FOUNDATION FOR THE FUTURE: MEETING THE PSYCHOSOCIAL NEEDS OF CHILDREN LIVING WITH HIV IN AFRICA

TECHNICAL BRIEF

AIDSTAR-One
AIDS SUPPORT AND TECHNICAL ASSISTANCE RESOURCES

JUNE 2011

INTRODUCTION

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 (U.N. Children's Fund [UNICEF], Joint U.N. Programme on HIV/AIDS [UNAIDS], and the World Health Organization [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 antiretroviral therapy (ART) are increasingly enabling children living with HIV to live longer and healthier lives (Mellins et al. 2004; Sopeña 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; Family Health International [FHI] 2007).

Psychosocial support (PSS) 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). PSS helps to build critical resiliency in children and supports families and caregivers to meet the multiple

BOX 1: CONTINUUM OF CARE: SERVICES FOR CHILDREN LIVING WITH HIV

- HIV testing and counseling as early as possible
- Antiretroviral therapy 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
- Psychosocial support: 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; housing support.

Adapted from FHI 2007.

needs of children (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, research has shown that it is particularly critical for the health and development of children living with HIV (King et al. 2009). Children living with HIV experience more subjective distress than their HIV-negative 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). Several studies also 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).

This technical brief describes promising practices in critical services related to the psychological and social

well-being of perinatally-infected children (aged 0 to 12 years) in Africa. These include the identification, testing, and counseling of children so that they are linked to appropriate support as early as possible, as well as the provision of ongoing PSS to help children and their families manage disclosure, stigma, and grief and bereavement processes. The information presented in this brief was collected through a review of published and gray literature, as well as from interviews with researchers and practitioners addressing the clinical, psychological, and social needs of children around the world. In addition, the brief highlights experiences of eight programs in South Africa and Uganda (see Box 2). Field-based technical reviews of these programs included in-depth interviews and focus group discussions with program staff, parents and caregivers of children living with HIV, and HIV-positive adolescents (Uganda) and young adults (South Africa). This brief is aimed at helping program planners, implementers, and service providers identify PSS activities and approaches for younger children living with HIV and their families that can be integrated into their treatment, care, and support efforts. For more detailed information, the final report from this activity is available at www.aidstar-one.com.

PROMISING PRACTICES

Programs working in South Africa and Uganda 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, families, and 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

BOX 2. 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, Mukono (supported site Naggalama Hospital)
- The AIDS Support Organization (TASO), Masaka

often overworked, dealing with competing priorities and limited in key skills to provide quality PSS for children.

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. 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" (youth in Uganda).

This section identifies promising practices from South Africa and Uganda that meet the psychological and social needs of children living with HIV in the following areas: 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. These promising practices also highlight how 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, as well as the children themselves. Some of the persistent challenges faced by these programs are also presented because they provide important context and guidance for how PSS can be effectively provided.

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 psychological and social support. 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 who 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; UNICEF, UNAIDS, and WHO 2010). WHO reports that only an estimated 15 percent of infants exposed to HIV who need 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 under 15 years are not receiving ART (Bandason et al. 2011; UNICEF, UNAIDS, and WHO 2010).

The program technical reviews highlighted several promising practices being used to identify children (see Box 3). Programs that interact with children or households exposed to HIV need to prioritize proper HIV testing and counseling, either through direct provision of testing services or through strong referral networks to government and community organizations that identify, counsel, and test children (e.g., hospitals/clinics, social support systems, government channels, etc.). Programs that provide HIV-related clinical care have multiple entry points for identifying adults and children who may be living with HIV, including prevention of mother-to-child transmission (PMTCT) and exposed baby programs, tuberculosis clinics, and palliative care services (or any health service where HIV testing is part of routine clinical diagnosis). Some approaches extend HIV testing and counseling beyond a static clinic location and bring them closer to where ex-

capacity of community-based resource persons (e.g., adult volunteers living with HIV) or institutions (e.g., faith-based groups) to screen for at-risk households and refer or accompany members of that household to a testing site. Finally, 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.

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

posed children may be. These include home-based visits, school-based voluntary testing and counseling, and community outreaches (particularly in remote areas).

Several promising practices identified through the technical reviews are very proactive in seeking out children potentially living with HIV, including house-to-house testing and counseling, and the use of index clients (either adults/parents or children) to access other family members—especially children—who might have been exposed to HIV (see Box 4). These approaches 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). Other approaches build the

the meds and when. This is when we are able to start to see what other needs the children have" (provider in South Africa).

As testing services are brought closer to children and families, special attention must be given to ensure that ethical considerations of proper consent, privacy, and confidentiality are correctly observed as per country-specific guidance/policy.

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 pre- and post-test 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 young children under two years of age—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 is addressed during post-test counseling. In the case of older children (e.g., eight 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. 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 correct information before or after testing: "I was hurt. They did not tell me they were taking off the blood sample for HIV testing," and "Doctors lied to me. They gave it a funny name, told me it was malaria. They gave my father the results, not me" (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.

Field reviews highlighted several promising practices (see Box 5). Many HIV testing and counseling programs have adopted standard protocols for children (dependent on age and/or developmental stage), including having time with both the child and the caregiver individually, as well as in a joint session. 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 caregiver and child. Some programs, particularly those that did not offer testing and counseling services, have counselors who can accompany a child and caregiver, providing a valued touchstone and friend throughout the testing process and then link children and parents to follow-up PSS.

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. As noted previously, there are good 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. However, things become less clear after the initial post-test discussion, and supporting the continuous process of disclosure—regarding both the child's status, as well as his or her parents'—is an important priority for PSS programs.

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 all impact the optimal disclosure process for the child, which may involve a long period of *partial disclosure*—where the child is given health and preventive information, but is not told that he or she has 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 that may involve multiple family members, such as home-based

BOX 5. PROMISING PRACTICES IN HIV TESTING AND COUNSELING FOR CHILDREN

- Counselors, trained in child counseling, manage testing and counseling process (and follow-up care, if possible)
- Provider accompanying child/caregiver through testing and counseling
- Clear, standardized protocols (and tools) for testing and counseling of caregiver and child
- 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)
- Hopeful, consistent messaging (reinforced by all providers, including counselors, laboratory staff, medical providers, etc.)
- Manageable, critical information (not to overwhelm with too much information)
- Immediate and continuous follow-up counseling.

testing and counseling, raise additional challenges in how pre- and post-test counseling are handled and how follow-up counseling should be structured for parents/caregivers and the children involved (potentially including both HIV-positive and HIV-negative children of varying ages/developmental stages, siblings, extended family, etc.).

Field reviews highlighted several promising practices that respond to critical needs of parents, caregivers, and children as they navigate the process of disclosure (see Box 6). Input from parents/caregivers during program technical reviews highlight the critical importance of the period immediately following

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; skills/information to talk with the child; and help to plan 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 members, etc.), so that they can also be engaged in providing continuous support for the child and increasingly involve the child in disclosure-related decisions.

Helping parents/caregivers 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 sup-

port the child" (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" (provider in South Africa).

Programs in both Uganda and South Africa are using several approaches to support disclosure and strengthen parents and caregivers on this issue (see Box 7). 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). 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 full 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).

Several programs in Uganda and South Africa use this approach of partial disclosure, using the child's own questions, level of comprehension, and health situation to guide the content and manner in which relevant information is imparted. 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:

> **BOX 6. PROMISING PRACTICES IN SUPPORTING DISCLOSURE TO CHILDREN**
>
> • Home-based ongoing counseling
> • Trained child counselor managing ongoing counseling of child and family
> • Counseling on partial and/or full disclosure tailored to developmental age and situation
> • Reinforcement of positive messaging
> • One-on-one skill building (e.g., role-playing conversations on disclosure)
> • Peer support and mentoring
> • Tools/approaches to facilitate disclosure (e.g., story books, play therapy)
> • Facilitated communication (e.g., conducting joint counseling sessions with child and caregiver)
> • Family conferences to assist with disclosure and build support.

"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?" (youth in Uganda).

Given the central role of the parent/caregiver in deciding what information will be shared with the child and when, several promising approaches build parent/caregiver capacities to understand disclosure-related issues and how to communicate with their child. These include providing counseling support

<div style="background:blue-box">

BOX 7. PROGRAM EXAMPLE: FACILITATING DISCLOSURE

Program: The AIDS Support Organization (TASO), Masaka, Uganda

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

Promising Practices:

- A child counselor to oversee the child/family's progress from testing through entire time in the program
- Support includes joint counseling sessions with the child (age five and older) and caregiver
- Facility includes a play center where counselors engage the child (via art, writing, general play, etc.) 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
- A team facilitates ongoing conversations around disclosure between caregiver and child, and with larger family as needed
- Support during crises (e.g., inadvertent disclosure, and stigmatization).

</div>

to parents/caregivers on disclosure; skill building via role-plays; facilitated disclosure where a trained provider is present during conversations with a child or with the larger family members; and developing disclosure plans that identify why, who, and when sharing information about the child's status may be helpful (e.g., creating opportunities to engage with peers living with HIV who have gone through similar experiences).

A number of programs have developed tools and approaches that are geared to the children, such as story books on disclosure. This gradual, tailored process creates an opportunity to reinforce positive messages and prepare the child for living positively once full disclosure happens. During focus group discussions with young people, several raised the importance of having the opportunity to talk with peers or adults living with HIV who have 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." Youth and providers alike emphasized the importance of positive, hopeful messaging throughout all communications with a child and especially with full disclosure to the child. 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.'"

Addressing Internal 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 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 living with HIV) because they're protecting their children. Children can be cruel and parents don't want people to be mean to their children" (provider in South Africa).

For vulnerable girls and boys in HIV-affected communities, including children who are living with HIV, 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 internal and external stigma around being labeled "vulnerable" or "orphaned," as well as being poor. The affect of these stigmas is 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 isolation and depression experienced by 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 cre-

ate, as well as some of the promising practices being used to overcome these issues (see Box 8). A systematic approach to understanding and addressing both external and internal stigma can aid with disclosure and enhance both demand and use of programs, as well as the delivery of critical services. Several promising practices emerging from the field-based technical reviews are directed at addressing external stigma, including aggressive community outreach that raises general awareness of HIV-related stigmas and seeks to break down negative practices toward families and children living with HIV. Others focus more deliberately on institutions for children, especially schools and churches. Programs in both countries respond to specific situations where stigma impacted a child client: "We have had problems with teachers

BOX 8. PROMISING PRACTICES IN ADDRESSING STIGMA

- Community outreach to raise awareness about HIV, to increase understanding of stigma and its impact, and to address stigma
- Targeted interventions to address negative stigma (e.g., in schools)
- Peer outreach and support, especially by youth living with HIV (e.g., through testimonies)
- Mentoring (e.g., older youth with younger child; via adult role models) and advocates to support children
- Support groups (for children, youth, caregivers)
- Informal interactions between both HIV-positive and HIV-negative children
- One-on-one counseling
- Consistent, positive messaging about HIV and living with HIV
- Tools/approaches (e.g., life skills, and REPSSI's Hero Books).

ostracizing our children in school, so we go to the schools and engage with the teachers" (provider in South Africa). An important aspect across programs is the engagement of adolescents and adults living with HIV to lead these 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 visit neighboring schools to share their experiences and promote the rights of those living with HIV).

Support groups and individualized counseling are critical approaches for helping children process difficult feelings and experiences, as well as build skills to fend off internalized stigma: "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" (youth in Uganda). Programs also highlighted having consistent, positive messaging on HIV (e.g., that it is not a death sentence, 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" (provider in South Africa). Tools like Hero Books (REPSSI 2007) 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 mention is that parents, caregivers, and providers need support in addressing their fears and guilt (both for their own situation if HIV-positive, as well as with regards

to the child), so that they are then able to provide positive support for the child.

Children living with HIV need opportunities to engage with children who are HIV-negative, although programs should be prepared to prevent or handle situations of inadvertent disclosure and ensure that HIV-specific needs/considerations are not lost. 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, alternatively, facilitate 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, manage, 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 children born and living with HIV. For these children, especially those living in high HIV-prevalence communities, there can be multiple forms of loss, from the death of parents, siblings, and 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, and 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/caregivers prepare for this loss, as well as cope with the subsequent grief (Christ 2000).

Grief and bereavement was an underaddressed area for several programs included in the field review, although some are making important strides in this area (see Box 9). 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" (provider in South Africa). 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–ap-

propriate 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 one 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, some programs did have several promising activities to address grief and bereavement (see Box 10). This includes preparing for an impending death of a parent, including developing succession or ongoing care plans for children; writing wills; and preparing memory boxes, books, family trees and other materials—often jointly with

BOX 9. PROMISING PRACTICES IN ADDRESSING GRIEF AND BEREAVEMENT

- Continuous screening and counseling for children and caregivers
- Prioritized support for acute situations (for child or caregiver/household)
- Targeted activities to prepare for the death of a parent/caregiver, including succession planning, will writing, memory boxes/books, genograms and family trees, etc.
- Activities/tools to use with the child to process loss and grief
- Contact throughout the death of a loved one (e.g., attend funeral, and home visit)
- Referrals for ongoing support, such as income-generating activities, social welfare.

BOX 10. 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 daycare centers, home-based activities, and hospice care.

Promising Practices:

- Strong emphasis on giving children opportunities to learn and talk about illness, death, and dying (if losing a loved one is imminent)
- Specific workbook Growing through Grief for older children
- Forums for children to interact and share, including daycare, support groups, play therapy, and theater groups
- Tools for building memories and facilitating communication (e.g., memory boxes)
- Support for adults through their own grief via counseling, genograms that map out family relationships, and medical histories.

the child, helping to facilitate communication—that help provide important family contexts, histories, and memories for the child to draw on going forward. 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.

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, and 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, have created opportunities for dedicating greater attention and resources for PSS (see Box 11).

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 (see Box 12). Many of these center on resource extension that maximizes efficient use of the time, staff, and funds available for PSS. Some of these promising practices include:

- *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

BOX 11. 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 12. PROGRAM EXAMPLE: ENSURING CONTINUOUS AND APPROPRIATE PSS

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

Background: NACCW's 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:
- 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.

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 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.* Some 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 and community members, and other providers interested in supporting the child.

- *Providing continuous assessment of PSS needs and responses.* Programs are 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; providing ongoing PSS assessments by trained personnel; and home-based interactions (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.* Many programs are finding small and large ways of making services and facilities more child-friendly and child-oriented. This includes having cheerful play areas with toys, activities such as drawing and letter writing for children to relax or interact with other children, and, in some cases, also providing an 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 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 following issues are overarching considerations

that impact provision and uptake of the range of services and promising practices noted in the previous section:

- Psychosocial support 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 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 in their own care, in preparation to transition to adult programs).

- 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.

- 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.

- Efforts have limited engagement with younger children, particularly in the four- to eight-year-old 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, psychological, and social well-being.

- 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 his or her 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 his or her own needs, as well as care for the child.

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 aged 0 to 12 years living with HIV. 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.

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. This is also an important stage to build support and prevent/address stigma within the household. Available resources could be used to maximize this window of opportunity:

- Prepare all cadres of providers for these important initial conversations by strengthening their skills and capacity in child and family counseling and communication.

- Work with the family to develop a care plan that includes appropriate disclosures 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.

- 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).

- Provide frequent post-test follow-up through home visits with the child and his or her primary caregiver, using a range of resource persons such as child counselors, community-based volunteers, HIV-model patients, etc.

- Facilitate discussions, counseling, and skill-building within the family/household to broaden the network of available caregivers.

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:

- 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.).

- Move support activities from clinics or program centers into the community (e.g., having peer support groups for children and caregivers at the village level).

- 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 work very closely with local government and community structures/groups to address acute situations (e.g., situations of abuse or violence against the child, and incidents of stigmatization in schools).

- 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.

- Maintain clear roles and reporting lines to a central resource person who can monitor the child's case, adjust care plans, provide supervision, and ensure privacy/confidentiality for children and caregivers.

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:

- Build the capacity of parents and primary caregivers (see Box 13). Given the importance of the primary caregiver, emphasis should be placed on developing simple forms of support (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.

- 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

---

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 adults and youth living with HIV.

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

---

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.

- 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.

- Create and support structured and unstructured forums for children living with HIV and their 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 to 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 adults living with HIV, etc.).

Reduce stigma within the immediate circles of care such as households, clinics, and schools.
Given the pervasiveness of harmful attitudes and influences in 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:

- Analyze programs for any elements that promote positive images of people living with HIV (e.g., peer role-modeling programs, and community drug distribution centers) or inadvertently reinforce negative stereotypes.

- Integrate stigma-reduction activities into trainings and meetings with program staff, including those working largely in the community.

- Build skills of child counselors and providers to address stigma throughout screening/assessments (e.g., care plans) and ongoing counseling of children and parents/caregivers.

- 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.

- Support targeted interventions to address negative situations in schools and general communities.

- Facilitate peer outreach, mentoring, and support groups for children and youth living with HIV.

RESOURCES

REPSSI (www.repssi.org)
- *Psychosocial Support Advocacy Toolkit*
- *Mainstreaming Psychosocial Care and Support Within Paediatric HIV and AIDS Treatment*
- *Mainstreaming Psychosocial Care and Support Through Child Participation*
- *Mainstreaming Psychosocial Care and Support: Trainer's Guide for Training Health Workers*
- *Making a Hero (Active Citizen) Book: A Guide for Facilitators*
- *Hero Book Anthology: A Collection of Hero Stories from Southern Africa*
- *Digital Hero Book Toolkit*

- *Tree of Life*
- *Memory Work Manual: Facilitator's Guide*

TASO (www.tasouganda.org)
- Child Counseling Course (Regional AIDS Training Network)
- Peer Counseling Course (for youth)

Baylor Pediatric AIDS Initiative (www.bipai. org)
- *Psychosocial Aspects of HIV/AIDS: Children and Adolescents* (www.bipai.org/Curriculums/HIV-Curriculum/Psychosocial-Aspects-of-HIV/AIDS--Children-and-Adolescents.aspx)
- Now You Know, Now What? Video Program (www.bipai.org/educational-resources/dvds-videos. aspx)

Catholic Relief Services/African Network for Care of Children Affected by HIV/AIDS
- *Psychosocial Care and Counseling for HIV Infected Children and Adolescents: A Training Curriculum* (2009) (www.pedaids.org/Press-Room/Events/2010/Psychosocial-care_high_res)

Children's Right's Centre (www.children-srightscentre.co.za)
- *My Living Positively Handbook* (www.childrensright-scentre.co.za/site/files/6592/pub2(1).pdf)
- *Helping Children Live with HIV* (www.childrensright-scentre.co.za/site/files/6592/pub1(1).pdf)

FHI (www.fhi.org)
- *Positive Connections – Information and Support for Young People Living with HIV* (to be published, 2011)

Sinomlando Centre for Oral History and Memory Work (www.sinomlando.ukzn.ac.za)

WHO (www.who.int/hiv)
- *WHO Recommendations on the Diagnosis of HIV*

Infection in Infants and Children (www.who.int/hiv/pub/paediatric/diagnosis/en/index.html)
- *WHO Policy Requirements for HIV Testing and Counselling of Infants and Young Children in Health Facilities* (www.who.int/entity/hiv/pub/paediatric/testing_counselling/en/index.html)

REFERENCES

Abadia-Barrero, C. E., and M. D. LaRusso. 2006. The Disclosure Model versus a Developmental Illness Experience Model for Children and Adolescents Living with HIV/AIDS in Sao Paulo, Brazil. *AIDS Patient Care and STDs* 20(1):36–43.

Bandason, T., L. Langhaug, M. Makamba, et al. 2011. "Burden of HIV Infection and Acceptability of School-linked HIV Testing among Primary School Children in Harare, Zimbabwe." Presentation at 18th Conference on Retroviruses and Opportunistic Infections, Boston, Massachusetts, March 2, 2011.

Bikaako-Kajura, W., E. Luyirika, D. W. Purcell, et al. 2006. Disclosure of HIV Status and Adherence to Daily Drug Regimens Among HIV-Infected Children in Uganda. *AIDS and Behavior* 10:85–93.

Brahmbhatt, H., G. Kigozi, F. Wabwire-Mangen, et al. 2006. Mortality in HIV Infected and Uninfected Mothers in Rural Uganda. *Journal of Acquired Immune Deficiency Syndromes* 41(4):504–508.

Brouwer, C. N. M., C. L. Lok, I. Wolffers, and S. Sebagalls. 2000. Psychosocial and Economic Aspects of HIV/AIDS and Counselling of Caretakers of HIV-Infected Children in Uganda. *AIDS Care* 12:535–540.

Brown, L. K., and K. J. Lourie. 2000. Children and Adolescents Living with HIV and AIDS: A Review. *Journal of Child Psychology and Psychiatry* 41:81–96.

Christ, G. H. 2000. Impact of Development on Children's Mourning. *Cancer Practice* 8(2):72–81.

Clay, S., V. Bond, and L. Nyblade. 2003. *We Can Tell Them AIDS Doesn't Come Through Being Together: Children's Experience of HIV and AIDS Related Stigma in Zambia 2002-2003*. Lusaka, Zambia: ZAMBART Project, The School of Medicine, University Teaching Hospital.

Cluver, L., and F. Gardner. 2007. The Mental Health of Children Orphaned by AIDS: A Review of International and South African Research. *Journal of Child and Adolescent Mental Health* 19(1):1–17.

Family Health International. 2007. *Scaling up the Continuum of Care for People Living with HIV in Asia and the Pacific*. Arlington, VA: FHI.

Ferrand, R. A, E. L. Corbett, R. Wood, et al. 2009. AIDS Among Older Children and Adolescents in Southern Africa: Projecting the Time Course and Magnitude of the Epidemic. *AIDS* 23(15):2039–2046.

King, E., M. De Silva, A. Stein, and V. Patel. 2009. Interventions for Improving the Psychosocial Well-Being of Children Affected by HIV and AIDS. *Cochrane Database of Systematic Reviews* (2):CD006733.

Lugada, E., J. Levin, B. Abang, et al. 2010. Comparison of Home and Clinic-based HIV Testing Among Household Members of Persons Taking Antiretroviral Therapy in Uganda: Results from a Randomized Trial. *Journal of Acquired Immune Deficiency Syndromes* 55(2):245–252.

Mellins, C. A., E. Brackis-Cott, C. Dolezal, and E. J. Abrams. 2004. The Role of Psychosocial and Family Factors in Adherence to Antiretroviral Treatment in Human Immunodeficiency Virus-Infected Children. *The Pediatric Infectious Disease Journal* 23:1035–1041.

Nuwaha, F., E. Tumwesigye, S. Kasasa, et al. 2009. "Population-level Changes in Knowledge of HIV Status, Stigma, and HIV Risk Behavior After District-wide Door-to-Door Voluntary Counseling and Testing." Presentation at the 16th Conference on Retroviruses and Opportunistic Infections, Montreal, Canada, February 11, 2009.

Ogden, J., and L. Nyblade. 2005. *Common at Its Core: HIV-Related Stigma Across Contexts*. Washington, DC: International Center for Research on Women and Change Project.

Regional Psychosocial Support Initiative (REPSSI). 2003. *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment*. Randburg, South Africa: REPSSI.

Regional Psychosocial Support Initiative (REPSSI). 2007. *Making a hero (active citizen) book: A guide for facilitators*. Randburg, South Africa: REPSSI.

Richter, L., G. Foster, and L. Sherr. 2006. *Where the Heart Is: Meeting the Psychosocial Needs of Young Children in the Context of HIV/AIDS*. The Hague, The Netherlands: Bernard van Leer Foundation.

Richter, L., L. Sherr, M. Adato, M. Belsey, U. Chandan, C. Desmond, et al. 2009. Strengthening Families to Support Children Affected by HIV and AIDS. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV* 21(1):3–12.

Rochat, T., C. Mitchell, and L. Richter. 2008. *The Psychological, Social and Development Needs of Babies and Young Children and Their Caregivers Living with HIV and AIDS*. Pretoria, South Africa: Department of Health.

Sopeña, S., M. Evangeli, J. Dodge, and D. Melvin. 2010. Coping and Psychological Adjustment in Adolescents with Vertically Acquired HIV. *AIDS Care* 22(10):1252–1258.

Stangl, A., V. Go, C. Zelaya, L. Brady, and L. Nyblade. 2009. "Stigma Measures and Measurement Tools: A Review to Inform Discussions about Developing Standardized Indicators to Support a Scaled-up Response to Reducing HIV Stigma and Discrimination." Working paper presented at Stigma Measurement Stakeholder Meeting at the International Center for Research for Women, Washington, DC, November 23-25, 2009.

Steele, R. G., T. D. Nelson, and B. P. Cole. 2007. Psychosocial Functioning of Children with AIDS and HIV Infection: Review of the Literature for a Socioecological Framework. *Journal of Developmental & Behavioral Pediatrics* 28(1):58–69.

Sutcliffe, C. G., S. Scott, N. Mugala, et al. 2008. Survival from 9 Months of Age among HIV-Infected and Uninfected Zambian Children Prior to the Availability of Antiretroviral Therapy. *Clinical Infectious Diseases* 47(6):837–844.

U.N. Children's Fund, Joint U.N. Programme on HIV/AIDS, and the World Health Organization. 2010. *Children and AIDS: Fifth Stocktaking Report 2010*. New York, NY: U.N. Children's Fund.

Were, W. A., J. H. Mermin, N. Wamai, et al. 2006. Undiagnosed HIV Infection and Couple HIV Discordance Among Household Members of HIV-Infected People Receiving Antiretroviral Therapy in Uganda. *Journal of Acquired Immune Deficiency Syndromes* 43(1):91–95.

Williams, P. L., D. Storm, G. Montepiedra, et al. 2006. Predictors of Adherence to Antiretroviral Medications in Children and Adolescents with HIV Infection. *Pediatrics* 118:e1745–e1757.

Wolff, B., B. Nyanzi, G. Katongole, et al. 2005. Evaluation of a Home-based Voluntary Counselling and Testing Intervention in Rural Uganda. *Health Policy Plan* 20:109–116.

World Health Organization (WHO). 2008. *WHO Recommendations on the Diagnosis of HIV Infection in Infants and Children*. Geneva, Switzerland: WHO.

WHO, UNAIDS, and UNICEF. 2010. T*owards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector – Progress Report 2010*. Geneva: WHO.