix, récompenses (par exemple, des trophées) ou récognitions __7. Des services de clinique __8. Des groupes de soutien __9. De la formation continue
8. Quels sortes de soutien psychosocial sont offertes aux fournisseurs de soins (soit les volontaires ou les membres de la famille)?	__1. Réunions de groupes de soutiens autodirigées __2. Réunions de groupes de soutiens avec un animateur __3. Du contact régulier avec un superviseur/mentor	
9. Si le projet fournit du soutien psychosocial aux clients, quelle est la forme de ce soutien (i.e. des groupes de soutien, etc.) ? Dans quelle mesure est-ce que ça se considère d'être pastoral/spirituel ?	Qui est-ce qui fournit le soutien ? Des non-professionnels formés ? Des travailleurs sociaux formés ? Des psychologues ? Est-ce que les programmes psychosociaux sont divisés par âge, groupe, ou sexe ?	
10. Comment est-ce que les fournisseurs des soins et les		

volontaires interagissent avec les cliniques et les cliniciens? Comment est-ce qu'ils sont surveillés?		
11. Pendant combien de temps est-ce que les clients participent dans le programme? Est-ce qu'il y a une stratégie de sortie pour les individuels ?		
Orientations, Liaisons et Intégration		
12. Est-ce que votre programme a des liaisons avec d'autres programmes, sois gouvernementaux, sois non-gouvernementaux (par exemple, des programmes de santé)?	Décrivez cette liaison. Est-ce que les mécanismes d'orientation sont formels ou informels ? Est-ce qu'ils sont financés? Est-ce que votre programme suit le nombre d'orientations? En général, diriez-vous que votre programme est concentré sur 1) la provision directe des services, ou 2) les orientations aux autres services et programmes existants (CRS et autres)?	Enumérez les ministères, agences, organisations, ou les programmes:
13. Est-ce que votre programme a des liaisons avec d'autres programmes: a) Contre la tuberculose? b) De provision de moustiquaires (ou autres programmes contre le paludisme)? c) De sécurité alimentaire d) De OEV e) De microcrédit	Si oui, quel(s) organisation(s) dirige(nt) ces programmes comment se produit l'integration? Est-ce que les clients participent dans des traitements DOTS ; si oui, est-ce que les fournisseurs de soin en aident?	
14. Est-ce que l'un des objectifs du programme est de fournir du soutien aux membres de la famille des clients ?	Si oui, comment ça se produit ?	
15. Est-ce le programme fournit du soutien alimentaire (en forme des vivres/rations)?	Si oui, quelles sortes and d'où les procurez-vous (USAID, Programme Alimentaire Mondial, achat local, etc.)? Quelles autres sortes de soutien alimentaire offrez-vous (éducation alimentaire, évaluation alimentaire, etc.)	

Dans l'Ère de la Thérapie Antirétrovirale (ART)	
16. Est-ce que vos clients reçoivent de l'ART (sois de votre programme, sois de n'importe quel autre service)?	D'où procurez-vous l'ART, quand est-ce que vos clients ont commencé à la recevoir, and et comment est-ce que ça se lie avec le projet?
17. Est-ce que l'avènement de l'ART a eu un effet sur votre programme de Prise en Charge à Domicile ?	Si oui, quelles sortes d'activités avez-vous ajouté au (et/ou soustrait du) charge de travail de votre personnel? Est-ce que les rôles des fournisseurs de soin ont changé? Comment est-ce qu'ils se sont adaptés? Est-ce qu'il y avait un besoin de former les fournisseurs de soin de nouveau ?
18. Si l'ART est disponible: Est-ce le programme fournit du soutien pour l'adhésion? Est-ce que vous fournissez de la programmation de Prévention Positive?	De quelle forme est ce soutien? (copains d'adhésion, DOTS, etc.) Comment se fournit la Prévention Positive? Est-ce que les activités psychosociaux d'aujourd'hui se différent de celles du temps avant l'ART?
19. Est-ce que l'avènement de l'ART a influencé les sortes de ressources nécessaires pour les programmes de Prise en Charge à domicile ?	Est-ce que ça a influencé votre capacité de procurer des ressources pour votre programme ? Comment ?
Le Suivi et l'Évaluation	
20. Comment suivez-vous le programme?	Enumérez les indicateurs principaux que vous utilisez au niveau individuel ainsi qu'au niveau programmatique (ou envoyez-nous votre plan du suivi et de l'évaluation). Avez-vous des challenges spécifiques concernant le suivi de votre programme ?
21. Est-ce qu'une évaluation de votre programme a été faite?	Si oui, quand et par qui ? Si non, est-ce que vous envisagez en faire ? S'il vous plait, pouvez-vous nous envoyer des photographes du programme, et une copie de l'évaluation (s'il y en a)?
22. A votre avis, quel est l'aspect le plus impressionnant de votre programme?	Pourquoi le trouvez-vous si important?
23. Quel est le domaine de votre programme qui a le plus grand besoin d'amélioration?	Pourquoi considérez-vous que ce domaine d'amélioration est si important?
24. Est-ce que vous avez observé d'autres changements dans la programmation de Prise en Charge à Domicile pendant les dernières quelques années?	Quels sont ces changements, et pourquoi se produisent-ils? Comment est-ce que votre programme peut adapter aux changements? Est-ce que vous agissez ainsi?

Appendix C: HBC Interview Contact List

	Name	Program Name	Country	Email	Phone
1	Augustine Govoechan	SEDEKON	Benin	agovoechan@crsbenin.org	(+229) 21 30 39 45 / 21 30 36 73
2	Flavio Lyra and partner agency reps	Construindo Solidariedade na Luta Contra a AIDS	Brazil	flyra@crs-brasil.org.br	
3	Maggie Janes	HIV/AIDS Livelihoods, Svay Rieng	Cambodia	mjanes@kh.seapro.crs.org	Tel: (044) 945 819/945 565; cell H/P: 012 222 106
4	Natalie Kruse-Levy	CRS/AHEAD; Maryknoll SoH and LS projects	Cambodia	nkruselevy@kh.seapro.crs.org	ph+855 23 211 165 and cell +855 12 907 805
5	Sende Djanrang	Home Based Care	Chad	dsende@crschad.org	tel: (00235) 51-7742 ou 629-5333/672-8937
6	Raphael Bajay	AMITIE	DRC	btchumah@crscongo.org	Tel +243 81 884 67 92; +243 81 700 50 52
7	Dr. Dehab Belay	Mekelle and Enderta HIV/AIDS Prevention, Care and Support Project	Ethiopia	dehabbe@crsethiopia.org.et	Tel 011 465 3593
8	Biniam Gebrehiwet and partner reps	HBC Program	Eritrea	biniamw@crseritrea.org	Tel (off): 291 1 151282 or Mobile: 291 7 119273
9	Ebrima Jarjou; Joanna Mendy	CRS Catholic Church HIV/AIDS Care and Support Project	Gambia	ejarjou@crsgm.org jmendy@crsgm.org	220 449 8000 ext. 312 or 220 449 8001 ext. 312.
10	Bansah God'sLove	Community Collaborative Care and Support Project (COMCESUP)	Ghana	goddypass2001@yahoo.co.uk gbansah@crsghana.org	ph +233 21 7010458 / 776735 / 784133/ 776188; cell +233 244 564 422
11	Sister Dee Smith	Proyecto Vida	Guatemala	pvida@intelnet.net.gt	From HQ: Dial 7110 followed by the respective extension. Guatemala VoIP extension is 4323
12	Elizabeth McMahon	HIV/AIDS Outreach Program (3 provinces)	China	mcmahon.eliz@gmail.com	
14	Peter Kagwe	APHIA II	Kenya	pkagwe@crsnairobi.org	254-735-802969 ; 254-720-848352/ 736-122123
15	Richard Mmanga and partner reps	Dedza Integrated HIV/AIDS and Food Security Project.	Malawi	rmmanga@crsmalawi.org	Tel.: +265-1-755-534, Mobile: +265-9-964-820 or +265-8-892-991
16	Imelda Davidson and Davor Dakovic from CRS; and, Sr. Sally Duigan and Patricia Orr from Kurisanani	Diocese of Tzaneen HIV/AIDS Response	South Africa	IDavidson@crsrsa.co.za	+27-11-884-1535
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