Stigma-Free Faith Communities

A Faith Leader's Guide to Ending the Stigma of HIV and AIDS

June 2013



A Stigma-Free Faith Community...

- 1. Talks openly about HIV and AIDS, as well as related issues such as sexual behavior and gender inequality
- 2. Consistently and repeatedly gives messages of compassion, not judgment, toward people living with HIV
- 3. Describes HIV and AIDS as medical conditions, not punishment for immoral behavior
- 4. Provides basic facts about HIV and AIDS, including methods of transmission, treatment, and prevention
- 5. Encourages all members to engage fully in the life of the faith community, regardless of HIV status
- 6. Focuses on providing care and support to people living with HIV, rather than on how they became infected
- 7. Encourages positive living through education and support groups for people living with HIV
- 8. Actively encourages testing for all members and facilitates access to voluntary counseling and testing
- 9. Affirms the individual responsibility of all members to know their HIV status and to refrain from behavior that risks transmission of HIV
- 10. Works proactively with other organizations to address HIV and AIDS issues in the wider community

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Is This Guidebook for You?

Ask yourself two questions:

- Are HIV and AIDS significant issues for your faith community?
- Do people with HIV see your faith community as a place of hope and support?

If you answered "Yes" to the first question and "No" to the second, then the stigma of HIV and AIDS is a problem in your faith community. This guidebook provides practical guidance about how to overcome stigma and how to transform your faith community into a place of hope and support for people living with the disease.

If you answered "Yes" and "Yes," you might consider taking this guidebook's self-assessment to confirm your answer, and then keep doing what you are doing.

If you answered "No" to the first question, then ask whether HIV and AIDS are significant issues for the wider community of which your faith community is a part. If HIV and AIDS are significant issues in the wider community, then they are probably also significant issues within your faith community. If HIV and AIDS are not significant in the wider community, then be grateful. But before ignoring them, consider whether they might simply be hidden and not discussed openly. If so, then this guidebook may help you prevent HIV and AIDS from becoming bigger problems.

May you receive divine guidance and strength as you fight to end the stigma of HIV and AIDS.

Dr. David Barstow Austin, Texas, USA June 2013

The Stigma of HIV and AIDS

There is a stigma associated with HIV and AIDS. Because HIV is primarily transmitted through sexual activity, people infected with HIV often face rejection and judgmental attitudes. People are dying because of the impact of this stigma. Fear of rejection causes people to avoid testing for the disease and to delay the treatment that would enable them to lead productive lives. Stigma is so widespread that it makes the pandemic itself worse – the disease spreads faster because of stigma.

Stigma can be eliminated if the world's faith communities take action to fight it. Historically, many faith communities have displayed strongly judgmental attitudes toward people living with HIV. In some communities, judgment has been replaced by silence, but that still reinforces stigma. Fortunately, when faith communities take proactive steps to fight stigma, they can successfully overcome it, becoming places of hope and support for people living with HIV.

Successfully ending stigma requires strong local leadership. The leaders of local faith communities are uniquely positioned to eliminate stigma among their members and within the wider community. This guidebook was written to help local faith leaders succeed in their efforts to end the stigma of HIV and AIDS.

This guidebook has three parts:

- Characteristics of a stigma-free faith community
- · Best practices for ending stigma
- A framework for incremental transformation

The first two provide the foundation, while the third describes the steps to take for successful transformation into a stigma-free faith community.

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Characteristics of a Stigma-Free Faith Community

Faith communities that have successfully eliminated the stigma of HIV and AIDS display ten characteristics, listed on the inside front cover of this guidebook, and described in more detail later. The process of becoming a stigma-free faith community involves turning each of these characteristics from a weakness into a strength.

Although there are complex interactions among the characteristics, they can generally be pursued in a sequential order, with each building on the previous ones:

- The first characteristic is about breaking the silence: if the complex issues surrounding HIV and AIDS cannot be discussed openly, it will be impossible to address stigma.
- The second characteristic is perhaps the most important: our faith traditions obligate us to treat all people with love and compassion, not judgment.
- The third, fourth, and fifth characteristics deal with factual knowledge: HIV is a disease; scientists understand how it is transmitted and how to prevent transmission; doctors know how it progresses and how to treat it; there is no need to fear casual contact with people who have HIV.
- The sixth and seventh characteristics deal with support: what faith communities can do to provide practical help to people living with HIV.
- The eighth, ninth, and tenth characteristics deal with fighting the pandemic more broadly: the importance of testing for all members; the need to avoid unsafe behavior; the need to reach out to the wider community.

1. A stigma-free faith community talks openly about HIV and AIDS, as well as related issues such as sexual behavior and gender inequality.

It is essential to discuss the issues surrounding HIV and AIDS openly. These topics may be difficult to talk about, because there may be cultural or psychological barriers to open discussion. But without open discussion, it will not be possible for a faith community to deal effectively with the stigma of HIV and AIDS. In many ways, this first step is the most difficult, requiring courage and empathy on the part of the leaders of the faith community.

Different faith communities may provide different opportunities for open discussion about issues related to HIV and AIDS. For some faith communities, worship services may be best. For others, there may be teaching sessions. The important point is that such topics are discussed openly and widely among the members of the faith community.

Key Question

 How often are HIV, AIDS, sexuality, gender, and similar topics discussed openly during worship services and other gatherings of faith community members?

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2. A stigma-free faith community consistently and repeatedly gives messages of compassion, not judgment, toward people living with HIV.

Love and compassion for all human beings are central to defeating the stigma of HIV and AIDS. Love and compassion are fundamental tenets of most faith traditions; yet these tenets can be very difficult to demonstrate, especially when confronted with all of the social, cultural and theological issues involved in the AIDS pandemic.

In order to end stigma, messages of compassion for people infected with HIV are more important than messages about individual responsibility to avoid infection. Messages of individual responsibility are important (see Characteristic #9), but can lead those infected with HIV to feel guilty or ashamed, and therefore unwelcome in the faith community. Messages of compassion and love must be emphasized in order to avoid creating feelings of guilt or shame.

In many faith communities, this is the greatest weakness among the ten characteristics of a stigma-free faith community. Turning this weakness into strength requires constant attention and repetition, both in words and in deeds, so that the faith community becomes a place of hope and support for people living with HIV.

Key Question

 Is it more common for worship messages to emphasize compassion and love for those infected by HIV, rather than individual responsibility to avoid infection?

3. A stigma-free faith community describes HIV and AIDS as medical conditions, not punishment for immoral behavior.

This is a fundamental issue that must be addressed. It is important for members of the faith community to recognize that HIV is a disease. Although infection may result from behavior that is considered immoral, immorality is not the root cause of the infection. Infection occurs when the virus enters a human body. This may happen in many ways, some associated with behavior that might be considered immoral, but also some that have nothing to do with moral or immoral behavior.

It is important to recognize the distinction between two dimensions of human behavior:

- "Moral" behavior, that is, behavior that is in accordance with religious and cultural norms
- "Safe" behavior, that is, behavior that does not risk transmission of HIV

There will always be disagreements about what behavior is "moral" or "immoral." But the "safe" dimension is factual, determined by science and medicine. In order to overcome stigma, it is important to recognize this distinction and to focus on safety, not morality.

Key Question

 How many members understand that, with respect to transmission of HIV, "moral" behavior may not necessarily be "safe" and "unsafe" behavior may not necessarily be "immoral?"

4. A stigma-free faith community provides basic facts about HIV and AIDS, including methods of transmission, treatment, and prevention.

It is essential that members of a faith community know the basic facts about HIV and AIDS, including modes of transmission, methods of prevention, and treatment protocols. This knowledge reinforces the recognition that HIV and AIDS are medical issues. Knowing the facts can also help dispel harmful rumors and myths, and enable members to understand what works and what doesn't work in preventing transmission of HIV.

Some topics may be challenging to discuss, such as the use of condoms. There may be a perception that discussing condoms encourages behavior that is considered immoral. But nonetheless, it is important for all to understand that condoms are an important way to prevent HIV transmission during sexual activity. Knowledge of condom use is literally a matter of life and death.

Key Question

 How many members understand and talk accurately about HIV and AIDS, as well as modes of transmission, treatment, and prevention?

5. A stigma-free faith community encourages all members to engage fully in the life of the faith community, regardless of HIV status.

Basic knowledge about transmission of HIV shows that there is no risk of transmission during casual interactions with people who have been infected. Consequently, there is nothing to fear when HIV-positive people participate in faith community activities. When members know these facts, messages of encouragement and acceptance lead to full engagement of people living with HIV in all faith community activities. This, in turn, leads members of the faith community to see the human side of the disease and to realize that people living with HIV are people first and HIV-positive second.

Key Question

 How many HIV-positive members freely participate in the normal activities of the faith community?

6. A stigma-free faith community focuses on providing care and support to people living with HIV, rather than on how they became infected.

When a person discloses that he or she is HIV-positive, the most important thing they need is unconditional acceptance. Yet, for many people, the first reaction to learning that a person is HIV-positive is to wonder how the person became infected. Motivated by compassion, members of faith communities should not ask about the cause of infection. Instead, they should express their acceptance of the person and ask how they can help.

Some members may not say anything because they are worried that they don't know how to help. But often, the most useful help is simply acceptance of the person and assistance with the practical aspects of living with HIV.

Key Question

 How many members have disclosed their HIV-positive status, either confidentially or publicly?

7. A stigma-free faith community encourages positive living through education and support groups for people living with HIV.

"Positive living" refers to certain aspects of personal behavior that enable people with HIV to lead long and productive lives. Positive living involves many challenges, including the protocols for medication and nutrition, as well as the logistics for getting to clinics for monitoring and medication.

Positive living also involves taking the proper precautions to prevent transmission of the disease to other people. Taking proper precautions involves an understanding of the facts about transmission and prevention, as well as self-discipline and encouragement from others.

Self-help or support groups can be very effective in helping people with HIV deal with all of these issues. For example, people in support groups can encourage each other to take their medication regularly and can learn how other people have addressed challenges similar to their own.

Key Question

 Are there active and helpful support groups, based in the faith community or the wider community, for people living with HIV?

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8. A stigma-free faith community actively encourages testing for all members and facilitates access to voluntary counseling and testing.

Everyone should know their HIV status, just like they should know other aspects of their medical condition. There is a tendency to think that only those involved in unsafe behavior need to be tested, but in fact, everyone should be tested, including those who think they are not at risk. There are two reasons.

One reason is medical. There are several different ways to become infected with HIV and people might be wrong when they think they are not at risk.

The second reason is related to stigma. If everyone gets tested, testing becomes a normal activity. Nobody is singled out because they have sought testing, and there is no longer a stigma associated with testing.

If members are asked who has been tested for HIV, and everyone raises his or her hand, then the faith community is well on its way to being stigma-free.

Key Question

 How many members have been tested for HIV infection and know their status?

9. A stigma-free faith community affirms the individual responsibility of all members to know their HIV status and to refrain from behavior that risks transmission of HIV.

The emphasis here is on personal responsibility. There are some things that must be done by leaders or by the faith community as a whole, but each person has individual responsibilities as well. One responsibility is to know their personal HIV status. Another is to refrain from unsafe behavior that risks transmission of HIV, either from themselves to others or from others to themselves.

In discussing the responsibility to refrain from unsafe behavior, it is helpful to recall the distinction between the "moral" and "safe" dimensions of human behavior, as noted with Characteristic #3. In the context of HIV transmission, personal responsibility focuses on avoiding unsafe behavior.

In discussing personal responsibility, it is also important to recognize that some people may not have free choice about unsafe behavior. For example, a woman who is raped cannot force her attacker to use a condom.

Key Question

 How many members recognize the need to take personal responsibility for avoiding HIV transmission?

10. A stigma-free faith community works proactively with other organizations to address HIV and AIDS issues in the wider community.

When a faith community develops the knowledge, compassion, and support to end stigma among its members, it can become a role model for other communities and a strong advocate for people living with HIV. A strong stigma-free faith community can help eliminate the stigma of HIV and AIDS in the entire community.

Key Question

• Is the faith community known as a place of hope, support and advocacy for people living with HIV?

Best Practices for Ending Stigma

A. Preach and teach about overcoming the stigma of HIV and AIDS.

Worship services, teaching sessions, and other faith community gatherings are important platforms to present and reinforce messages about stigma. Success will depend on repeated and consistent use of sermons and other teaching opportunities – at least once a month.

Specific message content may vary, but several broad categories are important:

Information – Focused on basic facts about HIV and AIDS, so that all members are well informed.

Acceptance – Emphasizing the worth of every human being, welcoming all to participate in the life of the faith community, regardless of HIV status.

Compassion – Focused on the moral obligation to treat all people with love and respect, regardless of HIV status.

Encouragement – Intended primarily for people who are worried about HIV and AIDS, reassuring them that the faith community is a place of hope and support.

Advocacy – Focused on the important role of faith communities in promoting the rights of HIV-positive people in the wider society, including the rights of people who may be culturally marginalized, such as women and children.

Responsibility – Emphasizing the need for members to deal personally with HIV: know their own HIV status and refrain from behavior that risks transmission of HIV. Messages of personal responsibility must be delivered carefully, to avoid driving away people who may feel they are being judged.

B. Present personal testimonies by people who are HIV-positive or personally affected by HIV.

Personal testimonies put a human face on the disease, and can change the focus from theoretical dogma to the complexities of life for real people.

C. Conduct educational sessions.

Early in the transformation process, there is a great need for factual information about HIV and AIDS. This can be provided during worship services or by having separate training sessions focused on facts.

D. Provide educational resources.

It is helpful to provide educational material such as books or pamphlets. Two topics are especially important: (1) basic facts about HIV and AIDS; (2) guidelines for positive living.

E. Conduct discussion sessions on specific topics.

Discussion sessions encourage interaction among members of the faith community. This is helpful for topics involving both facts and opinions, such as sexual norms, or gender issues. For some topics, separate sessions for men, women, and youth are best. For other topics, mixed groups might be better.

F. Provide testing and counseling facilities at the same time as worship services and other faith community activities.

It is important for all members of the faith community to be tested. The availability of testing facilities in conjunction with worship services and other faith community activities helps significantly. It is important for the results to be kept confidential and to have trained counselors available.

G. Organize support or self-help groups.

Support groups can help people living with HIV to cope with their condition. It is sometimes best to have separate support groups for men, women, and youth, or it may be best to have a mixed group. Support groups meet regularly for discussion about relevant topics, such as positive living and adherence to treatment plans. They are also a natural way to provide logistical help (e.g., travel to clinics). Finally, they can serve as a work team for income-generating activities. Working together in support groups also forms stronger bonds with the faith community as a whole.

H. Test faith community leaders publicly.

It can be very effective for the leaders of the faith community to be tested publicly for HIV. Such actions demonstrate that we are all in this together, that there is no "Us Against Them." The results should be kept confidential. If a faith leader is HIV-positive, he or she may later choose to be open about their status, perhaps as a personal testimony during worship, but it need not be disclosed immediately after testing.

I. Publicly display the commitment to ending stigma.

Prominently displayed posters, signs and banners are visible signs of commitment to eliminating the stigma of HIV and AIDS.

J. Conduct awareness activities with other community organizations.

Important activities with the wider community include educational campaigns, testing days, and recognition of World AIDS Day on December 1.

Recommended Best Practices

When turning particular characteristics from weaknesses into strengths, some of these best practices are more helpful than others. The following table indicates which best practices (labeled A through J on pages 14-16) are most helpful for which characteristics. Find the row with the number of the characteristic and consider the best practices that are marked.

For example, for Characteristic #5 ("A stigma-free faith community encourages all members to engage fully in the life of the faith community, regardless of HIV status."), Best Practices A (preaching and teaching), B (personal testimonies), H (public testing of leaders), and I (public displays or posters) are most helpful.

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Of course, other practices can also be used, so this chart should be used as a guideline, not a constraint.

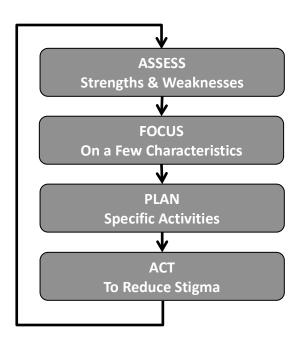
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Incremental Transformation

Eliminating the stigma of HIV and AIDS requires sustained effort over a period of time. This can best be done with a series of transformation cycles, each taking about six to twelve months. A cycle involves four primary activities:

- Assess Identify strengths and weaknesses among the ten characteristics
- **Focus** Select a few weak characteristics to focus on during the cycle
- **Plan** Develop a plan of action appropriate to the focus characteristics
- Act Perform the actions and turn the weaknesses into strengths

At the end of each cycle, repeat the assessment to check progress and to select the characteristics to focus on in the next cycle.



Incremental Transformation

Assess

Each transformation cycle begins with an assessment. The purpose of the assessment is to understand the specific circumstances in the faith community, in order to reinforce progress already made and to determine what to do next.

One way to do the assessment is simply to consider each of the ten characteristics and decide whether that characteristic is a strength or a weakness in the faith community, or whether it is neither a strength nor a weakness. Ask the Key Questions given with the descriptions of each characteristic to help decide.

The accompanying Action Planning Worksheet may be used to record the results of the assessment.

Focus

It is important to focus on only a few characteristics during each transformation cycle, because it is very difficult to do a good job on many characteristics at the same time. Generally, it is best to focus on two or three characteristics. The selection of focus characteristics depends on the specific circumstances of the faith community. The assessment results provide good guidance.

At the start, focus on characteristics with lower numbers that are not strengths. For example, if #1 is a weakness or neutral, it should be a focus of the first cycle, because it is not possible to strengthen other characteristics without breaking the silence.

A compassionate attitude is so important that Characteristic #2 should be a focus of every transformation cycle until it has become a significant strength.

Plan

After the focus characteristics have been selected, the next step involves planning the anti-stigma activities that will be done during the transformation cycle. The transformation cycle should generally take six to twelve months. The specific activities to pursue depend both on the focus characteristics and on the knowledge and experience of the leaders of the faith community. A number of best practices, based on several years of experience, were given earlier in this guidebook. The table on page 17 indicates which of these best practices are especially helpful for different focus characteristics. However, depending on the circumstances, other activities may also be appropriate.

Act

The final part of a transformation cycle involves performing the activities that were planned. In some cases, it may be wise to change the plan part way through the cycle to adapt to the changing situation.

In many ways, this is the only part of the cycle that really matters, because this is the part that will actually have an effect on the stigma of HIV and AIDS. This is also the part that requires perseverance, because there will be unexpected barriers and challenges to overcome.

Use the accompanying Action Planning Worksheet to record the results of each part of a transformation cycle.

Facing Challenges

Ending the stigma of HIV and AIDS is challenging. There are several reasons:

- You must change attitudes that have developed through many generations.
- You must discuss aspects of human behavior that many people find difficult to talk about.
- You must deal with controversial theological concepts.
- You must combine theological considerations with the realities of human lives in complex situations.
- You may meet with resistance from members of your faith community.

In order to meet these challenges, you, as a faith leader, must:

- Recognize the impact of stigma
- Commit to taking proactive steps
- Persevere until stigma has been overcome

It is helpful to remember that the stigma of HIV and AIDS is a matter of life and death. People in your community, and in communities around the world, are dying because of stigma. In many ways, stigma is the last battle in the struggle to defeat the AIDS pandemic. Medical science can treat the disease and prevent it from spreading, but only if people feel free to be tested and to seek help. The actions of local faith community leaders like you can ensure that we take full advantage of the medical advances and bring an end to the AIDS pandemic.

Example Transformation Cycle

Assess

The faith community determines that Characteristics #1, #4, and #9 are strengths, and that Characteristics #2 and #5 are weaknesses. The other characteristics are neither strengths nor weaknesses.

Focus

The faith community decides to focus on Characteristics #2 and #5, which are weaknesses, and Characteristic #3, which is not yet a strength.

Plan

The faith community selects Best Practices A, B and I:

A – Messages with information about the distinction between the "moral" and "safe" dimensions of human behavior (see Characteristic #3), as well as messages of acceptance, compassion, and encouragement

B – Personal testimonies of an HIV-positive individual and an HIV-positive faith leader

I – Posters on display in the worship center

4 Act

The faith community does the activities according to the plan. While doing the activities, it became apparent that the distinction between moral and safe behavior was too difficult for a single worship message, so Best Practice E was added:

E – Discussion sessions about the distinction between moral and safe behavior in the context of HIV

Incremental Transformation

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Characteristics	Weak	Strong	Focus											
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4. Provides basic facts about HIV and AIDS, including methods of transmission, treatment, and prevention		/			•		•	•	•					
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7. Encourages positive living through education and support groups for people living with HIV								•		•	•			•
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10. Works proactively with other organizations to address HIV and AIDS	1	1							1		1	1 .	_	Ι.

Stigma-Free Faith Community – Action Plan						
	3B	4				
Month	Planned Activities	Actual Activities				
Jul	Worship with message about the distinction between moral behavior and safe	Worship with message about the distinction between moral behavior and safe				
	behavior	behavior				
Aug	Worship with message about acceptance	Worship with message about acceptance Discussion session on the distinction between moral behavior and safe behavior				
Sep	Worship with message about compassion	Worship with message about compassion				
Oct	Worship with personal testimony of HIV+ individual	Worship with personal testimony of HIV+ individual				
Nov	Worship with message about encouragement Put up posters	Worship with message about encouragement Put up posters				
Dec	Worship with personal testimony of HIV+ faith leader	Worship with personal testimony of HIV+ faith leader				

Other Resources

EMPACT Africa provides online support for local faith leaders as they fight to end the stigma of HIV and AIDS:

- Stigma assessment of the faith community
- Action planning and tracking
- Monitoring and evaluation
- Lessons learned

EMPACT Africa also provides other services to faith communities:

- Stigma surveys
- Leadership training
- Stigma initiatives for denominations

For more information, visit:

www.empactstigmafree.org

There are many other online resources, including:

- UNAIDS (Joint United Nations Program on HIV/AIDS) www.unaids.org
- CABSA (Christian AIDS Bureau for Southern Africa) www.cabsa.org.za
- INERELA+ (International Network of Religious Leaders Living With or Personally Affected by HIV)
 www.inerela.org
- Stigma Action Network www.stigmaactionnetwork.org
- GNP+ (Global Network of People Living with HIV/AIDS) www.gnpplus.net
- Ecumenical Advocacy Alliance www.e-alliance.ch
- World Council of Churches www.wcc-coe.org

Publication and Distribution

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These materials were developed from a Christian perspective in southern Africa. EMPACT Africa is interested in working with third parties to adapt these materials to other faith traditions and other geographical regions, and to make them available in other languages.

If you are interested in reprinting these materials or adapting them to other settings, please contact:

resources@empactafrica.org

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Dr. David Barstow President, EMPACT Africa

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"Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world."

Ban Ki-moon, Secretary General of the United Nations

"We're not dying from the disease.

We're dying from the stigma."

HIV-positive member, Reformed Church in Zambia

"I think about all the people I've buried over the last several years. If we had started the EMPACT program earlier, many of them would be alive today."

Rev. Gerald Phiri, Church of Central Africa Presbyterian

EMPACT Africa is a 501(c)(3) non-profit organization, based in Austin, Texas, USA, dedicated to helping local church leaders in southern Africa end the stigma of HIV and AIDS in their congregations and communities. For more information, contact

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Donations may be made by check payable to "EMPACT Africa" or online at www.empactafrica.org. A donation of \$25 covers the cost of this guidebook plus copies for the leadership team of an African congregation in their own language.

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