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EQUIPPING PARENTS AND HEALTH PROVIDERS TO ADDRESS THE PSYCHOLOGICAL AND SOCIAL CHALLENGES OF CARING FOR CHILDREN LIVING WITH HIV IN AFRICA

AN AIDSTAR-ONE ACTIVITY FINAL REPORT

AIDSTAR-One
AIDS SUPPORT AND TECHNICAL ASSISTANCE RESOURCES

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ACRONYMS

ART	antiretroviral therapy
CCW	childcare worker
CLV	community liaison volunteer
CPC	children's palliative care
CV	community volunteer
CYCW	child and youth care worker
DPH	Drakenstein Palliative Hospice
FGD	focus group discussion
HBC	home-based care
HHCT	home health care team
ICRW	International Center for Research on Women
JCRC	Joint Clinical Research Center
KWT	King Williams Town
MUMYO	Mukono Multi-purpose Youth Organisation
NACCW	National Association of Child Care Workers
NPHRC	National Pediatric and Family HIV Resource Center
OVC	orphans and vulnerable children
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PMTCT	prevention of mother-to-child transmission
PSS	psychosocial support
REPSSI	Regional Psychosocial Support Initiative
TAG	Technical Advisory Group
TASO	The AIDS Support Organization
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	U.N. Children's Fund
USAID	U.S. Agency for International Development
USG	U.S. Government
VCT	voluntary counseling and testing
WHO	World Health Organization

INTRODUCTION

The U.S. President's Emergency Plan for AIDS Relief (PEPFAR), through the U.S. Agency for International Development (USAID) Africa Bureau and PEPFAR HIV Testing and Counseling Technical Working Group provided funding to AIDSTAR-One to implement an activity entitled *Equipping Parents and Health Providers to Address the Psychological and Social Challenges of Caring for Children Living with HIV*. Perinatally-infected children aged 0 to 12 years are increasingly being enrolled in treatment programs in Africa, and there is growing awareness of the psychological and social issues faced by these children, their caregivers, and their health providers. However, information about approaches addressing the psychological and social needs of children living with HIV, and the needs of their caregivers and health providers, is limited. For children growing up with HIV, care and treatment programs must address a range of interrelated challenges, such as when and how to disclose serostatus, how to help children and their families know how and to whom to disclose the child's status, how to help children adhere to medications, and how to equip children and their families to combat stigma.

The *Equipping Parents and Health Providers to Address the Psychological and Social Challenges of Caring for Children Living with HIV* activity sought to better understand the psychological and social challenges faced by perinatally-infected children aged 0 to 12 years in Africa, their parents/caregivers, and their health providers. It explored factors that contribute to the ability of children living with HIV to cope and thrive, and identified the tools and approaches being used to help parents/caregivers and health providers provide psychosocial support (PSS) to these children.

This final report provides general background information on the research effort and on key PSS issues, as well as the findings and recommendations emerging through this AIDSTAR-One activity. Two additional documents provide further information on this activity: an AIDSTAR-One technical brief (see www.aidstar-one.com) and a journal article (pending submission).

OBJECTIVES, ACTIVITIES, AND DELIVERABLES

As a result of recent guidance on scaling up pediatric care and treatment from the U.N. Children's Fund (UNICEF) and the World Health Organization (WHO 2008), and the re-authorization of PEPFAR (Lantos and Hyde 2008), which includes a focus on pediatric treatment, the number of children on antiretroviral therapy (ART) has grown substantially. For example, the proportion of those receiving PEPFAR-supported treatment who are children has already increased from three percent in fiscal year 2004 to eight percent in fiscal year 2010, with over 200,000 children aged 0 to 14 years under care globally (PEPFAR 2010). Thus, the needs of health providers and parents/caregivers for support and guidance to care for and counsel children to grow into emotionally and physically healthy youth and adults are increasing as well. This AIDSTAR-One activity, with technical leadership from a study team based at the International Center for Research on Women, was developed to explore critical issues involved in identifying and meeting the PSS needs of children living with HIV aged 0 to 12 in Africa with the aim of informing the field on how to better support efforts by programs, providers, parents, and caregivers to care for their children.

OBJECTIVES

This AIDSTAR-One activity was developed to meet the following objectives:

- To better understand the experiences and the psychological and social challenges faced by children in the context of growing up living with HIV, the factors that contribute to their ability to cope and to thrive, and how these differ based on age and sex
- To better understand the experiences and the psychological and social challenges of parents/caregivers and health providers in counseling and supporting children living with HIV, and the factors that help them to meet those challenges and to provide support to children
- To identify gaps in tools and approaches for equipping parents/caregivers and health providers to help children address these psychological and social challenges in age- and gender-appropriate ways, including those around disclosure of serostatus, stigma, and treatment adherence
- To identify the key priorities for program implementation, research, and policy guidance to better meet the most prevalent and important psychological and social needs of male and female children living with HIV
- To communicate the key priorities to PEPFAR partners and other program implementers, policymakers, and other stakeholders who mobilize and provide support to children living with HIV and their caregivers, in order to catalyze action that moves the field forward.

ACTIVITIES AND METHODOLOGY

To meet the previously mentioned objectives, the AIDSTAR-One study team completed a series of activities, beginning with a literature review and interviews with experts to help frame the larger PSS

needs of children living with HIV and their families, followed by technical reviews of programs in Africa to better understand the promising practices and persistent challenges of current PSS responses. The study team also established a Technical Advisory Group (TAG) to inform the research. The approach used for each of these phased activities is presented subsequently.

LITERATURE REVIEW AND ENVIRONMENTAL SCAN

In this phase, the study team conducted an initial review of peer-reviewed and gray literature on pediatric treatment in the United States and developing countries, with particular attention to the psychological and social issues of caring for children living with HIV. While the initial review covered a broad range of topics, there was an emphasis on understanding PSS considerations in the disclosure process, stigma, and adherence to medical treatment. A listing of the literature reviewed is presented in Appendix D.

To complement the information emerging from the literature, the team also completed an environmental scan, conducting interviews with over 50 representatives of organizations and institutions that support or deliver pediatric HIV services (see Appendix E for list of experts interviewed). The study team developed a semistructured interview guide that probed on key themes in the literature: the identification of exposed or diagnosed children living with HIV, testing, disclosure (how parents' HIV status and the child's own HIV status are disclosed to the child), adherence to treatment, and addressing external and internalized stigma. Experts were asked to share their experiences on each of these themes, as well as perceived research and program gaps and challenges, and current resources and programs that exist to help children, parents/caregivers, and providers deal with the challenges of raising a child living with HIV. The guides developed for each participant group are included in Appendix C.

The study team analyzed the literature and interview notes to identify common themes and priorities emerging in terms of prioritized PSS needs of children living with HIV and their families, persistent challenges/gaps in providing PSS, and promising approaches/responses to PSS needs, especially in the African context. Findings emerging from this first phase were used to help frame the larger picture of PSS needs, as well as guide the study team and U.S. Government (USG) colleagues in selecting the key themes to be explored further during the program technical reviews.

TECHNICAL ADVISORY GROUP

The AIDSTAR-One team, in consultation with USG colleagues, established a TAG to advise on the evolving research and review products emerging from this activity. The 13-member TAG was formed from a subset of experts included in the environmental scan, as well as a few other individuals working to support pediatric HIV programs in Africa. Participation was based on individual availability, and TAG input was focused on critical steps in developing the research (e.g., review of research protocol and data collection instruments), as well as reviewing dissemination documents (e.g., the technical brief and journal article). Appendix F provides a list of TAG members.

PROGRAM TECHNICAL REVIEWS

Technical reviews of current programs in Africa provide the primary data and field-based experience for this AIDSTAR-One activity. Key findings from the literature review and environmental scan were reviewed with staff from the Africa Bureau and PEPFAR HIV Testing and Counseling Working Group to determine the following subset of issues for the field-based technical reviews: 1)

identifying children for services and ongoing support; 2) HIV testing and counseling of children; 3) supporting the disclosure process; 4) addressing internalized and external stigma; and 5) addressing grief and bereavement.

The study team, in consultation with USAID and a TAG, identified several countries with a range of pediatric HIV care, support, and treatment programs in Africa. Further discussions with USG country teams led to the selection of South Africa and Uganda as the two countries to be included in the technical reviews.

The study team then worked closely with USG point persons in each country to identify programs that would represent a variety of service delivery approaches (e.g., clinic-based, community-based, etc.) in different settings (urban, peri-urban, and rural). Program selection also reflected the interest and availability of organizations and staff to participate in the study.

The following four programs were selected for South Africa:

1. St. Nicholas Bana Pele Network, Bloemfontein, Free State
2. Butterfly House, Drakenstein Palliative Hospice, Western Cape
3. Cotlands, Somerset West, Western Cape
4. National Association of Child Care Workers, King Williams Town, Eastern Cape

For Uganda, the four selected programs included:

1. Baylor Uganda, Kampala
2. Joint Clinical Research Center, Mbarara
3. Mildmay Uganda-supported site, Naggalama Hospital, HIV Clinic, Mukono
4. The AIDS Support Organization, Masaka

Study approaches and data collection instruments were developed based on findings from the literature review and expert interviews, as well as in consultation with the TAG. Centering on the core themes identified as critical areas for exploration, semistructured interview and focus group discussion (FGD) guides were developed for three distinct groups of research participants: providers of HIV-related pediatric care, parents/family caregivers of 0- to 12-year-old children living with HIV, and 15- to 24-year-old young people living with HIV (see Appendix C for data collection guides). The latter guide was designed to invite young people to reflect back on how their psychosocial needs were met or could have been better addressed when they were children. The study team focused on issues related to disclosure, stigma, and grief. In addition, the study team sought to understand current approaches and persistent gaps in identifying children for services and providing PSS to children living with HIV as they navigate the disclosure process, face stigma, and experience grief and bereavement. Conversations with program participants sought to capture the perspective of young people and their parents/caregivers and to identify approaches for improving the psychosocial well-being of children living with HIV.

Field-based technical reviews were conducted at each program through a series of in-depth interviews and FGDs between May and November 2010. Parents/caregivers and young people were invited by program staff to participate in a focus group if existing support or activity groups existed on-site. Otherwise, they were invited to take part in an individual interview. Provider participants

were identified by the leadership of each program and were invited to join a FGD or a key informant interview, based on their availability and scheduling preference.

The research protocol was reviewed by the Institutional Review Board of the International Center for Research on Women and received ethical approval from three in-country ethics committees: Uganda National Council for Science and Technology, University of Witwatersrand (South Africa), and Hospice Palliative Care Association (South Africa). Written informed consent was obtained from all participants prior to each interview or focus group using the language preferred by the participant—Luganda or Runyankole in Uganda, Xhosa or Sotho in South Africa, and English in both countries. Participants unable to read the documents were asked to provide verbal consent prior to beginning the interview or focus group. Members of the research team facilitated discussions in English and in local languages, and information was recorded through handwritten notes.

Data were collected through selective transcription of quotes and topics within each of the five key themes. Researchers conducting key informant interviews recorded notes relevant to each theme using a standardized data collection matrix. During FGDs, a note-taker recorded data within each of the themes of interest (identification of children, testing and counseling, disclosure, stigma, and grief and bereavement). These notes were then compared with those taken by the FGD facilitator to confirm consistency of themes. The research team reviewed the matrices at the end of each day to discuss the extent to which participants were able to address each of the themes, and the degree of agreement within and across participant groups and programs. When the team identified gaps in the responses relevant to a particular theme, this domain was prioritized for the remaining sessions at that program site. If the team reached consensus that saturation had been reached on any given topic, this line of inquiry would be de-prioritized in subsequent interviews. This triangulation helped to identify points of agreement among the three main perspectives represented by participants: young people living with HIV, family caregivers of children living with HIV, and program service providers. This process allowed for iterative validation of the data within and across focus groups as well as within and across each program site. Once all data had been collected for each country, the research team conducted cross-program analyses to identify common themes and recommendations, as well as to identify points of inconsistency. On the completion of all data collection, additional thematic comparisons were conducted to identify divergences and consistencies across the two country contexts.

DELIVERABLES

A priority for this AIDSTAR-One activity was to identify and communicate findings and recommendations emerging from the research study. As such, the study team completed several deliverables to share findings with and offer recommendations to stakeholders to move the field forward:

- This final report is a synthesis of findings and recommendations from all phases of the activity.
- The summary of case studies (see Appendix A) includes a brief program summary, promising practices, and persistent challenges from each of the program technical reviews in South Africa and Uganda.
- A technical brief was developed that presents a consolidated presentation of background on PSS, promising practices in the field, and recommendations going forward; the document is

targeted toward program and policy implementers of pediatric PSS and treatment programs; it is disseminated via the AIDSTAR-One website (www.aidstar-one.com).

- A journal article has been developed for submission and dissemination via a peer-reviewed journal (*AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV*).

FRAMING THE ISSUES

As a first step in this AIDSTAR-One activity, the study team reviewed the literature and interviewed experts to explore the overall context of PSS for children living with HIV in Africa (see Appendix D for a list of literature reviewed and Appendix E for experts consulted). This included developing a better understanding of several critical elements, such as:

- What is the current scale and situation of children perinatally-infected with HIV in Africa?
- How is PSS defined? What are the elements of PSS? Why and how is PSS important to building a strong mental, emotional, and physical future for children living with HIV?
- What are the specific PSS needs of children living with HIV and their families in Africa?
- What are the priority areas related to HIV care for children that necessitate strong PSS, particularly with regard to the disclosure process, stigma, adherence, and grief and bereavement? What role does/should PSS play? What other aspects of pediatric care benefit from good PSS?
- How is PSS provided for children and their families? Who is (or should be) involved in providing PSS? How are they equipped to do so?
- What are the challenges and gaps in providing PSS for children?

A synthesis of findings from the literature and environmental scan is presented subsequently, as well as brief discussion of the selection of themes to be explored further during program technical reviews.

OVERVIEW OF THE SITUATION OF CHILDREN LIVING WITH HIV IN SUB-SAHARAN AFRICA

In 2009, 2.5 million children under 15 years were living with HIV around the world, with the vast majority—2.3 million—in sub-Saharan Africa (UNICEF, Joint United Nations Programme on HIV/AIDS [UNAIDS], and WHO 2010). In that same year alone, an estimated 370,000 children were born with HIV (UNICEF, UNAIDS, and WHO 2010). For most of the history of the epidemic, the majority of children born with HIV in resource poor settings did not survive past infancy, let alone early childhood (Brahmbhatt et al. 2006; Sutcliffe et al. 2008). Now, however, recent studies indicate that 36 percent of infants living with HIV have a median life-expectancy of 16 years (Ferrand et al. 2009). Furthermore, advances in HIV testing for exposed infants and children and in providing ART are increasingly enabling children living with HIV to live longer and healthier lives (Mellins et al. 2004; Sopena et al. 2010). For these children, HIV is a chronic disease requiring a lifetime of continuous treatment, care, and support to ensure their physical and mental development, as well as their emotional and psychological well-being (see Box 1).

Box 1. Continuum of Care: Services for Children with HIV

- HIV testing and counseling as early as possible
- ART and adherence; counseling and support
- Opportunistic infections: prevention and treatment
- Growth and development monitoring
- Immunizations
- Palliative care: pain and symptom management; psychological, social, and spiritual support and end-of-life care
- Nutritional support, including optimum infant feeding
- PSS: support groups and counseling
- Orphans and vulnerable children: care, support, and protection
- Prevention services and education, including life skills and planning for future (including sexual and reproductive health)
- Additional support services: support to parents/caregivers, social welfare, legal aid, income generation activities, and housing support.

Adapted from: Family Health International 2007.

OVERVIEW OF PSYCHOSOCIAL SUPPORT

Psychosocial Support is an essential component of ongoing care for all people living with HIV. PSS is especially critical for children, creating the foundation from which they can establish their identity and place in society, manage their care and live positively, cope with challenges, and plan for their future (Regional Psychosocial Support Initiative [REPSSI] 2003; Rochat, Mitchell, and Richter 2008). PSS is the process of meeting a child's emotional, mental, spiritual, and social needs through a variety of approaches, such as one-on-one counseling, support groups, and play therapy (Clay, Bond, and Nyblade 2003; Richter, Foster, and Sherr 2006; Rochat, Mitchell, and Richter 2008; see Box 2). PSS helps to build critical resiliency in children and also supports families and caregivers to meet the multiple needs that children have (REPSSI 2003). While some children may have acute emotional and mental health needs that require more sophisticated care, basic and ongoing support from those within the child's sphere (e.g., family, relatives, friends, teachers, etc.) play an essential role in ensuring emotional development as the child matures.

While all children can benefit from PSS, the literature shows that it is particularly critical for the health and development of children living with HIV (King et al. 2009). Children with HIV experience more subjective distress than their peers (Brown and Lourie 2000; Cluver and Gardner 2007) and face multiple stressors related to HIV, including the illness and death of a parent, disclosure, stigma, discrimination, isolation, loneliness, and family conflict or uncertainty (Brown and Lourie 2000; Cluver and Gardner 2007; King et al. 2009). Studies also note that children living with HIV (aged 4 to 21 years) are at increased risk of experiencing mental health disorders: for example, compared with prevalence rates in the overall population, children living with HIV have a

Box 2. Defining Psychological and Social Support

REPSSI is a leader in developing approaches and tools for addressing the psychosocial needs of children living with HIV. REPSSI provides explanations of several concepts related to PSS, as follows.

REPSSI notes that each person is influenced by the integration of the psychological and social:

- Psychological components are the mind, thinking, emotions, feelings, and behavior
- Social components are the world or context in which we live—the environment, culture, traditions, spirituality, and interpersonal relationships with family, community, and friends, etc.

The psychosocial development of children can be defined as the gradual psychological and social changes that children make as they mature:

- Psychological aspects of human development—the capacity to perceive, analyze, and learn from experiences, understand oneself and others, and experience emotion
- Social aspects of human development—the ability to form attachments, especially to caregivers and peers, maintain satisfying reciprocal social relationships, and to learn and follow the social codes of behavior of one's own culture.

REPSSI's definition of PSS for children is “a continuum of care and support by which children, families, service providers and the broader community can influence children's social environment, as well as their individual capacities for both individual benefit and community/societal development.” REPSSI explains that this continuum ranges from care and support offered by caregivers, to family members, friends, neighbors, teachers, health workers, and community members on a daily basis. It is about ongoing, nurturing relationships that communicate understanding, unconditional love, tolerance, and acceptance.

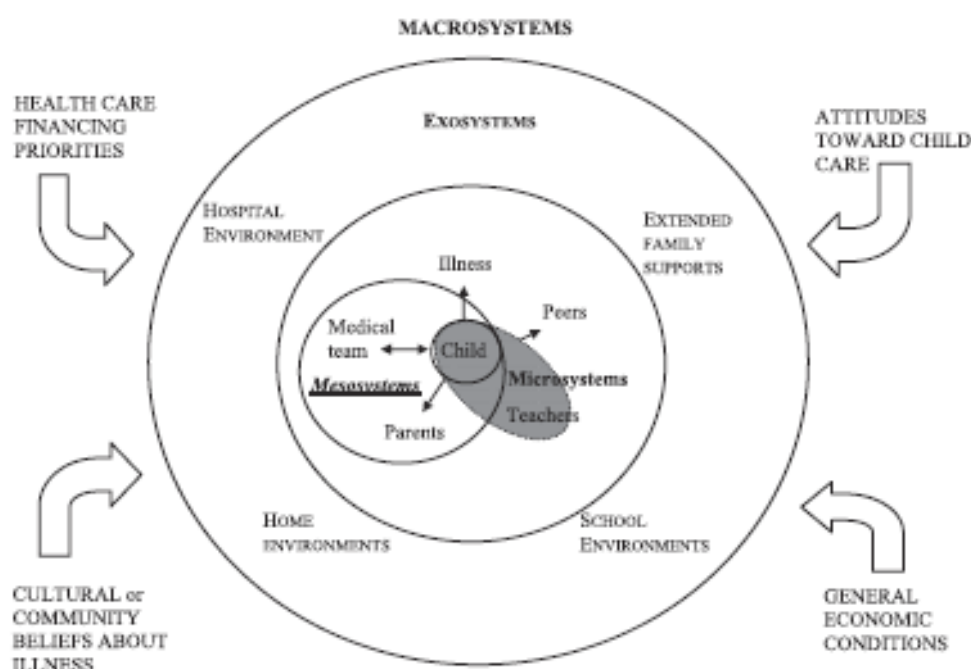
Source: REPSSI 2008.

7.1-fold increased risk of experiencing depression (Scharko 2006). In addition, several studies suggest that the psychosocial well-being of children and their caregivers can improve adherence to ART and clinical outcomes (Bikaako-Kajura et al. 2006; Brouwer et al. 2000; Mellins et al. 2004; Williams et al. 2006). Given the importance of PSS to the long-term well-being of children living with HIV, there is a critical need to ensure that continuous and individualized psychological and social services are fully integrated within a broad, integrated framework of care provided by parents, caregivers, and service providers (facility-, community-, and home-based) and adapted over time as children develop and mature (REPSSI 2003; Steele, Nelson, and Cole 2007).

Providing good PSS depends on the specific situation of the child, the local context in which he or she lives, and the resources and networks available to support his or her care. Therefore, it is difficult to identify a single model for providing PSS. REPSSI stresses a continuum of care and support offered by caregivers, family members, friends, neighbors, teachers, health workers, and community members on a daily basis to nurture the psychological and social aspects of a child's development (REPSSI 2008). A similar socioecological conceptualization is depicted in Figure 1, which lays out the multiple and interactive influences on a child's well-being, from those directly surrounding the child (e.g., caregivers, peers, and teachers) to the extended family and larger community (Steele, Nelson, and Cole 2007). The model also acknowledges some of the practical

realities that underline the provision of PSS or any service for children living with HIV, including economic considerations and cultural beliefs about HIV.

Figure 1. Model of Socioecological Conceptualization



Source: Steele, Nelson, and Cole 2007.

It is important to acknowledge that there are additional complexities when providing PSS services for young children with HIV, aged 0 to 12 years. PSS necessarily depends on parents, caregivers, service providers, and other adults around the child to provide a range of ongoing care and support. Also, there are challenges in knowing how and what to communicate with children. Services should be appropriately tailored to the developmental stage of each child, adapting as the child matures. Finally, with earlier testing and counseling, the time between initial diagnosis, initial treatment, and ongoing PSS is lengthened. While this can be an opportunity (allowing greater time to plan for and deliver quality care and support), this longer timeframe can also make it difficult to assess and meet children's ever-evolving needs and can increase the risk that a child may drop out of the health system and be lost to care.

EXPERT VIEWS ON PROVIDING PSYCHOSOCIAL SUPPORT FOR CHILDREN

In addition to the literature review, the study team consulted with over 60 experts working in pediatric HIV to better understand the issues involved in addressing psychological and social needs. Interviews raised several considerations that experts felt should underpin the provision of PSS for children with HIV aged 0 to 12, particularly in sub-Saharan African counties. These include broader issues that need to be factored into good PSS, as well as the specific priority areas—identification of children, testing and counseling, disclosure, stigma, adherence, and grief and bereavement—

identified for this first phase of the research. This section presents a summary of key points raised by experts.

GENERAL CONSIDERATIONS

Experts mentioned several overarching issues that affect PSS needs and provision for children living with HIV:

- **Addressing the whole child and the future adult:** Experts echoed the literature in viewing HIV as a chronic disease that necessitates planning for a lifetime of needs and experiences. They stressed the importance of building hope and resiliency for the future and ensuring that children plan for a full life (have aspirations, life skills, self-esteem, goals, etc.). This also means addressing some of the negative attitudes and emotions that can prevent a child from flourishing, such as fatalism, guilt, and shame. Finally, experts also mentioned the need to hear directly from children to ensure that their perspectives are incorporated into the larger understanding of PSS needs and effective responses.
- **Looking beyond the child's age:** Experts repeatedly noted the need to tailor services and communication with young children based on developmental stages and not age in years. Along with this is the need to have tools and guidelines that can be easily accessed and used by providers to assess developmental stages and deliver services accordingly. Experts noted that there may be provision variations/gaps for some subsets of children; for example, younger children (younger than 5 years) receive fewer services in some countries. There is also a challenge in ensuring a continuum of care as the child develops and transitions from infant to child to teenager and then adult care programs. Finally, several experts also noted the importance of preparing children for adolescence and adulthood, including addressing issues of sexuality, sexual and reproductive health, and abuse/violence.
- **Seeing HIV as a family concern:** Experts highlighted the lack of a single point person responsible for ensuring holistic and long-term care for the child. This adds to the challenge of trying to provide continuous PSS throughout the different areas and phases of a child's life, such as the following:
 - Between home, community (e.g., school), and formal health sector
 - Within home and family (e.g., with siblings, extended family, etc.)
 - Within formal health sector (e.g. from prevention of mother-to-child transmission [PMTCT] to pediatric clinics to outpatient services)
 - Across sectors (health, education, youth, etc.)
 - Over time.

Experts also noted the lack of a stable household environment for many children living with HIV, particularly in high-prevalence and resource-limited communities. Children can be moved from household to household and separated from home, siblings, friends, etc., adding to his or her PSS needs, as well as the challenge of providing continuous care. All of this highlights the importance of working with the larger family as a unit in meeting the needs of the child, including engaging with a range of caregivers and building their skills/capacities; having approaches/plans that look at the child's needs holistically (including meeting basic needs); understanding the larger family situation (e.g., caregiver stress, challenge of meeting needs of

both HIV-positive and HIV-negative children in the same household, etc.); addressing stigma within the family/community/facility; and building links between facilities and communities.

Several experts noted the need for programs to work more deliberately with parents, caregivers, and other adults in a child's life. Young children are entirely dependent on the decisions that adults make on their behalf; therefore, it is vital that parents/caregivers have the information and skills they need. As one expert observed, if adults can interact better with their children, "they [the children] will be okay."

- **Prioritizing networks of care:** Experts noted that there is often a lack of clear continuum or network of care for the child, with PSS provided piecemeal at best and without adequate communication/collaboration between the different PSS providers involved. Funding constraints often mean that there are insufficient numbers of trained staff to work with children, especially given the relative emphasis of medical care over PSS in many countries. Gaps in capacity (e.g., having trained child counselors), access to tools/resources, quality management (e.g., adequate supervision of PSS), and policy limitations (e.g., regulations that restrict which types of providers can deliver various services) are added challenges. All of these issues emphasize the need to develop networks of care involving family, community, facility, and government actors to address all needs of a child. Experts highlighted the need to strengthen links between levels/types of providers, explore new cadres of providers (e.g., lay social workers being piloted in some countries), develop true counseling skills (move away from giving advice or following scripts), and focus on quality of care (not simply reporting numbers reached). They noted that some children may have additional psychosocial needs (e.g., sexual abuse, severe mental illness, living in conflict areas) that need specialized attention; provision of these services should also be included within the larger network of care.
- **Meeting the basic needs of children living with HIV and their families:** In high HIV-prevalence, resource-constrained settings, limitations in human capacity, time, and funds compound the challenge of providing PSS at all levels—from clinics, to communities, to families, to individual caregivers and their children. Experts noted the reality that many families are struggling to meet basic needs, such as food, healthcare, shelter, and education costs, which leaves few resources (e.g., time, caregiver energy, funds, etc.) to address the psychosocial needs of children. A few experts pointed out that finding ways to support providers/caregivers in meeting these basic needs also helps empower them to feel like they can make a tangible difference for a child. Experts stressed the importance of acknowledging and addressing these needs through holistic programs or referral efforts.
- **Factoring in culture:** Experts noted that psychological services may not be culturally recognized, understood, or prioritized in many communities. PSS for children living with HIV is often "not on the radar" for families, communities, and providers, especially in cultures that are less open about emotional issues. In general, experts noted that psychological services are not prevalent in many sub-Saharan African countries. In addition, experts noted that specific topics, such as grief, are laden with cultural and traditional norms, especially when it comes to children.
- **Understanding gender:** While gender is now well established as an important factor in the HIV experience of adolescents and adults, experts noted a general gap in understanding if/how gender plays a role in pediatric HIV and PSS access, provision, and outcomes. Several gender issues were raised at the caregiver and family level, including the general recognition that the burden of care is largely placed on women, with low engagement of male caregivers. Family and social norms, such as household power dynamics and gender-based violence, may limit the

ability of female caregivers to act on behalf of the child. One expert noted the extra vulnerability and needs of children who have lost their mothers (scoring lower on emotional health, connectedness to family) versus those who lost their fathers (scoring lower on food security). Interestingly, experts were less able to identify clear gender issues for children living with HIV. Several noted anecdotal examples of how gender could be affecting girls' and boys' experiences with HIV (e.g., boys are less able to express emotions, parents are more likely to disclose to girls, etc.), especially related to early sexual activity and sexual and reproductive health needs, but some also highlighted the need for more research and data to determine how gender may be impacting the care of children living with HIV.

- **Investing in evidence:** Several experts noted the lack of evaluated PSS models, activities, and tools, making it difficult to put forward evidence-based options for programmers, policymakers, providers, and families on the ground. They highlighted the need for long-term research that follows the experience of a cohort of children who were born with HIV.

PRIORITY ISSUES

In addition to these broader considerations, experts provided input on specific aspects of caring for children living with HIV that need good PSS. Experts largely echoed priorities identified through the literature review, citing disclosure, stigma, grief and bereavement, and adherence as being critical areas for increased attention. Their reflections on some of the PSS needs, challenges, and recommendations are as follows:

- **Supporting disclosure to the child:** Several experts noted that disclosure is often the central issue that determines if, when, and how a child living with HIV receives the services and support he or she needs. Lack of readiness and willingness—both on the parent/caregiver side (e.g., reluctant to disclose their own HIV status) and the child's side—can be significant barriers to ensuring a child's well-being. Experts agreed that there is no one formula for how disclosure to a child is managed, noting that there are multiple disclosures (of the child's status, as well as the parents' status) over time. As one expert said, the focus should be on the “art of disclosure,” and less on the science, moving away from ideas that disclosure is a single event to be programmed on a “dosing curve based on a child's age and weight.” Instead, disclosure needs to be a process over time that allows for appropriate action regarding what information is shared (e.g., partial versus full disclosure), by whom, with whom, and when, factoring the readiness of the child and parent/caregiver. Several experts also commented that, in their experience, parents/providers often underestimate what children know or suspect, increasing the importance of communication that is better planned (in terms of content) and timed.

Based on their experience, experts highlighted several specific challenges and/or gaps in how disclosure is currently being supported, including low assessment of parent/caregiver readiness as individuals and as people responsible for a child, poor/incomplete assessment of child readiness, limited discussion or weighing of pros and cons of disclosure, and limited counseling support and disclosure tools/plans. Experts also noted several limitations in communication, including between providers and parents/caregivers (e.g., little counseling support for the carers, limited support to caregivers on how/when to disclose to the child), with the child (e.g., lack of provider and caregiver skills in how to communicate with children, limited guidelines on content of discussions with children), and insufficient capacity building in children so that they know when and how to share information about their status with others as needed (e.g., with peers, relatives, and teachers). This last point includes coping with inadvertent disclosure.

Experts stressed the need to develop guidelines/tools—or, perhaps more critically, make existing guidelines/tools more accessible and adaptable for field-based providers—to map the disclosure process, providing guidance on content and communication approaches specific to different developmental stages. These should be targeted toward children themselves (e.g., REPSSI’s “Talking Book” on disclosure for children and adolescents) or toward parents/caregivers (e.g., “How Can I Tell You?” by Mary Tasker).

- **Addressing stigma:** Stigma was also raised as a critical issue for children living with HIV, particularly in terms of how stigma affects parent/caregiver willingness to disclose to the child. Several experts noted that fears of talking openly about HIV and being HIV-positive can significantly prevent or limit disclosure across the board, which, in turn, becomes a barrier to accessing treatment, care, and support services. In addition to disclosure, stigma can negatively impact a parent’s/caregiver’s willingness or ability to support the child, influencing the situation/environment that the child lives in (e.g., low engagement from male adults, “child-tossing” or moving the child from house to house, etc.).

Experts mentioned several harmful effects of external and internalized stigma on the child, including lowering self-esteem and resiliency (coping with feelings of shame, blame, guilt, etc.); straining relations within family; reducing willingness to follow-through with care and treatment; and restricting social interactions, especially school (e.g., child does not want to be seen missing school for clinic visits or taking medications at school). Experts also mentioned that children pick up on signs of stigmatization within the family or communities and adapt accordingly (e.g., not asking questions and not displaying emotions openly); children can be good keepers of secrets, and as such, adults may underestimate what a child knows or experiences, or may think the child is coping well.

Stigma can also impact openness and effectiveness of available PSS activities (e.g., support groups). There may be acknowledged/unacknowledged provider stigma, which can then affect the quality and delivery of care to children, or the quality of interaction with parents/caregivers. A few experts noted that gender biases can compound this last issue, where providers spend less time and share less information with female caregivers (e.g., elderly relatives). In addition, fear of stigma may limit how openly and freely children (and adults) participate in activities like support groups (in terms of attendance, as well as in how much they are willing to share). At a community level, experts also noted a lack of interventions to address stigma, highlighting the need for approaches that share information and engage support for children living with HIV and their families without directly or inadvertently fostering stigma.

- **Coping with grief and bereavement:** Grief and bereavement was cited by several experts as being a neglected area of PSS for children living with HIV and their families. They noted that there is some effort to plan for the death of a parent (e.g., with succession planning, writing of wills, etc.) but that more PPS is needed to help a child cope with the loss or impending death of a parent/caregiver and any fears about what will happen to him or her. Here, again, experts highlighted the need to work with surviving caregivers/adults to help them address their own grief so that they are better able to then support the child. In terms of direct support for a child, experts spoke about the need to understand the cumulative grief a child experiences—grief from loss of a parent, from being infected, from stress over future, etc. There is limited acknowledgement of other losses like loss of opportunities (e.g., to go to school) or loss of having a free/true childhood (e.g., have to care for others). As with disclosure and stigma, experts noted the need to develop activities/tools/programs that help the caregiver and child

prepare for or cope with the different losses they experience. Several noted the Island Hospice in Zimbabwe as being a leading group on research and responding to children coping with grief.

- **Supporting adherence:** Discussions with experts regarding adherence often focused on the interrelationship between medical treatment and psychosocial issues, particularly stigma and disclosure. Given the relative richness of experience in looking at adherence, experts identified several areas that need greater understanding, especially in the context of care and support for children living with HIV, including the relationship between disclosure (of parent's status and child's status) and adherence, relationship between stigma and adherence, how/when to involve children more in their own care (linked to disclosure issues), how to improve caregiver understanding of (and confidence with) treatment/visit regimen (how to give drugs, ask questions, have mentors who help, etc.), and how to improve provider interactions with children and families/caregivers so that they are encouraged to continue treatment (do not feel dismissed, do feel that they are treated well and with respect).
- **Suggested approaches and resources:** Experts shared several program approaches and resources that address some of the PSS issues raised previously. Several centered on creating forums for children to interact with and learn from one another, including kids camps, support groups, peer-to-peer counseling, and tailored counseling by trained providers (e.g., specific to bereavement). They also cited support groups for caregivers, as well as parenting workshops, as being good approaches for building capacity to care for children. Experts recommended several programs that incorporated such activities and as potential case studies for the field review. In addition, experts highlighted specific resources (e.g., organizations, websites, curricula, guidelines, tools, etc.) specifically related to the provision of PSS for children, which are included in Appendix B.

FOCUS AREAS FOR TECHNICAL REVIEW

The study team, in collaboration with USG colleagues, used the previously mentioned findings from the literature review and environmental scan to determine the focus of field-based technical reviews. While multiple areas of PSS emerged, the study team selected five areas for the field work. These included two critical areas related to ensuring that more children are brought into the care system as early as possible: 1) identification of children, and 2) testing and counseling of children. The remaining themes selected focus on 3) the disclosure process, 4) stigma, and 5) grief and bereavement. These themes were chosen given their critical importance to if/how/when children and families access and benefit from PSS, as well as to the content and structure of PSS services. The interviews and literature review also helped to inform the selection of potential countries and programs for the technical review, as well as providing additional background information on several of the approaches being used in the field (as presented in the next section).

FINDINGS FROM PROGRAM TECHNICAL REVIEWS

The core of this AIDSTAR-One activity was a series of technical reviews of eight programs—four in South Africa and four in Uganda—currently working to meet the needs of children living with HIV (see Box 3). As part of their work, these programs are implementing several promising interventions that address the psychological and social needs of children living with HIV and their families. In such high HIV-prevalence, resource-constrained settings, limitations in human capacity, time, and funds compound the challenge of providing PSS at all levels—from clinics, to communities, to families, to individual caregivers and their children. In addition, many caregivers and families have a limited understanding of comprehensive PSS and may not be able to fully appreciate why it is essential to the overall well-being of the child. Providers and caregivers alike are overworked, dealing with competing priorities, and limited in key skills to provide quality care for children, all of which sideline the provision of PSS.

Despite these general challenges, programs are finding ways to identify children in need of services and work with parents, caregivers, and others to address psychological and social development as the child matures. Across the board, all of the programs visited recognized that a strong emotional and psychosocial foundation is critical to the future well-being of children living with HIV, something that was echoed by young people themselves: “When people love you, you love yourself and get the strength to go on” (a youth in Uganda).

The following sections highlight some of the specific promising practices emerging from the technical reviews (see Appendix A for case study summaries of each program review), along with comments by youth, parents/caregivers, and providers, and some of the background literature, for each of the five themes: 1) early identification and HIV testing and counseling of children; 2) pre- and post-test counseling for children and caregivers; 3) supporting the disclosure process; 4) addressing stigma; and 5) coping with and preparing for loss, grief, and bereavement. The final section presents some of the ways in which PSS programs are structuring their limited resources and activities to better respond to the needs of children and their families, especially in terms of building the skills and capacities of providers, parents, and caregivers—and the children themselves.

Box 3. Programs Participating in Technical Reviews

South Africa

- St. Nicholas Bana Pele Network, Free State
- Butterfly House, Drakenstein Palliative Hospice, Western Cape
- Cotlands, Western Cape
- National Association of Child Care Workers, Eastern Cape

Uganda

- Baylor Uganda, Kampala
- Joint Clinical Research Center, Mbarara
- Mildmay Uganda-supported site, Naggalama Hospital, Mukono
- The AIDS Support Organisation, Masaka

EARLY IDENTIFICATION AND HIV TESTING AND COUNSELING OF CHILDREN

Of primary importance is the early identification of children living with HIV who are in need of clinical care and PSS. Many children are never brought into the care system due to fear, stigma, lack of information, or the absence of a parent or adult decision maker who can take such action. Although the percent of children living with HIV that remain unidentified is difficult to state with certainty, experience with home-based testing and counseling suggests that large numbers of children exposed to HIV have not been tested; one study in Uganda found that 74 percent of household members (in exposed households) had never previously been tested (Were et al. 2006; Wolff et al. 2005).

While pediatric programs have responded to WHO's guidance on the importance of early identification and ART for infants and children, there are still significant gaps in coverage (WHO 2008; WHO, UNAIDS, and UNICEF 2010). WHO reports that only an estimated 15 percent of infants exposed to HIV needing testing are tested in the first two months of life (WHO, UNAIDS, and UNICEF 2010). While ART uptake has increased rapidly in recent years, currently 72 percent of children living with HIV who are younger than 15 years are not receiving ART (Bandason et al. 2011; UNICEF, UNAIDS, and WHO 2010).

Given this critical gap in the timely identification of children in need of services, it is important that all programs that interact with children or households exposed to HIV prioritize proper HIV screening, testing, and counseling, either through direct provision of testing services or through strong referral networks to government and community organizations that screen, test, and counsel children (e.g., hospitals/clinics, social support systems, government channels, law enforcement, etc.). Some good practices include:

- **Referral networks:** All of the programs visited had established referral networks to help bring children into care/services (as per each program's capacity), linking with area health facilities (e.g., hospitals that provide testing and counseling services for children), local authorities (e.g., structures that might identify households affected by HIV for government programs like cash grants), community groups (e.g., those providing support for vulnerable households), general communities, etc. This was particularly important in South Africa, where most of the programs visited did not have a sole focus on pediatric HIV (so did not, for example, proactively seek children who might be in need of testing services).
- **Clinic-based internal referrals and provider-initiated testing:** Several of the programs, especially in Uganda, provide HIV-related clinical care, thereby creating multiple entry points for identifying adults and children who may be living with HIV, including PMTCT and exposed baby programs, tuberculosis clinics, and palliative care services (or any health service where HIV testing is part of routine clinical diagnosis). Providers noted the challenge of ensuring seamless referrals, including issues of distance (e.g., where patients may need to access a different part of a facility) or over time (e.g., patients do not return to receive testing results or to enroll children into care).

Some approaches extend HIV testing and counseling beyond a static clinic location and bring them closer to where exposed children may be, including some that are very proactive in seeking out children (see Boxes 4 and 5):

- **Use of index clients:** Many of the programs access children (and other family/household members) who might be exposed to HIV through an adult or child client already receiving HIV-related care. This approach, along with house-to-house screening and testing (not conducted by any of the programs visited, but an approach used in several countries) have been particularly important in reaching exposed household members who otherwise would not have sought testing and follow-up services. In addition to being highly acceptable (Were et al. 2006; Wolff et al. 2005), home-based testing and counseling facilitates greater openness and support within the family and potential reductions in stigma more broadly (Lugada et al. 2010; Nuwaha et al. 2009).
- **Outreach testing and counseling services:** Several programs take testing and counseling services out into the community through home-based visits, school-based voluntary testing and counseling, and community outreaches (particularly in remote areas).
- **Identification and referrals by community resource persons:** Programs build the capacity of community-based resource persons (e.g., adult volunteers living with HIV) or institutions (e.g., faith-based groups) to identify at-risk households and refer or accompany household members to a testing site.
- **Awareness-raising on the importance of testing:** Broader efforts to build understanding of the importance of early testing, promote services, and reduce HIV-related stigma are also critical to facilitating the identification of children.

Box 4. Program Example: Identification of Children

Program: Baylor Uganda, Kampala

Background: Baylor provides comprehensive care and treatment for more than 5,000 children living with HIV and their families through clinic- and home-based services, including testing and counseling, clinical care and treatment, and PSS.

Promising practices:

- Community volunteers visit households to identify children or adults exposed to HIV, who are referred to the program for HIV testing.
- Home care teams offer home-based testing, counseling, and follow-up.
- Family clinics provide care to child patients and their families, a channel for reaching other children within the household who may be in need of services (or involved in supporting the child living with HIV).

Linkages between HIV testing and counseling services and subsequent, continuous care for those children (and families) identified as living with HIV are critical to ensure that children are not lost from the system, especially as there may be breaks in time or physical distances between relevant services: “Children are referred to us from the hospital. Then a home-based carer visits the family to follow up and make sure the parent knows how to give the meds and when. This is when we are able to start to see what other needs the children have” (a provider in South Africa).

One other consideration to keep in mind is the need to maintain high ethical standards in all testing approaches. As testing services are brought closer to children and families, special attention must be made to ensure that ethical requirements of proper consent, privacy, and confidentiality are correctly observed as per country-specific guidance/policy.

Box 5. Program Example: Identification of Children

Program: Joint Clinical Research Centre, Mbarara

Background: Joint Clinical Research Centre's Mbarara program is a Regional Center of Excellence, providing advanced testing, care, and treatment for 8,200 clients living with HIV. The program applies a holistic approach to care of children living with HIV, addressing their material, education, psychosocial, spiritual, and medical needs.

Promising practices:

- PMTCT and exposed baby clinics identify mothers and babies for testing and services.
- Outreach and campaign activities provide home-based testing and counseling services.
- Partnerships with community structures (e.g., churches) and leaders to help identify children who may be at risk or exposed to HIV.
- Community outreach to promote testing and provide referrals.

PRE- AND POST-TEST COUNSELING FOR CHILDREN AND PARENTS/CAREGIVERS

Ensuring that quality pre- and post- test counseling is accessible as part of HIV testing services is critical to identifying and linking children to clinical and psychosocial services as soon as possible. Discrete counseling given specifically at the time of testing is distinct from the ongoing counseling support provided for children living with HIV and their families. However, even as a discrete activity, HIV testing and related counseling is a critical first step to ensuring the longer-term care for the child; as such, there are multiple individuals and levels of counseling involved, depending on the child's age, developmental stage, disease presentation, and family situation. With children younger than 2 years—or in the case of HIV testing of parents (e.g., mother during PMTCT)—counseling is provided for the adult, and full disclosure of the parent's and child's status to the parent can be done during post-test counseling. In the case of older children (e.g., 8 years or older, depending on developmental level and national/program guidelines) and adolescents, pre- and post-test counseling for the child must also be considered, including partial or full disclosure to the child as appropriate.

During field visits with programs in Uganda and South Africa, the importance of this initial counseling session at the time of testing was highlighted for several reasons. Children and their parents or caregivers have special, and at times different, counseling needs that must be met to initiate and sustain care. Parents and caregivers need manageable, consistent, and hopeful information from the outset that can help them take some initial steps/decisions for the child's well-being. This is also an opportunity to identify any support that the parent/caregiver may need regarding his or her own HIV situation, including provision of couples testing and counseling.

For the child, pre- and post-test counseling must be tailored to the appropriate development stage, which requires skill in being able to correctly assess and adapt both the process and manner in which counseling is provided. For older, more mature children or adolescents, it is critical to engage with them directly. Youth in both countries expressed their anger at being taken for testing without being told why or given true information before or after testing: "I was hurt. They did not tell me they were taking off the blood sample for HIV testing" (a youth in Uganda); "Doctors lied to me. They gave it a funny name, told me it was malaria. They gave my father the results, not me" (a youth in

Uganda). Many of the programs reviewed dedicate specially trained child counselors for this initial counseling, which youth, parents, and caregivers found helpful. Parents, caregivers, and children consistently noted the need for additional information, counseling, and support following initial HIV diagnosis to help them process emotions and develop care plans specific to the needs and situation of the child.

Several HIV testing and counseling programs have adopted standard protocols for children (dependent on age/developmental stage), including having time with both the child and the caregiver individually, as well as in a joint session. It is important to note that while guidelines exist, much depends on the individual assessment of the child (especially for younger children aged 4 to 10 years) to determine what information should be shared and how. Creating time for joint counseling was highlighted as being a useful approach, allowing for the caregiver and child to hear and share information together with a trusted source, as well as providing an opportunity for the counselor to observe the interactions between the caregiver and child. Some programs, particularly those that did not offer testing and counseling services, have counselors who can accompany a child and caregiver through testing, providing a valued touchstone and friend throughout the process and then link children and parents to follow-up PSS.

A summary of promising approaches identified during the field technical reviews include:

- **Trained child counselor for managing testing and counseling process:** Many of the programs visited had cadres of staff/providers specifically trained to interact with children. Although caseloads were often an issue, providers and clients consistently mentioned the value of having a constant, well-trained counselor who could manage the child's case from testing through follow-up care (if possible).
- **Provider accompanying child/caregiver through testing and counseling:** Some programs have providers join children and their families throughout the testing and counseling process. This came up particularly for some South African programs that do not, themselves, provide testing services, and also for the Uganda programs: "We try to create a friendship with the children from the first moment we meet them in pre-test counseling. We escort them to the lab and stay with them during the test if they want us to be there" (a provider in Uganda).
- **Clear, standardized protocols (and tools) for testing and counseling of caregiver and child:** Most programs noted having clear protocols that could be followed during testing and counseling, adapted to the specific situation, including the following elements:
 - Inclusion of child in counseling, as appropriate to age and developmental stage (per country or program guidelines)
 - Individual sessions with parent/caregiver and with child (as appropriate)
 - Joint sessions with parent/caregiver and child (as appropriate).

It is important to note that child counselors reported using a formal assessment or their own judgment to determine the child's capacity/need for information and adjusted accordingly (especially for younger children).

- **Hopeful, consistent messaging:** This was repeatedly mentioned by providers and parents/caregivers as being very important. Programs noted that they made an effort to ensure that all providers who might come into contact with a parent/caregiver and a child during

testing and counseling (and follow-up care) reinforce these same messages, including counselors, laboratory staff, medical providers, etc.

- **Manageable, critical information:** Parents/caregivers noted that they were often not able to absorb information during post-test counseling and stressed the importance of keeping the content during this initial discussion simple and specific to caring for the child (based on the child's immediate situation and developmental stage).
- **Immediate and continuous follow-up counseling:** Related to providing manageable, critical information, parents/caregivers highlighted the importance of having access to counseling and information discussions with providers after the initial post-test counseling. This can include identifying and meeting the needs of the parent/caregiver, especially where support could facilitate care for the child (e.g., providing couples testing and counseling to support parent disclosure).

SUPPORTING THE DISCLOSURE PROCESS TO THE CHILD

Supporting the disclosure process is one of the better developed, documented, and resourced PSS elements, particularly in terms of clinic-based services. There are guidelines and practices in place to guide how initial pre- and post-test counseling with parents/caregivers and the child should be managed by trained providers (see Box 6). However, things become less clear after the initial post-test discussion, and supporting the continuous process of disclosure to the child—regarding both the child's status, as well as his or her parents'—is an important priority for PSS programs.

Box 6. Program Example: Facilitating Disclosure

Program: The AIDS Support Organization, Masaka, Uganda

Background: The AIDS Support Organisation's approach to 'Living Positively with AIDS' is holistic and includes the physical, psychological and emotional well-being of HIV-positive individuals, including children.

Promising Practices:

- A child counselor to oversee the child's/family's progress from testing through entire time in the program.
- Support includes joint counseling sessions with the child (age 5 and older) and caregiver.
- Counselors engage the child at a play center through art, writing, and general play to observe and assess.
- Interactive and tailored counseling approach based on the child's developmental stage and level of understanding (process of partial disclosure).
- Community volunteers provide follow-up.
- Team facilitates on-going conversations around disclosure between caregiver and child, and with larger family as needed.
- Support during crises (e.g., inadvertent disclosure, stigmatization).

The context of a child living with HIV adds complexity to how disclosure is managed. Disclosure of the child's HIV status to the parent or caregiver occurs during post-test counseling. However, the timing and nature of disclosure to the child about his or her status is difficult to standardize and should, in fact, be tailored to the child's specific situation. Factors such as development level, health condition, and home situation determine the optimal disclosure process for the child, which may involve a long period of partial disclosure—where the child is given information (e.g., about taking medicine, preventive message, etc.), but is not told that he or she is living with HIV—leading to full disclosure when the child is mature enough to understand the information. In the case of children, there are added complexities of disclosure about the parent's status, as well as third-party disclosure or informing other key caregivers (e.g., family members, teachers, etc.) about the child's status. Expanded channels for testing (e.g., home-based testing and counseling) that may involve multiple family members also raise additional challenges in how pre- and post-test counseling is handled and how follow-up counseling should be structured for parents/caregivers and the children involved (e.g., potentially including both HIV-positive and HIV-negative children of varying ages/developmental stages, siblings, extended family, etc.).

Input from parents/caregivers during program technical reviews highlight the critical time right after the point when they, and sometimes the child, learn of the child's positive status. They noted that they need continuous and varied follow-up, counseling, and guidance to process the initial grief, guilt, and fear of an HIV-positive diagnosis, build skills/information to talk with the child, and then plan forward on behalf of a young child. This includes finding ways to incorporate the opinions of children as they mature. Part of this forward planning also involves thinking through how, when, why, and to whom to disclose (family members, friends, schools, community resources, etc.) so that they can also be engaged in providing continuous support for the child and increasingly involve the child in decisions about to whom and how to disclose.

Helping parents/caregiver plan out when full disclosure will happen is particularly important. Delayed disclosure can impede the provision of additional services and support for the child: “Disclosure is a huge problem and interferes with our ability to support the child” (a provider in South Africa). Several providers noted that parents/caregivers often wait too long to disclose to the child, to the point that the child (or adolescent) is already aware of his or her HIV status: “I don't have a particular age that is best for disclosure, but the earlier, the better. Our kids are very bright and many will remind granny about medicine time. But the grannies see it differently, for example one child is 14, but the granny doesn't want to disclose until he is 16. I am telling her that the child knows already” (a provider in South Africa).

Programs in both Uganda and South Africa are using several approaches to support the disclosure process. One important evolution is the shift away from a single disclosure event to a more iterative process of partial disclosure over time, where providers share developmentally appropriate information about HIV that matches children's illness experiences and development stage (Abadia-Barrero and Larusso 2006). As one provider from South Africa described, “I tell a little child that he's sick and needs to take his medicine so he can be strong and play like other kids, but I don't tell him that he is HIV-positive unless he's old enough to understand and handle the news.” Studies suggest that this continuous approach of sharing information and gradually building a child's understanding of his or her illness helps to reduce some of the emotional distress of disclosure and reinforces adherence to medical treatment (Abadia-Barrero and Larusso 2006; Bikaako-Kajura et al. 2006; Brouwer et al. 2000; Mellins et al. 2004; Williams et al. 2006).

Promising practices that emerged during the technical reviews include:

- **Counselor trained in child counseling managing ongoing counseling of child and family:** As noted in the previous section on post-test counseling, having a trained child counselor to manage the ongoing care of the child—including issues around disclosure—was highlighted as being a strong approach. In several programs, this point person consolidates all information on a child's progress and can assess readiness of both the parent/caregiver and the child for disclosure.
- **Counseling on partial and/or full disclosure tailored to developmental age and situation:** Programs recognize that how disclosure is managed should be tailored to the individual situation of the child. Several programs use the approach of partial disclosure, using the child's own questions, level of comprehension, and health situation to guide the content and manner in which health and preventive information is imparted. This gradual process allows time for caregivers and providers to prepare the child for full disclosure. As a provider in Uganda noted, "It's not my decision whether or not to tell (the child), but if the parent asks, I advise partial disclosure so that they can give the young child information little by little." Young people commented on the need for individualized disclosure processes based on what information the child can handle: "You need to tell the character of the kid. Do you tell him fast or slow? Do you hit him in the face with it and teach him later, or teach first, then hit him with the truth?" (a youth in Uganda).
- **Approaches for children on disclosure and positive messaging:** Providers, caregivers, and especially youth all stressed the need for positive, hopeful messaging throughout their care. A number of programs have developed tools and approaches that are geared to children, such as story books on disclosure. This gradual, tailored process creates an opportunity to reinforce positive messages and prepare the child for living with HIV once full disclosure happens. One provider in Uganda expressed this clearly: "We want to give them hope but a hope that is not false. [We tell them,] 'Even with HIV, you can become the person you want to become. But to do that you have to grow up.'"
- **Peer support and mentoring:** Young people in particular, but also providers, highlighted the importance of creating opportunities for older children and adolescents to engage with peers living with HIV who have gone through similar experiences—particularly the experience of full disclosure. During focus group discussions, several youth valued being able to talk with peers or an adult living with HIV who had been through the experience of learning one's status. One youth in Uganda noted: "Right after you should go into peer support. Maybe it's hard for you to talk about, but so many people are talking so freely about it, you can talk." This was echoed by another youth in Uganda who said, "I want to talk with someone who has lived through it."
- **Skill building for parents/caregivers:** Most programs noted that they feel full disclosure (when the child is ready) should be done by the parent or caregiver. Interestingly, parents/caregivers often said that they preferred having a provider deliver this information, and even some youth echoed this. Parents/caregivers reported that they feel ill-prepared to handle such a difficult conversation (given their own personal feelings, as well as having to consider the well-being of the child), and several programs mentioned steps they have taken to build parent/caregiver confidence and skills to manage disclosure: "We train childcare workers to help mum disclose the child's status to him or her as early as possible so that the child can take responsibility for himself or herself" (a provider in South Africa). These include providing counseling support to parents/caregivers on disclosure; skill building via role-plays of

conversations with a child; facilitating disclosure where a trained provider is present during conversations with a child or with the larger family; and developing disclosure plans that identify why, who, and when sharing information about the child's status may be helpful (e.g., disclosing to a favorite teacher who can support taking of medicine during school hours or at boarding schools).

- **Facilitating broader disclosure and support for the child:** Many programs noted that disclosure of the child's status often involves more than the parent/caregiver and that they may need to facilitate discussions with other family members to ensure that the child has ongoing support. Programs mentioned approaches such as home-based counseling and having family conferences as some of the steps they take to assist with disclosure and build support.

ADDRESSING INTERNALIZED AND EXTERNAL STIGMA

HIV-related stigma plays a critical, sometimes unrecognized, role in the overall well-being of children living with HIV and their families. Stigma can assume many forms, including physical, social, verbal (language), and institutional discrimination, isolation, or abuse (Ogden and Nyblade 2005). Children and families affected by HIV face both external stigma—the negative attitudes and behaviors directed at them from outside people or groups (e.g., community members, schools, extended family, etc.)—as well as internal or self-stigmatization—the degree to which people living with HIV endorse the negative beliefs and feelings associated with HIV about themselves (Stangl et al. 2009). Situations with children can be complicated by a parent's or caregiver's own experience with internal stigma, which limit how he or she is able to interact with and support the child. Stigma can also push parents/caregivers to shield their children: “Parents don't tell [their children that they are HIV-positive] because they're protecting their children. Children can be cruel and parents don't want people to be mean to their children” (a provider in South Africa).

For vulnerable girls and boys in HIV-affected communities, multiple forms of stigma may affect their ability and willingness to participate in and benefit from programs. In addition to some of the more general stigmas associated with gender or HIV, these children also face internalized and external stigma around being labeled vulnerable or orphaned, as well as being poor. The experience of these stigmas are interrelated, with HIV-related stigma often being the most directly feared or experienced. Such stigmas can be manifested in many ways, from increased risk behaviors, to caregiver reluctance to access services and disclose status/information, to family and community neglect of the child, to the isolation and depression of the child and/or caregiver. PSS efforts to help children cope with harmful effects of feared and real stigma are critical to their well-being. As one youth in Uganda noted: “Children need a constant loving presence because they can often be isolated from others because of stigma.”

Current programs for children living with HIV consistently highlighted the barriers that stigma can create. A systematic approach to understanding and addressing both external and internal stigma can enhance both demand/use of programs and the delivery of critical services.

Several promising practices emerging from the field-based technical reviews are directed at addressing external stigma (see Box 7), including:

- **Community outreach to raise awareness about HIV and address stigma:** Several programs conduct or support (through nongovernmental organizations/community-based organizations,

peer groups, etc.) community outreach that raises general awareness of HIV-related stigmas and seeks to break down negative practices toward families and children living with HIV.

- **Targeted interventions to address negative stigma:** Providers noted that, given their limited time/resources, they often focus efforts more deliberately on institutions for children, especially schools and churches. Programs in both countries respond to specific situations where stigma impacts a child client: “We have had problems with teachers ostracizing our children in school, so we go to the schools and engage with the teachers” (a provider in South Africa). It is important to note that schools can be particularly challenging environments, and disclosure to teachers or administrators should occur only if the benefits outweigh potential risks to the child.

Box 7. Program Example: Addressing Stigma

Program: Mildmay Uganda-supported site, Naggalama Hospital, Mukono

Background: Naggalama Hospital, with support from Mildmay Uganda, provides HIV-related care for almost 3,000 clients in the area. For children, this includes facility-based clinical services and counseling, as well as community-based follow-up support and monitoring of the child’s status.

Promising practices:

- Individual counseling to address internalized stigma and develop positive self-image.
- Peer support groups for adolescents (aged 13 to 17 years) to share experiences with stigma.
- Peer interaction (providing a forum for sharing of experiences) through treatment adherence workshops.
- Staff follow-up (via visits and phone calls) to manage instances of discrimination.

- **Peer outreach and support:** An important aspect across programs is the engagement of both adolescents and adults living with HIV to lead efforts via awareness campaigns with model clients (e.g., adults living with HIV who have been identified and prepared to share their experiences in living positively with others) and role models, drama outreaches led by HIV-positive youth groups, and peer outreach in schools (e.g., adolescents living with HIV who visit neighboring schools to share their experience and promote the rights of those living with HIV).

All programs noted the importance and challenge of helping children address internalized stigma associated with HIV. Programs highlight having consistent, positive messaging around HIV (e.g., that it is not a death sentence, and that children can lead normal lives and should plan for their future) as being crucial to ensuring a confident, hopeful child; such messaging should be reinforced by all influential individuals in the child’s immediate sphere. Providers noted the importance of communication, physical contact, and social interaction with peers, family members, and resource persons to work through some of the difficult feelings and isolation a child may be experiencing: “So many kids don’t have anyone to talk to at home. They are alone. We want to support these kids. We want to see happy children” (a provider in South Africa). Promising approaches include:

- **One-on-one counseling:** As with most areas of PSS, individualized counseling by a trained provider (especially one with specific skills in working with children) is tremendously important. Programs try to create this, often having one provider who is dedicated to the long-term management of a child’s ongoing psychological well-being, including situations where a child may be experiencing stigma; as one youth in Uganda noted, “My counselor helped me see that whatever they said, I had the power to take it in or not, let it affect my life or not.” Even if that

one provider cannot meet all counseling needs, he or she can identify needs and bring others in as needed.

- **Support groups:** Such groups—for youths, parents, providers, etc.—were repeatedly noted during interviews and focus groups. Young people particularly noted that support groups were helpful in dealing with internalized stigma and being able to share with and learn from others who addressed the same difficult emotions/situations.
- **Mentoring and role modeling by adolescents/adults living with HIV:** Youth and providers noted the need for others (aside from trained counselors) to be involved in coaching children/adolescents as they cope with HIV. In particular, this includes having opportunities for younger children living with HIV to interact with older youth living with HIV or with adult HIV role models. Youth suggested both formal (e.g., peer support groups) and informal opportunities to interact with others to build skills/resources to live positively, including addressing stigma. Some of the previously identified practices (such as peer drama groups and outreach) also build critical self-esteem, which children can draw on when facing stigma.
- **Interactions between HIV-positive and HIV-negative children:** Several providers noted that children need opportunities to engage with children who are HIV-negative. This was particularly true for several of the South Africa programs, which did not necessarily base activities/services around the child's status. While this can do much to prevent or reduce stigmatization, it is important to acknowledge that programs should be prepared to prevent or handle situations of inadvertent disclosure and ensure that HIV-specific needs/considerations are not lost.
- **Resources:** Tools, like Hero Books (REPSSI) or *My Living Positively Handbook* (Children's Rights Centre), allow creative and confidential ways for children to express what they are going through and process the feelings of guilt, shame, and grief associated with internalized stigmas.

An important point to highlight is that parents, caregivers, and providers need support in addressing their fears and guilt (both for their own situation if living with HIV, as well as with regard to the child), so that they are then able to provide positive support for the child.

Some programs noted that activities such as community-based drug distribution centers may help reduce stigma by encouraging clients to access these services openly and more conveniently; these actions can then be seen as routine by others in the community. However, providers, caregivers, and children also noted that being part of a program clearly associated with HIV (e.g., people know that a particular clinic or provider focuses on HIV-related care) or having labels (e.g., on uniforms, hats, vehicles, etc.) can foster stigma or increase client perceptions of being stigmatized. These highlight how even small things can unintentionally reinforce negative and harmful attitudes or foster greater understanding and support for people living with HIV; programs need to create time and space for exploring stigma (at different levels and settings) and build individual and community capacities to prevent and manage the effects of stigma and reduce stigma.

PREPARING FOR AND COPING WITH LOSS, GRIEF, AND BEREAVEMENT

Loss is often an inherent part of any child's life, but it has increased importance for children born and living with HIV. This research effort focused on the grief experience of the child born and

living with HIV. For these children, especially those living in high HIV-prevalence communities, there can be multiple forms of loss, from death of parents, siblings, or friends, to having an unstable home environment (e.g., moving from one household to another, and loss of income), to perceived or real lack of opportunities (e.g., unable to play freely, or lack of sense of future or purpose; Steele, Nelson, and Cole 2007). Studies show that children are particularly affected in the year before experiencing the death of a parent, highlighting the importance of interventions that help a child and his or her parents and caregivers prepare for this loss, as well as cope with grief afterwards (Christ 2000).

Grief and bereavement was generally an underaddressed area for several programs included in the field review. Providers noted that they often come up against cultural or caregiver reluctance to talk openly about death and loss with children: “We have many kids who don’t want to talk about loss. The cultural situation is that children are not part of death. The idea is that children don’t know anything, so they don’t need to know. Children don’t even go to the graveside. They don’t have closure” (a provider in South Africa). Similarly, a caregiver observed, “Even a child of 3 years can know that someone has died, but we don’t talk to them about it” (a caregiver in Uganda).

While programs often had specific activities to support children through a loss or the impending death of a parent, few had a continuous and individualized approach that incorporates established best practice on age/developmental stage–appropriate approaches to helping a child process grief. Providers noted that this is due, in part, to their own limited capacity and time to support children through grief; as a provider in Uganda said, “There is a lot more for me to learn. I learned how to deal with children’s grief and bereavement by doing it, but I don’t always know what to say.”

Despite these limitations, programs did have several promising activities to address grief and bereavement, particularly the South African programs (see Boxes 8 and 9). These include:

- **Continuous screening and counseling for children and caregivers:** Case managers or child counselors provide continuous assessments of the child’s situation, including impending or

Box 8. Program Example: Coping with Grief and Loss

Program: Cotlands, Western Cape

Background: Cotlands provides shelter and services for “abused, abandoned, HIV-positive, orphaned and terminally ill children from birth to 12 years.” In Western Cape, Cotlands operates two residential facilities and a home-based program that reaches into rural communities. The majority of children in the home-based care program are living with HIV. An interdisciplinary team of health providers and nongovernmental organization professionals monitor and follow-up on each child’s medical, social, and emotional needs.

Promising practices:

- Regular assessments to screen for PSS needs at the clinic and during home-based care (children with acute needs are referred back to the interdisciplinary team for management and counseling referrals).
- Screening specifically on dealing with grief and on fostering a sense of emotional safety and bonding.
- Specialized sessions with trained therapists.
- Grief and bereavement counseling for parents/caregivers (provided by social workers).
- Bereavement counseling for staff (provided by external counselors).
- Referrals to external organizations for therapy and spiritual support.

experiencing death/loss. This ongoing support can also then help to prioritize specialized care as needed for acute situations (for child or caregiver/household).

- **Targeted activities to prepare for death of parent/caregiver:** This was generally one of the better addressed aspects of grief for many programs. Activities include developing succession or ongoing care plans for children; writing wills; and preparing memory boxes, books, family trees, and other materials—often jointly with the child, helping to facilitate communication. These activities help provide important family contexts, histories, and memories for the child to draw on going forward.
- **Activities/tools to use with child to process loss and grief:** Several programs use tools to help a child work through the loss of loved ones, such as the St. Nicholas Bana-Pele Network's *Growing through Grief* workbook. Some programs also have tools that can be used with a child who has questions about his or her own death.
- **Contact throughout bereavement of loved one:** Even simple steps, such as attending the funeral or making a phone call after a death, can be an important form of support for a child or caregiver experiencing loss, reinforcing a sense of connection and support to others. Home visits and counseling following a death also provide an opportunity to continue working through the grief process and monitor for and/or screen children for signs of trauma/grief and provide referrals (including those to meet basic needs of the family).
- **Referrals for ongoing support:** In many of the communities visited, meeting basic needs is a daily concern. The death of a parent or adult has significant implications for the welfare of the child and his or her family. Programs noted that, wherever possible, they facilitated linkages to social support programs, such as income-generating activities and social welfare.

Box 9. Program Example: Helping Children Cope with Grief and Loss

Program: St. Nicholas Bana-Pele Network, Free State, South Africa

Background: Bana Pele focuses on providing palliative care for children with life-threatening conditions, including HIV. It provides psychological, spiritual, and clinical care through day care centers, home-based activities, and hospice care.

Promising practices:

- Strong emphasis on giving children opportunities to learn and talk about illness, death, and dying.
- Specific workbook, *Growing through Grief*, for older children.
- Forums for children to interact and share, including day care, support groups, play therapy, and theater groups.
- Tools for building memories and facilitating communication (e.g., memory boxes).
- Support for adults for their own grief via counseling and genograms.

STRUCTURING THE PROVISION OF PSYCHOSOCIAL SUPPORT

PSS is important for all programs that provide treatment, care, and support for children living with HIV and their families, including those that focus on clinical management of pediatric HIV (e.g., ART programs, palliative care programs), and others that prioritize support for orphans and vulnerable children. The shift toward a continuum of care approach, as well as a more family-

oriented system of care, has created opportunities for dedicating greater attention and resources for PSS.

Despite the challenges of operating in high HIV-prevalence and resource-constrained settings, programs in South Africa and Uganda are incorporating promising practices within the way they structure and deliver PSS services. Many of these center on resource extension that maximizes efficient use of the time, staff, and funds available for PSS (see Boxes 10 and 11):

- **Addressing basic household needs:** Programs have broadened their activities to reflect the realities of the children and families they serve. In addition to psychological care, programs may provide (or refer to other programs that provide) support for legal services (e.g., will writing and succession planning) and access to education (e.g., financial support and scholarships). Several programs reported that they form close linkages with other groups in the community (e.g., child protection agencies, social welfare groups, income-generating activities, etc.) to ensure that children and their families are part of the broader network supporting their welfare.
- **Expanding the continuum of carers:** All programs that were interviewed in South Africa and Uganda work with a range of counselors (general, child, and adherence), clinical providers, therapists, social workers, home-based care teams, community volunteers, and model patients to provide clinical and PSS services and monitor the well-being of the child and family. While this can add to challenges of maintaining clear roles, strong internal and external referrals, capacity building, quality control and supervision, having more resource persons available—especially those who can be accessed in the community or through home visits—is valued by the families of children living

Box 10. Family-based Approaches

While there is global recognition of the importance of family-based models of HIV-related care and support (Richter et al. 2009), programs have yet to fully adopt this approach. A few of the programs reviewed for this brief have initiated some family-focused activities, such as home-based testing (accessing the family via an adult or child index client); family conferences to address critical situations regarding the child's physical, psychological, and social status; and support to facilitate disclosure within the family. Youth and caregivers were positive about such steps, noting that they helped to open up discussion within the home, especially with critical groups that might otherwise not be engaged, like siblings.

Box 11. Program Example: Ensuring Continuous and Appropriate PSS

Program: National Association of Child Care Workers, Eastern Cape, South Africa

Background: The National Association of Child Care Workers' Isibindi program engages a variety of providers and volunteers to provide ongoing support for children living with HIV and families (among others). Isibindi's Circles of Care model trains community members to support families, along with program providers.

Promising practices:

- The program invests in and engages a range of providers, including those based in the community.
- A primary provider is responsible for conducting ongoing assessments of the child's status and family situation.
- Care plans are developed for each family depending on specific needs and circumstances; plans are adjusted based on assessments.

with HIV. In addition, this approach can bring cost savings, as programs can decentralize basic services and make more efficient use of highly-trained providers.

- **Identifying a primary case manager:** Many programs coordinate care of the child through one main provider (e.g., a child counselor) who manages the client (and family) from his or her entry to the program; facilitates referrals to other program, partner, or community resources; conducts regular assessments of the child's psychosocial status; adapts and maintains a central care plan and file; and serves as the primary contact person for caregivers, family members, and other providers interested in supporting the child.
- **Continuous assessment of PSS needs and responses:** Programs are also finding ways to ensure that children are continuously assessed for their psychological and social status and that ongoing support is adjusted accordingly as the child matures. A good example of this is in monitoring disclosure and facilitating the transition (with the parent/caregiver) from partial to full disclosure. Assessment practices include having initial in-depth psychological and social assessments by trained providers and/or multidisciplinary teams (e.g., Butterfly House's Team Around the Child); developing a central, tailored care plan for each child based on his or her identified needs, disease presentation, and home circumstances; and providing ongoing PSS assessments by trained personnel and home-based screening (e.g., by volunteers, adherence counselors, etc.). Such practices also help program staff and providers prioritize children with acute mental health needs and allow for a more rational and fair allocation of scarce resources.
- **Creating a friendly environment for the child:** Finally, many programs are finding small and large ways of making services and facilities more child-friendly and child-oriented (see Box 12). This includes having cheerful play areas with toys, activities (e.g., drawing and letter writing) for children to relax or interact with other children, and in some cases, also providing an

Box 12. Program Example: Providing Holistic and Flexible PSS

Program: Butterfly House, Drakenstein Palliative Hospital, Western Cape

Background: Butterfly House is the day care program for Drakenstein Palliative Hospital, which provides facility- and home-based care to meet the needs of those living with life-threatening and life-limiting illnesses. Butterfly House is a community resource center where children, parents, and caregivers can access a range of programs for holistic care—physical, social, emotional, cultural, spiritual, and educational. Butterfly House currently provides care for 200 vulnerable children (54 of whom are living with HIV) and 300 adults.

Promising practices:

- Individual counseling provided by a psychologist, play therapist, play aunties, social workers, and teachers.
- Youth day care programs include afterschool homework clubs; individual tutoring by teachers; life skills program; job skills including crafting, catering, and computer skills; and recreational activities including ballroom dancing and drama.
- Preschool program (up to 9 years of age) includes school readiness groups; life skills and healthy living activities; individual play sessions; individual play therapy (on referral); and recreational activities including drama, games, and crafts.

opportunity to be observed by counselors or to engage with a play therapist. Volunteers (e.g., “play aunties”) who interact with children in both clinic and community settings can also provide a familiar and comforting link for children. Programs use everything from colorful aprons to videos in waiting areas to create a welcoming environment. Several programs provide snacks for children during long clinic days, something that is particularly appreciated by caregivers and the children themselves.

PERSISTENT CHALLENGES

Despite the efforts of these and other PSS programs, there are some persistent gaps and challenges in providing individualized, continuous, quality support for children living with HIV and their families. The issues raised here are overarching considerations that impact provision and uptake of the range of services and promising practices noted in the previous section.

1. PSS needs to be tailored to the specific situation of the child (based on development stage, disease presentation, and home/family circumstances) and adapted over time as the child matures and his or her needs evolve. Programs are challenged to develop approaches, activities, and human resources that have the capacity to address immediate PSS needs, while also helping a child and his or her family prepare for the future. The need for a flexible and long-term approach affects both the content of PSS activities (e.g., having a program that gradually builds critical understanding and life skills to address emerging sexual and reproductive health questions/needs) as well as the way in which services are provided (e.g., engaging more directly with older children and adolescents, and in preparing to transition to adult programs).
2. Program- and household-level resource constraints and general poverty directly impact the psychological and social well-being of children—as well as restrict if and how services are offered and utilized. When time, person-power, and funds are limited, other issues (e.g., basic needs and clinical treatment) take priority. Even within South African households that receive child care grants, basic needs were cited as the primary concern.
3. PSS efforts remain heavily driven by and dependent on clinic- or program-based providers and activities, with some decentralization to the community level via social workers, adherence counselors, home-based care teams, volunteers, etc. When programs give limited attention to building the skills and agency of children and caregivers to meet their own PSS needs, efforts are highly vulnerable to shifts in program staffing, funding, and support. Facility- and program-based orientations typically do not address the expressed needs of children—especially adolescents—who are looking for peer- and youth-led initiatives that complement the support given by well-informed providers. Parents and caregivers also voiced a similar need to build their own skills and abilities to care for their children. Programs, providers, caregivers/parents, and children lack opportunities and channels to learn from one another, whether through peer support groups at a village level or the sharing of tools/curriculum between programs.
4. Efforts have limited engagement with younger children, particularly in the 4- to 8-year-old age range. These are critical years in early childhood development, and more could be done to systematically work with young children and caregivers to build resilience and form positive behaviors/attitudes in how they learn to manage their own physical and psychological and social well-being.
5. Most programs focus on a single caregiver, often female (given the generally limited engagement of or by male caregivers) and elderly, who often has PSS and other needs of their own. While some programs try to broaden the number of people caring for a child and provide some support, generally the burden of care still falls on one person who may be struggling to meet their own needs, as well as care for the child.

EMERGING THEMES

In addition to the specific promising practices highlighted previously, there are several broader themes that can shape how programs and providers work with caregivers and children to identify, support, and monitor psychosocial well-being.

1. **PSS needs to be tailored to the specific situation of the child (based on development stage, disease presentation, and home/family circumstances).** One of the main points that emerged consistently across all conversations with programs, experts, parents/caregivers, and young people is that each child is different and that services/support must respond to his or her situation and adjust over time. This means that there is no simple, standard, or static package of PSS that programs and families should provide. Instead, PSS provision should involve a more complex process of assessing and meeting the evolving needs of children as they mature as well as helping them lay a foundation for the future.
2. **The underlying program model or approach can influence the way in which children are identified as HIV-positive. The type of model also influences how PSS is included in the intervention, and the extent to which caregivers and providers are equipped to meet the PSS needs of children living with HIV.** In South Africa and Uganda, the study team had two different contexts to explore: both countries have a relatively long experience responding to pediatric HIV, with South Africa generally having more resources at its disposal to support this response. The program selection process (by virtue of the USG focal points) also reflected two different approaches that countries and donors are using to identify and support children living with HIV: 1) via pediatric care programs (Uganda) and 2) through programs for orphans and vulnerable children (South Africa). This underlying difference—with the former often applying more of a medical model and the latter focusing on broader social support (although also providing clinical services through hospice care)—seems to create some patterns in terms of psychosocial programming, as follows:
 - a. Services related to psychosocial care can be prioritized differently. Many of the Ugandan programs bring a medical care or clinical research orientation to their programs, focusing on the critical treatment needs of children. PSS can be well integrated into medical care, but some of the approaches used (including staffing and resource allocation) seemed to be structured more around adherence monitoring and were not fully geared to screen for and address broader psychosocial issues. In addition, PSS services were often discontinued or scaled back when funding cuts or shortages occur.

Within the orphans and vulnerable children approach, children living with HIV comprise one category within a broader range of vulnerable children. In some ways, this may help reduce HIV-related stigma (although not the stigmas related to being labeled as an orphan or as vulnerable), as HIV-negative and HIV-positive children are often integrated and receive similar services. Identifying and addressing PSS needs are at the core of services provided within this model. At the same time, HIV-specific needs and provider/parent/caregiver/child capacities may be lost (e.g., being able to support children with disclosure issues).

- b. In general, the programs with a clinical or medical orientation have a more proactive approach to identifying children and bringing them into care. All of the Uganda programs employ strategies to screen for children in their communities that might be in need of HIV testing or services. While the study team did not specifically compare these approaches to clinical diagnosis (HIV diagnosis that occurs within the context of a child presenting with symptoms), program experience does suggest that these proactive steps may lead to earlier identification of more children at risk or exposed to HIV. As a result, they are serving large numbers of children, although the provider to child/caregiver ratio is one that can minimize the frequency and quality of interaction.
 - c. With the South Africa programs, the orientation on care and support for vulnerable children has facilitated strong models of addressing the psychological needs of children (including those who are living with HIV), especially with regard to processing emotions and dealing with grief and bereavement. Children and caregivers have access to additional providers (e.g., social workers) and resources (e.g., social cash grants). Interestingly, although these programs are generally smaller in scale, the issue of overloaded providers holds consistent across all programs in both countries.
3. **Programs rely on multiple types of providers (in clinics and in communities), volunteers, and partners to meet the PSS needs of children, which is both a strength and a challenge.** Several of the programs reviewed were strengthened by having multiple types and layers of providers and volunteers responding to children's needs, especially those that involve youth and adults living with HIV. Youth and caregivers appreciate having more timely access to resource persons in their homes and villages via home-based care visits, outreaches, community drug distribution centers, resident volunteers, and expert patients, etc. Participants in the program review frequently voiced an interest in having more activities moved from the clinic setting to the community (e.g., having peer support groups for children and caregivers at the village level). Similarly, working with partners results in broader access to a variety of critical resources (e.g., livelihood training and support, home construction, financial resources, etc.) and reduce the burden on any one program. Several programs also work very closely with local government and community structures/groups to address acute situations (e.g., situations of abuse or violence against the child, or incidents of stigmatization in schools).

While more staff, volunteers, and partners can help meet program objectives, this also raises several challenges. First and foremost, all programs face constraints around the resources available for their activities. Programs also consistently noted gaps in capacity building, training (especially for community-based volunteers), and tools in critical areas like skills to communicate with children. Overlapping roles can also make it more challenging to monitor a child's situation and supervise quality of care. There are also considerations in balancing program needs with protecting the privacy of children and their families; youth expressed their anger at finding that their HIV and health status had been shared with others (e.g., school administrators) without their knowledge.

During the reviews, study teams also identified some of the steps that programs have taken to maximize the potential of having large, diverse teams, including:

- a. Having one provider as the primary point person for each child, even if several others are involved in providing care. This individual can be responsible for regular assessments of the child, be the internal and external reference point regarding the child, be included in all consultations regarding the child, and have responsibility for maintaining records/plans for

the child and his or her family. Such an approach helps to ensure consistency and continuity in identifying and addressing both immediate and longer-term PSS needs.

- b. Creating and adapting a central plan that identifies a child's needs based on his or her developmental and home situation. This single plan can then be used by all involved in providing care and support to ensure a consistent response.
- c. Developing capacity building plans for each partner to ensure that skills and services meet quality standards.

4. **Few programs deliberately develop the skills and agency of caregivers and children (especially younger children) to meet their own PSS needs and support others.** While programs may have individual activities or interventions that work with caregivers or children to build their capacities, these were few (and several had been discontinued due to funding cuts) and limited in time provided and topics covered. Given the importance of the primary caregiver, this is a consistently missed opportunity to ensure that some simple forms of support (improved listening and communication, opportunities for play, etc.) happen within the home. Youth repeatedly noted the need for peer support, particularly for younger children, and appreciated both structured and informal opportunities for interacting with other children living with HIV (e.g., during clinic days, support groups, camps, etc.). They particularly expressed the need to be better prepared to manage their own situation (e.g., knowing when, who, and how to disclose to others), noting that they needed more time with professional, well-informed resource persons who can provide accurate and complete information and guide them in making good decisions. In addition, there were few activities that brought caregivers and children together, either simply to facilitate interaction or to more deliberately address an issue or build joint capacity.

In talking with youth and parents/caregivers, the following related themes emerged:

- a. *Disconnects between what youth want for themselves, as well as what parents/caregivers and providers think they want:* This was particularly evident during conversations around disclosure, where youth were divided as to when and how the process should be handled. Interestingly, there were also differences in how youth felt about being treated as special. Some felt that they like that their specific situation and needs were called out (a view often shared by providers and caregivers), while others wanted to be treated like regular children and resented always being treated as different. These issues reinforce the importance of engaging more with youth in tailoring their own care and the approaches used to meet their needs, which also implies better listening and communication by providers, parents, and caregivers so that they are better able to support children's needs. Youth also highlight the importance of empowering young people to serve as advocates and active participants in the development and implementation of PSS programs for themselves and their peers.
- b. *Very limited efforts to address the emotional and psychological needs of parents and caregivers:* Most programs access children through a primary caregiver who is expected to make decisions, access services, and use resources on behalf of the child. The specific needs and vulnerabilities of these caregivers are often neglected; yet these may strongly influence if, when, how, or how well the caregiver is able to act on the child's behalf. Programs may need to identify and address the specific needs of the caregivers themselves, including health issues, violence prevention/mitigation/care, economic empowerment, etc. Caregiver skill levels, particularly for elderly caregivers, may also need to be addressed, and a more deliberate effort to work directly with caregivers and build skills (e.g., intergenerational

communication) may make a significant difference in the extent to which boys and girls can benefit from programs.

- c. *Supporting the providers:* Several programs highlighted issues of provider burnout, which is not surprising given the intense issues that they address and the heavy caseloads that many of them carry. Few programs had systematic ways of providing internal counseling support or addressing stress. One does provide grief and bereavement counseling for staff, which is a useful model for other programs to adapt and expand to include other issues.
5. **The move toward a more family-based approach to care and support creates important opportunities for programs to provide more targeted PSS and build caregivers and child capacity to address their own needs and prepare for the future.** While few of the programs reviewed have made the full shift to a family-based model, some activities do have a family focus, such as home-based testing and counseling (accessing the family via an adult or child index client), family conferences to address critical situations, and support to facilitate disclosure within the family. Youth and caregivers were generally positive about such steps, noting that they helped to open up discussion within the home and with some critical groups, like siblings. While family-based approaches will be critical, especially for younger children, programs also noted that for older children and adolescents, a family setting may be inhibiting (e.g., talking about issues in front of parents/caregivers or siblings). This again highlights the importance of having approaches/activities that are flexible and can be tailored to the specific needs of a child (and family) as he or she matures.
6. **The increasing life-expectancy for children living with HIV and the lengthening time spans between critical moments (e.g., between testing and full disclosure to the child) creates some challenges and opportunities in ensuring appropriate and timely support for children.** For children living with HIV, there are critical moments that affect their psychological and emotional well-being (e.g., the moment of full disclosure). However, as they themselves have expressed, they need and want longer-term responses to address the continuous processing they do around understanding their HIV status and health needs; planning and managing disclosure; coping with uncertainty, grief, and loss; and addressing internalized and external stigmas. For both children and their caregivers, there was consistently a missed opportunity to provide greater support and build parent/caregiver and child capacity after the initial disclosure of the child's status to the parent/caregiver (and, if appropriate, to the child). Participants repeatedly expressed the need for additional counseling, planning, and problem solving once they had time to process the initial diagnosis, but few programs had extended post-test follow-up. In many cases, where the duration of partial disclosure may cover several years, this also provides an opportunity to work closely with parents/caregivers, families, and the child to build skills, foster support, and prepare for the future. Several youth also commented that they realized their HIV status prior to full disclosure from their parent/caregiver, and providers/caregivers similarly noted that children often "know more than you think." This highlights the importance of having approaches that can monitor a child's evolving understanding of his or her situation and respond in a timely manner.
7. **In exploring the themes of disclosure, stigma, and grief and bereavement, the interrelationships between these did not always emerge clearly.** One interest of the study was to understand how the key issues of disclosure, stigma, and grief and bereavement may interact and affect the provision of care for children living with HIV. Interestingly, these interrelationships were not always evident in the comments made by providers,

parents/caregivers, and youth. Stigma was repeatedly raised as a factor in if/how disclosure occurs—from the parent/caregiver to the child, as well as the child/caregiver to others. To some extent, openness about HIV status was also noted as a way to address stigma in the community and to help children cope with internalized stigma. However, the interrelationships with grief and bereavement generally were not brought forward, either in terms of stigma or in terms of impact on disclosure process.

8. **Larger and interrelated underlying issues—especially poverty, gender, and stigma—limit the ability of programs, households, and individuals to respond to children’s needs.**

- a. *Poverty:* Throughout all conversations with providers and caregivers, concerns around meeting the basic needs of children (for food, shelter, education, etc.) were raised repeatedly and strongly. Even in South Africa, where government-funded social programs provide additional support (e.g., social cash grants), caregivers repeatedly expressed their preoccupation with needing better livelihoods and additional resources to care for all of their children. In Uganda, it was striking how these concerns overrode any priority placed on PSS and how good caregiving was often associated with being able to meet these basic needs.
- b. *Gender:* As with poverty, gender-related issues may also be affecting the ability to provide PSS and the extent to which services benefit boys and girls. In talking with program implementers, most only identified gender as a concern with caregivers, who are largely women, and in relation to adolescent concerns (regarding sexuality, need for adolescent sexual and reproductive health services, addressing situations of sexual violence, etc.). Involvement by male caregivers is consistently low in program and family responses, and while programs are being more deliberate about promoting positive norms around men as caregivers and creating more space for them in programs, these efforts are relatively new and limited in scale and range (e.g., several efforts are linked to PMTCT). In thinking about how boys and girls access and benefit from programs, there was generally no perception of gender issues, but it was also evident that gender is not often consistently used to analyze activities/impact. For example, the AIDS Support Organization is currently enrolling more girls than boys, and staff are uncertain if there may be gender issues that are affecting access and uptake of services.
- c. *Multiple stigmas:* While HIV-related stigma is one of the specific areas explored during the program reviews, it is worth mentioning stigma in a broader sense here, given how critical a factor it is for youth and caregivers. For vulnerable girls and boys in HIV-affected communities, multiple forms of stigma may be affecting their ability to participate in and benefit from programs. In addition to some of the more general stigmas associated with gender or HIV, these children also face internalized and external stigma around being labeled vulnerable or orphaned, as well as being poor. These stigmas are interrelated, with HIV-related stigma often being the most directly feared or experienced. Such stigmas can be manifested in many ways, from increased risk behaviors by boys and girls, to caregiver reluctance to access services and disclose status/information, to family and community reluctance to engage in supporting the child. A more systematic approach to understanding and addressing the various stigmas and their impact will enhance demand/use of programs and the delivery of critical services, as well as the well-being of those experiencing stigma.

9. **Lack of tested and evaluated tools, activities, and services, and larger programs for providing PSS.** In general, few PSS tools and approaches have been systematically evaluated to determine effectiveness of addressing psychosocial needs. And while some approaches seem

cost-effective (e.g., using more lay providers or volunteers to work with children in communities), there is limited evidence on the quality of such efforts or what is needed (e.g. training, supervision, etc.) to ensure quality is maintained. Investment in appropriate evaluations will be critical to help governments, programs, and families determine which PSS activities are the best investment of their scarce time and resources.

RECOMMENDATIONS

As current programming efforts in South Africa and Uganda illustrate, there are promising practices that can be adapted to enhance the psychological and social well-being of children living with HIV aged 0 to 12 years. Recognizing that parents, caregivers, providers, and program staff are often overburdened and under-resourced and public health planners and implementers have limited resources, the following recommendations may help programs prioritize specific areas for greater attention and maximize available resources to effectively support children living with HIV and their families. Even if programs cannot take on each recommendation in full, some of the subrecommendations may be manageable and effective in strengthening current efforts. Many of these recommendations should not require significant resources to implement, especially those that emphasize the role of caregivers, parents, community members, and/or children and adolescents in programming. Where staffing, technical capacity, time, and financial resources are limited, programs can concentrate efforts on a few initiatives that have repeatedly emerged through this research as priority areas for greater PSS.

1. **Dedicate trained personnel and project resources to work with the child, caregiver, and family in the period immediately following testing and disclosure of results.** Parents and caregivers identified the time after HIV testing as being critical to their own psychosocial well-being and to effective planning for care of the child. Available resources could be used to maximize this window of opportunity:
 - a. Prepare all cadres of providers for these important initial conversations by strengthening their skills and capacity in child and family counseling and communication.
 - b. Work with the family to develop a care plan that includes appropriate disclosure to others, clinical treatment and adherence, psychosocial well-being and support (including ensuring access to education, social interactions, etc.), succession planning (as relevant), and other services/referrals to assist with the family situation.
 - c. Identify and address concerns related to the parent/caregiver that may have an impact on the child's care (e.g., couples testing and counseling).
 - d. Provide frequent post-test in-home follow-up visits with the child and his or her primary caregiver using a range of resource persons (e.g., child counselors, community-based volunteers, model patients living with HIV, etc.).
 - e. Facilitate discussions, counseling, and skill-building within the family/household to broaden the network of available caregivers.
2. **Expand the continuum of carers to include more community-based resource persons and partners to meet the PSS needs of children while maintaining a central point person to monitor and coordinate care.** Programs are strengthened by having multiple types of complementary providers and volunteers responding to children's needs closer to home. Key approaches include:

- a. Extend trained resource persons (especially youth and adults living with HIV) to interact with children, caregivers, and families in their homes and villages to ensure more timely and frequent access to care (e.g., via home-based care visits, outreach, community drug distribution centers, resident volunteers, and expert patients, etc.).
 - b. Move support activities from clinics or program centers to the community (e.g., having peer support groups for children and caregivers at the village level).
 - c. Link caregivers and families (and adolescents/youth, as appropriate) with partner organizations to increase access to a variety of critical resources and support (e.g., food gardens, livelihood training and support, home construction, financial resources, etc.) and reduce the burden on any one program. Several programs also work very closely with local government and community structures/groups to address acute situations (e.g., situations of abuse or violence against the child, or incidents of stigmatization in schools).
 - d. Enhance understanding and capacity of key government and community structures to foster sustained PSS, as possible. In particular, this includes the school system, child protection and law enforcement agencies, and local government.
 - e. Maintain clear roles and reporting lines to a central resource person who can monitor the child's case, maintain a care plan, provide supervision, and ensure privacy/confidentiality for children and caregivers.
3. **Invest in building the capacity of caregivers and children and create forums for them to meet their own PSS needs and support others.** By building capacity and by supporting forums for children, parents, and caregivers to support each other, programs can encourage a more responsive, sustainable model for basic PSS. Approaches include:
- a. *Build the capacity of parents and primary caregivers (see Box 13 for additional details):* Given the importance of the primary caregiver, emphasis should be placed on developing simple forms of support (e.g., improved listening and communication, opportunities for play, etc.) that happen within the home. Capacity building and skills transfer (and role modeling) can be integrated simply and inexpensively into all interactions between trained providers and caregivers.
 - b. *Facilitate skills development of all children living with HIV to manage their own care:* Youth particularly expressed the need to be better prepared to manage their own situation (e.g., knowing when, who to, and how to disclose to others, and how to manage stigma). They needed more time with professional, well-informed resource persons who could provide them with accurate and complete information and guide them in making good decisions.
 - c. *Cultivate ability of older children, adolescents, and youth living with HIV to provide peer support and serve as resources:* Youth repeatedly noted the need for peer support, particularly for younger children, and appreciated both structured and informal opportunities for interacting with other children living with HIV (e.g., during clinic days, support groups, camps, etc). In particular, they stressed the importance of peer support and youth-led forums/activities that allow them to share information and counsel and guide one another; older youth repeatedly saw an opportunity to help younger children adjust and live positively with HIV. A more deliberate effort during the initial stages of HIV care may help build a set of resources around a young person that will provide ongoing support and help children build resilience and capacities to manage their psychological and social well-being in the future.

Box 13. Equipping Providers, Parents, and Caregivers

Building skills and understanding:

- Trainings and workshops (linked to clinic days) on HIV information, parenting, and communication skills
- One-on-one skill building (e.g. role-playing conversations on disclosure)
- Facilitated communication (e.g., conducting joint counseling sessions with child and caregiver)
- Family conferences to assist with disclosure and build support.

Creating channels and forums for peer support:

- Separate peer support groups for children and caregivers, including those that focus on grief and bereavement
- Outreach and role modeling by adult and youth living with HIV.

Meeting caregiver needs:

- Counseling support for caregiver disclosure, grief, and bereavement
- Support and referrals to meet basic needs, including linkages to income-generating activities.

d. *Create and support structured and unstructured forums for children living with HIV, parents, or caregivers to interact with peers, providing an important opportunity for people to meet, share experiences, and learn from one another:* These need not be resource-intensive and could benefit from being decentralized from a program/clinic setting by being brought into the community and led by young people or caregivers. Interactive sessions might simply bring children together to play (with adult supervision) or could be formed around specific issues/activities of interest (with some technical resource or facilitation, as needed). Forums could be led by experienced youth or caregivers, or by trained community resources (e.g., community volunteers, model adult clients living with HIV, etc.).

4. **Reduce stigma within the immediate circles of care such as households, clinics, and schools.** Given the pervasiveness of harmful attitudes and influences in the households, schools, and communities where children living with HIV reside, it is important that all people and programs involved in providing HIV-related services address stigma while building the capacity of individuals and families to address stigma directly. Approaches include the following:
 - a. Analyze the program for any elements that promote positive images of people living with HIV (e.g., peer role modeling programs, or community drug distribution centers) or inadvertently reinforce negative stereotypes.
 - b. Integrate stigma-reduction activities into trainings and meetings with program staff, including those working largely in the community.
 - c. Build skills of counselors to address stigma throughout child screening/assessments and ongoing counseling of children and parents/caregivers.

- d. Develop skills and opportunities for community-based resource persons—especially youth and adults living with HIV—to interact with children and household members and address stigma.
- e. Support targeted interventions to address negative situations in schools and general communities.
- f. Facilitate peer outreach, mentoring, and support groups for children and youth living with HIV.

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APPENDIX A:

MEETING THE PSYCHOLOGICAL AND SOCIAL NEEDS OF CHILDREN LIVING WITH HIV IN AFRICA: SUMMARY OF CASE STUDIES IN SOUTH AFRICA AND UGANDA

INTRODUCTION

Technological advances, such as antiretroviral therapy, increasingly allow children who are HIV-positive to live longer and healthier lives. These advances have led to an effort to expand access to and utilization of appropriate HIV testing of infants and children who have potentially been exposed to HIV during pregnancy. As a result of these efforts, more children have been identified as living with HIV and are in greater need of continuous psychological and social services that are integrated within a broad framework of care provided by parents/caregivers and service providers (both facility- and community-based) and adapted over time as children age and develop.

For children growing up and living with HIV, care and support must go beyond medical management of HIV to address a range of interrelated issues, such as how to help children and their families know when, how, and to whom to disclose the child's status; how to equip children and their families to combat external and internalized stigma; and how to manage grief and bereavement. With more children living longer with HIV, parents/caregivers and service providers need support and guidance on how best to care for and counsel children to grow into emotionally and physically healthy youth and adults.

This activity, funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), through the U.S. Agency for International Development (USAID), is designed to collect and present information that may help parents/caregivers and service providers more effectively address the complex needs of children living with HIV in sub-Saharan Africa. While there are many needs that require stronger responses, this project focuses on five areas that impact on the overall well-being of an HIV-positive child:

1. Identifying children for services and ongoing support
2. HIV testing and counseling of children
3. Supporting the disclosure process
4. Addressing internalized and external stigma
5. Addressing grief and bereavement.

To better understand the current ability of providers, parents, caregivers, and children to address these needs, the project conducted technical reviews of eight projects serving children living with HIV in Africa, four projects each in South Africa and Uganda. This document presents summaries of each of the technical program reviews, highlighting current approaches, good practices, and persistent gaps/challenges for each of the five priority areas (identifying children, HIV testing and counseling, disclosure, stigma, and grief and bereavement). In addition, this report includes a synthesis of some of the common themes emerging across the eight programs and identifies some of the opportunities and challenges that many programs face.

METHODOLOGY

The technical reviews built on earlier phases of the project, including a review of existing literature and consultations with numerous experts working to address the psychosocial needs of HIV-positive children. The study team, in consultation with USAID and a Technical Advisory Group, identified several countries with a range of pediatric HIV care, support, and treatment programs in Africa. Further discussions with U.S. Government (USG) country teams led to the selection of South Africa and Uganda as the two countries to be included in the technical reviews.

The study team then worked closely with USG point-persons in each country to identify programs that would represent a variety of service delivery approaches (e.g., clinic-based, community-based, etc.) in different settings (urban, peri-urban, and rural). Program selection also reflected the interest and availability of organizations and staff to participate in the study.

The following four programs were selected for South Africa:

1. St. Nicholas Bana Pele Network, Bloemfontein, Free State
2. Butterfly House, Drakenstein Palliative Hospice (DPH), Western Cape
3. Cotlands, Somerset West, Western Cape
4. National Association of Child Care Workers (NACCW), King Williams Town (KWT), Eastern Cape.

For Uganda, the selected programs included the following:

1. Baylor Uganda, Kampala
2. Joint Clinical Research Center (JCRC), Mbarara
3. Mildmay Uganda-supported site, Naggalama Hospital, Mukono
4. The AIDS Support Organisation (TASO), Masaka.

Two study teams were formed to lead the technical reviews in each country; teams included staff members from the International Center for Research on Women (ICRW), as well as technical consultants based in Africa. Ethical approvals were obtained from ICRW's Institutional Review Board, as well as from the following in-country boards: Hospice Palliative Care Association, University of Witwatersrand in South Africa, and the Uganda National Council for Science and Technology.

Team members conducted the Uganda reviews in May and June 2010, with the South African reviews following in October and November 2010. While study participants and interview guides were tailored to each program, data collection was generally consistent across the eight technical reviews. Data collection methods included in-depth, semistructured interviews with key informants (within government and civil society) and program staff members, as well as focus group discussions with program staff, parents/caregivers of HIV-positive children, and HIV-positive adolescents and young adults. Based on Institutional Review Board requirements, the age ranges of youth included in

the study differed in the two countries: in Uganda, participating youth were aged 15 to 18 years, while in South Africa, young adults were all over the age of 18 years. As a result, many of the South African young people were not perinatally infected with HIV (although some were parents of HIV-positive children), which affected the experiences and opinions that they were able to share. To the extent possible, the study team also sought to include both male and female participants, though this balance was determined by staff composition and the level of involvement of male caregivers.

Interviews with key informants in government and civil society explored the larger context of pediatric HIV, highlighting current strengths and gaps in the national response to support HIV testing of children and provide care for HIV-positive children. Interviews and focus group discussions with program staff covered the successes and challenges in their programs for HIV-positive children, focusing on HIV testing, as well as the provision of psychosocial support for children and their caregivers. With each program, the study team sought to understand current approaches (including tools and resources) and persistent gaps in identifying children for services, testing and counseling, supporting the disclosure process, addressing stigma, and supporting grief and bereavement. Focus groups with program participants sought to gather the same information as well as determining additional needs of both children and caregivers to improve the psychosocial well-being of HIV-positive children. Ethical consent was obtained from all participants prior to each interview and focus group. Local consultants facilitated discussions in local languages, and information was recorded through handwritten notes.

CASE STUDY SUMMARIES FROM SOUTH AFRICA

ST. NICHOLAS BANA PELE (“CHILDREN FIRST”) NETWORK

BLOEMFONTEIN, FREE STATE, SOUTH AFRICA

On November 17 to 19, 2010, the ICRW research team conducted a visit to St. Nicholas Bana Pele (“Children First”) Network in Free State. Over the course of the visit, the team met with Bana Pele Network leadership as well as service providers and program clients at two network partner sites: Viljoenskroon Hospice and Ladybrand Hospice. The data used for this case study summary were collected through interviews and focus group discussions with 10 individuals, including the Bana Pele project leader and the network development manager. At Viljoenskroon, participants (all female) included three child and youth workers, a hospice general manager, and a staff nurse. The participants (all female) in interviews at Ladybrand Hospice included a social work manager, an assistant day care teacher, and a nursing manager.

PROGRAM DESCRIPTION

Model:

St. Nicholas Bana Pele is part of the International Children’s Palliative Care Network and is a subgrantee of the Hospice Palliative Care Association. In this role, Bana Pele strengthens and manages a network of organizations that care for children with life-threatening conditions, including HIV. The organization was founded in 2008 in the Motheo district and now operates in other parts of Free State as well. Bana Pele aims to increase access to palliative care for children and to develop children’s palliative care (CPC) across a wide range of health, welfare, and education professions. The St. Nicholas Bana Pele *Network* was recently introduced by St. Nicholas Children’s Hospice in Bloemfontein, Free State, as a pilot project to develop a network of services to children who need palliative care to ensure that they are kept within a safety net of services and provides for an appropriate continuity of care. The Bana Pele model adheres to the three core components of CPC, namely psychosocial, spiritual, and clinical care. Many of the partner organizations have previously focused on the provision of adult palliative care, but all had a children’s program in place. A key aspect of the CPC network initiative has been to demonstrate the importance of pediatric and adult service integration. Through this network, Bana Pele has partnered with organizations such as the Viljoenskroon and Ladybrand Hospices to provide tools and build capacity in CPC.

Potential partner organizations are assessed by Bana Pele and provided with recommendations for improvements to service provision, including psychosocial services. Bana Pele works jointly with the partner organization to draw up a capacity development plan so that they can benefit from training that adheres to the Hospice Palliative Care Association standards. This training uses a variety of curricula, including pediatric palliative care for caregivers, home-based care (HBC) pediatric

palliative care, and psychosocial palliative care for children, in addition to short courses on specific thematic areas and skills. Funding is provided for partner organizations based on the number of children served by the program and the development plan.

Client base:

Still in the early stages of the pilot, Bana Pele has now expanded its model to cover additional towns in Free State. These include the catchment areas of the two hospices visited by the ICRW team: Manyatseng, Mauersnek, Viljoenskroon, Rammulotsi, and the surrounding farming communities. The Viljoenskroon Hospice has provided services to terminally ill patients and their families since 1993 and has included services to HIV-affected families since 1997. The clients of Viljoenskroon Hospice include 448 school-aged orphans and vulnerable children (OVC) who receive psychosocial services and day care, 312 families receiving HBC, and the community at large using social and support group activities offered through eight schools, 35 churches, and two clinics in the area. Ladybrand Hospice provides nursing services to 148 patients, social services to 333 OVC and 104 foster parents, and education to 16 children through a day care center.

Services:

Through the Bana Pele Network, the hospices and their partners provide a number of services to clients and their families. These include an array of clinical, social, and educational services, as follows.

Children:

- Early childhood development/day care (0–6 years)
- Middle childhood development program (7–13 years)
- Homework supervision and tutoring for exams
- Play therapy (on referral)
- OVC theater group (during vacation)
- Gardening
- HBC (clinical and psychosocial monitoring).

Adolescents/young adults:

- Adolescent development program (14–18 years)
- Psychoeducational groups (e.g., substance abuse, and sex education)
- Income-generation activities (e.g., Beads of Life).

Parents/adult clients:

- HBC (clinical and psychosocial monitoring)
- Food security programs (e.g., food gardens and food parcels)
- Thandanani Time Gogo (program for grandmothers providing relationship building, communication, sensory stimulation, etc.)

- Support groups
- Income-generation activities and permanent employment (e.g., Rose Charity Fashion Academy).

Bana Pele in Bloemfontein also provides an inpatient facility and offers various additional services including a fully fledged resource center that offers psychosocial support (PSS) materials. The recent expansion of the model has resulted in the development of small portable resource units for these PSS materials that can be utilized by partner organization networks across a wider geographic area.

Staffing:

The hospice teams that provide care and support to children are multidisciplinary and comprise staff members from numerous network partners. Ladybrand Hospice consists of three departments: nursing, social work, and administration. In the nursing department, there is a nursing manager, a nursing assistant, an auxiliary nurse, and a team of eight home-based carers. The home-based carers are supervised by an HBC coordinator. The social work team includes a social work manager, an OVC coordinator, a social auxiliary worker, and an orphan program coordinator. The administrative department includes a funding coordinator, an administrative manager, and a day care center teacher. The Viljoenskroon Hospice staff is comprised of the OVC program team and the HBC program team. The OVC team is comprised of three child and youth care workers (CYCW), and an auxiliary social worker, while the HBC team includes 13 HBC workers.

External linkages:

The St. Nicholas Bana Pele Network recognizes that individual organizations are unable to meet all the medical and psychosocial needs of their clients. As such, the organization capitalizes on the large number of service organizations in Free State to create a network that facilitates referral and maximizes the support provided to clients and their families. These network partners include hospitals, clinics, antiretroviral therapy sites, nongovernmental organizations, schools, HIV testing and counseling provision organizations, and faith-based organizations. Specific partners named include the Cancer Association of South Africa, Sunflower House Children's Hospice, the Department of Social Development, Kerklike Maatskaplike Dienste, and Rose Charity Fashion Academy. The two hospices receive funding from a variety of international and national sources, including the European Union, Absa Bank, Hospice Palliative Care Association, DG Murray, AIDS Foundation South Africa, the Department of Social Development, and Lotto. Viljoenskroon also receives both funding and student volunteers from S.K. Netherlands.

Good practices within the general model/approach:

- Network approach involves a variety of organizations in the provision of care and support based on their areas of expertise
- Capacity development plan to ensure that partners are trained and up to standard
- Network partners recognize the importance of understanding local traditional practices and engage traditional healers as service providers
- Ongoing assessment of children's psychosocial needs allows for tailoring of home-based visit schedules and care plans based on changing individual needs
- Network approach fosters strong linkages between the school, home, and community environments to create a solid continuum of care and support for OVC.

Gaps/challenges:

1. Limited parental engagement outside of home visits poses a challenge for ensuring continuity of care and appropriate monitoring of child's well-being.
2. Families in the local communities are plagued by poverty, which often renders children's home environments unstable and unable to ensure basic nutrition, hygiene, and safety.
3. Funding of program activities is inconsistent and limited, frequently leading to the termination of psychosocial programs that serve large numbers of children.
4. CYCWs and home-based carers are responsible for such large numbers of clients that they are held accountable for the quantity of visits rather than the quality of care provided.

IDENTIFICATION OF CHILDREN**Current approach/activities:**

The hospices under the Bana Pele Network serve terminally ill patients and their families, irrespective of their HIV status. However, the majority of adult clients identified for hospice care by the partners are people living with HIV. As such, while positive HIV status is not a criterion for treatment or receipt of the services offered, the vast majority of the families served by Bana Pele are affected by HIV. Referrals for hospice care come from local doctors, clinics, and hospitals that have identified a family dealing with critical illness and with limited or no financial resources to pay for care. Children of identified families are enrolled in program activities with the consent of parents/caregivers. Children who receive services from Bana Pele may also be referred by schools, community-based organizations, and local social workers if they are orphans (having lost at least one parent) identified as having serious social or medical concerns (malnourishment, emotional problems).

Once a child has been identified for the program, he or she is assessed using a developmental checklist. This includes an evaluation of fine/gross motor skills; language; cognitive, social, and emotional development; socioeconomic status and needs; and spiritual development. This assessment is completed by a nursing sister or the early childhood development provider, and referrals for specific services or program activities are made based on the assessment.

Good practices in the identification of children:

- Strong linkages to hospitals, the social work system, and law enforcement helps with the identification of children in need of PSS
- Using a family-based approach (via adult index clients) to identify children who might need services and support
- Ongoing assessment of PSS needs aids in identifying and addressing health problems and emotional needs as they arise.

Persistent gaps/challenges:

The approach to identifying children for services relies on referrals from multiple outside sources and network partners, and can also depend on having adult clients (through whom, children are identified). This lack of a systematic and proactive approach for identifying children in need could lead to a failure to identify many eligible children in need of support. Several providers also

identified an enormous challenge in the process of identifying children and families for services; clinics frequently refer families without their consent, which raises ethical challenges for the service provision teams when they invite families to receive services.

TESTING AND COUNSELING

Current approach/activities:

Bana Pele partners do not provide HIV testing and counseling for children through their core program activities. However, the outreach activities conducted by home-based carers include home-based testing and counseling of adults. If a child is present, the home-based carer will encourage having the child tested at nearby clinics/hospitals that are meant to provide pre- and post-test counseling. Likewise, when parents are referred to the hospices for care, testing of their children for HIV is recommended but it is not standardized as part of the basic services.

Good practice in testing and counseling:

- Home-based testing and counseling for adults provided through outreach to farming and less accessible communities.

Persistent gaps/challenges:

As with other approaches that have a palliative care component, Bana Pele partners often see adult and children clients who have already been through testing and counseling at another facility. Program staff (home-based carers and social workers) have noted, however, that caregivers and families often have very limited understanding of their HIV status and related care, which may indicate that they did not receive proper counseling or follow-up care.

DISCLOSURE

Current approach/activities:

Providers encourage families to disclose a child's status as a critical step toward providing appropriate care and support to their children. While no specific age was identified as the ideal time for disclosure, providers embrace the philosophy of “the earlier, the better” when it comes to telling a child about his or her HIV-positive status. Despite not having any concrete tools to aid in disclosure, CYCWs feel comfortable advising and supporting families and caregivers through the process. Providers recognize that avoidance of disclosure is a significant barrier to the provision of optimum care. As such, the Viljoenskroon Hospice team has administered household questionnaires to better understand some of the problems their clients and community members face around status disclosure.

Good practices in supporting the disclosure process:

- CYCWs are trained in a 14-module National Association of Child Care Workers curriculum that provides them with skills to support families through the disclosure process
- Story books are used to promote dialogue that can aid in disclosure
- Proactive approach to researching challenges to disclosure.

Persistent gaps/challenges:

Caregivers and providers frequently mentioned that families had not yet openly addressed or acknowledged the HIV-positive status of adult family members, which rendered them unprepared to disclose a child's status. HIV-positive parents readily admitted that their reluctance to disclose their own status makes it even more difficult for them to talk to their child about his or her status.

STIGMA

Current approach/activities:

Stigma was widely acknowledged as a critical issue faced by families affected by HIV. Bana Pele partners are proactive in addressing stigma through aggressive community outreach activities that extend to farming and rural communities as well. Providers work closely with schools to engender friendlier learning environments for children affected by HIV. Similar partnerships with local churches aim to reduce stigma through education and, thus, to create more hospitable and supportive communities. Children and adolescents also benefit from the use of “hero books,” for which they serve as the authors, illustrators, and main characters. These books provide a medium for exploring and discussing the challenges they face and help to mitigate the impact of external and internal stigma.

Good practices in addressing stigma:

- Aggressive community outreach and education to reduce stigma
- Partnership with schools and churches to reduce stigma in communities
- Acknowledgment of the powerful negative impact stigma can have on care and interest in adapting service provision to reduce stigma
- Development and use of visual aids to educate and dispel myths about HIV.

Persistent gaps/challenges:

Providers, caregivers, and youth all identified stigma as a challenge to disclosure, including both feared and experienced stigma. Providers believe that stigma is an especially powerful disincentive for men, whom they view as less likely to disclose their status than women. A persistent problem faced by Bana Pele providers is that the community tends to associate the hospices with HIV. As such, attendance at support groups and parental involvement in training opportunities is often low. Similarly, home visits are not always welcomed, even by families in dire need of the medical and social services provided. While site-based services are also comprehensive, home visits are widely regarded by providers and clients as more personalized and better tailored to the needs of individual families and patients. Providers also noted that association with the hospices can be stigmatizing for children even if it is not associated with HIV, as they are labeled by other children as “sick” or as “orphans.” In light of these challenges, and in the interest of providing the best possible care, the hospices are considering using unmarked vehicles for home visits and are also working to re-brand their organizations within the communities as service providers for patients with any terminal illness.

GRIEF AND BEREAVEMENT

Current approach/activities:

CYCWs felt very strongly that children need to have opportunities to learn and talk about illness, death, and dying if the trauma caused by losing a loved one is to be minimized. They use story books to stimulate conversations about illness and offer a number of creative outlets for helping children

deal with the pending or experienced death of a loved one. Children are offered the opportunity to develop memory boxes to store keepsakes of loved ones who are terminally ill or who have already passed away. Older children can participate in grief and bereavement groups at Viljoenskroon Hospice, where they are guided through the “Growing through Grief” workbook. Ladybrand Hospice providers recognize the importance of supporting adults through their own grief as well as the grief of the children they care for after the death of a loved one. Adult clients use genograms (visual tools to map out family relationships and medical histories) to talk about their losses, traumas, and partnerships. This provides hospice staff with information about how to best support caregivers and, thus, the children for whom they are responsible.

Good practices in addressing grief and bereavement:

- Numerous tools and strategies, like story books and memory boxes, offered to children and parents to help process and talk about grief
- Recognition of cultural norms regarding conversations about illness, death, and grief.

Persistent gaps/challenges:

There was overwhelming agreement among hospice staff that death and dying are taboo as topics of discussion by many families. This reluctance to talk about death was recognized as an obstacle to providing appropriate support to children during their bereavement. As discussed previously, both hospices have implemented a number of strategies to address this unmet need for support.

HIGHLIGHTED TOOLS/RESOURCES

For child clients:

- Memory boxes
- Feeling wheel
- Growing through Grief workbooks
- Multidimensional needs assessment tool
- Hero books
- Holiday camp.

For adolescent clients:

- Teen support group (weekly).

For parents/caregivers:

- Thandanani Time Gogo training programs for grandmothers
- Relationship evaluation scale (parent/caregiver and child)
- Community-based support group
- Genograms.

For providers:

- Regional Psychosocial Support Initiative training for grief and bereavement
- Debriefing with pastors, care for carers
- Promoting early childhood development with pediatric palliative care checklist
- Graphical information, education, and communication tools about HIV (community awareness and education).

TOOLS/RESOURCES NEEDED

While there are a number of useful tools that are incorporated into the comprehensive set of activities provided by these Bana Pele partners, interviewees identified some areas of unmet need. Providers and caregivers mentioned that more and better quality books and information are needed to educate children about HIV and help providers better meet the needs of the children in their care. They also expressed a great deal of concern about the quality of education provided to children after they leave the intensive, tailored day care programs offered by their organizations.

ADDITIONAL NOTES

In addition to these findings specific to the key themes of this review, several critical challenges were identified that prevent parents, caregivers, and providers from meeting all the psychosocial needs of HIV-positive children.

Care for Carers

Providers emphasized their need for ongoing support due to the stressful nature of their work. Burnout was acknowledged as a common problem faced by CYCWs and home-based carers, given the intense nature of their relationships with children and families they serve. The case load of providers makes it very difficult for them to provide the quality of care that they would like to provide, with nursing sisters seeing up to 30 patients in a day and each CYCW being directly responsible for more than 100 children. While the hospices offer monthly debriefings with pastors as a form of support for these providers, this was widely considered insufficient to meet their needs for care. One provider suggested recreational outings and other social activities to help relieve the stress of providing care to terminally ill patients.

Training of Parents/Caregivers

Providers clearly identified the importance of involving parents and caregivers in the network of care and support for their children. However, they expressed frustration with the level of parental involvement in activities offered in communities and on-site. Turnout for the twice yearly parenting skills workshops is quite low, and there are few other opportunities to engage parents and increase their capacity to provide PSS to their children. Providers want to advocate for focused training for parents and caregivers to help them understand the child's developmental needs. The lack of involvement by fathers and other males was identified as a significant gap in the community's ability to provide adequate care and support to children. It was noted that only one male caregiver interacts with the day care activities of his child at Ladybrand Hospice.

Adolescent Health

While interviews were focused on the needs of children 0 to 12 years of age, all the providers emphasized the importance of helping adolescents learn about sex and sexuality as critical components of HIV prevention efforts. They also highlighted the importance of helping parents and caregivers understand the specific needs of adolescents and how these needs change as they mature. In addition, providers cited high levels of substance abuse among adolescents as a concern for their health and well-being. Providers reported that children in the communities where they work begin to be sexually active as young as 10 years of age, and that OVC are more likely to report early age of sexual onset. These findings indicate that education about sexuality and HIV prevention should also be part of the services offered to younger children as well as to adolescents.

Traditional Beliefs

The influence of traditional beliefs and superstition was commonly mentioned as a challenge to the provision of palliative care and support to both adults and children. To address this, the hospice outreach initiatives aim to dispel myths (i.e., that HIV and/or death are caused by witchcraft). However, they also recognize the importance of involving traditional healers as part of the cadre of providers caring for HIV-affected families, as they are widely consulted when families confront an illness. As such, the programs make an effort to invite traditional healers to participate in the training sessions offered by Bana Pele Network partners.

BUTTERFLY HOUSE, DRAKENSTEIN PALLIATIVE HOSPICE

WESTERN CAPE, SOUTH AFRICA

A site visit to Butterfly House was conducted on October 5 to 8, 2010. The data used for this case study summary were collected through interviews and focus group discussions with 27 individuals (all were female, unless otherwise indicated): 6 HIV-positive young adults (aged 18 and older), 6 parents/caregivers (1 male) of HIV-positive children, 3 Butterfly House administrative staff, 9 home-based carers, 2 nursing sisters, and 1 social worker.

PROGRAM DESCRIPTION

Model:

Founded in 2008, Butterfly House is the day care program of Drakenstein Palliative Hospice (DPH). Its vision is to “provide quality holistic care for the community, in the community and with the community.” Butterfly House functions primarily as a community resource center that strives to meet the needs of those living with a life-threatening and life-limiting illness, most commonly HIV and cancer. It is important to note that HIV is integrated into this broader set of medical issues and that, therefore, program activities often combine HIV-positive and -negative children. Butterfly House is situated in an informal settlement between Paarl and Wellington in the Western Cape. It is funded amongst other organizations, by the U.S. President’s Emergency Fund for AIDS Relief, Diana Princess of Wales Memorial Fund, and a private Norwegian funder. The organizational structure of DPH provides for a home-based care division that includes palliative nursing and palliative psychosocial care as well as adult, youth, and early childhood development programs.

Client base:

The population served by Butterfly House includes children affected by and living with HIV, vulnerable children, and their parents and caregivers. Currently, Butterfly House serves some 200 vulnerable children, 54 of whom are HIV-positive, and 300 adults (110 of whom require medical support for HIV and cancer).

Services:

Targeted children and their parents and caregivers access a range of programs at Butterfly House that are structured around holistic themes (physical, social, emotional, cultural, spiritual, and educational). The focus on holistic care emphasizes the importance of a healthy mind and body through services and activities that promote hygiene, nutrition, health education, and a positive mental attitude. The core services include:

1. Youth day care programs (after school homework club; individual tutoring by teachers; life skills program; job skills including crafting, catering, and computer skills; and recreation activities including ballroom dancing and drama)
2. Individual counseling provided by a psychologist, play therapist, “play aunties,” a social worker, and teachers
3. Preschool (up to nine years of age) program (school readiness groups; life skills and healthy living activities; individual play sessions; individual play therapy on referral; and recreational activities including drama, games, and crafts).

In addition to these services, Butterfly House provides a variety of activities for young adults in the center’s catchment area. These include:

1. A young adult program for young men (psychosocial support [PSS] group, food provision, gardening and community cleaning project, soccer team, drama, healthy living education program that also addresses gender issues, and job creation activities)
2. A young adult program for young women (healthy living education groups, and life skills and empowerment groups)
3. Adult day care programs (crafts groups, job creation groups, support group for caregivers, medical group, and a psychosocial group).

Staffing:

The core Butterfly House staff consists of 20 home-based carers, 5 nursing sisters, 3 social workers, 1 play therapist, 1 senior school and early education teacher, an administrative staff of approximately 6 people, and a variable number of long-term volunteers. An interdisciplinary team—the Team Around the Child—reinforces the emphasis on holistic care, follow-up, and management of child clients. This includes home-based visits (one to four times per month, depending on need) by home-based carers to follow-up primarily on treatment issues, although they can screen for acute PSS concerns.

External linkages:

As an extension of DPH, Butterfly House provides day care programs and is focused on the needs of children and the community at large. Butterfly House and DPH do not provide any testing and counseling services except in partnership with other organizations.

Good practices within the general model/approach:

- Child-friendly approach, with dedicated early childhood development teacher, home-based care worker, and play therapists
- Team Around the Child provides multidisciplinary follow-up and management of child clients
- Holistic approach and meeting clinical, emotional, and social needs, as well as other basic needs (education, food, etc.)
- Internal referral system between medical and psychosocial arms of program (from nursing sisters/home-based carers to social workers)
- Creativity and flexibility in designing programming to meet the perceived needs of the client population.

Gaps/challenges:

1. Despite emphasis on holistic care, material needs and medical attention for children and adults can override PSS concerns.
2. While staff are highly skilled, they sometimes feel ill-equipped to address HIV-specific needs of children, such as disclosure.
3. Staff are aware of other service provision organizations in the community, but linkages are minimal and there is even a sense of competition and territorialism over clients and neighborhoods.
4. A tiered internal referral system increases the likelihood of missed opportunities for identification of needs and appropriate follow-up.
5. Xhosa community was consistently described as the neediest population in the Butterfly House catchment area, but few of the staff members speak Xhosa.

IDENTIFICATION OF CHILDREN**Current approach/activities:**

The mission of Butterfly House is to serve orphans and vulnerable children in Fairyland and neighboring communities, irrespective of their HIV status. This means that Butterfly House's programs and services are provided to a diverse group of children with a range of medical and psychosocial needs. Individuals are referred by local clinics and hospitals for care at DPH based on the identification of acute physical health concerns, including a consistent failure to report for clinic visits or challenges with adherence to medication, and severe illness. As such, children served by Butterfly House may be the direct recipients of care from the DPH program, the child of a DPH patient, or a child who lives in the surrounding area and in need of extracurricular and social services.

Approximately three weeks after a child's enrollment in the program, Butterfly House conducts a baseline assessment using the Palliative Programmes Assessment Scale. This tool is meant to identify children's needs in various areas of psychosocial development, including self-confidence, self-efficacy, and accountability. To track patient progress, this assessment scale is completed at regular

intervals (mid-year and year-end) by Butterfly House staff across all programs. A social worker is also present at the first visit to assess social circumstances (e.g., need for food parcels, counseling, and other special services) and to assist with grant applications, as necessary. Other than the referral system for HIV-affected children (described subsequently), there is no formal system for identifying HIV-positive children for enrollment in program activities.

Good practices in the identification of children:

- Interdisciplinary team assesses and provides follow-up care to children
- Initial assessment aims to document an array of medical and psychosocial needs
- Functioning system of referrals from local clinics
- Children of HIV-positive adults are followed-up as vulnerable children.

Persistent gaps/challenges:

Many of the family caregivers interviewed expressed uncertainty about how Butterfly House had identified them or their children for services. There seems to be a gap in communication to the patients from the Infectious Disease Clinic, DPH, and Butterfly House. Family caregivers also expressed some confusion about how they and their children were selected for certain activities and programs within the many options offered by Butterfly House.

TESTING AND COUNSELING

Children who are tested through government clinics and the hospital are referred to Butterfly House for services, but continue to receive medical treatment from local clinics. Children whose parents/caregivers are identified through external testing and counseling processes may also be referred to Butterfly House to receive services. As such, not all of the children who receive services from Butterfly House have received counseling or testing for HIV. Interview participants overwhelmingly identified the quality of HIV testing provided by these external sites as inadequate, often citing a complete lack of pre- and post-test counseling. This gap highlights the importance of providing PSS to families immediately following the diagnosis of both parents and children.

DISCLOSURE

Current approach/activities:

Parents/caregivers, providers, and HIV-positive young people all discussed the multiple challenges related to disclosure of a child's HIV-positive status. One factor influencing parents' handling of disclosure is that children are being tested and found positive in infancy or early childhood, resulting in longer periods of time between initial diagnosis and disclosure to the child. This often means that parents have to tackle such challenging questions as how to manage disclosure over time and when/how to disclose to siblings (a related issue of inadvertent disclosure). Parents expressed uncertainty about when to tell a child that he or she is HIV-positive; some mothers stated that when the child was a certain age (often 10 to 13), they would feel the child would be ready to hear and understand this information. Parents, providers, and HIV-positive young adults all mentioned that each child has a different capacity to understand what it means to be HIV-positive, and that the decision about disclosure should be based on both age and other factors, including emotional

maturity and ability to keep the information confidential. Butterfly House social workers can be made available to support parents and provide guidance on the disclosure process.

Good practices in supporting the disclosure process:

- Home-based carers provide close and consistent follow-up with clients and help screen for PSS concerns and material needs
- Child-friendly approach; an early childhood development room and extracurricular activities at the facility allow for interaction between children who are HIV-positive, HIV-negative, and children whose status is unknown.

Persistent gaps/challenges:

There was a high level of disagreement among providers about the most appropriate time to disclose to a child, but there was agreement that a child's age alone was an insufficient criterion for determining readiness to learn about his or her status. The period immediately following initial disclosure was identified as a missed opportunity to help caregivers adjust and plan for the long-term care of the child's medical and psychosocial needs. Home-based carers cited disclosure as one of the most challenging aspects of their work and indicated that they did not feel fully equipped to handle sensitive questions and to advise parents about disclosure. Home-based carers felt that Butterfly House social workers were good resources for helping parents navigate the disclosure process. However, they felt that the onus was on them as the providers with the most direct contact with children to identify disclosure needs and flag them for the social workers who could discuss the way to handle the situation with the parent.

STIGMA

Current approach/activities:

Much of the difficulty associated with decisions about disclosure was attributed to fear of stigma. All participants in interviews and focus group discussions clearly identified both internal and external stigma as concerns that prevent parents from telling children about their status or disclosing this status to friends and other family members. Many family caregivers stressed that their decision about disclosing to the child was based on an assessment of whether the child was capable of keeping his or her status private. This was seen as critical in order to avoid being mistreated by people in the community. As Butterfly House programs are not solely for HIV-positive young people, providers felt that there was less stigma associated with participating in Butterfly House activities or attending events at the center. However, parents and providers also mentioned the importance of interaction with other HIV-positive children and role models as a means of building self-efficacy and addressing stigma in the household, school, and community.

Persistent gaps/challenges:

Several participants mentioned that the arrival of a hospice vehicle or team member to their homes causes concerns about stigma, as neighbors will assume that they or their children are being treated for HIV. It is clear that there is room to do more to build child and parent caregiver capacity to address stigma proactively and constructively. Family caregivers and Butterfly House care workers suggested that Butterfly House offer groups specifically for parents and family caregivers of HIV-positive children and for the children themselves to provide an opportunity to discuss the health and social issues unique to them. The design and recruitment of participants for any such group would

need to be conducted with care, given the frequently expressed fear of gossip and insults directed toward parents, family caregivers, and children when HIV-positive status is revealed. One young person also raised the issue of spiritual and religious factors that both drive stigma (e.g., being rejected by church), but could also provide solace in managing internalized stigma.

GRIEF AND BEREAVEMENT

Current approach/activities:

Currently, children who demonstrate emotional problems (including aggression or withdrawal) may be identified by the home-based carer during a regular visit and referred to the social worker and/or play therapist for counseling. Given that Butterfly House is part of a larger palliative care program and framework, the providers acknowledge grief and bereavement as a long-term issue for children, whether related to HIV, to other illnesses, or to a violent community. In response to the identified need for support during the grieving process, the team planned to launch a children's bereavement group in November 2010. One of the staff social workers would lead this group, which would provide regular meeting times for children identified as in need of additional counseling after a loss.

Good practices in addressing grief and bereavement:

- Acknowledgement of grief and bereavement as a long-term issue for children that is not adequately addressed by the community, by families, or by programs
- Plans to launch a children's bereavement group to provide support to those children who have experienced the death of a parent, loved one, or neighbor
- Trained team comprised of a trauma therapist and social workers dedicated to crafting services around the needs of children and their caregivers.

Persistent gaps/challenges:

Providers believed that children need to be more involved in addressing the things that affect them, particularly the death of a family member. However, there is concern about how to engage parents and children around such issues given the perception of low levels of emotional literacy in the community in general and among the Xhosa population in particular. Young people noted that it is very difficult to talk about HIV within the Xhosa community, which increases their sense of rejection and internal/external stigmatization. Home-based carers felt that they had enough information to identify children who were displaying emotional problems and who, thus, required additional support from the social work team. However, they did not feel that they understood what treatment would be provided and what sort of home-based monitoring they, as home-based carers, should provide to children after play therapy or counseling. Parents and family caregivers expressed a similar lack of knowledge regarding the individual therapy/counseling sessions for their children or why their child had been referred.

HIGHLIGHTED TOOLS/RESOURCES

- Palliative Programmes Assessment Scale
- Program attendance monitoring
- Tree of Life methodology to be used for the grief and bereavement group.

NEEDED TOOLS/RESOURCES

In addition to the needs identified previously, participants also mentioned others that they felt would help them better meet the needs of HIV-positive children. A young family caregiver expressed her need for basic training on caring for children, a view that was echoed by providers as well. It was also suggested that a network or support system for young family caregivers would be particularly useful and would provide an outlet for discussing the issues faced by siblings or family members who became de facto parents of HIV-positive children at a young age. Young people also mentioned the need for materials and activities that help them “take their mind” away from their daily situation, including sports and recreational activities. Some additional tools and resources that were identified are as follows:

- Assistance with disclosure
- More accessible grants (they can take up to four months to access)
- Meetings with multidisciplinary hospital team to discuss treatment, care, and support needs
- Healthcare providers who are supportive and caring
- Group for “grannies” (and family caregivers) who are caring for HIV-positive children.

ADDITIONAL NOTES

In addition to these findings specific to the key themes, several critical gaps were identified in the skills and resources parents, family caregivers, and providers are able to tap into when caring for an HIV-positive child.

Care for Carers

Home-based carers stressed the need for ongoing support to providers due to the emotional toll that their work takes on them. They suggested further training both in technical areas of their work and in “caring for carers.” The gap in parent-child communications was also identified as an obstacle to disclosure and appropriate management of children’s HIV.

Programming for Parents and Caregivers

Parents and family caregivers who attended activities at Butterfly House reported enjoying their time and appreciating the efforts the staff make to provide food and to get them out of the house. However, there seems to be some confusion about the purpose and availability of such activities. Family caregivers suggested that their time could be better utilized, either by providing an income-generating activity or a support group in which they could openly talk to other parents facing the same types of issues they face (whether related to caring for an HIV-positive child or not). Others expressed the need for additional emotional or social support but did not believe that they, as adults, could attend activities at Butterfly House. The Butterfly House leadership plans to develop and implement a program to train mothers in sensory stimulation and other key aspects of childcare in 2011.

Social Grants

Both providers and parents/caregivers mentioned social grants as one of the core mechanisms for meeting a family’s basic needs. Such grants were discussed in every conversation. Some respondents had received support from Butterfly House staff to apply for a grant, while others felt frustrated by

the process, often citing that they were unable to adequately provide for their children while they were waiting for a grant to materialize. This was especially true among elderly caregivers, who were overwhelmed by the responsibilities of caring for multiple children and managing a large household at an advanced age.

COTLANDS

SOMERSET WEST, WESTERN CAPE, SOUTH AFRICA

A site visit to Cotlands Somerset West was conducted on October 18 to 20, 2010. The data used for this case study summary were collected through interviews and focus group discussions with 24 individuals (all were female): 5 HIV-positive young adults (aged 18 and older), 8 parents/caregivers of HIV-positive children, 2 home-based care (HBC) workers, 1 psychosocial manager, 1 early childhood development coordinator, 1 HBC coordinator, 1 nursing manager, 1 social worker, 1 staff nurse, 1 assistant nurse, 1 early childhood development practitioner, and 1 child worker.

PROGRAM DESCRIPTION

Model:

Founded in 1936, Cotlands was originally created as a care center for unwed mothers and their infants. Headquartered in Johannesburg, Cotlands now operates in six provinces across South Africa. Over the years, Cotlands has expanded its work to offer shelter for “abused, abandoned, HIV-positive, orphaned, and terminally ill children from birth to twelve years of age, as well as community based services to vulnerable children in five provinces of South Africa.” The vision of Cotlands is to provide “caring for vulnerable children across South Africa,” and the organization’s mission statement is “to provide exceptional models of care to children and their families by empowering them to improve their quality of life through specialized interventions and sustainability projects.”

Client base:

In Western Cape, Cotlands operates two residential facilities covering in the southwestern area of the Cape, Boland, and the West Coast. The program also provides services in the Helderberg area, including rural areas, through its HBC program. Cotlands currently provides care for approximately 30 children through its hospice services, 20 children through its “sanctuary,” and 63 families through HBC. The majority of children in the HBC program are living with HIV.

Services:

Children and their parents and caregivers access a range of services depending on identified needs and status of the child’s health. The core services are tailored to meet the needs of two groups of children: those who are HIV-positive and those orphaned by HIV. These services include the following:

1. A residential pediatric hospice providing palliative care for between 26 and 30 children (0 to 6 years of age). Children are either HIV-positive and cannot be cared for by their biological families or have been abandoned due to their condition. These services include pain management and all components of palliative care. The hospice also provides care and treatment to children suffering from other illnesses including tuberculosis, malnutrition, and fetal alcohol syndrome.

2. A sanctuary caring for up to 20 children (2 to 6 years of age) who have been abandoned, abused, and/or orphaned. The sanctuary aims to provide care until the children can be reunited with their families or suitable placements in foster families can be arranged.
3. Through the HBC program, two HBC workers and a nurse provide medical support (pill counts, adherence) to children who have been discharged from residential care.
4. Early childhood development programming is at the core of all the services provided to children served by Cotlands. The approach is based on the National Early Learning Development Standard for Children, which aims to improve the holistic development of children through utilization of creative approaches toward learning, language, literacy, and communication.

Staffing:

The core Cotlands staff in Somerset West consists of the following professional staff: a director, an HBC coordinator (with a team comprised of an outreach nurse and HBC assistants), a psychosocial manager (with a team comprised of a sanctuary coordinator, sanctuary staff, and early childhood development practitioner), and a clinical services division (comprised of a nurse manager and four teams headed by a nurse with supportive carers). This core team is supported by three other divisions: human resources (training and volunteers); fundraising division (corporate and community), and services division (laundry and kitchen staff, etc.). An interdisciplinary team, pooling different providers involved in meeting the medical, social, and emotional needs of children, work together on monitoring the child's status and providing follow-up services.

External linkages:

Among other donors, Cotlands receives funding from the South African Department of Health. This linkage supports the implementation of Cotlands activities, as do critical linkages with a broad network of local partners, including PATCH, the Helderberg Child Abuse Centre; Yabonga; Bell Valley Social Work; and local clinics and hospitals.

Good practices within the general model/approach:

- Interdisciplinary team provides follow-up and monitoring of the medical, social, and emotional needs of child clients through a team of health and nongovernmental organization professionals
- Strong referral and network system aims to provide for a continuum of care once children have been discharged from Cotlands
- Parents/caregivers are trained during child's residence at Cotlands to prepare them for continuing the care regimen at home after discharge
- Parents/caregivers are deeply satisfied with the quality of medical care their children receive while in residence at Cotlands
- To promote maintenance of good health, foster care is frequently arranged for children who do not have a home to return to on discharge.

Gaps/challenges:

1. Parental concern about meeting the basic needs of children is a pressing issue that takes priority over psychosocial needs.

2. Programmatic focus on adherence to medical needs ensures that children stay healthy but psychosocial support needs are underemphasized after discharge.
3. Stigma associated with Cotlands vehicles and staff causes tension around home visits.
4. HBC workers dedicate significant time to talking with and training parents but do not interact as much with children.

IDENTIFICATION OF CHILDREN

Current approach/activities:

Given that Cotlands provides medical care to children with a range of illnesses, positive HIV status is not a criterion for treatment or receipt of the services offered. However, the principal mechanism by which children are identified for treatment at Cotlands is through local hospitals and clinics. A child who is seen in a local medical facility and is deemed to be in need of immediate and intensive medical care will be referred to Cotlands. In addition to this mechanism, children are frequently identified by community-based social workers and law enforcement officials who refer children who are living on the street and/or are in acute need of medical treatment.

Children identified for services are assessed using a tool originally developed by Bell Valley Social Work and tailored by Cotlands staff to meet the needs of their patients. While this is not a validated and standardized tool, it provides some measure of assessment of psychosocial needs to guide the decisions made by the interdisciplinary team. Social workers and nursing sisters conduct the assessment, and referrals for additional services are made following a discussion in interdisciplinary team meetings. The core domains of psychosocial well-being assessed by the tool include spiritual, relationships, cultural, and emotional state.

Good practices in the identification of children:

- Strong linkages to hospitals, the social work system, and law enforcement helps with the identification of children in need of treatment
- On-site HIV testing of all children on enrollment in residential program.

Persistent gaps/challenges:

The approach to identifying children for treatment relies on receipt of referrals from outside sources and network partners. This could lead to a failure to identify many eligible children in need of care. However, it is important to note that the Cotlands facilities are able to effectively cater to the needs of a limited number of children at a time. The facilities operate at capacity and are not able to absorb any more referrals into their current care and treatment system.

TESTING AND COUNSELING

Current approach/activities:

Cotlands does not provide voluntary counseling and testing of HIV through its program. If a child referred for antiretroviral treatment and broader care has received an HIV test from another facility, the results of the test will be recorded in his or her file at Cotlands. If no previous test result is available, the referred child will receive a test (as part of routine medical testing) prior to beginning residential treatment at Cotlands. As mentioned previously, all children enrolled for inpatient care at Cotlands are tested through on-site facilities to confirm their status and determine an appropriate

treatment regimen. As many of the children served by the residential program are deemed too young to receive counseling, counseling at this stage is provided to the parents or caregivers. When children are over the age of four years, they receive counseling using stories and in conjunction with counseling for their parents or caregivers.

Persistent gaps/challenges:

Children referred to Cotlands (often in need of significant medical care) have already been tested for HIV and may have received counseling at that time. Cotlands emphasizes routine medical testing for residential patients, and this may create challenges in how supportive counseling is provided, especially for children, and by whom. As part of the ongoing support in residential care and HBC, the main concern for Cotlands staff and caregivers is with disclosure.

DISCLOSURE

Current approach/activities:

All of the interview and focus group participants identified disclosure of a child's HIV-positive status as a major challenge to providing appropriate care and to seeking support. Parents/caregivers who had not yet disclosed agreed that they would tell their child about his or her status when the child reached an age at which he or she could understand "what it meant to be HIV-positive." Many parents cited seven or eight years of age as the ideal time to have this conversation with the child. Parents expressed a need to be assisted and supported in telling a child about his or her status; one parent was supported in the disclosure process by the Cotlands HBC team, who explained the medical aspects of the illness to the child. Disclosure is one of the issues frequently discussed at interdisciplinary team meetings, which allows the entire team to discuss each child's situation and make recommendations regarding his or her disclosure.

Persistent gaps/challenges:

Many of the mothers interviewed are HIV-positive and have not disclosed their own status to their families, including their children. They acknowledge that their own lack of disclosure makes it even more difficult for them to talk to their child about his or her status. Home-based carers cited disclosure as one of the most challenging aspects of their work, indicating that they support parents in disclosure but that they also need support to help them better meet the needs of the families they serve. Some providers felt that involvement in the disclosure process was beyond the scope of their work and stated that they rely on community-based social workers to help address such psychosocial needs. It is unclear whether these social workers have the capacity, time, and training to adequately support caregivers and children with disclosure. Both caregivers and providers noted the lack of any tool to help make decisions about disclosure and to provide appropriate information to children in the disclosure process.

STIGMA

Current approach/activities:

All participants in interviews and focus group discussions clearly identified both feared and experienced stigma as factors that prevent parents from telling children about their status or disclosing this status to friends and other family members. This fear of stigma also prevents some parents from attending support groups in their communities. There was agreement that while it is important to be careful about disclosure, it is exhausting to keep a "secret" of that magnitude. Many

caregivers stressed that their decision about disclosing to the child was based on an assessment of whether other people would treat the child poorly. Several caregivers cited examples of being verbally abused or treated with disdain in their communities and households due to stigma around their own or their child's HIV status. In contrast, caregivers felt that they are treated well by Cotlands staff and that they are not subjected to any stigma for being the parent of an HIV-positive child. One provider echoed this sentiment, saying that stigma arises in the clinics, "but not at Cotlands."

Persistent gaps/challenges:

Both caregivers and providers mentioned the risks that being visited by Cotlands staff can bring, as members of the family or community generally associate the organization with HIV. In response to this, home-based carers no longer wear Cotlands t-shirts when conducting home visits. Parents also suggested that the Cotlands team raise community awareness to help reduce stigma and to make it easier for people to talk about HIV openly without the fear of being ostracized.

GRIEF AND BEREAVEMENT

Current approach/activities:

Cotlands aims to identify and meet the emotional needs of children, which can include dealing with grief as well as fostering a sense of emotional safety and bonding. Currently, children who demonstrate emotional problems (including aggression or withdrawal) may be identified by the home-based carer during a regular visit. In the event that a problem is identified, it will be noted in the child's file and discussed by the interdisciplinary team at the next meeting. Following this discussion, the child will likely be referred to a community social worker for counseling. Cotlands offers a grief and bereavement program for parents, which is provided by social workers. External counselors are brought in to provide bereavement counseling for staff as well, and referrals can be made to external organizations for therapy and for spiritual support. Children in residence at Cotlands receive holistic care and assessment, which includes specialized sessions with therapists as deemed necessary by the interdisciplinary team.

Good practices in addressing grief and bereavement:

- Flagging of children who demonstrate emotional problems/needs during home-based care visits, referred back to the interdisciplinary team for management
- Specialized sessions with therapists for residential children, as determined via regular assessments
- Support for parents and caregivers, as well as for staff
- Sensory stimulation, part of the core training provided to staff and caregivers, promotes both emotional and physical well-being of children.

Persistent gaps/challenges:

Providers believed that caregivers need to be taught how to communicate with their children, and that this is especially challenging when the subject is the death of a loved one and/or the fear and grief that accompany disclosure. Caregivers also expressed a desire to know how to address the grief that their children experience. However, at present there is no forum for providing this type of skill-

building for caregivers. Young people who have experienced such a loss could benefit from individual counseling and/or from a support group, but neither of these options is provided for by Cotlands. As mentioned previously, children who are identified by the HBC team as requiring therapy can be referred to a social worker, but it seems that follow-up on such referrals is limited. Several providers expressed frustration at the gaps in coordination with community-based social workers, which indicates that children's emotional needs are not being met with any consistency after they are discharged from Cotlands.

HIGHLIGHTED TOOLS/RESOURCES

- Assessment tool (developed by Bell Valley) used at every HBC visit tracks child's spiritual, material, nutritional, emotional, medical, and developmental status
- Training in sensory stimulation is provided to home-based carers and to parents to promote engagement and interaction with children
- Employee well-being program acknowledges the importance of caring for caregivers and providers
- National Early Learning Development Standard for Children.

NEEDED TOOLS/RESOURCES

In addition to the previously identified gaps, study participants also mentioned others that they felt would help them better meet the needs of HIV-positive children. The mother of an adolescent felt very strongly that the child needed to be part of a group with other HIV-positive young people. Parents and caregivers expressed a need for opportunities to talk about the challenges of caring for an HIV-positive child and to share coping strategies without the fear of stigma. It is possible that such opportunities and skill-building will be offered through the Macassar Community Centre, to open in 2011 and will offer the following:

- Sensory stimulation groups for children aged 3 to 5 years old
- Parenting skills workshops
- Arts and crafts
- Life skills training
- Groups for fathers
- Homework program.

ADDITIONAL NOTES

In addition to these findings specific to the key themes, several critical gaps were identified in the skills and resources parents, caregivers, and providers are able to tap into when caring for an HIV-positive child.

Training of Parents/Caregivers

During a child's residence at Cotlands, parents receive training in basic care, sensory stimulation, and treatment adherence. While these are critically important to the child's well-being, parents also

identified a need to understand how their children's needs would change over time so that they can better prepare for such changes. This would help them identify signs of important emotional and physical changes and, thus, more effectively meet children's needs.

Care for Carers

Home-based carers emphasized the need for ongoing support to providers due to the emotional toll that their work takes on them. They suggested that the current employee wellness program be offered on a more regular basis.

Social Grants

Both providers and parents/caregivers mentioned social grants as one of the core mechanisms for meeting a family's basic needs. The need for and the challenges associated with such grants were discussed in every conversation. Some respondents felt frustrated by the grant application process, often citing that they were unable to adequately provide for their children while they were waiting for a grant to materialize. This was especially true among foster parents who often faced the reality of caring for multiple nonbiological children and managing a large household.

NATIONAL ASSOCIATION OF CHILD CARE WORKERS

KING WILLIAMS TOWN, EASTERN CAPE, SOUTH AFRICA

On October 24 to 27, 2010, the ICRW research team conducted a visit to the National Association of Child Care Workers (NACCW) site in King Williams Town (KWT). The focus of the visit was on the Isibindi "Circles of Care" model and the NACCW Safe Park. The data used for this case study summary were collected through interviews and focus group discussions with 27 individuals (all female, unless otherwise indicated): 4 HIV-positive young adults (aged 18 and older), 8 parents/caregivers of HIV-positive children, 11 Isibindi childcare workers (CCWs; 6 male), 1 program coordinator, 1 co-director of the Child and Youth Center, 1 senior Isibindi mentor, and 1 nursing sister.

PROGRAM DESCRIPTION

Model:

NACCW is an independent, not-for-profit organization whose mission is to provide "the professional training and infrastructure to promote healthy youth and child development and to improve standards of care and treatment for troubled children and youth at risk in family, community, and residential group settings." The Isibindi "Circles of Care" model was developed by NACCW and introduced in 2005. It is currently implemented in 55 sites in eight provinces with over 40 partners. At the core of the model is training of community members to serve as volunteer child and youth workers. Unemployed community members are screened, selected, and trained to service families in their own communities. The training covers a range of skills, including observation, behavior management, communication, and assessment. The NACCW Safe Park model is a further component of the Isibindi program, and it is currently replicated by over 20 organizations in South Africa. Safe Parks allow for children to play in safe places with adult supervision and also provides extracurricular activities and academic support.

Client base:

The NACCW/Isibindi community program catchment area extends approximately 100 km on either side of KWT, serving 103 children from 47 families. Since its inception, the program has provided services to 650 families and 1,499 children. The main Isibindi Safe Park is located just outside of KWT, with four informal safe parks located in surrounding villages. The residential crèche (nursery) serves over 100 children under the age of 18 who have been orphaned by HIV or who have been abused or neglected by their families and are in need of a safe and nurturing place to live. Daytime crèche services are available to community members and children who receive other services from NACCW.

Services:

The Isibindi model provides a wide range of activities for young people in the catchment areas it covers. These include programs for young children, their parents, and older adolescents and young adults. The program develops care plans for each family depending on specific needs and circumstances. The plans draw from discussions with the caregiver, as well as from the care worker's observation (e.g., if the primary caregiver is overwhelmed), outlining steps to improve the situation. While multiple providers support each child, one provider is responsible for ongoing assessments to ensure continuity.

Children:

- Residential crèche for children 0 to 18 years old who have been orphaned by HIV and abused/neglected
- Sports
- Homework supervision and tutoring
- Psychoeducational groups (e.g., substance abuse)
- Toy libraries
- Early childhood development/daytime crèche.

Adolescents/young adults (18 and older):

- Adolescent development program
- Phandulwazi Daily Life Skills Program (vocational training, etc.)
- Empowerment programs (young men and young women)
- Gender trainings (to be introduced soon).

Parents/caregivers:

- Food security programs (e.g., food gardens and food parcels)
- Parenting skills programs (budgeting, food gardens, and household management)
- Holiday (vacation) camp program to address parenting skills and healing (intensive work around children's physical and sexual abuse).

Staffing:

The Isibindi team in KWT comprises 18 CCWs (6 males, 12 females), 2 supervisors, 1 project manager, and 19 volunteers. This team partners with the KWT Child and Youth Care Centre, whose team is central to the implementation of the Circles of Care and Safe Park models. Coordinators from the Centre supervise an Isibindi project manager and report to the KWT centre directors and an Isibindi mentor who visits the site monthly. The Isibindi project manager oversees two supervisors who are each responsible for a team of 8 CCWs and a supervisor.

External linkages:

International funders for Isibindi activities include the U.S. President's Emergency Fund for AIDS Relief, the Royal Netherlands Embassy, and the Swedish International Development Cooperation Agency. The program also receives funding from national donors including DG Murray, the Nelson Mandela Children's Fund, the Anglo-American Chairman's Fund, and Lotto. Isibindi has strong programmatic and service provision linkages with a number of community-based agencies, including Grey Hospital, Bisho Hospital, LoveLife Peer Educators, local schools, and local clinics.

Good practices within the general model/approach:

- Model of care provided by CCWs creates a relationship with families that is based on mutual respect and trust
- Holistic program philosophy centers on a strong focus on child protection in social, medical, home, and educational settings
- Ongoing assessment of children's psychosocial needs by a primary provider
- Tailored care plans, adjusted based on individual needs (as identified during assessments)
- Isibindi staff are proactive in addressing potential problems with stigma and discrimination in schools
- Extensive referral and network system provides for a continuum of support for children in day and residential programs.

Gaps/challenges:

1. Due to the high level of poverty in the Isibindi communities, concern about meeting the children's basic needs often supercedes parental attention to psychosocial needs.
2. Limited availability of in-house and partner-based expertise in the provision of care for acute psychological problems makes it difficult to adequately address these needs.

IDENTIFICATION OF CHILDREN**Current approach/activities:**

The focus of service provision by NACCW is on vulnerable children, irrespective of their HIV status. As such, a positive HIV status is not a criterion for treatment or receipt of the services offered. The principal mechanism by which children are identified for NACCW services, and for residential care in particular, is through local hospitals, clinics, police, social workers, and the Department of Social Development. Children who participate in Isibindi activities in the community

may also be identified by CCWs as vulnerable and in need of more intensive intervention through the crèche or partner organizations. However, CCWs encourage HIV testing of client children whose parents are known to be HIV-positive. In addition, many parents self-refer their families to Isibindi after hearing about the services provided in their communities.

Once a child has been identified for the program, he or she will be visited on a daily basis by the CCW in his or her community. CCWs complete an individual development plan for each child and family they support, covering a range of domains including behavioral problems and communication. The program represents an integrated response to the needs of children. While this includes tutoring and homework support and other social activities for all children, the particular needs of children living with HIV are also addressed through the use of tools such as the *My Living Positively Handbook*, which provides an important opportunity to involve caregivers.

Good practices with the identification of children:

- Strong linkages to hospitals, social work system, and law enforcement helps with the identification of children in need of psychosocial support
- Ongoing assessment of psychosocial support needs aids in identifying and addressing health problems and emotional needs as they arise.

Persistent gaps/challenges:

The approach to identifying children for services relies on referrals from multiple outside sources and network partners. Without a more systematic and proactive approach for identifying children in need, there may be other eligible children in need of support who are not reached.

TESTING AND COUNSELING

Current approach/activities:

NACCW does not provide testing and counseling for HIV through its Isibindi program activities. Families participating in Isibindi activities and receiving services from the program are encouraged to take their children for testing and provide relevant information about testing sites. CCWs also make themselves available to accompany caregivers and children to testing sites if they are asked for this direct support. The majority of female caregivers interviewed mentioned that they had discovered their own positive status during pregnancy and, thus, had their children tested as infants with little involvement from the program. Children enrolled in the residential program receive HIV testing if documentation of their status is not on file and/or if they show any symptoms of illness.

Good practices with testing and counseling:

- HIV status is confirmed for all children on enrollment in the residential program
- Accompanying parents/caregivers and children for testing as needed
- Children who test positive for HIV are guided through the *My Living Positively Handbook* by CCWs, who provide daily interaction and follow-up.

Persistent gaps/challenges:

As noted previously, NACCW does not provide testing and counseling as part of its direct service. In general, referral centers are available if testing is required, and the other good practices taken by

the project team help minimize this gap. One challenge may arise if caregivers refuse to have their child tested, especially if that interferes with the type/level of care provided. Also, given how significant challenges around disclosure are, it may add to the complexity if NACCW teams cannot be part of the process and quality of testing and counseling provided (e.g., not knowing what information is shared with the child or caregiver).

DISCLOSURE

Current approach/activities:

Providers and caregivers reported that CCWs consistently encouraged disclosure of HIV-positive status to children, including the child's own status and that of the parents/caregivers. CCWs reported receiving training to help them support parents through the disclosure process, including disclosure to school officials, family members, and non-medical providers of support. However, all of the interview and focus group participants identified disclosure of a child's HIV-positive status as a major challenge to providing appropriate care and to seeking support. Parents/caregivers who had not yet disclosed the status agreed that they would tell their child about his or her status when the child reached an age at which he or she could fully understand the diagnosis and its accompanying health and social implications.

Good practices with supporting the disclosure process:

- CCWs are recognized as supportive and knowledgeable resources for assisting in the disclosure process
- Acknowledgement of fear of stigma as a key reason parents are reluctant to disclose a child's status.

Persistent gaps/challenges:

Caregivers and providers frequently mentioned that families had not yet openly addressed or acknowledged the HIV-positive status of adult family members, which rendered them unprepared to disclose a child's status. HIV-positive parents readily admitted that their reluctance to disclose their own status makes it even more difficult for them to talk to their child about his or her status.

STIGMA

Current approach/activities:

While stigma was widely acknowledged as an important issue faced by families affected by HIV, participants agreed that their association with NACCW/Isibindi did not contribute to their experiences with stigma. One provider explained that Isibindi staff do not identify themselves as service providers for families affected by HIV, but for "families with defined challenges." This sentiment was echoed by other providers and caregivers, who noted that children were free to play and participate in activities because they were offered in the community without specifically targeting children by their HIV status. Isibindi proactively addresses stigma in schools by sensitizing educators and school staff about the needs of HIV-positive children and involving them as active members of the child's circle of care. The program has also effectively promoted and involved its clients in church-based initiatives to reduce stigma in the community.

Good practice in addressing stigma:

- Proactive initiatives to reduce stigma in schools and in the community.

Persistent gaps/challenges:

The most frequently identified challenge to disclosure was stigma, stemming from both feared and experienced stigma. Caregivers and HIV-positive young adults repeatedly mentioned fear of mistreatment for themselves and/or their children if community members were to learn of their status. There was general agreement that HIV is not discussed openly in their communities and that this adds to stigma. Caregivers cited a fear of rejection and of being blamed for their condition or their child's as a reason for avoiding HIV-related service programs. However, it is worth repeating that the community and interviewees largely did not associate NACCW and Isibindi with HIV.

GRIEF AND BEREAVEMENT

Current approach/activities:

NACCW identifies support for grief and bereavement as a critical component of its psychosocial support to families. As such, the program offers a variety of activities and support services to bereaved children, adolescents, and adults. These include the development of memory boxes to store keepsakes of loved ones who are gravely ill or who have already passed away. Isibindi also supports bereaved clients through therapeutic activities such as drawing family trees and creating memory books to help them reconnect to experiences with their deceased loved ones. Persona dolls are also used to help children talk about their emotions and problems. These have been used to identify issues around bereavement as well as physical and sexual abuse. Older children may be offered journals and guidance in writing about their emotions, while younger children may be offered play therapy using clay to express their feelings. Through the Adolescent Development Program at Isibindi Safe Park, young people can participate in group activities to help them process their grief, including letter writing and a candle-lighting ceremony in honor of loved ones they have lost. For caregivers, NACCW will provide support in succession planning and preparing for the future of the child.

Good practices in addressing grief and bereavement:

- Numerous activities and strategies to work with children, including memory boxes and books, family trees, persona dolls, letter writing, and group sessions
- Support to caregivers in thinking through future care of the child.

Persistent gaps/challenges:

Overall, NACCW offers a wide variety of methods for helping clients of all ages address their grief. However, it is unclear whether the tools used by CCWs are adequate for identifying the need for grief and bereavement support, and what process is used to determine the most appropriate method for each client.

HIGHLIGHTED TOOLS/RESOURCES

For child clients:

- *My Living Positively Handbook* (Children's Rights Centre)
- Memory boxes and memory books
- Family trees
- Persona dolls

- Feelings wheel
- Multidimensional needs assessment tool.

For adolescent clients:

- Male and female empowerment program.

For parents/caregivers:

- Ongoing parenting skills education: budgeting, gardening, and household management
- Holiday (vacation) camp program to address parenting skills and healing (intensive work around children's physical and sexual abuse)
- Income-generation opportunities (e.g., bead making) for older caregivers.

For providers:

- Training in needs assessment.

NEEDED TOOLS/RESOURCES

While there are a number of useful tools that are incorporated into the comprehensive set of activities provided by Isibindi, study participants identified several areas of unmet need. Caregivers, children, and providers mentioned tools or activities that they felt would help them better meet the needs of HIV-positive children. These include:

- A nurse and psychologist on staff
- Income-generation activities and training
- Stress management and coping skills
- Support groups for HIV-positive adolescents and young adults
- Support groups for HIV-positive parents and parents of HIV-positive children
- Training to other providers (teachers, social workers) in childcare basics.

ADDITIONAL NOTES

In addition to these findings specific to the key themes, several critical gaps were identified in the skills and resources parents, caregivers, and providers are able to tap into when caring for an HIV-positive child.

Care for Carers

Providers emphasized their need for ongoing support due to the emotional toll that their work takes on them. CCWs mentioned burnout as a common problem faced by their peers, given the intense nature of their relationships with children and families in the Isibindi program. One stated that in child care, there are no tools for them to use as resources and that the CCWs themselves are the tools. Families come to depend on the CCWs and regard them as trusted members of their most intimate support network, which places enormous emotional burden on these providers. While

CCWs were able to identify ways that they care for each other (e.g., celebrating each other's birthdays), there was no organizational effort to provide them with this needed care. NACCW recognizes the emotional burden that this work places on CCWs, and responds to their needs on a continuum of care that includes individual and group sessions, supervision, mentorship, and team-building activities. The program "Caring for the Caregivers," piloted in KWT, is emphasized as a key component of supporting this team as they provide care to children and their families.

Training of Parents/Caregivers

Providers clearly identified the importance of caring for parents and providing them with support. They noted that if parents were relieved of some of their emotional and financial stresses, they would be better able to care for their children. Both providers and caregivers emphasized the need for creating supportive environments to help parents come to grips with their own diagnoses as a critical step in being able to meet the needs of their HIV-positive children. Young adults interviewed felt that they have specific needs as people living with HIV and as parents of young children; they expressed an interest in support groups that would provide an avenue for discussion of their unique challenges.

Male Involvement

The lack of involvement by fathers and other males was identified as a significant gap in the community's ability to provide adequate care and support to children. This concern was applied to children regardless of their HIV status. Isibindi has made an effort to close this gap by engaging male community members in their activities and training men as CCWs. The program also offers a male empowerment project that aims to support young men in developing skills and addressing fundamental issues such as employment, communication, and health.

Community Education

Many interviewees highlighted the importance of community levels of stigma as significant barriers to HIV-positive children being able to live happy, healthy lives. They called for more intensive activities to change community attitudes toward HIV as a means of reducing stigma and creating a more supportive environment for families affected by HIV.

Alcoholism

Providers frequently mentioned alcohol abuse as a significant problem that directly impacts parents' ability to care for their children. They attributed a number of gaps in child care to alcoholism, which they viewed as very common in the surrounding communities.

CASE STUDY SUMMARIES FROM UGANDA

BAYLOR INTERNATIONAL PEDIATRIC AIDS INITIATIVE

KAMPALA, UGANDA

The ICRW research team conducted a visit to the Baylor International Pediatric AIDS Initiative program site in Kampala from May 22 to 25, 2010. The data used for this case study summary were collected through interviews and focus group discussions with 31 individuals: 17 HIV-positive youth (9 female, 8 male, aged 15 to 18 years), 8 parents/caregivers (all female), 2 peer counselors, 2 home health care workers, 1 play therapist, and 1 counseling coordinator.

PROGRAM DESCRIPTION

Model:

The Baylor College of Medicine-Bristol-Myers Squibb-Texas Children's Hospital-Children's Clinical Center of Excellence in Kampala was officially opened in 2008. Located on the site of Mulago Hospital, the center now delivers HIV care and treatment to more than 5,000 HIV-positive children and family members. The facility offers an on-site laboratory for HIV testing, as well as a pharmacy, a nutrition unit, and large triage and exam rooms. The core components of the program center on the provision of medical care by a team of nurses and doctors. In addition to the clinic-based services, Baylor also offers a growing community care component through its cadre of community volunteers (CVs) and home health care teams (HHCTs).

Client base:

Baylor's pediatric program serves approximately 5,000 HIV-positive children. While the clinic also provides care to their families, the children are considered the index patients for care. HHCTs and CVs provide services to families within a 50-km radius of the center.

Services:

Baylor provides testing and counseling for HIV, including both pre- and post-test counseling for children and adults. The center also provides a wide spectrum of medical care for HIV-positive patients to help them manage their health and to address opportunistic infections. These services are provided both at the clinic and through monitoring and adherence support in the communities. The pediatric program also provides numerous psychosocial support services to children, including the following:

1. Counseling with trained child therapists
2. Support groups for children and adolescents

3. Recreational activities and play therapy
4. Theater and choral groups
5. Residential five-day camps.

Staffing:

The Baylor team, dedicated to providing care and support to pediatric HIV patients, includes both professionals and lay workers in the clinic and community settings. The core team consists of 6 child counselors, 1 counseling coordinator, 12 home health care workers, 180 CVs, 1 play therapist/teacher, and several pediatricians and nurses. CVs are supervised by HHCTs and are equipped by the project to provide basic nursing and counseling support for clients, including supporting drug adherence, home hygiene, and community activities.

External linkages:

As previously described, the Baylor model expands services beyond the clinic and into communities through its cadre of volunteers and health care workers. There appear to be no other linkages with community-based organizations or service providers.

Good practices within the general model/approach:

- Family clinics provide medical care to index child patients and their parents/caregivers in a shared appointment, from testing to comprehensive child-centered HIV services
- CVs help to bridge the gap between periodic clinic visits and the need for ongoing care and support
- Strong model of extracurricular and artistic programming provides an outlet for self-expression by HIV-positive children and adolescents
- Doctors and counselors establish long-term relationships with their child clients from voluntary counseling and testing through “graduation” to adult care.

Gaps/challenges:

1. Very large case loads make it difficult for child counselors, HHCTs, and doctors to provide the quality of care they would like to (HHCTs see 3 families/day, doctors see 22 children/clinic day, and counselors see 15 to 20 children/day);
2. A weak external referral and networking system to non-clinical care organizations limits the program’s ability to meet clients’ basic needs (e.g., access to livelihood support, financial resources, etc.)
3. Despite the popularity and positive effect of arts-based activities, these are in jeopardy due to funding challenges.

IDENTIFICATION OF CHILDREN

Current approach/activities:

Parents/caregivers and HIV-positive youth reported that the decision to bring a child for testing had been made as a result of the child’s chronic illness. Some caregivers reported that it was entirely their

decision, while others had been encouraged by clinic staff to have the child tested. More recently, children are also identified through Baylor's outreach efforts in the clinic's surrounding communities. CVs often identify HIV-affected families with a child whose status is unknown and/or who are showing symptoms of HIV infection. These children can be referred to the clinic or to HHCTs for testing.

Once children are identified as HIV-positive, parents/caregivers are encouraged to continue seeking care and support for the child through Baylor. Their health status is monitored through monthly meetings at the clinic between parents/caregivers and staff. CVs and HHCTs also provide support in the monitoring of children's health status, identifying any emergent issues and referring the child to Baylor for treatment.

Good practices in the identification of children:

- Outreach in surrounding communities
- Screening and referral by CVs.

Persistent gaps/challenges:

The approach to identifying children for services relies heavily on parents/caregivers being able to recognize symptoms of chronic illness and deciding to bring the child for testing. It also relies on community-based volunteers to aid in the identification of children who may be HIV-positive. These CVs are unable to visit all the families in their catchment areas and identify all potential cases.

TESTING AND COUNSELING

Current approach/activities:

The Baylor team acknowledges the importance of creating a secure and safe environment for children and their parents as they go through the process of testing and counseling. As such, the program offers a dedicated area for supervised play and play therapy, which serves as a safe place for children to spend time during pre- and post-test periods, and while awaiting their test results. This also gives the play therapist an opportunity assess the child's readiness to receive HIV-positive results and to provide relevant recommendations to the parent/caregiver about whether and how to disclose to the child. Children are also encouraged to play in this area during their parents' clinic visits. Counselors on duty make every effort to provide direct support to children during testing and counseling, accompanying them to the laboratory, and staying with them during the test if the children so choose.

Good practices in testing and counseling:

- Supervised play area available for children during pre-/post-test periods
- Standardized process for pre- and post-test counseling.

Persistent gaps/challenges:

Despite the many efforts described previously, there were several persistent challenges to the provision of a supportive testing and counseling environment for children. Counselors and young people acknowledged that the number of clients who attend the clinic each day places a strain on providers' ability to dedicate adequate time to the needs of each patient. Young people and parents felt that their medical needs were taken care of but that their pressing need for material or psychosocial support was often not of concern to clinic providers. Young people expressed frustration with the testing process, as they recall not being told the reason for their test or that the test would require a blood sample. One challenge faced with the play area is that it is an open space and, thus, does not provide a confidential and secure area for children to share their fears, concerns,

and questions. It was also noted that there are no standards or tools used to assess a child's readiness for disclosure.

DISCLOSURE

Current approach/activities:

Baylor counselors and staff overwhelmingly support partial disclosure to children based on his or her age and developmental stage. They work to empower the parents/caregivers to disclose to the child directly, providing encouragement and advice throughout the process. If parents request that a counselor be present when the child learns about his or her status, the counseling team will do so in order to provide support to both the child and the parent.

Good practices in supporting the disclosure process

- Counselors provide ongoing support to parents and children to aid in the disclosure process
- Clear guidelines for disclosure assist counselors in preparing parents/caregivers for disclosing to children.

Persistent gaps/challenges:

Young people expressed frustration with the ways in which their own status was disclosed to them. Some felt that the disclosure process was too regimented and that the adherence to procedures left them feeling that their needs were not adequately considered by the program or by parents/caregivers. They also expressed anger with having their status disclosed to third parties, including relatives, without their express consent. Young people suggested that peer support be offered immediately after a child finds out about his or her status, emphasizing that children may not talk right away but that they will be encouraged to talk about their own situations if such communication is modeled for them by peers.

STIGMA

Current approach/activities:

Stigma was cited as the most important obstacle to disclosing a child's status directly to the child as well as to others in the family and community. However, the youth interviewed also felt grateful for the opportunities the program provided them for talking to and receiving support from peers. Through the support groups and artistic activities, young people reported feeling more confident about themselves and less inclined to avoid disclosure due to fear of stigma.

Good practices in addressing stigma:

- Peer support groups provide support to help combat stigma
- Adolescent groups empower young people as advocates and artists educating their communities about HIV.

Persistent gaps/challenges:

As a result of fear of stigma, many young people reported that their caregivers and providers had given them untruthful information about their health problems. Young people expressed resentment and anger toward both parents and providers; they articulated the importance of telling children the truth from a young age, gradually and depending on their age and ability to comprehend. These youth also highlighted the importance of interacting with HIV-negative young people in order to reduce stigma, and suggested that the program consider this as a critical gap in the existing model for psychosocial services.

GRIEF AND BEREAVEMENT

Current approach/activities:

While the interviewees all recognized death and loss as a common experience for the children and young people who receive care through Baylor, there were no explicit efforts to provide grief and bereavement support through the program. Children are encouraged to use spiritual coping mechanisms to deal with their own illness and other problems they encounter. There is a platform for worship provided within the clinic, and group reading of scripture is an activity in which many young people participate. While these activities and support groups do provide some outlet for addressing grief, this is just one of many critical topics that are discussed within such groups, making it difficult to ensure that adequate attention and time is provided. It was mentioned that the home health care workers provide grief and bereavement counseling to children at home, but they receive little to no training to provide this level of care. Home health care workers are also limited by their case load, which generally allows them to visit each patient house once every three months.

Persistent gaps/challenges:

There are limited efforts to address grief and bereavement within the Baylor program. Given the importance of these issues to the overall well-being of the child, the program would be strengthened by providing a more consistent response, particularly in training and supporting home health care workers who interact with children in the home environment.

HIGHLIGHTED TOOLS/RESOURCES

For children and adolescents:

- Kids clubs (8- to 12-year-olds who have disclosed HIV status)
- Peer support groups
- Peer counselors
- Choir and performing arts activities
- Baylor residential camps (9- to 11-year-olds)
- On-site play therapy.

Needed Tools/Resources

While study participants felt that Baylor was largely able to meet the medical needs of HIV-positive children, they identified a number of resources that they feel are critical to meeting children's psychosocial needs. Key among these are services that would serve the children directly as well as those aimed at their parents/caregivers and providers, as follows:

Children:

- More avenues for interaction with HIV-negative children in supportive environments
- Books and general educational materials for children to read in the waiting area.

Families/caregivers:

- Stronger linkages with other community-based service organizations to help meet family needs (income generation, education costs, etc.)
- Training in communication with children/adolescents
- Support groups in the communities
- Basic counseling skills
- Counseling for parents/caregivers to help manage stress of disclosure, etc.

Providers:

- Training in grief and bereavement care
- Stress management for staff.

ADDITIONAL NOTES

In addition to these findings specific to the key themes, this research revealed that clients are grateful for the medical services provided by Baylor, but that they see significant room for improvement around the quality of care. Key areas mentioned included making the site itself more child-friendly through art work or colorful walls, and placing greater emphasis on a child's holistic needs rather than just managing his or her medical problems.

JOINT CLINICAL RESEARCH CENTER

MBARARA, UGANDA

The ICRW research team conducted a visit to the Joint Clinical Research Center (JCRC) program site in Mbarara from May 31 to June 2, 2010. The data used for this case study summary were collected through focus group discussions and in-depth interviews, conducted both in the clinic, as well as in catchment communities. Focus groups were conducted with 35 individuals: 12 HIV-positive youth (6 female, 6 male, aged 15 to 18 years) and 18 parents/caregivers (13 female, 5 male). Interviews were conducted with one parent/caregiver, two counselors, a community volunteer, and the site director.

PROGRAM DESCRIPTION

Model:

The JCRC (Kampala) was founded in 1991 and pioneered the use of antiretrovirals in Uganda in 1996. Its Mbarara program, based out of Mbarara Hospital, is one of JCRC's eight regional centers of excellence. JCRC Mbarara provides sophisticated laboratory services and is the regional referral point for DNA testing for children 18 months and younger. In addition, JCRC Mbarara provides care and treatment for approximately 8,200 HIV-positive patients. The program applies a holistic approach to care, especially for children, that addresses their material, educational, psychosocial, spiritual, and medical needs. Staff see their program as being 50 percent facility-based and 50 percent community-based, collaborating with a network of partners to meet patient needs.

Client base:

JCRC Mbarara serves 8,200 HIV-positive patients, including children (aged 0 to 17 years). Children aged 0 to 12 make up 77 percent of all pediatric intake and 41 percent of the total annual intake.

Services:

JCRC Mbarara provides a broad range of medical, care, and support services for HIV-positive patients to help them manage their health and to address opportunistic infections. These services are provided at the clinic, through home-based care (HBC) teams, and through monitoring and adherence support in the communities. Regular (monthly) visits for child patients are scheduled, and JCRC provides funds for transport, as well as food for the children during clinic days.

Multidisciplinary teams (including medical care personnel, as well as community volunteers and counselors) conduct home visits within an 80-km radius of the clinic, with community liaison volunteers (CLVs) providing ongoing home-/community-based follow-up. HBC teams and outreach workers also provide home-based testing. The pediatric program also provides psychosocial support services to children and caregivers, including ongoing, individualized counseling for children, life skills training, peer support groups for children and for caregivers, kids clubs, residential camps for children under 12 years, spiritual support via pastor visits in clinics and village follow-up, and community- and school-based sensitizations.

Staffing:

The clinic has over 30 staff and volunteers, including medical professionals (doctors and nurses) and counselors (general and adherence counselors and a child counselor, trained through TASO). JCRC also has 50 CLVs, 30 of whom are HIV-positive, who have been trained in communication skills (although not specifically to communicate with children), health education, and adherence counseling. Staff and CLVs provide HBC and services, much of this around adherence and medical care, but can also screen for psychosocial issues.

External linkages:

As noted, the JCRC model expands services beyond the clinic and into communities through its cadre of volunteers and health care workers. JCRC also partners with other organizations to provide a range of services: including links with the Uganda Women's Effort to Save Orphans for school bursaries (JCRC provides school materials); the National Forum for People Living with HIV, which provides a counselor who screens for depression in children; and others (e.g., Compassion and TASO) for support group services for parents and caregivers. JCRC also teams with other organizations to provide mosquito nets, water purification tablets, and other products for patients.

Good practices within the general model/approach:

- Strong community orientation, with dedicated home-based care staff/teams who spend the majority of their time in the community
- HIV-positive CLVs as experienced resources and role models for children and caregivers
- Networks with other organizations to meet broader needs of HIV-positive adult and child clients.

Gaps/challenges:

1. Very large case loads make it difficult for medical staff, counselors, HBC teams, and CLV care teams to provide the frequency of contact or quality of care they would like to. CLVs often have to prioritize children who have been missing their clinic visits or who are deteriorating healthwise, leaving other children who are stable or have non-urgent needs without contact.
2. While JCRC includes many community-based approaches, the focus of these is often on adherence to medical treatments. While this is an important approach and does ensure monitoring of and support to children, deeper psychosocial support issues, such as stigma, are not always fully addressed.
3. With prevention of mother-to-child transmission (PMTCT) programs, there are some mothers who do not return to collect test results, and therefore, they (and their children) miss out on enrolling into ongoing care and support services.

IDENTIFICATION OF CHILDREN**Current approach/activities:**

JCRC Mbarara is a well-known HIV clinic in the area and is a referral center for other clinics and within the general community. As a result, JCRC often accesses children via referrals or through parents/caregivers who come in seeking services for themselves and/or their children. The program also has several proactive approaches for identifying children who might be exposed to HIV (or at risk) such as community outreach to screen and provide testing; PMTCT and exposed baby clinics; school-based voluntary counseling and testing (VCT) programs; and working with local church and community leaders to identify mothers and children who might need testing and services. Community outreach programs also provide referrals back to the clinic for children whom they suspect have been exposed to HIV or are exhibiting symptoms.

Good practices in the identification of children:

- PMTCT and exposed baby clinics to identify mothers and babies for testing and services
- Outreach and campaign activities to provide home-based testing
- Links with community structures/leaders (churches, schools, etc.) to help identify mothers and children in need
- Community outreach to encourage testing and provide referrals.

Persistent gaps/challenges:

As noted previously, some mothers do not return for testing results, and the program does not have adequate systems to follow-up in all cases. With the variety of community and outreach screening and testing programs, there is the challenge of ensuring appropriate consent and confidentiality. For example, with school-based VCT, parent days are conducted to obtain consent.

TESTING AND COUNSELING**Current approach/activities:**

JCRC Mbarara has multiple avenues for offering routine testing and counseling, including PMTCT and exposed baby clinics, school-based testing and counseling (sometimes with HIV-positive peer

counselors and/or drama groups), and testing and counseling community outreach and campaigns (including home-based testing). Counselors provide pre- and post-test counseling, and doctors also provide post-test counseling in the case of a positive result—something that is seen to lend credibility to the discussion on ongoing care. Child counselors are available to conduct pre- and post-test counseling with children.

Good practices in testing and counseling

- Supervised play area available for children during pre-/post-test periods
- Standardized process for pre- and post-test counseling.

Persistent gaps/challenges:

Despite the many efforts described here, there were several persistent challenges to the provision of a supportive testing and counseling environment for children. Although JCRC can provide home-based testing, there are currently no family-based approaches (using either an adult or child as an index client) in place. Another concern is with school-based VCT, where negative results are given directly to the student, while positive results are left with the school head (it is unclear from discussions with staff if school heads are prepared to handle this or if health care workers/counselors can follow-up with the child/family directly). This raises concerns of confidentiality and raising stigma.

DISCLOSURE

Current approach/activities:

Providers at JCRC stress that the focus is on developmental readiness of the child to determine the best disclosure process, not chronological age. Doctors and counselors reported considering the optimal age of disclosure at 10 to 12 years; however, both provider and caregivers concurred that disclosure should be encouraged once a child starts asking key questions (especially regarding medical care or drugs). Adolescents shared an initial disclosure range of 10 to 15 years, noting that the child, in their opinion, should be old enough to “decide what they want to do with their life.”

The program provides supported disclosure, where a counselor is present if a parent/caregiver is having difficulty discussing this with the child. Positive visual tools of children sharing their status and achievements are also used to help facilitate discussions between the caregiver and child (with provider support). JCRC also takes some steps to build a larger caregiving team for the child. In cases where the primary caregiver is elderly (often illiterate), a second caregiver (often a mature child) is informed about the HIV-positive child and is included in ongoing care and support. Also, JCRC will convene a family conference to help disclose to other family members (including siblings) and encourage broader family support for the child. JCRC also encourages children to disclose to teachers and school, and the program will provide individual counseling and school sensitizations sessions to support this.

Good practices in supporting the disclosure process:

- Counselors provide ongoing support to parents and children to aid in the disclosure process
- Family conferences assist with disclosure and encourage support
- Support to children who want to disclose within their school.

Persistent gaps/challenges:

Young people expressed frustration with the ways in which their own status was disclosed to them. Many adolescents expressed anger that their status had been disclosed to them too late, leaving them anxious about their health status for too long and also leaving them more susceptible to internal and external stigma. Youth also expressed a need for more interactions (at the village level) with other HIV-positive youth who can provide guidance and also serve as role models for younger children.

STIGMA

Current approach/activities:

Stigma was raised during discussions with youth and caregivers, affecting their emotional well-being, disclosure, and their ability/willingness to adhere to medical treatments. JCRC's program has a particular focus on the school arena, and conducts outreaches to encourage testing and reinforce positive messages about HIV and HIV-affected people. This includes having HIV-positive peer counselors, drama groups, and expert patients provide information and counseling as needed. JCRC also conducts broader community sensitizations, as well as trainings with leaders (church, local leaders, etc.) to build understanding of HIV and support for HIV-positive individuals. HIV-positive CLVs are particularly important in helping to address stigma within communities.

Good practices in addressing stigma:

- Role-modeling of HIV-positive CLVs, peer counselors, expert patients, and drama groups
- Adolescent groups empower young people as advocates and artists educating their communities about HIV.

Persistent gaps/challenges:

Adolescents asked for more interactions with HIV-positive peers, fearing stigma from HIV-negative children, particularly at the village level. They also see this as an opportunity to provide each other with peer support and role models (especially for younger children).

GRIEF AND BEREAVEMENT

Current approach/activities:

While the interviewees all recognized death and loss as a common experience for the children and young people who receive care through JCRC, there is no specialized approach or training to address grief and bereavement. It was mentioned that grief and bereavement are included as topics during caregiver workshops, and that non-program community support (Neighbor in Need groups) may be available to help address financial needs. JCRC CLVs do visit and counsel children after the death of parent, encouraging the child to come for extra counseling as needed. The program will also reach out to other relatives to support the child and ask local leaders how children can be helped. JCRC also has some funds available to assist with education needs.

Good practices in addressing grief and bereavement:

- CLV visits with the child after the death of a parent
- Networking with family and community leaders/resources to support the child.

Persistent gaps/challenges:

The program does not have a specific approach for supporting children in processing grief and loss.

HIGHLIGHTED TOOLS/RESOURCES

For providers:

- Counseling checklist
- Disclosure guidelines issued by the Ministry of Health
- Provider-initiated counseling and testing in clinic settings by the Ministry of Health
- CLVs handbook
- Antiretroviral therapy flipchart for CLVs
- Starting the ARIEL Children's Clubs (supported by the Elizabeth Glaser Pediatric AIDS Foundation).

For children and caregivers:

- Comic book on disclosure: "Jessica's Secret" comes with laminated pictures to accompany audio CD and facilitator's guide
- "Straight Talk" newspapers
- Luka's Story (book about disclosure issues)
- Tower of strength—questions/answers about HIV
- Albums/photos of children who are HIV-positive
- Best facts about antiretroviral therapy (for clients).

NEEDED TOOLS/RESOURCES

While study participants felt that JCRC was largely able to meet the medical needs of HIV-positive children, they also noted that many materials and programs had more of a health focus. Therefore, the participants requested materials that more directly address psychosocial needs, especially for younger children. Specifically, they requested more flyers on positive living and videos about HIV-positive children and how they cope.

MILDMAY UGANDA

NAGGALAMA, MUKONO, UGANDA

The ICRW research team conducted a visit to the Mildmay Uganda-supported site at Naggalama Hospital in Mukono from May 26 to 28, 2010. The data used for this case study summary were collected through interviews and focus group discussions with 21 individuals: 7 HIV-positive youth (4 female, 3 male, aged 15 to 18 years), 7 parents/caregivers (all female), 6 counselors, and a research officer.

PROGRAM DESCRIPTION

Model:

Mildmay International is a Christian charity that was founded in 1866 to address the cholera epidemic in London. For more than 20 years, Mildmay has provided care for people living with HIV in several countries throughout Eastern and Southern Africa. Mildmay International began work in Uganda in 1993, delivering HIV care and treatment, prevention work, rehabilitation, training, and education. This work is based on the fundamental belief that people with HIV should be able to live life to their full potential. The program in Uganda is now Mildmay's largest in terms of the number of clients served. Mildmay Uganda also supports (through the provision of drugs and laboratory tests) the delivery of care and treatment for many outreach clinics, and serves as an advocate for the rights of those living with and affected by HIV. The site at Naggalama Hospital in Mukono District, Mildmay's largest supported site, was established in order to provide a dedicated service center to meet the high levels of demand for HIV care at a location that removed the cost and time barriers related to traveling to Kampala for care. The Naggalama site links with the larger Mildmay for support with laboratory services, drugs, staff training, and monitoring.

Client base:

The HIV clinic at Naggalama Hospital offers care to more than 2,881 men, women, and children living with HIV in the surrounding area. Mildmay Uganda has a total of more than 21,000 patients nationwide. This includes 1,000 children aged 0 to 18 years, of which 400 are 0 to 14 years old.

Services:

Through its clinic-based approach to care, Mildmay Uganda supports provision of a wide variety of health services for the management of HIV and opportunistic infections, including prevention of mother-to-child transmission (PMTCT), testing and counseling services, and a vaccination program for human papilloma virus. In addition, the facility provides other health services, including psychiatry, dentistry, ophthalmology, physiotherapy, as well as cancer screening. Counseling services include general counseling and health talks during outpatient clinics, as well as specific child and adherence counseling. While the emphasis is on facility-based services, there are community-based counselors and volunteers available to provide follow-up support and monitor children's health status.

Staffing:

The Naggalama Hospital team dedicated to providing care and support to pediatric HIV patients includes professionals and lay workers in the clinic and community settings. The core team consists of an HIV coordinator, a doctor for quality care, an assistant HIV coordinator, a head nurse, a hospital-based counselor, 2 community-based counselors, and 14 home visitors. There are also volunteer HIV-positive peer educators who reach out to others in the community. All lay community volunteers received a three-week training course that focused on home-based care, the basics of counseling, HIV testing and counseling, and adherence counseling.

External linkages:

In general, there are limited linkages with other organizations in the area. However, one critical link that the HIV program has is to the local nongovernmental organization Mukono Multi-purpose Youth Organisation (MUMYO). MUMYO has community-based volunteers who have been given basic counseling skills and provides these lay counselors to the hospital to support and monitor the

health status of HIV patients. As noted, the hospital receives technical and logistical support from Mildmay Uganda in Kampala.

Good practices within the general model/approach:

- Mildmay builds capacity of the hospital to offer HIV services (Mildmay does not directly provide the services)
- Clinical service model provides preventive and treatment services (free for children) for a range of physical health problems
- Monday clinics offer older children the opportunity to share experiences with each other while they wait to receive medication
- Young children (under 10 years of age) are offered opportunities to play, write, and paint together during Monday clinics.

Gaps/challenges:

1. Very large case loads make it difficult for staff to provide the quality of care they would like to (counselors see 5 to 10 clients daily).
2. The program structure provides few opportunities for children to interact with their peers.
3. The program's focus on provision of medical care detracts from its attention to patients' psychosocial needs.
4. MUMYO counselors do not have adequate training beyond the basics in providing counseling to children; only the head counselor reported having undergone a six-month training (through the TASO curriculum).
5. Children's basic nutritional needs are often not met at home, which presents challenges for their treatment adherence and health status.

IDENTIFICATION OF CHILDREN

Current approach/activities:

The main method for identifying children is through family contact; adult index clients are strongly encouraged to bring children in for testing, and these children are given priority. In addition, children are identified as they are brought to the clinic when they begin to exhibit symptoms. Naggalama also identifies a small number through PMTCT programs. While participants mentioned some community outreach efforts (including some screening and referrals by community volunteers) that encourage bringing children for testing, the focus of community-based work was on the provision of post-test care. Once children are identified as HIV-positive, they receive regular home visits by MUMYO community counselors and volunteers. Through these visits, they provide information about basic nutrition, hygiene, and adherence to treatment protocols. Children's health status is monitored through these visits and by community volunteers. Community counselors then report on children's progress and/or problems during monthly meetings with hospital staff.

Good practices in the identification of children:

- Active encouragement of all adult clients to bring children within the household for testing; those children are given priority when brought in
- Children born to HIV-positive mothers are identified and targeted for pediatric care through PMTCT services
- Identification by community volunteers.

Persistent gaps/challenges:

If children are not identified at birth or through adult index clients, there are few other targeted efforts to identify children and bring them in for treatment. This model of identification relies heavily on community-based volunteers to aid in the identification of children who may be HIV-positive. Given their work load and their limited interaction with the hospital and clinic staff, community volunteers and community counselors alone are unable to ensure that all children in need of care will be referred to the hospital.

TESTING AND COUNSELING**Current approach/activities:**

Mildmay Uganda ensures that the standardized Ministry of Health protocol for the testing and counseling of children is followed at all supported sites, including Naggalama. These guidelines recommend disclosure for children aged 12 years and above. Children under the age of six years are tested with their parents present, and the pre-/post-test counseling is provided to the parents or caregivers. For those children aged 6 to 12 years, there are two stages of post-test counseling. First, counselors meet the parents alone to give the parents the results and post-test support while the children are offered toys and time to play in another area. They then meet the parents and child together to talk about other preventive measures (e.g., not sharing sharps).

Efforts are made to ensure all children 12 years and older are disclosed to, but the timing for this is on an individual basis and relies heavily on caregiver willingness and readiness. After the caregiver has been given the results, they are counseled on the importance of disclosure to the child. Disclosure will take place at a time when the caregiver is ready and when the child is deemed able to handle it by the caregiver and counselor. Disclosure generally involves a session with the caregiver to assess the caregiver's readiness and provide support for disclosure. This is followed by another session with the child alone to evaluate what the child knows. After this, the child and caregiver are brought together for the caregiver to disclose in the presence of the counselor, and further support is offered in follow-up sessions at the facility and within the community.

Good practices with testing and counseling:

- Standardized nationally approved procedure for testing and counseling of children
- Testing and counseling provides an opportunity to speak with the parent and child together, as well as individually
- Toys are provided for children while their parents receive post-test counseling.

Persistent gaps/challenges:

Despite the clarity of the guidance provided to counselors, parents and young people reported a number of critical gaps in the testing and counseling services they have received. Parents felt that there was not enough time allocated to their post-test counseling and that they were thus forced to wait until the next appointment to have their fears, questions, and concerns addressed. The pre-/post-test counseling protocol has not been adapted for children under the age of 6 years, and the counseling team generally does not have any specific tools or training to help them provide counseling to children under the age of 12 years.

DISCLOSURE

Current approach/activities:

While there were conflicting opinions about the best time and way to tell a child about his or her HIV-positive status, the importance of handling this initial disclosure was highlighted by everyone interviewed. Counselors encourage parents to tell children about their status early and try to provide them with the skills and information they will need in order to do so. While the program's preference is for caregivers to take charge of disclosure, counselors acknowledge that they often end up accompanying the parent during the conversation or leading the conversation while the parent is present. Counselors recommend that for children in boarding school (and sometimes those in day schools), parents disclose to a favorite teacher or the school nurse in order to facilitate treatment adherence while in school.

Good practice in supporting the disclosure process:

- Counselors provide ongoing support to parents and children to aid in the disclosure process.

Persistent gaps/challenges:

Young people reported frustration with the way disclosure is handled, especially when parents/caregivers delay sharing information due to their own fears. Some children visit the clinic on their own to find out why they are sick (e.g., has a skin rash). Counselors recognized that they did not have all the skills and tools they felt were necessary for providing appropriate support to children and parents in the disclosure process. While they would like to provide parents/caregivers with training on communicating with their children about HIV, they do not feel that they have the capacity and knowledge to provide this. Given the emphasis of keeping children in school, there was also little discussion of children out of school, in terms of disclosure or other psychosocial needs. The challenges associated with managing a discordant household, especially when there are several HIV-negative children and only one HIV-positive child, were also mentioned.

STIGMA

Current approach/activities:

Fear of stigma and isolation was identified as a significant obstacle to disclosure to the child and to other family and community members. Participants described a variety of discriminatory practices directed toward HIV-positive children in the home and school. Facility staff are responsive to reports of discrimination, often visiting or phoning the home to address the issue within the family. Counseling helps to address internalized stigma and promotes a positive self-image, though it is not adequate to protect children from the ill effects of experienced stigma. Peer groups for adolescents (13 to 17 years old) provide a forum for seeking support from others who have had similar

experiences. Beginning at the age of 13, children aware of their status can participate in an adherence workshop which, though it essentially has a medical focus, also provides a supportive environment with peers.

Good practices with addressing stigma

- Peer groups for older adolescents to share experiences with stigma
- Adherence workshops provide another opportunity to interact with peers
- Program staff follow up on (via visits or phone calls) reports of discrimination.

Persistent gaps/challenges:

There are currently no programs or activities to reduce stigma in schools or in the communities. Community health education efforts have not addressed stigma or sensitization about HIV. While there are support groups for older children offered through Mildmay support, there are no structured groups for young children to explore stigma and improve their resilience to discrimination.

GRIEF AND BEREAVEMENT

Current approach/activities:

Death of a parent or other loved one was cited as a common experience for the children and young people who receive care through Mildmay-supported HIV clinics. While the need for support through their bereavement was recognized, there are no structured activities or services to address this need. Counselors frequently mentioned that grieving children should be loved and offered toys to play with; while the latter was referred to as “play therapy,” counselors had received no training in such therapy. Counselors also mentioned that they are able to refer children to a community-based counselor for grief work, but this person has not received any systematic training on grief and bereavement. The counselors also admitted that they do not always know if a child has experienced the death of a loved one, given that the time they can allocate to each patient is limited.

Persistent gaps/challenges:

This issue is not addressed directly by the program.

HIGHLIGHTED TOOLS/RESOURCES

For children and adolescents:

- Peer support groups
- Recreational therapy
- Adherence groups

For families, caregivers, and providers:

- Mildmay Uganda training course “Communicating with Children.”

NEEDED TOOLS/RESOURCES

Interview and focus group participants largely agreed that Naggalama Hospital, supported by Mildmay Uganda, was able to meet the medical needs of HIV-positive children. However, there were numerous suggestions of resources and tools they would like to see incorporated into the program and that they feel are critical to meeting children's psychosocial needs. Key among these are services that would serve the children directly as well as those aimed at parents/caregivers and providers, as follows:

Children:

- More play equipment and drums in the waiting area
- Peer groups and role models for younger children
- Drama groups to encourage interaction and release stress.

Families/caregivers:

- Stronger linkages with other community-based service organizations to help meet family's needs (income generation, education costs, etc.)
- Information, education, and communication materials about parenting an HIV-positive child
- Child communication skills
- Counseling for parents/caregivers to help manage stress of disclosure, etc.

Providers:

- Training in grief and bereavement care
- Stress management for staff.

ADDITIONAL NOTES

In addition to these findings specific to the key themes, this research revealed that the daily stressors faced by families introduce substantial challenges to meeting children's psychosocial needs. Poverty and a family's inability to provide for children's basic needs were frequently mentioned by parents, providers, and young people alike. Spirituality was also mentioned as an important component of children's lives, but one that could not be fully explored in the face of so many other challenges and, in particular, when parents and children avoid interactions with community and congregation members for fear of being stigmatized.

THE AIDS SUPPORT ORGANISATION

MASAKA, UGANDA

The ICRW research team conducted a visit to The AIDS Support Organisation (TASO) in Masaka from May 19 to 21, 2010. The data used for this case study summary were collected through interviews and focus group discussions with 41 individuals: 13 HIV-positive youth (11 female, 2 male, aged 15 to 18 years), 7 parents/caregivers (6 female, 1 male), 5 child counselors (4 female, 1 male), 8 general counselors (6 female, 2 male), 3 field officers (all male), a male community volunteer

(CV), a female social support officer, a male doctor, a female laboratory staff member, and another female staff member.

PROGRAM DESCRIPTION

Model:

TASO was founded in 1987 in Uganda with a mission “to contribute to a process of preventing HIV infection, restoring hope and improving the quality of life of persons, families, and communities affected by HIV infection and disease.” TASO’s approach to “Living Positively with AIDS” is holistic and includes the physical, psychological, and emotional well-being of HIV-positive individuals. TASO Masaka was established in 1988 and provides a wide range of clinic-based, outreach, and community-based services for patients within a 75-km radius of the facility. The organization is moving toward a more family-based approach and already relies on strong community relations/engagement to provide support for clients. TASO has also initiated community drug distribution points, which increases timely access to medications and also provides referrals for testing and/or other services.

Client base:

TASO has traditionally focused on adult clients, but also serves the families of HIV-positive adult clients living in communities around Masaka. TASO Masaka has approximately 30,000 total registered clients, of which 7,200 are currently active. Children aged 0 to 17 years comprise a relatively small group of their client base, with 632 boys and girls actively obtaining services. Interestingly, TASO’s records show that there are more girls enrolled than boys, although there is no clear reason for this.

Services:

TASO Masaka provides a wide range of medical services at the facility and through outreach and home-based initiatives, including testing and counseling, antiretroviral treatment, and management of opportunistic infections. Counseling support is a central approach within TASO’s model, and a counselor works closely with medical staff to manage each patient’s care. For children enrolled with TASO, each child is assigned to a specific child counselor, who then tracks the child’s progress throughout (although other providers and counselors are also involved in providing psychosocial support). There are strong linkages between the counseling and medical care parts of the program (e.g., use of one patient chart) to ensure a common understanding of service needs. The pediatric program also provides numerous psychosocial and “welfare” support services to children, including the following:

- Counseling with trained child therapists
- Peer support groups for older adolescents (groups for younger adolescents aged 10 to 14 years have been discontinued due to budget cuts)
- Play center at clinic for children to use during clinic days
- Provision of therapeutic feeding and tea/lunch during clinic visits
- Educational support
- Provision of scholastic material.

Staffing:

The TASO team includes 80 staff working both in the clinic and in surrounding communities. Many team members are long-time TASO staff/volunteers, either within Masaka or from other TASO branches. Staff include 19 medical personal (doctors, nurses, and laboratory technicians) and 21 counseling staff. Of the counselors, seven are trained child counselors who are responsible for managing child clients. The program also relies on community-based individuals, including volunteers and model patients, to follow-up with patients and liaise with community groups/structures (Note: TASO interacts with communities to identify opinion leaders and invites them to join the team).

External linkages:

TASO's approach cultivates linkages within the community, including other clinics and providers (especially for referrals), local government agencies, and community organizations and structures. TASO also works with multiple partners, including Heifer Project International, World Vision Uganda, GOAL, Rotary Club of Masaka, and the Masaka District Diocese Organization, to help HIV-affected individuals and families meet some of their livelihood and household needs.

Good practices within the general model/approach:

- Care-focused mission and approach for staff, activities, and services with integrated clinical care
- Holistic and tailored approach including medical and psychosocial support, as well as other basic needs (education, food, etc.)
- Child-friendly approach, with dedicated child counselor who oversees the child's progress
- Strong links between medical and counseling arms of the program (shared client chart, internal referrals), with clear role definition
- Consistent, positive, hopeful messaging across services and providers
- Workshops with caregivers to provide essential information, build skills, and share experiences.

Gaps/challenges:

1. TASO Masaka has a well-defined package of holistic care for children that it would like to provide, but staffing and other resources are limited. TASO notes that they are seeing an increasing number of child clients (particularly 5 to 15 years of age) requiring specialized services and care.
2. With funding shortfalls, psychological and social support activities have been cut back, both for children (peer support groups, memory books) and their caregivers (caregiver workshops, training in will writing and succession planning).
3. TASO's staff are committed to their mission, and child counselors form strong relations with their patients and families, often extending after a child transitions into adult care. However, with only six child counselors serving over 600 children (as well as their other client load), staff are overloaded and unable to have the frequency or quality of contact with each child as they desire.

4. Discussions with children and parents reinforced this sense of a strong relationship/bond between patients and TASO staff; they view TASO as a “large family.” Interestingly, this also raised the possibility of creating dependency on program staff to meet multiple, ongoing needs and relatively limited activities to empower children and caregivers.

IDENTIFICATION OF CHILDREN

Current approach/activities:

TASO uses many different approaches to proactively identify at-risk children in the Masaka area in addition to receiving referrals from other clinics/programs or caregivers (often elderly grandparents) who “walk in” to obtain services for children in their care. Many children are identified via HIV-positive adults who are already TASO clients or come in for prevention of mother-to-child transmission services. TASO will use adult clients as index clients to access other family and household members who may need testing and services, providing home-based testing as needed. Outreach services and community activities (e.g., drama groups) are also used to identify children. CVs and members of TASO-supported communities identify and refer children they think may be in need of HIV testing.

Good practices in the identification of children:

- Home-based testing for family/household members, using HIV-adults as index clients
- Screening and referrals by CVs and community members
- Outreach activities.

Persistent gaps/challenges:

One question for all pediatric HIV programs is whether they are identifying and reaching all children in need. TASO often identifies children through their HIV-positive biological parent(s), as well as other avenues of identifying children. TASO staff reported the sense that they have a good understanding (if not full coverage) of children in need of services within their catchment area, and that their response is only limited by the lack of resources. As previously noted, currently more girls are receiving care than boys, which staff could not account for; while this may simply reflect the situation in Masaka, it may be an indication of possible gender issues that impact if/how children are identified and access services.

TESTING AND COUNSELING

Current approach/activities:

HIV testing and counseling is a relatively recent aspect of the program, because TASO—traditionally, a care- and support-oriented organization—largely receives referrals for individuals who have been tested elsewhere and then are sent to TASO for ongoing services. Testing and counseling, including home-based testing, is focused on family members of index adult clients, as well as children who enter through the prevention of mother-to-child transmission program. TASO does receive some walk-in clients who request testing services, as well as referrals of new clients (who then need to be tested) from other clinics. TASO follows established counseling protocols, with pre-test counseling (sometimes provided for a group to cope with patient load and minimize waiting time) and post-test counseling done with the child alone, caregiver alone, and jointly with the two. CVs conduct home follow-up visits to monitor the situation and provide some on-site counseling after testing.

Good practices in testing and counseling:

- Time allowed during actual testing for children to express worries and for provider to reassure child
- Home-based testing (using HIV-positive adults as index clients)
- Joint counseling with child and caregiver (for children five years and older)
- Post-test follow-up through CVs
- Play center for children to interact with others and engage in activities (e.g., art and writing) around the time of testing and counseling.

Persistent gaps/challenges:

Some of the challenges raised by counselors and youth include what children are told when they are brought for testing. Youth repeatedly expressed their anger at being lied to about the reason for visiting the clinic. Although there is pre-test counseling, both groups felt that there is little sensitization for children about the testing process, and the laboratory technician noted that she takes time to let children express their worries and to reassure them during the actual test.

DISCLOSURE**Current approach/activities:**

Disclosure as an ongoing process was identified by counselors, parents/caregivers, and youth as a critical concern and as a component of the ongoing support that TASO provides. Counselors and staff support partial disclosure to children based on their age and developmental stage. Counselors use a variety of tools (e.g., observation of the child in a play center, art/writing activities, discussions with the child, and home visits to assess the situation) to determine the child's level of understanding and readiness for disclosure. They particularly said that they use the questions that a child asks (about visits to the clinic and about taking medicine) as a gauge for sharing more information about HIV and living positively. Caregivers also noted that they feel they should disclose (and sometimes feel pressured to do so) as a child increasingly asks questions about his or her medical care.

TASO generally encourages disclosure to the child to come from the caregiver or parent. If they are unable to do so, counselors will help them prepare for the discussion (e.g., via role-plays) and be present to help address any problems that arise. Young people had varied feedback regarding disclosure, including the timing of initial disclosure (although there was a general consensus that children should be told relevant and truthful information sooner rather than later), who should disclose (there was a preference for having a professional disclose, who can provide appropriate and accurate information in stages), and the situations of disclosure (youth noted that home-based testing allowed for more open discussion within the family, including around disclosure). One interesting note that emerged is that with many children having HIV-positive parents/caregivers who have themselves been through TASO's program as a patient, those parents/caregivers are able to draw on their own experiences to support a child through the disclosure process.

Good practices in supporting the disclosure process:

- Disclosure is seen as a process, tailored to the child’s situation and developmental capacity
- Capacity building and support for caregivers to disclose to the child
- Home-based testing to facilitate disclosure within the family
- CVs can assist with disclosure issues within the home during adherence follow-up and other visits.

Persistent gaps/challenges:

Young people expressed frustration with the ways in which their own status was disclosed to them, although there were varied ideas in terms of what a good disclosure process should be. Youth acknowledged the importance of knowing about HIV and transmission to their ability/willingness to adhere to treatment. Several youth and caregivers also noted the challenge of handling disclosure when there are other young children in the household who may inadvertently share information with others before the child/family is ready. In general, empowering and supporting young people as they disclose to others—a crucial issue for youth—was not as systematically addressed by the program (although staff/volunteers can provide some assistance based on specific situations or needs).

STIGMA**Current approach/activities:**

Addressing stigma is a central issue for TASO, and the program has specific efforts to promote positive images, attitudes, and support for those living with and affected by HIV. TASO’s long-term presence in Masaka (and strong links in the community) has generated respect for the program, but also can lead to stigmatizing of individuals who are seen traveling to the clinic or have home- or school-based visits. In general, there was a sense from providers that community stigma has decreased, but youth noted the continuing need to address both internal and external stigma. Ongoing counseling and peer support groups, especially for older youth, help youth share experience related to stigma.

TASO staff and volunteers are very active in the community to sensitize members about HIV in general and about living positively with HIV. Community drug distribution centers are seen as also decreasing stigma, as HIV-positive clients openly obtain their medications. HIV-positive “expert” patients and adult and youth role models are active in the community specifically to raise awareness about stigma and can step in with staff to address acute situations that may arise. TASO works with schools to create a more supportive environment for HIV-positive students, and HIV-positive youth are also encouraged if they wish to speak out.

Good practices in addressing stigma:

- HIV-positive volunteers, expert patients, and youth peers serve as role models to community members and to HIV-positive youth
- Community-based drug distribution centers
- School-based sensitizations and promotion of youth living positively with HIV.

Persistent gaps/challenges:

TASO's community presence and orientation has helped to create a broader understanding about HIV and build community responses to support people living with HIV. Youth and caregivers noted that many counseling and peer support activities, however, are still clinic-based and requested additional support activities that could be easily accessed within their village/community. Schools are also critical environments—as noted by both youth and caregivers—and both groups requested that more be done to build school-based support (via teachers and school counselors).

GRIEF AND BEREAVEMENT

Current approach/activities:

While all staff, caregivers, and youth noted the importance of death and loss as a common experience for the children and young people who receive care through TASO, there is limited program activity to help children/families prepare for or mitigate the effects. While staff will provide grief counseling, they have not received extensive training, especially community-based volunteers (who are likely to be closer to the situation), nor is there adequate supervision. Staff will help parents and caregivers think through future care of the child, and counselors will pay special attention during clinic days to ensure that a bereaved child is engaged in activities and is interacting with other children. Some important programs for children and caregivers—creating memory books, and facilitating succession planning and will writing—have been suspended due to funding shortages. When a death does occur, CVs and staff will attend the funeral and try to visit children at home to provide ongoing counseling, limited financial support, and refer the family to other local resources to address acute situations (e.g., property grabbing) or ongoing concerns (e.g., livelihood support).

Good practices in addressing grief and bereavement:

- Succession planning/counseling and will writing support
- Memory books
- Home-based follow-up to assess how the child is coping
- Referrals to community leaders, structures, and other organizations to meet needs.

Persistent gaps/challenges:

In general, staff acknowledge that this is an underaddressed area for TASO, especially when the death or loss involves someone other than a parent (e.g., a sibling or friend). There are gaps in clinic- and community-based responses throughout the immediate impact of a death, as well as longer-term support needed to cope with the loss of a parent (something particularly noted by youth). This includes having a system in place to address children who have multiple caregivers or are moved from family to family. Program staff, especially field-based volunteers, need specific training to help children and families cope with grief and loss.

HIGHLIGHTED TOOLS/RESOURCES

For children and adolescents:

- Child counselors
- Peer support groups
- Peer role models
- Clinic play center.

NEEDED TOOLS/RESOURCES

While participants felt that TASO has strong approaches for meeting both the medical and psychosocial needs of HIV-positive children (and is used as a resource by other organizations), they identified several tools/resources that they feel are critical for both children and caregivers. Key among these are services that would serve the children directly as well as those aimed at their parents/caregivers and providers are as follows:

- Books and information, education, and communication materials on sexuality (for children 10 years and older)
- Basic HIV information via drama or other appropriate mechanisms for HIV-positive and HIV-negative younger children
- User-friendly disclosure guides for semiliterate parents/guardians
- Training on verbal and nonverbal communication with children (for both staff and caregivers).

APPENDIX B: MATRIX OF TOOLS/RESOURCES

Title	Author/ Publisher	Date published	Summary of tool/resource purpose	Users				Beneficiaries				Subject area					
				HIV+ Child	HIV Affected Child	Caregivers	Service Providers	HIV+ Child	HIV Affected Child	Caregivers	Service Providers	Capacity Building	Disclosure	Adherence	Stigma	Grief - Bereavement	Communication
Asking Questions and Getting Answers: Choosing the Best Treatment for Your Child	Mary Jo O'Hara, RN, MSN, CPNP; Carolyn K. Burr, RN, MS; Nancy Lerner- Weiss, MSW, LCSW	1998	This document gives a medically focused overview of children's antiretroviral options/treatment for parents to utilize.			√	√	√				√					
Caring for Children, Youth and Families: Family Centered-Care Training Package	Unknown	Unknown	Gives a schedule (but not the training materials themselves) for a 6 day training for family case workers and community workers that goes over child development stages; child's needs including mental; ART and health care including adherence; issues for families affected by HIV; and psychosocial support.				√	√	√	√		√		√			
Care for Children Infected and Those Affected by HIV/AIDS: A Handbook for Community Health Workers	Save the Children UK	2003	Guide for community health workers but is more directed to caregivers on children and HIV. Covers medical issues but also issues on disclosure, communication, and grief.			√		√	√	√		√	√				√
Complex Issue of HIV Disclosure To Children and Adolescents in the Forefront	National Pediatric and Family HIV Resource Center (NPHRC)	1999	Presents American Academy of Pediatrics guidelines and recommendations from NPHRC which suggest that disclosure is a process; advocates for a multisystem approach which can address places where support is needed; and presents some resources around disclosure.				√	√		√			√				

Title	Author/ Publisher	Date published	Summary of tool/resource purpose	Users				Beneficiaries				Subject area					
				HIV + Child	HIV Affected Child	Caregivers	Service Providers	HIV + Child	HIV Affected Child	Caregivers	Service Providers	Capacity Building	Disclosure	Adherence	Stigma	Grief - Bereavement	Communication
Counseling Children: A Manual	Faith Azalea Harding, Ed.D	2008	Provides some content for community workers addressing the emotional needs of children affected by or living with HIV.	√		√						√	√				
Delivering Antiretroviral Therapy in Resource- Constrained Settings Lessons from Ghana, Kenya and Rwanda	Robert Ritzenthaler, Family Health International	2005	Case studies from Ghana, Kenya, and Rwanda on ART programs. Gives lessons learned/recommendations for designing ART programs, including recommendations on counseling patients. Does not specifically address children.				√					√					
Development of HIV Diagnosis Disclosure Model	Vitharon Boon- Yasidhi	Unknown	This model features an assessment process that examines a caretaker's readiness to lead the disclosure process and prepares them with the knowledge and skills to lead the process. Measures in children include positive changes in adherence and self-confidence.			√	√					√	√				
Disclosure of Illness Status to Children and Adolescents With HIV Infection	Committee on Pediatric AIDS	1999	Cites preliminary results that children who know their HIV status have higher self-esteem than those who don't. Recommends that physicians NOT withhold diagnosis from children (even at the parent's request). Age, psychosocial network, family dynamics, and clinical status are issues to consider.				√	√					√				
Facilitating Care and Support through Kids Clubs	REPSSI and the Olive Leaf Foundation	2009	Manual designed to equip kids clubs leaders/youth leaders with knowledge and skills that they will need to start up and run kids clubs. Not specific to HIV.	√	√			√	√			√					

Title	Author/ Publisher	Date published	Summary of tool/resource purpose	Users				Beneficiaries				Subject area					
				HIV + Child	HIV Affected Child	Caregivers	Service Providers	HIV + Child	HIV Affected Child	Caregivers	Service Providers	Capacity Building	Disclosure	Adherence	Stigma	Grief - Bereavement	Communication
Going to Scale: Lessons Learned from the IMPACT Project on Meeting the Needs of Orphans and Other Vulnerable Children	Family Health International	2008	Recommendation on how to design national programs to address OVCs. Provides lessons learned from IMPACT projects in 13 countries.				√	√	√	√		√					
Group Work with HIV/AIDS-Affected Children, Adolescents, and Adults: A Curriculum Guide	Family Ties Project	2001	A curriculum that provides support, education, and life skills to adults and children living with or affected by HIV in Washington D.C. Exercises/modules cater to those children that are affected by or living with HIV and their caretakers.			√	√	√	√	√		√	√				√
Guidelines on Counselling Children Who are Infected with HIV or Affected by HIV or AIDS	Southern African AIDS Training Programme	2003	These guidelines are specific to the counselor's role in disclosure, pre-/post-test counseling, and how to address the various needs and support of the child. (It looks like this was developed with consideration of the developing world.)	√			√	√	√			√	√		√	√	√
HIV/AIDS Care and Treatment: A Clinical Course for People Caring for Persons Living with HIV/AIDS	FHI Impact & USAID	2004	Clinical guidelines for how to manage/treat HIV; has module on children; nothing on psychological or social support.				√	√				√					
How to Tell Children That a Loved One Has a Serious Illness	Children's Hospice International	Unknown	Specific to the UK, this gives some guidance around disclosure with children living with HIV. A disclosure framework for National Health Service clinicians is presented as part of the document.			√	√	√	√				√			√	
Human Rights Watch Submission Regarding the Kenya National HIV/AIDS Strategic Plan, 2009-2014	Human Rights Watch	2009					√	√				√					

				Users				Beneficiaries				Subject area					
Title	Author/ Publisher	Date published	Summary of tool/resource purpose	HIV+ Child	HIV Affected Child	Caregivers	Service Providers	HIV+ Child	HIV Affected Child	Caregivers	Service Providers	Capacity Building	Disclosure	Adherence	Stigma	Grief - Bereavement	Communication
Information and Action Tool for Supporting Children, Families, and Communities	Human Sciences Research Council and REPSSI (South Africa)	2006	Tool helps community workers communicate with supervisors, group leaders, and mentors about the needs of children and families as well as assessing families' capacity to provide psychosocial support.				√	√		√		√					
Journey of Life	RESSPI	Unknown	Tool designed to encourage reflection, dialogue, and action among all people who interact with children and can contribute to their care, support, and protection. Not specific to HIV-positive children.			√	√	√									√
Kids ART Education Series - The Children's Treatment Literacy Toolkit: Responding to the HIV and AIDS Related Needs of Children in Southern Africa	Southern Africa HIV and AIDS Information Dissemination Service	2008	A treatment literacy toolkit that examines issues around treatment and adherence through games and exercises that target kids. This is targeted toward the developing world context.	√		√	√	√		√		√	√	√	√		√
Living Positively with Self-Esteem: Experiences of Working with Children Living with HIV/AIDS	Save the Children in Uganda	Unknown	A Case Study of Health Alert in Northern Uganda. Includes disclosure and male involvement.				√	√		√		√	√				
Living with HIV (Chapter 5 of Caring for Children with Special Needs)	New York State Department of Health	2003	Provides some pointers/guidance for parents of children living with HIV about disclosure; directed towards parents in the United States.			√		√	√				√				
Living with X: A Body Mapping Journey in the Time of HIV and AIDS, a Guide for Facilitators	RESSPI	2007	Body mapping technique manual to do as an exercise with people living with HIV.				√	√				√					

				Users				Beneficiaries				Subject area					
Title	Author/ Publisher	Date published	Summary of tool/resource purpose	HIV + Child	HIV Affected Child	Caregivers	Service Providers	HIV + Child	HIV Affected Child	Caregivers	Service Providers	Capacity Building	Disclosure	Adherence	Stigma	Grief - Bereavement	Communication
Mainstreaming Psychosocial Care and Support within Pediatric HIV and AIDS: Treatment for Health Care Workers Working with Children and Families Affected by HIV and AIDS	REPSSI (South Africa)	2008	Guide for service providers and caregivers that describes psychosocial issues surrounding HIV-positive children (grief, disclosure, adherence, and communication); gives recommendations and "how to" steps.			✓	✓	✓				✓	✓	✓		✓	✓
Mainstreaming Psychosocial Care and Support within Pediatric HIV & AIDS Treatment	RESSPI	Unknown	Guide designed for health care workers for integrating psychosocial support and biomedical issues and approaches to pediatric AIDS.				✓	✓				✓					
Mainstreaming Psychosocial Care and Support into Home-Based Care	RESSPI	Unknown	Guide on integrating psychosocial care into home-based care programs.				✓	✓		✓		✓					
Mainstreaming Psychosocial Care and Support within Food and Nutrition Programmes	RESSPI	Unknown	These guidelines provide practical steps to mainstream psychosocial support and care into organizations' food or nutrition programs. Food and nutritional support programs offer a unique opportunity to reach many children with psychosocial support.				✓	✓				✓					
Mainstreaming Psychosocial Care and Support into Economic Strengthening Programmes	RESSPI	Unknown	Guidelines giving practical steps for mainstreaming psychosocial support into economic strengthening programs for caregivers and HIV-positive children.				✓	✓				✓					

				Users				Beneficiaries				Subject area					
Title	Author/ Publisher	Date published	Summary of tool/resource purpose	HIV+ Child	HIV Affected Child	Caregivers	Service Providers	HIV+ Child	HIV Affected Child	Caregivers	Service Providers	Capacity Building	Disclosure	Adherence	Stigma	Grief - Bereavement	Communication
Mainstreaming Psychosocial Care and support within Early Childhood Development	RESSPI	Unknown	Programs and Centers focusing on early childhood development are extremely valuable in addressing the holistic needs of children and their families. Mainstreaming psychosocial support into early childhood development programs tries to build on this notion of holistic care to support the full development of the child and family.				√	√				√					
Making a Hero (Active Citizen) Book; a Guide for Facilitators	RESSPI	Unknown	Book designed to support a child to identify one significant but manageable psychosocial obstacle that is standing between them and their goals, and to further support them to find ways to gain more power over this obstacle. Does not address children living with HIV specifically.				√	√	√			√					
Memory Work Manual; a Facilitator’s Guide	REPSSI and International Federation of Red Cross and Red Crescent Societies	2002	Manual for memory work, which is the deliberate setting up of a safe space in which to contain the telling of a life story. The manual highlights memory work techniques that are designed to help HIV affected families cope with death and grief.			√		√	√	√		√				√	
Mobilizing Children & Youth into their Own Child- & Youth-led Organizations	Kurt Madoerin and REPSSI	2008	This publication explores child- and youth-led organizations from many different angles, amongst others, HIV prevention, the critical role of adults within these organizations, and economic strengthening.				√	√	√			√					

Title	Author/ Publisher	Date published	Summary of tool/resource purpose	Users				Beneficiaries				Subject area					
				HIV + Child	HIV Affected Child	Caregivers	Service Providers	HIV + Child	HIV Affected Child	Caregivers	Service Providers	Capacity Building	Disclosure	Adherence	Stigma	Grief - Bereavement	Communication
My Living Positively Handbook	Children's Rights Centre	2006	Tool directed to children to talk about HIV and living positively. Discusses how disease is transmitted, ART, and disclosure; has participatory exercises to facilitate the learning of this information and has an adult-focused complementary tool.	√								√	√				√
Pediatric Disclosure: Talking to Children about HIV	International Center for AIDS Care and Treatment Programs: Columbia University Mailman School of Public Health	Unknown	Guide about the issues and importance of child disclosure; also addresses communication and adherence.				√	√		√		√	√	√			
Protocol for Child Counseling on HIV Testing, Disclosure and Support	Family Health International	2007	Counseling guidelines for children and their parents/guardians about HIV in India. Holistic approach to counseling considering HIV as one among many other issues in a child's life. Includes sections on grief, stigma, and disclosure.	√			√	√				√	√	√	√	√	√
Psychosocial Care and Support Mainstreaming Guidelines	RESSPI	2008	Guide for organizations on how to mainstream psychosocial support. Includes pediatric HIV programs.				√	√				√					
Psychosocial Support Advocacy Toolkit	RESSPI	2008	Toolkit focuses on psychosocial support advocacy to create an environment which protects the rights, health, and welfare of children and young people, whether orphaned, affected by HIV, or victims of war and abuse.				√	√				√					

				Users				Beneficiaries				Subject area					
Title	Author/ Publisher	Date published	Summary of tool/resource purpose	HIV+ Child	HIV Affected Child	Caregivers	Service Providers	HIV+ Child	HIV Affected Child	Caregivers	Service Providers	Capacity Building	Disclosure	Adherence	Stigma	Grief - Bereavement	Communication
Supportive Care Issues for Children with HIV Infection (Chapter 18)	New York State Department of Health AIDS Institute	2001	Gives recommendations to health care professionals on meeting the psychosocial and medical needs of children living with HIV. Includes issues of grief, developmental stages, disclosure, adherence, and HIV affected siblings.				✓	✓	✓			✓	✓	✓		✓	
Taking Medication for HIV	Stephen Head	2003	Protocol regarding medication for HIV-positive children; nothing about psychosocial issues.	✓				✓						✓			
Talking with Children, Young People and Families about Chronic Illness and Living with HIV	Edited by Jennifa Miah; National Children’s Bureau	2004	Guide for professionals on how to talk to families and children with HIV. Covers issues of disclosure and HIV affected children, developmental understanding of the illness, and disclosure with young gay patients.				✓	✓	✓	✓		✓	✓				
Teen Talk Living with HIV	Lori Wiener, PhD; Lauren V. Wood, MD	2004	This is targeted towards the HIV- positive teenager about issues regarding intercourse and birth control.	✓				✓					✓				
The GHAIN Programme for Orphans and Vulnerable Children: Achievements and Lessons	Global HIV/AIDS Initiative Nigeria (GHAIN)	2007	Gives a description, results/lessons learned, and recommendations for policymakers out of GHAIN’s OVC program. Program services included psychosocial support along with health, nutrition, shelter, life skills, and legal support.				✓	✓	✓			✓					
The Mental Health Needs of Vulnerable Children and their Caregivers in Low Income Areas; a Training Guide	Brian Robertson; REPSSI	2008	Training guide designed for health care workers who do not have child and adolescent mental health training. It educates caregivers and HIV workers about the emotional development and mental health needs of vulnerable children as essential for their well-being.				✓					✓					

Title	Author/ Publisher	Date published	Summary of tool/resource purpose	Users				Beneficiaries				Subject area					
				HIV + Child	HIV Affected Child	Caregivers	Service Providers	HIV + Child	HIV Affected Child	Caregivers	Service Providers	Capacity Building	Disclosure	Adherence	Stigma	Grief - Bereavement	Communication
The Talking Book: Safe Disclosure to Children with HIV and AIDS	REPSSI	Unknown	Tool for disclosure does not have to be read, a button is pressed on each illustrated page and the book “talks” to the caregiver and guides them how to disclose and explain the child’s HIV status to the child.			✓		✓					✓				
The Tree of Life	Ncazelo Ncube-Mlilo (REPSSI) and David Denborough (Dulwich Centre Institute of Community Practice)	Unknown	The Tree of Life sets out to create safe spaces for children affected by HIV, poverty, or conflict to speak of loss, hope, connection, and courage. It is specifically used as a tool that can deal with loss and bereavement. To be used with groups of children.				✓	✓	✓			✓				✓	
Tracking Your Health: A Guide to Creating a Tracing Book	REPSSI, Canadian AIDS Treatment Information Exchange	2007	Tracing book for HIV-positive children that helps them keep track of their medications and issues related to ART.	✓				✓						✓			
Treatment Issues for HIV-Positive Adolescents	Neal D. Hoffman, Donna Futterman, and Alice Myerson. <i>AIDS Clinical Care</i>	1999	Overview of psychosocial and medical issues and adherence with HIV-positive adolescents for service providers. Includes brief discussion of disclosure, adherence, and grief.				✓	✓				✓	✓	✓	✓	✓	
Understanding HIV Basics	REPSSI and CATIE	Unknown	Tool integrates psychosocial support issues into biomedical aspects of HIV treatment; deals with adherence to and resistance and side effects of HIV medication.			✓		✓				✓		✓			
Weaving Hope for our Children: Home Based Care as an Entry Point for Psychosocial Care and Support for Children affected by HIV and AIDS	REPSSI, Hospice Association of Zimbabwe, and New Zealand Agency for International Development	Unknown	Manual intended to build capacity of the home-based care volunteer so that they can have an increased awareness and understanding of psychosocial issues of children as they go about their work in the home-based care environment.				✓	✓				✓					

				Users				Beneficiaries				Subject area					
Title	Author/ Publisher	Date published	Summary of tool/resource purpose	HIV + Child	HIV Affected Child	Caregivers	Service Providers	HIV + Child	HIV Affected Child	Caregivers	Service Providers	Capacity Building	Disclosure	Adherence	Stigma	Grief - Bereavement	Communication
Working with Parents in HIV-Affected Families: A Guide for Providers	National Pediatric & Family HIV Resource Center	2001	Provides providers with guidance around psychological needs (mental health and coping) with HIV-positive children in context of the United States.				✓			✓		✓	✓				

APPENDIX C: DATA COLLECTION GUIDES

KEY QUESTIONS FOR OLDER ADOLESCENTS LIVING WITH HIV

1. Introduction
 - a. Explain objectives of research
 - b. Introduce research team and participants
 - c. Obtain informed consent from participants
2. Background data
 - Current age
 - Gender
 - Living situation/orphan status
 - Relationship to current caregiver
 - School attendance/completion status
 - Work status
 - Length of time with program X/age when joined program X
3. Main questions
 - a. *Recall of Initial Counseling and Testing Experience*
 - Do you remember or have you been told about the first time you were tested for HIV?
 - How old were you when you were first tested for HIV?Describe what happened when you were tested (probes):
 - Who took you to be tested? (*If not your parent or primary caregiver, do you know why he/she was not involved?*)
 - Do you know why this person decided to have you tested for HIV?

- Did anyone tell you why you were going to the clinic that day? Did you know what was happening?
- Before the test, did your parent/caregiver or any of the clinic staff explain what was going to happen? What did they say?
- Did the provider suggest that you seek follow-up help? What kind of help did he/she recommend?

Describe your reaction (probes):

- Do you remember how you felt at each of these points? How did you feel about the way that the providers treated you during this process?
- What made the process difficult for you? What do you think would have made it an easier experience? (*older/younger age, more/less info, discuss with other people*)
- Did anything help make the experience easier for you?
- What help or support do you wish you had had from your parent or caregiver? From other people?
- What made it possible/difficult for you to receive this follow-up help?
- Are there other services you wish had been available to you?
- If you knew a young person that you thought needed to go for counseling and testing (someone under age 12), how would you handle this? What would you do the same or differently?

b. *Initial Diagnosis of own HIV-positive status*

Try to think back to the first time you were told that you are HIV-positive.

- How old were you when you first were told about your status?
- Who was the first person to tell you?
- What did he/she say?
- At the time, did you understand what it meant for you to be HIV-positive?
- Do you feel that the information you received in this initial disclosure was appropriate? Would you have wanted more, less, or different information than what you received?
- Do you remember how you felt about the news of your status?
- What sort of support did you need at that time? Did you receive it?
- Did this conversation happen too soon or too late, given what you were going through at the time?
- What happened in the days that followed this disclosure? Who did you talk to or want to talk to?

- Did you have the information or skills you needed to deal with this situation?
 - i. If so, what were the skills, information, or resources that were most helpful to you? Who helped you acquire these skills, information, and resources?
 - ii. If not, what would have helped you get through that period?
- Is there anything you wish your parent/caregiver had done differently during this time?

c. *Disclosure*

When you first knew and understood that you were HIV-positive, what other people in your life also knew?

- Who was the first person you told about being HIV-positive? Why?
- Who else knew about your status then?
- Who made the decision to tell these people about your status?
 - i. If you made the decision, why did you want these people to know?
 - ii. If you did not make the decision, who did?
- How did you know what to say to these people when you disclosed your status for the first time?
- How did you feel then about others knowing you are HIV-positive?
- Since these first disclosures, who else have you talked with about your status?
- Who was the last person you told that you are HIV-positive? Why did you tell this person? Did you know what to say?
- What is the hardest thing about telling people? Did you have the support and skills you needed to cope with this?
- Were there people you wish had known, so that they would understand what you and your family were going through? Or so that you could talk with them?
- What would have helped to make the process of disclosure an easier experience? And what would you do differently if you could start over?
- Does it get easier to tell people that you are HIV-positive? How or why?

d. *Stigma*

Many people who are HIV-positive are nervous about disclosing their status because they are afraid other people will react negatively or will treat them differently.

- When did you start to be aware of stigma (even if you didn't have a word for it)? Would you share some examples of the stigma you've seen? (Probe for where stigma was coming from as in other sections.)
- Was this stigma directed at you? At your family members? At other people in your life?
- How did this make you feel?

- Are there specific points in time or instances where stigma was a particular issue for you? When? Why?
- Did you talk with anyone about how stigma made you felt then? Who? Were they able to help you?
- What might have helped you more?
- As you've grown older, how have you learned to cope with stigma? Who do you talk with now to help with this?
- What kinds of information and skills have you acquired to deal with HIV-related stigma? When and how did you acquire this information and these skills?
- Based on your experiences, what types of resources (help, information, or support) would help young children cope with stigma or prepare for facing stigma?

e. *Grief and Bereavement*

Try to think back on your experiences as a child. You may have already experienced some significant losses in your life.

- What are some of the losses you experienced? People close to you? Other things?
- Are there some losses that you experienced because you are HIV-positive? How are these different from the losses other (HIV-negative) children face?
- How did you feel about these losses?
- When you felt this way, who could you talk to about your fears or your sadness? Were there different people you went to for support depending on the situation (or what you were feeling)?
- What kinds of things did you do to feel better when you felt sad or frightened? Who has helped you do these things?
- If you were trying to help a young child who was dealing with grief, what kinds of things would you do or want to be able to offer in support?

f. *Worries*

As an HIV-positive young person, what do you worry about?

- How do you cope with these worries? Who are the people who help you in your life? How do they help?
- What questions do you still have about your life or your future?
- Where can you find the answers?

g. *Getting Help*

What support would you like to have to help you deal with all of the challenges you've mentioned?

- Which of these needs/challenges does this program meet for you?
- Why were you interested in joining this program?

- Did you have any difficulties joining the program? What information did you need to join?
- What information do you need to make decisions about positive living?
- What are the obstacles that prevent you from having the type of support that you want to have?
- What skills or tools do you need? What would help you gain these skills or access these tools?
- What sort of support would you most like to see young HIV-positive children receive from the adults in their lives? (From others?)

KEY QUESTIONS FOR PARENTS/CAREGIVERS OF HIV-POSITIVE CHILDREN

1. Introduction

- a. Explain objectives of research
- b. Introduce research team and participants
- c. Obtain informed consent from participants

2. Background data

- Number of children under care (in total and HIV-positive)
- Relationship to HIV-positive child
- Key points of time in life of HIV-positive child (current age of child, age at diagnosis, age of child when he or she came under the care of caregiver)
- Status of the parent/caregiver(s)?

3. Main questions

a. *Indicators for the HIV-positive child*

When did you first begin to worry about the health of your child?

- How old was your child at this time?
- What did you see or suspect that suggested that the child was ill?
- What did you do about your worry that the child was ill?
- Did you talk with anyone about your concerns? Who? Why? Were they helpful? How?
- Did anyone help you? Who? How?

b. *Counseling and Testing*

When did you have your child tested for HIV?

- How did you decide to have your child tested for HIV? What prompted you to take this action?
- Did anyone tell you to get your child tested? Who? Why?
- How did you find out what to do and where to go to get your child tested?

- How old was your child at this time? What did you tell your child about going to get tested?
- Did you have any difficulty in knowing what to say or how to say it?
- What happened when you took your child for testing? Who did you see before testing? What did they tell you? What did they tell your child? What happened during the test? What did they tell you and/or your child after the test?
- What were your thoughts and fears on that day?
- What did people say to you that helped you?
- What did people say that confused you or hurt your feelings?
- What other information or support would you have liked to have on that day?
- What happened in the time after the test?
- Did the provider suggest that you seek follow-up help? What kind of help did he or she recommend?
- What made it possible/difficult for you to receive this follow-up help?
- Are there other services you wish had been available to you?
- Did your child react in any way to being tested? How did you cope with this?

c. *Disclosure*

Does your child know that he or she is HIV-positive?

- How old was your child when he or she found out? Were you the person to tell your child about their status?
- How long was the time between knowing your child's status and disclosing this to him or her?
- How did you know the right time and age to tell your child? Were there signs in your child's development or other events that prompted you to disclose?
- Did anyone help you to make this decision? Who? What kind of help or support did they provide?
- What did you say to your child? Did you feel like you knew what you wanted to say and how you wanted to say it?
- Were there things that you wanted to be sure your child understood before telling your child that he or she was HIV-positive? (e.g., the concept of private information?)
- Did anyone provide information or guidance about this? Explain further.
- How did your child respond? How did you handle this?
- What questions did your child ask? Were you able to answer all these questions?

- Do you think your child understands what it means to have HIV? If yes, what makes you think this? If no, what information do you think your child does not understand and why?
- What additional support or information would you have liked to have had at that time?
- Aside from your child, who else have you disclosed their status to? Who was the first person? Why? Who else? Why? (potential disclosure tree activity)
- Have you talked with your child about other people who know his/her status? How did your child react to other people knowing? Has your child ever asked you to disclose to someone? Who? Why?
- Have you talked with your child about when and how he or she should disclose their status to others? (probe on key social interfaces for the child, like friends or schools)
- Did anyone help you think through disclosures with other people (either by you or by your child)? What information or support would you have wanted at the time? What resources have been helpful to you in making decisions about disclosure?
- If you have **not** told the child about their HIV status, what prevents you from telling him or her?
- How does not telling your child affect your ability to care for him or her? How does it affect your ability to communicate about other things?
- What advice would you give another parent/caregiver who is concerned about telling their child that the child has HIV?

d. *Stigma*

- Do other people know about your child's HIV status or ask you about your child's status? How do you respond when they ask? How do they respond when you tell them or do not tell them?
- How do people treat your child? Was there a difference before and after they learned of the child's status?
- What have you done that helps the child respond to life and people that may not treat them kindly? What else has helped the child? What else would you want to do?
- How does the way that people treat your HIV-positive child affect your child's ability to cope with the knowledge of their HIV status and talk to others about it?
- How do people treat you when they find out you are caring for an HIV-positive child? Was there a change from the way they were before they knew the child is HIV-positive?
- How does this affect your ability to care for the child?
- How does this affect how you feel when you are with health care workers, counselors and others?

- What is the future of a child who is HIV-positive compared to a child who is HIV-negative? (use story or drama approach to build out and identify areas of psychosocial support needed)
- In what ways do you think being HIV-positive affects how your child lives their life?

e. *Grief and Bereavement*

- Has your child lost someone near to them? How did your child show their grief or sadness?
- When the child lost a loved one, did they understand or want to know the cause of death? Does it make a difference if the death is HIV-related? Did the child have any questions or worries about their own death?
- How do you respond to your child's sadness?
- Did anyone give you good advice or books? What were they?
- What support from programs or providers did you receive (for example, referrals to other services, or ongoing counseling)?

f. *General Worries*

- As a caregiver or parent of an HIV-positive child, what do you worry about? (possible activity to breakdown and/or prioritize areas of concern, focusing on psychosocial support-related issues)
- How do you cope with these worries? Is there someone who helps you with these worries?
- Is there an organization or clinic that helps you with these worries? A spiritual group? A friend? Family members?
- What questions do you still have about your child and their health? Their future?
- Where do you think you can find the answers?
- Are there specific worries that you have about your ability to care for your child? (probing on psychosocial support) What would help you provide better care?

g. *Getting Help*

What are obstacles for getting help? What help do you still need?

- What are the obstacles that prevent you from getting the help you need? (use Journey of Life pictures to prompt discussion)
- What are the obstacles affecting your HIV-positive child?
- What affect has being HIV-positive had on your child's life?
- What affect has taking care of an HIV-positive child had on your life?
- How did you find out about program X? Why were you interested? What needs did this meet for you or for your child?

- Did you have any difficulties joining the program? What information did you need to join? What did you tell your child about the program?
- What would you like to be able to do that you can't do now?
- What additional information, skills or tools do you need to help provide care for your child?
- Is there any advice that you would give to people helping families with HIV?
Advice for new caregivers of children with HIV?

KEY QUESTIONS FOR PROVIDERS

1. Introduction

- a. Explain objectives of research
- b. Introduce research team and participants
- c. Obtain informed consent from participants

2. Counseling and Testing

- a. Identifying or screening children within the facility for counseling and testing services
 - In general, how are children identified for counseling and testing services?
 - What screening for possible HIV-positive children occurs within HIV-related programs for adults (e.g. counseling and testing programs, care programs, tuberculosis clinics, etc.)? How is this handled? How are children identified as at risk then referred for counseling and testing?
 - What screening of children occurs within the facility system for general services (e.g., basic primary care clinics)? How are children suspected of being HIV-positive identified? How are they then referred for counseling and testing?
 - When a child is identified for possible counseling and testing, what do parents/caregivers think about (consider) in deciding when and how to obtain counseling and testing services for their child?
 - What counseling or support do you provide for parents/caregivers as they make this decision?
 - What additional skills or tools are needed to help parents/caregivers at this time?
 - How do you know if parent/caregivers actually follow-through and bring their child for testing? What follow-up is provided?
 - If testing does not happen, what follow-up is conducted?
 - What additional skills/tools do you need to do your job well?
 - For facilities/community groups who do not provide HIV testing, where are they referred/ linked?
- b. Identifying or screening HIV-positive children in the community
 - Do you primarily go out into the community or do people come to you?

- Do you identify HIV-positive children in the community? How do you identify such children?
 - Do parents/caregivers come to you about a child who might have HIV? How do parents/caregivers come to suspect the child might be HIV-positive?
 - What happens when you suspect there is a child living with HIV? What actions do you take? With whom?
 - In such a situation, what do you discuss with the parent/caregiver? What are some of the challenges you face in talking with parents/caregivers?
 - How do you encourage parents/caregivers to take the child for counseling and testing? What follow-up do you conduct to ensure that counseling and testing happens? What are the linkages between the facility and community-based services?
 - What do you do when you are not able to take action or encourage parents/caregivers to act?
- c. Provision of facility-based counseling and testing services
- What skills and tools do parents/caregivers have to make decisions about counseling and testing? What skills and tools do they need?
 - What skills and tools do children have to make decisions about counseling and testing? What skills and tools do they need?
 - How does your program support parents/caregivers and children with the counseling and testing process?
 - What happens when a parent/caregiver brings a child to you for counseling and testing? Who do they interact with? Who is involved in the various steps involved in counseling and testing?
 - What are the most important things you do to provide good counseling and testing services when meeting children and parents?
 - What are the important issues for parents to be aware of? What do you do to ensure that parents understand these issues?
 - What role does the child play in the counseling and testing process? How are they included/excluded in the pre-test, testing, and post-test counseling phases?
 - How do you determine if and/or how a child should be included in the counseling and testing process? What criteria help to determine what or how much you discuss directly with the child?
 - Between the ages of 0-5 what do you say to children during the counseling and testing process? What do you say to children 6-9 and 10-12?
 - If actual age is not the main characteristic used to determine what to say to the child, what is? How do you determine this? What variations in counseling and testing occur based on this aspect of the child?

d. Provision of referrals and care services

- After testing, what referrals do you frequently make and how do you ensure that referrals are followed through?
- What sort of aftercare is provided? After family and children leave your hospital or voluntary counseling and testing center, what services are available to them? Who ensures that they take advantage of these services?
- How do you refer or link children to psychosocial support programs? What discussions do you have with parents/caregivers about such programs? How do you follow-up to ensure this has happened?
- What other links between facility and community-based services exist? What more should be in place to support children and their parents/caregivers?

3. Disclosure

- What factors (things) do parents/caregivers consider (or do you ask that they consider) in deciding when to inform their HIV-positive child about his or her status? What about disclosing to others, like friends or teachers?
- How do you advise families about when and how they should disclose the child's status to the child?
- What are the factors you take into account in giving this advice? (listen for chronological vs. developmental age)
- How do you advise families about when and how they should disclose the child's status to others (like family members, teachers, friends, etc.)?
- How do parents/caregivers view disclosure? What issues does it bring up for them (e.g. their own status, or their sense of loss)?
- How do your services prepare parents/caregivers to make both immediate and long-term decisions about when to disclose the child's HIV status to them?
- Do you ever find yourself in situations where the parents/caregivers are reluctant to disclose to the child and/or to others? Does this prevent you (or other providers) from providing the care that the child needs? How do you handle such a situation?
- What are the ways that children find out (discover) that they are HIV-positive?
- What skills and tools do parents/caregivers have to make decisions around disclosure to the child? What skills and tools do they need?
- What skills and tools does the child have to make decisions about their life? What support, skills, and tools does the child need?
- How does your program support parents/caregivers with disclosure?
- How does your program support the children around disclosure?

4. Stigma

- When a child is HIV-positive, how do people in the community react to the child? What about in the facility?
- How do people in the community treat the parent/caregiver of an HIV-positive child? In the facility?
- In your experience, how does the child respond when they discover they are HIV-positive? What forms of internalized stigma can emerge?
- How do you support the child as he or she faces internal or external challenges due to their status?
- How do health care providers respond to spending time or taking care of HIV-positive children? What is the range of their responses? What about community-based providers?
- How do **providers** such as yourselves help HIV-positive children cope with the negative attitudes that people have toward an HIV-positive child?
- What can **parents** do to help their HIV-positive children respond to the negative attitudes that people have?
- What have been some of the approaches or methods that **programs** use to assist these children and those who care for them to be less affected by these attitudes? What are the messages they send to these children and their caregivers/parents?
- If there was no stigma about HIV, no negative attitudes, would that change what you say to parents/caregivers about disclosing the child's HIV-positive status to them?
- Would it change what you say to parents/caregivers and children about what to say to adults and other children when a child in the family is HIV-positive?

5. Grief and Bereavement

- What losses do you look for when a child is HIV-positive?
- How are these losses manifested in the child? What emotions or behaviors do you see?
- Think about a child whose parent has died recently—is there any difference in the way the child now behaves?
- How do you recognize when a child is grieving for a parent or caregiver who has died? What screening do you do? How do you respond?
- How do you recognize when a caregiver's grief affects the care and support of the child? How do you respond?
- If you identify that a child is grieving, what do you do? How does this affect the level or style of care that you provide?
- What skills and tools do parents/caregivers have to help them respond to the child who is told they are HIV-positive? To the child when a caregiver/parent has died?

- What support does the program provide to caregivers/parents to help their HIV-positive child cope with grief?
- What skills and tools do parents/caregivers have to cope with their own grief and bereavement regarding a close relative who has died?
- What skills and tools do parents/caregivers have to help them plan for the present and future of their HIV-positive child?
- How does the grief of the parent/caregiver affect their ability to care for the HIV-positive child?
- When an HIV-positive person dies does it affect the way the family can publicly express their grief compared to when an HIV-negative person dies? Does it affect the way they mourn—how they show it, who they tell and who comes to the funeral?
- How do programs help or support the grief and mourning process for a family when an HIV-positive person dies?
- What follow-up or referral services are provided for children who are mourning the death of their parent? Their caregiver? Their sibling?

6. The Provider's Experience

- What do you like about your job?
- What is difficult about your job?
- In your job, what would you like to do that you cannot do now?
- If there was something more you could do to support HIV-positive children and/or their parents/caregivers, what would that be?

INTERVIEW GUIDE FOR ENVIRONMENT SCAN

1.	<i>Interviewer</i>	
2.	<i>Date</i>	
3.	<i>Respondent name/title</i>	
4.	<i>Respondent organization</i>	
5.	<i>Respondent contact information</i>	
6.	<p><i>Overview of project: As you know, more and more HIV-positive children are being enrolled in treatment programs, and there is growing awareness of the importance of a strong psychological and social foundation to better equip children with HIV and their families for some of the issues they will face. Information about approaches that aid in providing this foundation is limited. We are hoping you can help us identify tools and approaches that are currently being used to help HIV-positive children, parents and caregivers, and health providers in addressing the psychological and social challenges faced by HIV-positive children and their families.</i></p>	
7.	<p>Please describe any programs you know of that are providing services and support to HIV-positive children and/or their caregivers and/or health providers.</p> <p><i>Probes:</i></p> <p><i>How are children who are exposed or diagnosed as HIV-positive identified in these programs (e.g., in-patient wards, PMTCT, out-patient, etc.)?</i></p> <p><i>How is HIV discussed in the context of testing (e.g., child, family, etc.)?</i></p> <p><i>How is parent's serostatus disclosed to children?</i></p> <p><i>How is the child's status disclosed to the child?</i></p> <p><i>How are children helped to adhere to treatment?</i></p>	

	<i>How are children their families equipped to combat external and internalized HIV-related stigma?</i>	
8.	Do you have contact information for these programs?	
9.	What are current gaps in providing HIV-positive children with psychological and social support? (i.e., what is still needed to better equip HIV-positive children, their parents, their caregivers, and/or their health providers in addressing the psychological and social needs of these children?)	
10.	<p>What gender-specific issues are associated with providing psychological and social support to HIV-positive children? (i.e., are there gender-related barriers to accessing or utilizing services, or to providing children with support?)</p> <p><i>Probe:</i></p> <p><i>Are there issues specific to mothers in providing support? Fathers? Female caregivers? Male caregivers? Female health providers? Male health providers?</i></p> <p><i>Because of gender norms, do experiences of children receiving or not receiving support differ based on sex?</i></p>	
11.	If someone else were to work with HIV-positive children 0-12 years of age and their families, what are the three most important psychological and social issues you would recommend that they be mindful of?	
12.	What are the three areas that you believe we need to better understand when working with HIV-positive children to help them have a strong foundation for their psychological and social well-being?	

13.	Do you have any other advice about how to learn more about this issue (reports, studies, names, or other sources of information)? Who else should we talk to for names of programs that provide psychological and social support to HIV-positive children and their families?	
14.	Do you have any questions for us regarding this project?	
15.	Follow-up	

APPENDIX D: LIST OF LITERATURE REVIEWED

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APPENDIX E: LIST OF EXPERTS INTERVIEWED FOR ENVIRONMENTAL SCAN

Last Name	First Name	Organization
Abrams	Elaine	International Center for AIDS Care and Treatment Programs, Columbia University Mailman School of Public Health
Bachman	Gretchen	USAID, HIV/AIDS
Barnhart	Matt	USAID Malawi
Becker	Susan	HRSA Global
Bowsky	Sara	USAID, Africa Bureau
Brakarsh	Jonathan	Consultant, Zimbabwe
Close	Kristin	Baylor International Pediatric AIDS Initiative, Uganda
Cox	Naomi	Linden Care Foundation, Guyana
Dastur	Sarah	AED, Speak for the Child Program
Ekpo	Gloria	AED, BASICS
Ferris	Bob	USAID, HIV/AIDS
Field-Nguer	Mary Lyn	AED
Foster	Geoff	Consultant, Zimbabwe
Fulton	Nicole	mothers2mothers
Gibbons	Amanda	AIHA
Greenberg	Aaron	UNICEF, Child Protection Unit, NY
Hejoaka	Fabienne	Centre d'Etudes Africaines
Hull	Beri	ICW
Kalyesubula	Winnie	Mildmay Uganda
Kayita	Janet	UNICEF, Kenya
Kheshavarzian	Ghazal	UNICEF
Kindy-McPherson	Jennifer	The Theresa Group (Canada)
Lentfer	Jennifer	Firelight Foundation
Lovich	Ronnie	Save the Children
Mak'Anyengo	Mary	Kenyatta Hospital, Kenya
Manda	Karen	UNICEF Malawi
Margolese	Shari	Advocate (Voices of Positive Women, ICW), Canada
Marston	Joan	HPCA South Africa
McCullough	Rose	EGPAF
Medrano	Tanya	Family Health International
Mellins	Claude Anne	HIV Center for Behavioral and Clinical Studies, Columbia University
Miller	Anna	EGPAF Zimbabwe

Mwombeki	Fabian	AIHA, Tanzania
Odiachi	Angela	USAID Malawi
Okero	Amolo	WHO Geneva
Parks	Marie	University of Maryland, School of Medicine, Dept. of Pediatrics
Parsons	Ross	Johns Hopkins University
Rabinowitz	Linzi	Researcher, South Africa
Rochat	Tamsen	Africa Centre for Health and Population Studies, University of KwaZulu Natal
Rotheram-Borus	Mary Jane	UCLA, CHIPTS
Salmond	William	EGPAF Uganda
Schenk	Katie	Population Council, HIV/AIDS
Schilsky	Allison M.	CDC, C&T Team
Schweitzer	Anna Marie	Baylor Romania
Semrou	Katherine	Boston University School of Public Health
Senefeld	Shannon	Catholic Relief Services
Simon	Jonathan	Boston University School of Public Health
Smith	Shelley	Foundation for Hospices in SSA
Steinitz	Lucy	Family Health International
Tepper	Vicki	University of Maryland School of Medicine, Pediatric AIDS Program
Thahane	Lineo	Baylor Lesotho
Vorley	Kate	USAID Kenya
Vujovic	Marnie	Researcher, South Africa

APPENDIX F: TECHNICAL ADVISORY GROUP MEMBERSHIP LIST

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