



Discussion Guide

State Of Denial

A Film by Elaine Epstein



www.pbs.org/pov

Letter From The Filmmaker

NEW YORK, 2003

Dear Viewer,

When speaking of the world's AIDS epidemic, I think it's an all too common practice of individuals to assume that it's an issue that is no longer a threat. In the West we assume that the epidemic is under control due to the availability of antiretroviral drugs. However the drugs are not a cure-all, and more importantly, these medications are not widely available. Millions are dying all over the world, mainly in developing countries, because they lack access to this treatment.

As a native South African, I have witnessed first hand the death and devastation that HIV/AIDS has wreaked in this area of the world. Before moving to New York and becoming a filmmaker, I specialized in AIDS public health working closely with communities to create grassroots interventions and assisting in developing a national AIDS plan.

With the fall of apartheid came the hope that South Africa's HIV epidemic would be contained. Yet this new-found freedom the South African people had fought so hard for has been overshadowed by a new struggle. Today South Africa has the highest number of HIV-positive people in any one country in the world. Nearly 5 million people are infected with the virus, with almost 2,000 new infections occurring daily.

In making *State of Denial* I wanted to allow the people of South Africa to have a voice. I felt that the television programs I was seeing on AIDS in Africa did not reflect my experience with the epidemic or the people affected by it. I often felt like I was watching a nature program about the mating habits of some exotic species—always with some white, male, foreign correspondent wandering at a distance through the townships telling viewers how things are, or how he sees them without ever getting up close and giving the people the opportunity to speak for themselves.

There is a perception of Africa as a strange, unknown place, with people unlike you or me. I wanted to combat that view and show a different side of the AIDS epidemic in Africa, an inside perspective with South Africans telling their own personal stories. *State of Denial* introduces you to those people. It takes you into their lives and into their homes. It taps into the universal emotions of anguish, fear and hope and shows you people, not that different from you or me, who are facing a horrific crisis.

Shortly before I started shooting in 2000, South African President Thabo Mbeki consulted dissident scientists who believe that HIV is not the cause of AIDS. Since adopting this ideology, Mbeki has been responsible for the obstruction of efforts to reduce infection rates and has prevented people from gaining access to life-saving antiretroviral medication. Some human rights abuses are obvious, others less so, but none should slip under the radar.

Unless there is political will and leadership on a global scale to address this crisis, this epidemic will not be contained. It is my greatest hope that *State of Denial* will be a catalyst for this change.

Elaine Epstein



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Introduction

The feature length documentary, *State of Denial*, exposes viewers to a tragedy that, until recently, has remained nearly invisible to most Americans – the AIDS epidemic in South Africa. The film takes viewers into the lives of people struggling to survive with HIV in the face of social stigma, a severe lack of access to lifesaving treatments, and their president, Thabo Mbeki's controversial stance on the connection between HIV and AIDS. A film of quiet outrage, *State of Denial* weaves the personal with the political in an uplifting portrait of ordinary people struggling to survive.

Key Issues

State Of Denial focused on the challenges of the AIDS epidemic, but also reaches beyond a story about a disease to look at issues of globalization, government policy, relationships between wealthy countries and developing nations, medical research, poverty, and sex. This range of issues will be of interest to many different people in your community, including people who are involved with:

- **African Americans**
- **AIDS education, activism, prevention, and treatment**
- **Children's Rights / Children's Welfare**
- **Costs of Prescription Medications**
- **Developing Nations**
- **Disease Prevention**
- **Diversity Issues**
- **Economics**
- **Globalization**
- **Human Rights**
- **Medical Insurance / Universal Health Care**
- **Medical Research**
- **Poverty**
- **Public Health**
- **Race and Racism**
- **Sex Education**
- **Sexually Transmitted Diseases (STDs)**
- **South Africa**
- **Sub-Saharan Africa**

As it tells the stories of individuals whose lives are changed not only by their health status, but also by the choices made by drug companies, their government, and the prejudices of their community, *State of Denial* helps viewers consider how the spread of a disease like AIDS changes family life and society. It provides a complex lens that can serve as an excellent catalyst for dialogue around issues of poverty, power, and policy.

Potential Partners

State of Denial is appropriate for a variety of settings and is especially recommended for use with:

- **Colleges and universities, including student groups, medical schools, and departments of Biology, Political Science, Sociology, International Studies, and African Studies**
- **AIDS activist groups and support services**
- **Medical professionals and researchers**
- **Groups dealing with diversity and/or racism**
- **Organizations focused on economic justice and equity issues**
- **Doctors Without Borders and other human rights organizations**
- **Churches, synagogues, mosques, and other religious institutions**
- **Your local PBS station and their Program Club: www.pbs.org/programclub/about.html**
- **Community Organizations with a mission to promote education and learning such as P.O.V.'s national partners Elderhostel Learning in Retirement Centers, members of the Listen Up! network, or your local library**

Key People and Updates



Thabo Mbeki is the president of South Africa.



mining town.

Buyile Montagne is a retired nurse who travels more than three hours a day from her home in Johannesburg to run a home-based care program in Carletonville, a gold



Manto Tshabala-Msimang is the South African Minister of Health.



Donna, an HIV-infected middle-class white South African, is pregnant with her second child.



daughter Chipho do not.

Mary, an HIV-positive mother of two, fights to get her infected children access to treatment. While Mary's son Gift meets the criteria for a clinical trial and receives treatment, Mary and her



Dr. Daya Moodley is a young research scientist, carries on a fight for implementation of mother-to-child transmission prevention program.

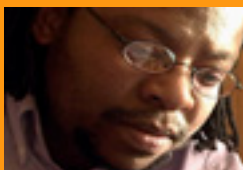


able treatment for all.

Zackie Achmat, co-founder of the Treatment Action Campaign, has taken on both the South African government and the drug companies in a public campaign demanding afford-



Mandla is an HIV positive man who contemplates his own death and pleads with God to spare his wife so that his children will not be orphaned.



Lucky Mazibuko is an HIV positive journalist who braves social scorn and physical threats to write a weekly newspaper column about living with AIDS.



access to treatment, disappointment in their leader, and their reasons for not voting in the local government election.

The Zola Support group These young, dynamic, HIV positive men and women speak frankly on current issues and events occurring around AIDS in South Africa: lack of

Background Information

SOUTH AFRICA'S HISTORY

South Africa's trek towards modern nationhood began with colonial conquest, first by the Dutch (known as the Boer) in the 1600s, and then by the British in the 1700s. By 1910, wars between the British and Dutch and between the white settlers and indigenous tribes, including Khosian, Bantu, Xhosa, and Zulu chiefdoms, resulted in British control of the territory.

As in the history of other colonial nations, white settlers brought slaves and disease, and forcibly dispossessed indigenous inhabitants of land, water, and livestock. Christian missionaries and commercial interests actively worked to suppress indigenous culture.

In 1948, these racial policies were consolidated into the formal, legal discrimination known as apartheid. Under apartheid, rights of citizenship were confined to whites alone and violent enforcement was common. Based on racist beliefs in white superiority and an economic need for low-paid mine workers, apartheid stripped the black majority of nearly all rights. Segregation was ruthlessly enforced, requiring blacks to obtain residence, travel, and work permits. Sexual relations between races were outlawed. Skilled jobs were reserved for whites and black laborers were often required to leave their families, who were restricted to "homelands" away from urban centers and mines. These homelands lacked basic services, including electricity, running water, sewers, and quality schools.

THE END OF APARTHEID

In 1961, South Africa declared its independence from the British Commonwealth, but its new constitution continued the brutal practices of apartheid. Protests and strikes inspired by Ghandi, American civil rights activists, and labor movements across the globe, led by people like Nelson Mandela of the African National

Congress (ANC) and Steve Biko of the Black Consciousness Movement, brought increasing attention to apartheid and reawakened a sense of pride and self-esteem in black people.

In 1977, news of the brutal death of Steve Biko while in government custody led to unprecedented global outrage. Individual countries, as well as the United Nations, instituted a range of economic sanctions and cultural boycotts. The South African government eventually responded with a series of reforms, e.g., recognizing black trade unions and ending the pass laws. In 1990 they released political prisoners, most notably, Nelson Mandela.

Under an interim plan, South Africa held its first democratic election in April 1994. The ANC emerged with a 62% majority and installed Nelson Mandela as the country's first black president.

SOUTH AFRICA TODAY

In South Africa's second democratic election, held in 1999, Thabo Mbeki succeeded Nelson Mandela as president and the ANC increased its majority to a point just short of two-thirds of the total vote. Today, Mbeki governs a nation that is about twice the size of Texas with a population of about 43 million people, three-quarters of whom are black. According to the Joint United Nations Programme on HIV/AIDS, approximately 20% of the South African population is infected with HIV/AIDS. The epidemic has skewed the average life expectancy for a South African to 46.5 years old.

The country continues to struggle to create democratic structures, educate a population that was denied schooling for decades, and rebuild from the devastating poverty created by apartheid.

Adapted from: <http://www.gov.za/yearbook/2002/history.htm>

Background Information

WHAT IS AIDS?

AIDS stands for Acquired Immune Deficiency Syndrome. Scientists believe that the disease is caused by the Human Immunodeficiency Virus (HIV), which is usually transmitted sexually. It can also be contracted when an infected person's blood enters another person's bloodstream, for example, via an open wound, shared needles, or the placenta from mother to fetus. AIDS cannot be contracted from casual contact. Because we know how it is transmitted, the disease is preventable.

Symptoms can take from 2 to 10 years to begin appearing, so it is possible for people to carry and transmit HIV without knowing it. That is why many health educators, advocates, and governments encourage people who may have been exposed to be tested.

Without medication, HIV destroys an infected person's immune system. Once the immune system becomes sufficiently weak, the infected person is prone to being attacked by opportunistic diseases, including, but not limited to, TB, cryptococcal meningitis, PCP and Karposi Sarcoma. The immune systems of healthy people can fight off many of the diseases that attack people with HIV, but if left untreated, they can often be fatal or de-habilitating for people with HIV. When the immune system has deteriorated very badly and the infected person regularly falls ill with opportunistic diseases, the person is said to have AIDS.

AIDS IN SOUTH AFRICA

When *State of Denial* began filming in 2000, the South African government refused to publicly provide anti-retroviral drugs known to be effective in treating AIDS.

This is due in part to President Mbeki's controversial questioning of the link between HIV and AIDS, commonly accepted by mainstream science. In place of antiretroviral drug treatments, South African government officials have urged the world community to answer the AIDS epidemic by addressing poverty and malnutrition. Though both are widely recognized as factors that cause disease, this position has infuriated many in the country who argue that the denial of the connection between HIV and AIDS and the refusal to provide drugs amounts to a fatal negligence. Citing the toxicity of some AIDS drug treatments, a lack of evidence of the drugs' long-term effects, and skepticism about Western drug companies who have historically used poor black South Africans in early drug trials only to abandon them later, the South African government maintained its position of cautious delay. They have suggested that a government with limited resources cannot afford to offer drug protocols that, if taken incorrectly, can make the problem worse.

The government's refusal to provide antiretroviral drugs effectively renders them inaccessible for the majority of South Africans, since exclusive patents given to pharmaceutical companies prohibitively drive up the private cost of the medications.

Background Information

Policy Update:

SOUTH AFRICA

In August 2003, in response to several years of public pressure, the South African government changed its policy of refusing to provide drugs routinely used to treat HIV and AIDS in other countries. They agreed to begin planning a national treatment program. In affirming the change, a Cabinet statement said, "Government shares the impatience of many South Africans on the need to strengthen the nation's armoury in the fight against AIDS." The announcement came after a four-day national conference on AIDS in Durban, the first held there since the International AIDS Conference that is shown in the *State of Denial*. Despite these changes, AIDS will continue to take a huge economic and social toll on South Africa.

U.S. POLICY

In 2003, U.S. President, George W. Bush, traveled to Africa and pledged \$15 billion over five years to fight global AIDS. However, Congress has not yet actually appropriated those funds.

TAC – THE TREATMENT ACTION CAMPAIGN

Zackie Achmat, the Chair of TAC, is one of the people featured in *State of Denial*. TAC was founded in 1998 to campaign for greater access to treatment for all South Africans, by raising public awareness and understanding about issues surrounding the availability, affordability and use of HIV treatments. T.A.C. actively



opposes President Mbeki's position that HIV does not cause AIDS and rejects the notion that an AIDS diagnosis is an automatic death sentence.

Instead it emphasizes the potential of treatment, working to ensure access to affordable and quality care for people with HIV/AIDS, and to prevent and eliminate new HIV infections. TAC has specifically asked the South African government to provide AZT and Nevirapine for pregnant women in order to prevent mother-to-child transmissions. It has also campaigned against profiteering by drug companies, demanding that they lower the costs of all HIV/AIDS medications.

Photo: Sven Cheatle

Members of the Zola Support Group share their stories and experiences of living with the disease.

Background Information

Excerpt from the **Statement by the Minister of Health on the establishment of a National Task Team to develop a detailed operational plan for an Antiretroviral Treatment Programme for South Africa:**

On the 8th August 2003, Cabinet requested the Ministry of Health to develop as a matter of urgency a detailed operational plan on an antiretroviral treatment programme by the end of September 2003.

Accordingly, I have appointed a National Task Team to co-ordinate the drafting of an operational plan on behalf of the government. The task team comprises mainly senior officials from the Department of Health and experts in the health sector to complement the skills of the Department of Health.

Dr. Anthony D. Mbewu, the Executive Director for Research at the Medical Research Council of South Africa, will chair the Task Team. Dr Nono Simelela, the Cluster Manager for HIV & AIDS, Tuberculosis and Sexually Transmitted Infections in the Department of Health will continue to co-ordinate the activities of this plan. Some members of the task team will comprise a core team and work full time on this project while others will assist to convene focused consultations with relevant stakeholders and also act as a reference advisory group to the Task Team. [To read the full statement including the list of names of the task force members go to www.gov.za/issues/hiv/taskteamartp.htm]

In addition, the National HIV and AIDS Treatment Task Team will be assisted by a team of experts from the Clinton Foundation AIDS Initiative, established by former U.S. President, William Jefferson Clinton, which is led by Mr Ira Magaziner.

Over the next six weeks National HIV and AIDS Treatment Task Team will work closely with provincial health authorities and will consult broadly with national and international experts and various South African stakeholders.

During this period, the National HIV and AIDS Treatment Task Team will develop a detailed operational plan and implementation schedule.

[To see the entire schedule and find out which areas the task force will address in developing the plan go to www.gov.za/issues/hiv/taskteamartp.htm]

Dr. ME Tshabalala-Msimang

Minister of Health

20 August 2003

Using This Guide

This guide is designed to help you use *State of Denial* as the centerpiece of a community event. It contains suggestions for organizing an event as well as ideas for how to help participants think more deeply about the issues in the film. The discussion questions are designed for a very wide range of audiences. Rather than attempt to address them all, choose one or two that best meet the needs and interests of your group.

Planning an Event

In addition to showcasing documentary films as an art form, screenings of P.O.V. films can be used to present information, get people interested in taking action on an issue, provide opportunities for people from different groups or perspectives to exchange views, and/or create space for reflection. Using the questions below as a planning checklist will help ensure a high quality / high impact event.

- ***Have you defined your goals?*** With your partner(s), set realistic goals. Will you host a single event or engage in an ongoing project? Being clear about your goals will make it much easier to structure the event, target publicity, and evaluate results.
- ***Does the way you are planning to structure the event fit your goals?*** Do you need an outside facilitator, translator, or sign language interpreter? If your goal is to share information, are there local experts on the topic who should be present? Will you involve people from South Africa and/or people living with AIDS or HIV so they can speak for themselves? How large an audience do you want? (Large groups are appropriate for information exchanges. Small groups allow for more intensive dialogue.)
- ***Is the event being held in a space where all participants will feel equally comfortable?*** Is it wheelchair accessible? Is it in a part of town that's easy to reach by various kinds of transportation? If you are bringing together different constituencies, is it neutral territory? Does the physical configuration allow for the kind of discussion you hope to have?
- ***Will the room set up help you meet your goals?*** Is it comfortable? If you intend to have a discussion, can people see one another? Are there spaces to use for small break out groups? Can everyone easily see the screen and hear the film?
- ***Have you scheduled time to plan for action?*** Planning next steps can help people leave the room feeling energized and optimistic, even when the discussion has been difficult. Action steps are especially important for people who already have a good deal of experience talking about the issue(s) on the table. For those who are new to the issue(s), just engaging in public discussion serves as an action step.

Facilitating a Discussion

Controversial or unusual topics often make for excellent discussions. By their nature, those same topics also give rise to deep emotions and strongly held beliefs. As a facilitator, you can create an atmosphere where people feel safe, encouraged, and respected, making it more likely that they will be willing to share openly and honestly. Here's how:

Preparing yourself:

Identify your own hot button issues. View the film before your event and give yourself time to reflect so you aren't dealing with raw emotions at the same time that you are trying to facilitate a discussion.

Be knowledgeable. You don't need to be an expert on AIDS, South Africa, or developing nations to facilitate a discussion, but knowing the basics can help you keep a discussion on track and gently correct misstatements of fact. If you need more background information than is provided in this guide, check the resources listed on pages 17 and 18.

Be clear about your role. You may find yourself taking on several roles for an event, e.g., host, organizer, projectionist. If you are also planning to serve as facilitator, be sure that you can focus on that responsibility and avoid distractions during the discussion. Keep in mind that being a facilitator is not the same as being a teacher. A teacher's job is to convey specific information. In contrast, a facilitator remains neutral, helping move along the discussion without imposing their views on the dialogue.

Know your group. Issues can play out very differently for different groups of people. Is your group new to the issue or have they dealt with it before? Factors like geography, age, race, ethnicity, religion, health, education, and socioeconomic class can all have an impact on comfort levels, speaking styles, and prior knowledge. If you are bringing together different segments of your community, we strongly recommend hiring an experienced facilitator.

Finding a Facilitator

Some university professors, human resource professionals, clergy, and youth leaders may be specially trained in facilitation skills. In addition to these local resources, your local hospice or HIV/AIDS support group may have trained facilitators available.



Photo: AnneB Zetler
Filmmaker Elaine Epstein

Facilitating a Discussion

Preparing the group:

Consider how well group members know one another. If you are bringing together people who have never met, you may want to devote some time at the beginning of the event for introductions.

Agree to ground rules around language. Involve the group in establishing some basic rules to ensure respect and aid clarity. Typically such rules include no yelling or use of slurs and asking people to speak in the first person (“I think...”) rather than generalizing for others (“Everyone knows that...”).

Ensure that everyone has an opportunity to be heard. Be clear about how people will take turns or indicate that they want to speak. Plan a strategy for preventing one or two people from dominating the discussion. If the group is large, are there plans to break into small groups or partners, or should attendance be limited?

Talk about the difference between dialogue and debate. In a debate, participants try to convince others that they are right. In a dialogue, participants try to understand each other and expand their thinking by sharing viewpoints and listening to each other actively. Remind people that they are engaged in a dialogue.

Encourage active listening. Ask the group to think of the event as being about listening, as well as discussing. Participants can be encouraged to listen for things that challenge as well as reinforce their own ideas. You may also consider asking people to practice formal “active listening,” where participants listen without interrupting the speaker, then re-phrase to see if they have heard correctly.

Remind participants that everyone sees through the lens of their own experience. Who we are influences how we interpret what we see. So everyone in the group may have a different view about the content and meaning of film they have just seen, and all of them may be accurate. It can help people to understand one another’s perspectives if people identify the evidence on which they base their opinion as well as share their views.

Take care of yourself and group members. If the intensity level rises, pause to let everyone take a deep breath. You might also consider providing a safe space to “vent,” perhaps with a partner or in a small group of familiar faces. If you anticipate that your topic may upset people, be prepared to refer them to local support agencies and/or have local professionals present at your event. Because there is still a lot of misinformation about HIV and AIDS and because there is still the danger of discrimination based on that misinformation, be prepared to protect the interests of anyone who is asked to reveal their HIV-positive status.

General Discussion Questions

Immediately after the film, you may want to give people a few quiet moments to reflect on what they have seen or pose a general question and give people some time to themselves to jot down or think about their answer before opening the discussion. Unless you think participants are so uncomfortable that they can't engage until they have had a break, don't encourage people to leave the room between the film and the discussion. If you save your break for an appropriate moment during the discussion, you won't lose the feeling of the film as you begin your dialogue.

One way to get a discussion going is to pose a general question such as:

- **If you could ask anyone in the film a question, who and what would you ask and why do you want to know the answer to that particular question?**
- **Two months from now, what or who do you think you will remember from this film and why?**
- **Did anything in the film surprise you? If so, what? Why was it surprising?**
- **What insights or new knowledge did you gain from this film? How do you think the new insight might change you?**



Photo: Courtesy of E-TV
President Mbeki responds in Parliament to strong criticism of his HIV/AIDS policies.

Discussion Questions

SOUTH AFRICAN POLITICS

South Africa's Minister of Health says, "You forget about the environment in which you operate, issues of sanitation, issues of water, issues of nutrition, and if you don't address those issues, it doesn't matter how much you give drugs. It will not solve the problem." Is it possible to address the needs of people with HIV and AIDS or to prevent its further spread without addressing poverty, as President Mbeki has argued? How might you help South Africans deal with poverty, as well as with AIDS?

In your opinion, are the citizens of South Africa well served by President Mbeki's emphasis on the links between poverty and disease, and his denial that AIDS is caused by HIV? Why or why not?

Do you think the cost of drugs and/or the patent system is a factor in getting medications to South Africans who need them? If so, how? How is the situation in South Africa different from or similar to the situation in the United States? Who has access to drugs or to health insurance that might cover the cost of drugs and who does not?

President Mbeki will not support AIDS treatments that are known to be toxic arguing that "These drugs are becoming as dangerous to health as the thing that they are supposed to treat." Do you find his argument compelling?

How did apartheid policies that forced black men to work far away from their families play a role in the development of the sex trade and the spread of AIDS? Why didn't the destructive patterns created by apartheid end when apartheid was officially eliminated? What other factors might be involved in keeping such patterns going?

PERSONAL BELIEFS AND DECISIONS

Donna originally believed that she wouldn't get HIV because "this thing you'd heard about didn't happen to you, you know, didn't move in your social circle." In actuality, who is most likely to be infected with HIV? How does denial play a role in the spread of a disease like AIDS? In the U.S., how has the association of AIDS with the gay community influenced concern or development of effective public policy on the issue? How has it served to obscure the epidemic in Africa, which is not concentrated in the gay community?

Some of those profiled in State of Denial will not take antiretrovirals that might help them stay healthy because the medications are not available to their fellow citizens. What do you think you would do if you were in their situation?

Journalist Pearl Ratsekeg notes that "most of the people who declared their [HIV positive] status" have been women. Why do you think that might be? In your opinion, what impact has gender had on public policy and AIDS-related services in South Africa? How about in the U.S.? How do attitudes about gender influence beliefs about HIV and AIDS?

Many people in South Africa suspected that Parks Manklahlana, President Mbeki's personal spokesperson, died from AIDS. If it were true, why wouldn't President Mbeki want that fact to become public?

Discussion Questions

POLICY ISSUES

Granny does not want to be tested for HIV because “If we have it, we have it. Nothing can be done about that. I don’t want to know.” What kinds of things might encourage people to be tested? What kinds of policies make it less likely that people will come forward to be tested? Should testing be mandatory? If so, should it be mandatory in every country, or just in African or developing nations?

Why are people afraid or ashamed to say publicly that they have AIDS? What might be done to allay that fear? Should those with AIDS be required to be identified publicly?

Activist Zackie Achmat suggests that pharmaceuticals should not be a business involving profit because medicine is an “essential commodity.” Do you agree or disagree? What are the benefits and costs of having profit-driven companies control the pharmaceutical marketplace?

Zackie Achmat breaks South African law by bringing in drugs from abroad for people with AIDS. What would you do in his situation? Is it okay to break the law if you think the law is immoral or if by breaking it you are saving peoples’ lives?

Some people have argued against providing poor people with the drug “cocktails” because if a complex and rigid regimen is not followed, the drugs can become ineffective and spawn resistant strains of the virus. Others, like Dr. Violari, see the argument as patronizing, trusting that poor people can understand the danger as easily as anyone else and are capable of following instructions. If it was your decision to make, would you provide drug cocktails for everyone, or would you require that certain conditions be met? If you would opt for requiring that conditions be met, what conditions and why? In the U.S., for whom are drug cocktails available and how do they get access?

AIDS drugs are expensive and one of the reasons that South Africa’s government has resisted providing medication is because they can’t afford it. What is the responsibility of the rest of the world to help developing nations provide medications? In your opinion, what, if anything, should be done to make sure that those who need AIDS drugs get them, no matter where they live?

Compare the AIDS policies of the South African government with current policy in the U.S. To familiarize yourself with that policy, you might try imagining that you have just received notice that you are HIV positive. What is your next step? Where would you go for medical help? What medical services are available and how would you pay for them? If your illness disables you, how will you care for your children, keep a job, take care of daily personal business, etc.? Who is nearby to offer support? Once you have all the answers, compare your experience with someone who is different from you in any or all of the following areas: gender, citizenship status, comfort speaking English, sexual identity, age, religion, employment status, race, ethnicity, literacy level, access to the Internet, and housing situation. How do these various factors influence access to and quality of care?

An interviewer asks President Mbeki if he would take an AIDS test, a request the President refuses. In your view, would it help the situation in South Africa if the President or other leaders took AIDS tests? How powerful are role models? Who are the role models in your community? Should they be asked to take AIDS tests? Why or why not?

Taking Action

Invite the group to brainstorm possible actions they might take on the issues raised in *State of Denial*. The ideas below may help you get started:

- One of the things we see in the film is a support group. How do support groups help? Are there such groups available to HIV positive people in your community? If not, what might you do to help create one? What about other necessary services? Find out what services are available and what services people need. If the two lists don't match, brainstorm things you might do to make sure that people get the services they need.
 - In your view, what are the most important steps that South Africa could take to prevent the further spread of AIDS? How might you help with those steps? How do those steps compare to what the U.S. needs to do? What prevention efforts exist in your community and are they effective? If not, what you might do to make them more effective?
 - Brainstorm ways that you might honor the memories of those who have died from AIDS, both in Africa and in your own community. One famous memorial is the AIDS quilt. If you were making a quilt square for someone you "met" in the film, what would you include in the square and why?
 - Misinformation about HIV and AIDS has been common in many countries, sometimes resulting in such negative consequences that, like several of the people in *State of Denial*, people are afraid to tell others about their HIV status. What might you do in your community to make sure that everyone has accurate information?
 - It is nearly impossible to do effective AIDS prevention education without talking about sex. How comfortable are you discussing sex publicly? In relation to the spread of AIDS, what is the impact of the taboo around such discussions? Have you discussed AIDS and how to stay safe with your own children, friends or family members? If not, how might you arrange to get the people you love the information they need? How would you feel about discussing HIV/AIDS or safer sex with a new partner? Do you/would you raise the issue with a new partner?
- What kind of sex education is offered in your school district? Does the school provide effective education about AIDS as well? If not, find ways to work with your school and community to make sure that young people have the prevention education they need to keep themselves safe.
 - President Mbeki's statement that there was no link between HIV and AIDS has had a direct impact on many South Africans, with some people stopping their medication or refusing to use condoms. This reaction demonstrates the importance of educating public figures, such as celebrities, athletes, and politicians. How might you make sure such education happens in your community? How might you make sure that influential people know about the situation in Africa?
 - Mandela's company dismissed him because of his illness and the days of work it caused him to miss. Is this kind of dismissal appropriate practice? For what length of time is it fair to ask a business to continue paying a worker who can't work? Are there policies in place where you work or study to protect workers who are sick from losing their jobs? Has the Americans with Disabilities Act been effective in protecting American workers from being fired like Mandela? What kinds of policy might be helpful for the South Africans to implement?
 - Mandela talks about wanting to live for "the sake of the children." What programs and services are available in your community for children who lose parents to AIDS or other illnesses? How might you or people in your community help provide the needed support services for children who are orphaned by AIDS in Africa?
 - Brainstorm ways to help people in South Africa and Africa. Check out the resource section of this guide and find out about South African groups dealing with HIV. Find out how you or your organization can help these groups or other groups in the U.S. working around issues of HIV/AIDS in South Africa.

Resources

P.O.V.'s State Of Denial Website

www.pbs.org/pov/stateofdenial

P.O.V.'s *State of Denial* website provides additional resources and links.

Is There a "State of Denial" in the U.S.?

As HIV/AIDS has exploded in the developing world, many argue that the developed world has become almost complacent about the disease. Public health officials, AIDS activists, and educators speak about stigma, awareness, and attitudes about the epidemic in the U.S.

South African Government's Position:

Statement by the South African Minister of Health on the establishment of a National Task Team to develop a detailed operational plan for an Antiretroviral Treatment Programme for South Africa. Read the entire statement.

The AIDS Rebel: Zackie Achmat

Learn more about the co-founder of the Treatment Action Campaign in an article by activist Samantha Power. Achmat has taken on both the South African government and the drug companies in a public campaign demanding affordable treatment for all.

Behind the Lens

Producer/director Elaine Epstein, a native South African who has worked extensively in AIDS and public health, offers a unique insider's view of the complex forces driving the disease's spread — and the debate around it — in South Africa.

State of Denial website:

<http://www.stateofdenial.org>

Includes a film synopsis, how to get involved, upcoming screenings, and more.



Photo: Sven Cheatle

Chipho back at school after starting antiretroviral therapy.

What's Your P.O.V.?

P.O.V.'s online Talking Back Tapestry is a colorful, interactive representation of your feelings about State Of Denial. Listen to other P.O.V. viewers talk about the film and add your thoughts by calling 1-800-688-4768.

www.pbs.org/pov/talkingback

Resources

WEB SITES:

Aid for AIDS

www.aidforaids.net

Provides money and bus passes, vitamins and pharmaceutical for HIV or AIDS patients. Cost: Free

Artists for a New South Africa (ANSA)

Artists for a New South Africa (ANSA) is a non-profit organization founded and supported by artists, activists and others dedicated to furthering democracy and equality in South Africa and civil rights in the U.S.

African Services Committee, Inc.

<http://africanservices.org>

African Services Committee provides health, social, and legal services to African immigrants and refugees in the New York metropolitan area and technical assistance to African NGOs.

Bailey House, Inc.

www.baileyhouse.org

Bailey House is dedicated to providing housing, support services and technical assistance to individuals and other HIV/AIDS service providers in New York City and nationwide.

Black Coalition on AIDS

www.bcoa.org

Provides education to improve the health care for blacks affected with AIDS, or at risk of infection with AIDS, through program development, policy formation, resources exchange, and advocacy.

Doctors Without Borders USA, Inc.

www.doctorswithoutborders.org

Doctors Without Borders/Medecins Sans Frontieres (MSF) is an independent, private, international medical relief organization aiding victims of armed conflict, epidemics, natural and man-made disasters, and others who lack healthcare due to social marginalization.

Health GAP

www.healthgap.org

Dedicated to eliminating barriers to global access to affordable life-sustaining medicines for people living with HIV/AIDS as key to a comprehensive strategy to confront and ultimately stop the AIDS pandemic.

Treatment Action Campaign (TAC)

www.tac.org.za/home.htm

The Treatment Action Campaign (TAC) campaigns for greater access to treatment for HIV/AIDS for all South Africans by raising public awareness and understanding about issues surrounding the availability, affordability, and use of HIV treatments. TAC is also committed to preventing new HIV infections and improving the affordability and quality of health-care access for all.

Treatment Action Group (TAG)

www.aidsinfonyc.org/tag

Founded in January 1992, the Treatment Action Group is the only organization in the U.S. dedicated solely to AIDS research advocacy. TAG focuses on the public and private AIDS research effort to improve the drug development process, speed the pace of medical advances in treating HIV disease and its opportunistic infections, and ensure that the government spends its AIDS research dollars wisely.

South Africa Government Online

www.gov.za/issues/hiv

This website provides official information from the South African government on its HIV/AIDS policies.

To rent or purchase *State Of Denial* please call
California Newsreel at 415-284-7801



P.O.V. is now in its 16th season. Since 1988 P.O.V. has worked to bring the best of independent point-of-view documentaries to a

national audience. The first series on television to feature the work of America's most innovative documentary filmmakers, P.O.V. has gone on to pioneer the art of presentation and outreach using independent media to build new communities in conversation about today's most pressing social issues.

Major funding for P.O.V. is provided by the John D. and Catherine T. MacArthur Foundation, the National Endowment for the Arts, the New York State Council on the Arts, the Open Society Institute, PBS and public television viewers. Funding for *Talking Back* and the *Diverse Voices Project* is provided by the Corporation for Public Broadcasting. P.O.V. is presented by a consortium of public television station including KCET/Los Angeles, WGBH/Boston, and WNET/New York. Cara Mertes is executive director of P.O.V. P.O.V. is a division of American Documentary, Inc.

Above: WGBH Educational Foundation and Medical Library
The AIDS "cocktail" medication

Front cover (top): Rob Oakley

Demonstrators protest against the South African government's AIDS policies and the high price of antiretroviral drugs.

Front cover (bottom): Sven Cheatle

Mary, an HIV positive mother struggles to access treatment for her two HIV infected children.

P.O.V. Interactive

www.pbs.org/pov

P.O.V.'s award-winning web department creates a web site for every P.O.V. presentation. Our web sites extend the life of P.O.V. films through community-based and educational applications, focusing on involving viewers in activities, information, and feedback on the issues. In addition, pbs.org/pov houses our unique *Talking Back* feature, filmmaker interviews and viewer resources, and information on the P.O.V. archives as well as a myriad of special sites for previous P.O.V. broadcasts. P.O.V. also produces special sites for hire, specializing in working closely with independent filmmakers on integrating their content with their interactive goals.

American Documentary, Inc.

www.americandocumentary.org

American Documentary, Inc. (AmDoc) is a multimedia company dedicated to creating, identifying, and presenting contemporary stories that express opinions and perspectives rarely featured in mainstream media outlets. Through two divisions, *P.O.V.* and *Active Voice*, AmDoc is a catalyst for public culture, developing collaborative strategic engagement activities around socially relevant content on television, on line, and in community settings. These activities are designed to trigger action, from dialogue and feedback, to educational opportunities and community participation.

