Are Faith-Based Organizations Assets or Hindrances for Adolescents Living with HIV? They Are Both

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This paper examines the myriad of public health, sociological, political, and theological issues that are at play when faith-based organizations (FBOs) provide HIV prevention, treatment, and support services to adolescents. It is a case study of these issues as they play out among adolescents living in informal settlements across Nairobi. This paper examines these issues in three sections: a background on the role of FBOs in coordinated, sustained responses to HIV; a description of the particular influence of religion on HIV prevention and sexual health programs for adolescents in Nairobi's informal settlements living with HIV and receiving their health care from FBOs; and a discussion of the results of a series of workshops held with these adolescents to identify their specific

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needs and assess whether FBOs could adequately address them.

Background

Across sub-Saharan Africa, FBOs are the largest nongovernmental provider of HIV services for children living with HIV.[1] They provide pediatric HIV treatment services; address complex psychosocial needs; offer housing, education, and nutritional programs; and support family networks to help children whose parents have died from HIV stay in extended family systems rather than be institutionalized in orphanages. Religious institutions such as local worshipping communities (e.g., Christian congregations and Muslim *masajid*), FBOs, and faith-based health facilities contributed an estimated $5 billion in 2006, an amount equal to the aggregate funding of all global bilateral and multilateral agencies.[2] Throughout the region, faith-based health systems provide a substantial portion of HIV services, including primary medical care, prevention, and support services. The U.S. President's Emergency Plan for AIDS Relief (PEPFAR)—the U.S. government's global HIV response—is coordinated through the Office of the Global AIDS Coordinator and Health Diplomacy (OGAC) within the U.S. Department of State. OGAC estimates that over 50 percent of HIV services are provided by the faith-based sector in many countries in sub-Saharan Africa.[3] In Nairobi, Kenya—where the case study of this paper was conducted—an analysis sponsored by PEPFAR on the percentage of HIV services provided by the faith-based sector found that 48 percent of all people living with HIV who are currently on antiretroviral therapy (ART)—a regimen of medications that slow HIV replication —received care from FBOs. Fifty-one percent of children living with HIV on ART in Nairobi received care from an FBO.[4] Thus, without question, FBOs play a vital role in HIV service delivery for all people living with HIV and have been global leaders in the response to the particular needs of children.

In short, in the case of HIV, religion acts as a double-edged sword.

Religion, however, has also been a social driver of the stigmatization of some socially marginalized communities with high HIV prevalence and burden, including men who have sex with men, sex workers, and people who use drugs.[5] Furthermore, religious debates about the appropriate context for sexual activity and about the potential moral hazard of using any forms of contraception—specifically condoms for HIV prevention—have an undeniable effect on overall HIV prevention, as well as on sexual and reproductive health programs

around the world.[6]

In short, in the case of HIV, religion acts as a double-edged sword. It creates an impetus for offering comprehensive, sustainable HIV programs for some groups, such as children, and it also serves as a driver of stigmatization for others, such as sex workers, men who have sex with men, and people who use drugs. FBOs offer essential, high-quality HIV treatment services, but they also struggle to provide comprehensive HIV prevention, as well as sexual and reproductive health services.[7] FBOs face a tension between religious/moral teachings on sexual behaviors and HIV prevention messages and programs. The first privilege the moral superiority of certain kinds of sexual expression over others (sex inside of marriage is valued while sex outside of marriage is frowned upon), while the second express no preference for the moral rightness or wrongness of consensual sexual acts but focus on how to avoid transmitting an infectious virus during those acts. FBOs are in a difficult position trying to negotiate these two frameworks.

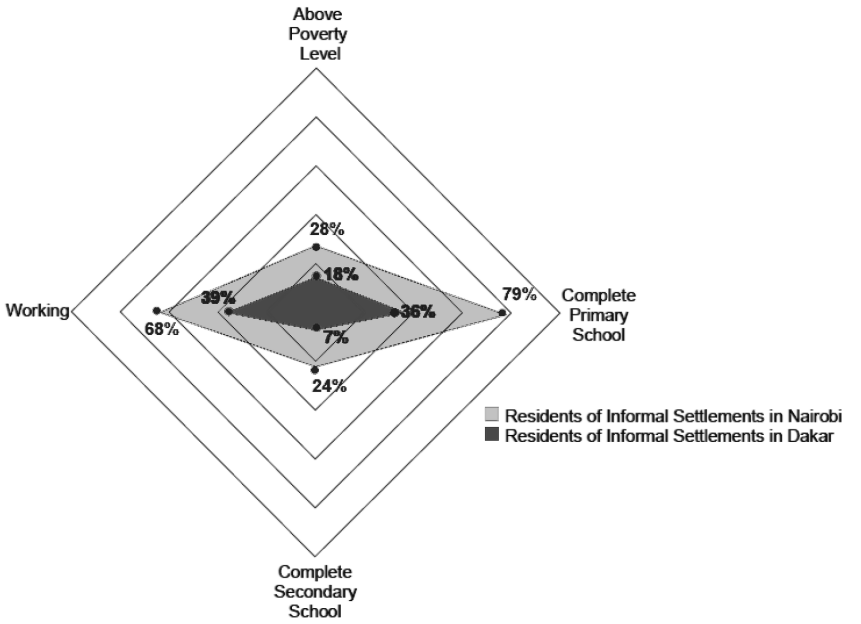
Faith-based pediatric HIV programs feel this bind in specific ways. They are essential providers of HIV prevention, treatment, and support services for women and children living with HIV. Their capacity to get these services to those who need them means that millions of women living with HIV are provided medications by FBOs during their pregnancy that drastically reduce the likelihood they will give birth to an HIV-positive child. For those children who are born HIV-positive, the possibility of a long, healthy life is a reality because FBOs provide ARTs for millions of children around the world. As the increased availability of these antiretroviral medications has prolonged the lives of affected children, many are growing into adolescence. FBOs are uncertain how to address the HIV prevention and sexual health needs of these adolescents. For adolescents living with HIV who grow up in the informal settlements around Nairobi, these challenges are exacerbated by the myriad social, economic, and educational disparities that characterize life among the urban poor in Kenya's capital. For these adolescents, the FBOs that are essential resources for addressing such social, economic, and educational needs are at the same time ill equipped to address HIV prevention and sexual health needs. FBOs are, in short, both an asset and a hindrance for these young people.

The Impact of FBOs on Services for Adolescents in Informal Settlements

Informal settlements, also referred to as slums, are home to millions of people across sub-Saharan Africa. The residents of informal settlements often live in

semi-permanent housing built on land to which they have no legal claim. In Nairobi, informal settlements regularly lack core infrastructure, such as electricity, reliable water sources, and waste management systems, due to long-standing governmental policies rooted in the assumption that limited infrastructure investments discourage the continued growth of the settlements. Such policy is decidedly ineffective—an estimated 60 percent of Nairobi's residents live in informal settlements—and there are some indications that these policies are changing (albeit slowly) following the 2010 ratification of a new constitution that specifically addresses contentious issues of land ownership.[8] Depending on the status of these governmental policies, residents in informal settlements may not have access to social services such as medical facilities or schools. Despite this lack of resources, informal settlements have grown rapidly in Nairobi because they provide the only affordable housing to the large number of people in the city who cannot afford the high costs of living associated with apartment rental or home ownership. Informal settlements are home to millions of people living with, or at risk for, HIV infection in Nairobi. These residents face a variety of socio-structural challenges that complicate comprehensive HIV service delivery. These macro-level forces have a profound impact on the residents of informal settlements in Nairobi.

Fig. 1: Economic and educational attainment of residents in informal settlements in Nairobi and Dakar



A 2010 study conducted by the World Bank found that residents of Nairobi's settlements actually fare better than residents of similar communities in Dakar, Senegal, in terms of economic and educational attainment.[9] According to the study, a higher percentage of people who live in Nairobi's settlements have completed both primary and secondary school than those who live in informal settlements in Dakar. Furthermore, in comparison to residents in Dakar, residents of Nairobi's informal settlements were more likely to be employed and to receive incomes above the established poverty level for the country (see Figure 1).

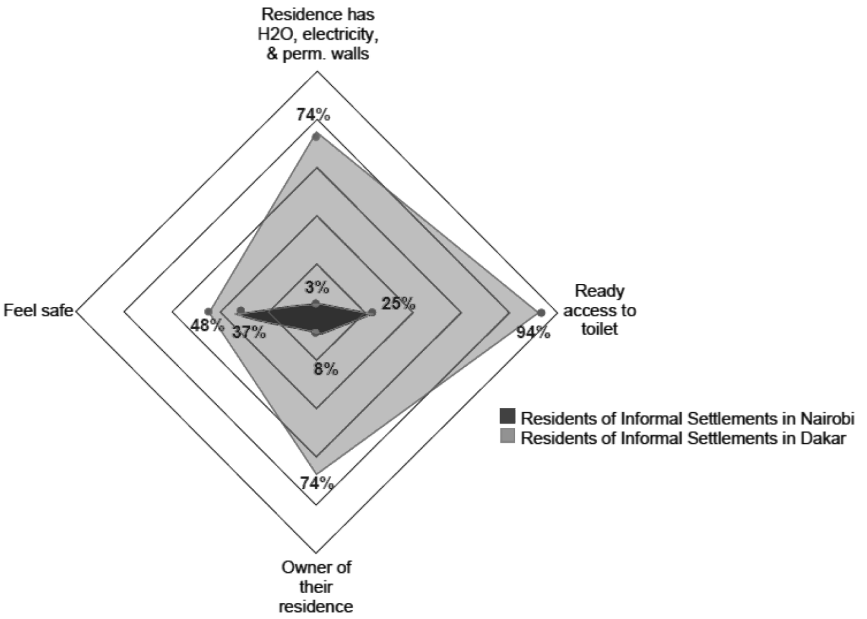
These comparative advantages do not translate into improved living conditions for the residents of Nairobi's informal settlements. In fact, these residents face far worse conditions than the residents of Dakar despite higher economic and educational attainment. Only 3 percent of residents of informal settlements in Nairobi have permanent walls, electricity, and water in their homes compared to 74 percent of the residents in Dakar. Similarly, only 8 percent own their own home compared to 74 percent of those in Dakar. Again, only 25 percent of inhabitants of Nairobi's informal settlements have ready access to a toilet, compared to 94 percent in Dakar (see Figure 2). Governmental policies impact the level of infrastructure in informal settlements and a myriad of social and economic forces affect residents' capacities to obtain secure housing. In the context of these complex, interrelated factors, FBOs offer distinctive resources to the residents of informal settlements in Nairobi. They provide organizational capacity, infrastructure, sustainable programs, and linkages to outside partners. In less tangible ways, FBOs draw on and help sustain trust and a framework of shared values.

From 2008 to 2012, PEPFAR worked to understand the contributions of FBOs to HIV service delivery in Nairobi's informal settlements. PEPFAR staff worked with the Interfaith Health Program at the Rollins School of Public Health at Emory University to carry out a case study in one informal settlement, Mukuru kwa Njenga, to assess the level of essential services provided to people living with HIV in Nairobi's informal settlements. Mukuru kwa Njenga is a settlement with an estimated 200,000–600,000 residents located approximately 11 kilometers southeast of the city center of Nairobi.[10]

The work was carried out in collaboration with not only the Interfaith Health Program, but also St. Paul's University in Kenya. Key findings revealed that numerous FBOs and community-based organizations (CBOs) exist in Mukuru. One of the consequences of governmental policies to limit infrastructure investment in informal settlements has been the relative invisibility of local, grassroots resources that develop in these communities when viewed from the

outside. This was clearly the case in Mukuru.[11] Prior to this analysis, PEPFAR and the government of Kenya had identified 54 organizations as providers of HIV services in the settlement. The analysis revealed 288 organizations, an increase of more than 500 percent in the number of known organizations. Many of these organizations are small, local CBOs that lack their own facilities; these organizations run programs, all considered essential by members of the community, in spaces provided by churches and mosques.

Figure 2: Indicators of living conditions among residents of informal settlements in Nairobi and Dakar



FBOs provide a substantial portion of these essential services in Mukuru, including:

- 100 percent of all intensive inpatient or outpatient HIV services;
- 22 percent of economic empowerment activities;
- 42 percent of food distribution programs;
- 62 percent of HIV prevention programs;
- 48 percent of programs for girls and young women.

In short, the work carried out by PEPFAR demonstrates the essential role that FBOs play in providing services for people in informal settlements living with or at risk for HIV. The large number of socio-structural factors that these

residents face present real, long-standing challenges, and FBOs offer capacities for a sustainable response.

The impact of religion, however, on the provision of services for adolescents living with HIV is complex and varied. While FBOs provide essential services, the challenges that most FBOs face in offering comprehensive HIV prevention and sexual and reproductive health services leave these young people struggling to make informed decisions about sexual health and HIV prevention as they move toward adulthood. In 2013 and 2014, the Interfaith Health Program worked with PEPFAR to better comprehend both the resources and barriers that FBOs create for adolescents living with HIV.

One hundred sixty HIV-positive adolescents from eight informal settlements across Nairobi were invited to a series of community workshops designed to assess their needs and priorities in relation to HIV services and to other challenges they faced as they grew up in these communities. Findings from the workshops demonstrated the varied influence of religion on access to HIV services and on sexual health beliefs and behaviors. The workshops asked young people about the most prevalent and influential sources of information about sexuality, the role of religion on sexual beliefs and behaviors, the relative importance of various services provided to the young people by FBOs, and the level of trust placed in various kinds of organizations (including, but not limited to, FBOs) in their communities.

Young people growing into adulthood in informal settlements face a number of challenges. For adolescents living with HIV, addressing socioeconomic barriers is as important to their long-term security as is access to HIV treatment. The workshops revealed interesting characteristics about organizations that young people identified as the most trusted in addressing these challenges. During the workshops, participants named any organization that offered important services. From this list, participants then ranked those organizations based on their trustworthiness. As evident in Figure 3, participants named 73 organizations they deemed most trustworthy across eight informal settlements. A crucial conclusion is that FBOs are named more frequently than any other type of organization, including governmental programs. While this finding might not be surprising due to long-standing policies

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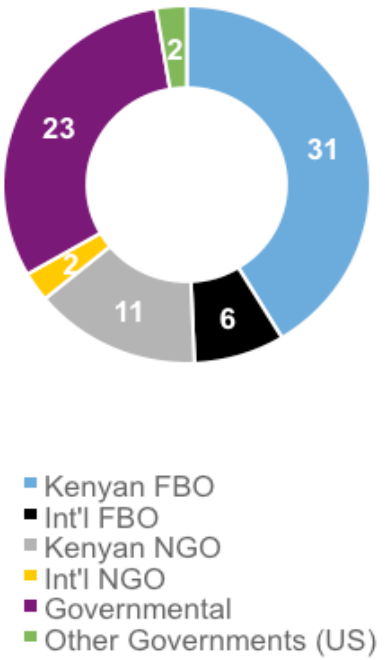
in Kenya that limit the number of government-funded initiatives offered in the settlements, the fact that FBOs were identified more frequently than their peers in secular civil society organizations demonstrates the potential of FBOs in particular to address adolescents' psychosocial needs. In addition, the adolescents trusted Kenyan FBOs and NGOs more than their international counterparts. Thirty-one Kenyan FBOs were named most trusted, while only six international FBOs were identified. Similarly, 11 Kenyan NGOs were named most trusted, while only two international NGOs were mentioned.

Figure 3: Types of organization most trusted among HIV-positive adolescents living in informal settlements in Nairobi



Not all informal settlements are the same. In Kibera, another informal settlement in Nairobi often described as the "largest slum in Africa," an extensive network of governmental and nongovernmental programs has been created.[12] As a result, governmental facilities are the most frequently cited asset in Kibera by workshop participants from this settlement. However, the central role of government facilities is unique to Kibera, and there are few government services in other settlements. For example, in contrast to youth in Kibera, HIV-positive youth from Mukuru named only one governmental facility as trustworthy. Historically, the national government in Kenya has not provided substantial health or infrastructure services in Mukuru. The relative importance of FBOs for HIV-positive adolescents in these two settlements also varies. The adolescent participants in Kibera named only one FBO, whereas the Mukuru participants named eight.

As part of the workshop, 25 statements about HIV risk and sexual health were read aloud to participants. The statements were designed to assess knowledge and beliefs of HIV transmission and sexual health among the participants. Each participant responded to the propositions with "Agree," "Disagree," or "Uncertain." If more than 90 percent of participants provided the same answer to a statement, that statement was labeled as one in which consensus was reached. Participants did not reach consensus on 15 of the 25 statements. In the aggregate analysis of the workshop data, these statements were broken down into three separate categories: (1) different opinions about the meaning of sex, (2) uncertainty about HIV transmission risk and disclosure of HIV status, and (3) uncertainty about moral teachings and sexual behavior.

Different Opinions about the Meaning of Sex			
Statements	Total (n=160)		
	Agree	Disagree	Uncertain
1. What is sex? How do I define it?			
a. Kissing is sex	100 (63%)	55 (34%)	5 (3%)
b. Sex without penetration is not real sex	77 (48%)	45 (28%)	38 (24%)
2. How should boys and girls act?			
a. Girls never pressure boys to have sex, pressure always comes from boys	20 (13%)	101 (63%)	39 (24%)
b. Girls are not supposed to negotiate for condom use	4 (3%)	121 (76%)	35 (22%)
c. It is more important for a girl to be a virgin when she gets married than for a guy	37 (23%)	86 (54%)	37 (23%)

The variety of opinions expressed by participants reveals differences in perceptions about what exactly counts as sex—which sexual behaviors might properly be labeled as "sex" in distinction from those that were understood to be "fooling around." FBOs often speak to adolescents in generalities about sexual health, and young people cite that the most frequent sexual health message communicated by FBOs is "no sex before marriage." Does vaginal sex in the missionary position count as the type of "sex" that faith communities are exhorting young people to abstain from? What about oral sex? What about open-mouth kissing? Which behaviors are allowed under the prohibition "no sex before marriage," and which ones must be avoided? Young people in general are confused when they try to make these distinctions.[13] For adolescents living with HIV, this uncertainty about what behaviors precisely constitute "sex" can create confusion and uncertainty, which may in turn lead to behaviors that carry a risk for HIV transmission. In addition, there were different opinions about appropriate norms for sexual behavior for young men and young women. These differences have an impact on the ways in which young women and men view themselves and the ways they view others.

Uncertainty about HIV Transmission Risk and Disclosure of HIV status

Statements	Total (n=160)		
	Agree	Disagree	Uncertain
1. What behaviors can transmit HIV and/or lead to unwanted pregnancy?			
a. Condoms have pores	52 (33%)	49 (31%)	59 (37%)
b. One can't be infected with HIV if s/he has sex for the first time	3 (2%)	133 (83%)	24 (15%)
c. One can't be infected with HIV if s/he has only one sexual partner	10 (6%)	114 (71%)	36 (23%)
d. Anal sex cannot lead to HIV infection	8 (5%)	109 (68%)	43 (27%)
e. Girls can't get pregnant during their periods	27 (17%)	94 (59%)	39 (24%)
2. Should I disclose my HIV status?			
a. One should not share her/his HIV status with friends	82 (51%)	35 (22%)	43 (27%)

In some instances, workshop participants showed an impressive level of knowledge on HIV transmission, but in others, commonly held perspectives demonstrated the need for further education about condoms and risky behavior. For example, one-third of the participants agreed with the statement that condoms have pores and 37 percent were uncertain. Fifteen percent were uncertain

about whether someone could become infected with HIV the first time they had sex. Almost a quarter were uncertain about whether having a single sexual partner would keep a person from becoming infected and failed to account for an HIV-positive person being in a monogamous relationship with someone who was not infected. Almost one-third either believed that anal sex was not a risky behavior for infection or were uncertain.

High levels of uncertainty were not limited to facts about HIV transmission. Adolescents living with HIV were almost evenly split on disclosing HIV status to friends, with 51 percent believing they should not share, while 49 percent believed they should disclose or were unsure. Comprehensive HIV prevention education that includes counseling to help these young people weigh the pros and cons of disclosure is important for them, but the participants' responses indicate they were not receiving it.

Uncertainty About Moral Teachings and Sexual Behavior

Statements	Total (n=160)		
	Agree	Disagree	Uncertain
1. What are my normal beliefs about sex?			
a. Sex is immoral	4 (2.5%)	135 (84%)	21 (13%)
b. If I am in a loving, committed relationship, it is okay to have sex	50 (31%)	90 (56%)	20 (13%)
c. It is healthy to think about sex	65 (41%)	81 (51%)	14 (9%)
d. Abstaining too long is abnormal	10 (6%)	134 (84%)	16 (10%)

Participants were asked to identify their own moral perspectives related to sexual expression. Fifty-six percent believed that sexual expression in a committed relationship (that is not marriage) was wrong, while 31 percent believed it was acceptable, and 13 percent were unsure. Sixteen percent either thought that any sexual expression (within or outside of marriage) was immoral or were unsure. Fifty-one percent thought that thinking about sex was unhealthy. Taken together, these responses reveal that HIV-positive adolescents living in Nairobi's informal settlements are trying to make sense of their HIV status, their sexual feelings, their moral and religious worldviews, and social norms. Such efforts are difficult for any young person,

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but the challenges are exacerbated for HIV-positive adolescents. Many FBOs are often not well equipped to address these challenges due to competing moral beliefs about the importance of HIV prevention, the context for appropriate sexual expression, and the appropriateness of condom use.

At the same time, FBOs are the largest nongovernmental provider of such services for HIV-positive children. As the children who receive these services grow into adolescence, FBOs could be well placed to offer comprehensive HIV services—including HIV prevention and sexual and reproductive health services—to young people. However, the widespread discomfort FBOs demonstrate in the area of sexual health creates a dilemma for these adolescents. In Nairobi's informal settlements, FBOs are an essential resource. They provide important services and offer their space to other local CBOs in these communities. For adolescents living with HIV in these settlements, FBOs are named as the most important and most trusted organizations for providing educational, economic, and social support services—more than any other kind of organization. The impact of FBOs on services for adolescents living with HIV is complex, with FBOs serving as both an asset and as a hindrance to the most important health, social, economic, and educational challenges these young people face. Ongoing efforts to build and sustain comprehensive HIV programs and to lower the rate of new HIV infections are key components of initiatives sponsored by global funders such as PEPFAR and UNAIDS to strengthen commitments to respond to the global HIV epidemic.[14] These funders are also working to build FBOs' capacities to be essential partners in such efforts.[15] Such capacity building should contain specific resources to help FBOs offer effective, comprehensive HIV prevention and sexual and reproductive health services for the people they serve. Such resources could include programs to assist FBOs in clarifying their own commitments to HIV prevention and sexual and reproductive health services in the context of the competing moral frameworks described above. They could provide examples of FBOs that have framed their decisions to offer such services in moral and theological frameworks in order to make the case that HIV prevention and sexual health services need not be antithetical to the religious values of FBOs. While such efforts may be contentious, they are necessary if the tremendous resources of FBOs are to be made available to adolescents living with HIV.

Conclusion

Great advances in the fight against HIV have been made in the area of pediatric

prevention and treatment. Efforts to prevent transmission of the virus from mother to child have resulted in millions of children living free of HIV infection. In addition, great strides in making antiretroviral regimens available to those children who are HIV-positive mean that these children are likely to live a full, healthy life. Faith-based organizations have been some of the largest and most trusted providers of HIV services to mothers and children who are living with HIV. These same organizations, however, are often less successful in providing comprehensive HIV prevention and sexual health services to these same patients as they grow from childhood to adolescence to adulthood because of tensions between comprehensive sexual health education and religious teachings about sexuality and sexual behaviors. This paper has summarized the complex role that FBOs play in addressing the health and psychosocial needs of adolescents living with HIV in the informal settlements of Nairobi, Kenya. For these adolescents, FBOs are trusted providers of economic, psychosocial, and educational programs, yet these young people are also struggling to negotiate transitions into adulthood and to make informed, responsible choices about their own sexual health. The FBOs that these young people trust could be important resources in these transitions, but these FBOs also struggle to provide comprehensive sexual health and HIV prevention services. As such, the ongoing global response to HIV should include specific initiatives to equip FBOs to provide comprehensive HIV prevention and sexual health services so that the children whom these FBOs care for so effectively might have the opportunity for a full, healthy life.

Notes

1. United Nations Children's Fund and World Conference of Religions for Peace, *Study of the response by faith-based organizations to orphans and vulnerable children* (United Nations Children's Fun and World Conference of Religions for Peace, January 2004).

2. United Nations Children's Fund, *Partnering with Religious Communities for Children* (United Nations Children's Fund, January 2012).

3. See: Office of the Global AIDS Coordinator, "Building Capacity for Sustainability," in *U.S. President's Emergency Plan for AIDS Relief: First Annual Report to Congress* (Washington, DC: U.S. Department of State, 2015).

4. Ibid.; U.S. President's Emergency Plan for AIDS Relief, *Building on Firm Foundations: The 2015 Consultation on Strengthening Partnerships Between PEPFAR and Faith-based Organizations to Build Capacity for Sustained Responses to HIV/AIDS* (Washington, DC: U.S. Department of State, 2015).

5. Scott Evertz, *How Ideology Trumped Science: Why PEPFAR Failed to Meet Its Potential* (Center for American Progress and the Council for Global Equality, January 2010).

6. Helen Epstein, *The Invisible Cure: Why We Are Losing the Fight Against AIDS in Africa* (New York: Picador, 2007).

7. The quality of care and reach to geographically isolated communities of FBOs is evident in pediatric programs in particular. See: Mariana Widmer et al., "The role of faith-based organizations in maternal and newborn health care in Africa," *International Journal of Gynecology and Obstetrics* 114, no. 3 (2011):

218–22; See also: Paula Tibandebage and Maureen Mackintosh, "The market shaping of charges, trust and abuse: health care transactions in Tanzania," *Social Science & Medicine* 61, no. 7 (2005): 1385–95.

8. Jason Patinkin, "Nairobi, Kenya," *The Rockefeller Foundation's Informal City Dialogues* (blog), https://nextcity.org/informalcity/city/nairobi; Also see: Ambreena Manji, "The Politics of Land Reform in Kenya 2012," *African Studies Review* 57, no. 1 (2014): 115–30.

9. Sumila Gulyani et al., *Poverty, Living Conditions, and Infrastructure Access: A Comparison of Slums in Dakar, Johannesburg, and Nairobi* (Washington, DC: The World Bank, 2010).

10. John Blevins et al., "Community Health Asset Mapping: A Mixed Method Approach in Nairobi," in *Mapping, Cost, and Reach to the Poor of Faith-Inspired Health Care Providers in Sub Saharan Africa*, ed. Quentin Wodon and Jill Olivier (Washington, DC: The World Bank, 2012).

11. For a full description of this work, see: John Blevins et al., "Community Health Asset Mapping."

12. Such claims are quite common though not universally agreed upon. For example, see: Andrew Harding, "Nairobi Slum Life: Into Kibera," *BBC News: World Edition*, October 4, 2002, http://news.bbc.co.uk/2/hi/africa/2297237.stm; See also: Dambisa Moyo, "Why Foreign Aid is Hurting Africa," *Wall Street Journal*, March 21, 2009.

13. See: John Blevins, "Tough Negotiations: Religion and Sex in Culture and Human Lives in the United States and Africa," in *When Religion and Health Align: Mobilising Religious Health Assets for Transformation*, ed. James R. Cochrane, Barbara Schmid, and Teresa Cutts (Pietermartizburg, South Africa: Cluster Publications, 2012).

14. For a discussion of these efforts within PEPFAR, see: U.S. Department of State, *PEPFAR 3.0: Controlling the Epidemic: Delivering on the Promise of an AIDS-Free Generation* (Washington, DC: U.S. Department of State, 2014); For a discussion of these efforts within UNAIDS, see: UNAIDS, *Fast-Track: Ending the AIDS Epidemic by 2030* (Geneva: UNAIDS, 2014).

15. In fact, PEPFAR and UNAIDS are working together to build FBO partnerships in support of sustained HIV responses. A two-year partnership was announced in September 2015. See: "PEPFAR-UNAIDS Partnership: Strengthening Faith Community Partnerships for Fast Track," United States President's Emergency Plan for AIDS Relief, September 28, 2015.