IMPORTTANT NOTE: This is a creative dissertation. The following contextual essay accompanies the video *AIDS Through Music* found at https://vimeo.com/98964794. The passoword is oweNbOrda931$

DISSERTATION

***The Social Conditions that Fostered the Development of HIV/AIDS Policy 1981-1990 as Described in the Extended Musical Composition* When We No Longer Touch**

by

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Abstract

AIDS was first identified on June 4, 1981 by a report of an unusual cluster of pneumocystis carinii pneumonia (PCP) among a small group of gay men in Los Angeles. AIDS has affected all aspects of health and global policy since that time. This creative dissertation utilizes an interdisciplinary approach to establish a relationship between the development of HIV social policy as related to the struggles and history of People Living with AIDS in the years 1981-1991, and the resulting HIV-related public policy. The author uses the extended musical composition, *When We No Longer Touch,* by Kristopher Anthony using lyrics by Peter McWilliams as the vehicle for exploring this relationship. The interdisciplinary process employed accesses elements of traditional policy, metaphoric, and ethnomusicological analysis to identify key links among policy, poetic text, and music. These three analytical pillars are enhanced by complementary information from leadership studies, ritual studies, thanatology, and memoir. The musical composition provides social commentary, memorialization of life's events, a canvass for grappling with giving meaning to tragedy and offers a framework for hope for the future. The creative dissertation is in the format of a concert performance with accompanying documentary video that brings together major events of AIDS history in this period with music from the composition as the accompanying score augmented by related policy outcomes. The public performance brings a new voice to the ritual commemoration of World AIDS Day. A professional performance of choral works which express the author's involvement in the AIDS epidemic and *When We No Longer Touch* were presented. The lecture recital is accompanied by three contextual essays: (1) provides the historical context in which the work was written linking poetic texts used in the composition to the social conditions of the time and the resulting policy; (2) provides an overview of my personal involvement in the AIDS epidemic and details information about my creative process and the delivery of

my final concert on December 6, 2008; (3) addresses current issues in AIDS policy and articulates challenges for the future. Advances in medical technology, treatment regimes and advances in public policy have brought new challenges to the fore.

Contents

Prologue to the Dissertation

I began my journey as a leader in the HIV[1] epidemic in 1983. I have spent the last 25 years in care giving, dissemination of scientific information, advocacy and new program development, all the while maintaining my life as a professional musician. I remember being an attendee at the first meeting of the National Catholic AIDS Conference in 1984. So little about the disease was known. So many projects were being developed. Such pain was in the air that you could not help but weep. It was at this first meeting that I had a deeply personal encounter with God. This dissertation project is an intermediate stop in this ongoing process, an opportunity for intentional integration of AIDS policy development, social context, music, and personal experience.

The interdisciplinary process I have employed has elements of traditional policy and metaphoric and ethnomusicological analysis to identify key links among policy, poetic text, and music. These three analytical pillars are enhanced by complementary information from leadership studies, ritual studies, thanatology and memoir. These elements coalesce and become a new voice in the public ritual of World AIDS Day. This creative dissertation presents a newly developed approach to the concepts of public ritual as described by (Etzioni, 2000).

This public performance breaks open the role of music as it functions to provide social commentary and memorialization of life's events. It is a canvass for grappling with giving meaning to tragedy and offers a framework for hope for the future. The essays which follow provide context to my exploration of HIV policy in the early years of the epidemic from 1981 to 1990. These years were filled with fear, uncertainty and death: first in the gay community and then in the racial and ethnic heterosexual community. I have used the extended choral work *When We No Longer Touch* (Anthony, McWilliams, & Seelig, 1990) by Kristopher Anthony as the canvass upon which this analysis is

developed. The composer and poet are both members of the community deeply impacted by AIDS, as are the performers by which the work was initially performed.

Anthony, himself a Person Living with AIDS (PWA), composed this multi-movement work for male choir and chamber ensemble using poetic texts written by Peter McWilliams. McWilliams's poems outline the stages of death and dying identified by Elizabeth Kübler-Ross. Anthony links these poems to traditional requiem texts creating a structural framework for a reflection on life, death, and hope, a modern requiem ritualizing the AIDS crisis.

Three essays follow. The first provides the historical context in which the work was written. Poetic excerpts taken from McWilliams's poetry are used to label each of the sections of the essay. The policy analysis that follows links poetic texts used in the composition to the social conditions of the time and the resulting policy. Ultimately, this analysis was the foundation of the development of a 22 minute video documentary. The first essay closes with an analysis of the poetic text in relationship to the requiem texts selected by Anthony.

The second essay provides an overview of my personal involvement in the AIDS epidemic. This background is important to understanding how a professionally trained musician began and maintained a career in public health and how the union of these career paths led to the development of this dissertation project. The essay provides detailed information about my creative process and the delivery of my final concert on December 6, 2008.

Finally, the third essay addresses current issues in AIDS policy and articulates challenges for the future. Advances in medical technology, treatment regimes and advances in public policy have brought new challenges to the fore. The sections of this essay do not include poetic texts. The music and poetry of this current era are still being written.

Essay I – HIV Policy Development

Introduction

The study of HIV policy development for management of HIV prevention, access to care, disease interventions and public institutions is a study of the impact of difference on the evolution of societal response. Recent advances in technology and treatment have made possible a reassessment of the social framework by which HIV-related health policy has developed to address the needs of the American public. Initially, the individual's need for confidentiality, legal protections against discrimination and profound social stigma, magnified by a lack of medical information and options, was addressed through policy and systems that drew upon the framework developed by Mill (1998) in *On Liberty.* As reassessment continues, a communitarian approach as detailed by Etzioni (1993) in *The Spirit of Community* is increasing the norm.

AIDS activists took a libertarian approach in their response to HIV. Historically, the delivery of HIV/AIDS care and services has been derived from the position that the rights of the individual were paramount. In the libertarian model, the voices of individuals were represented through direct action and political expression. As discussed by Etzioni (1993) in *The Spirit of Community* in the case of seat belt use, libertarians long argued adamantly that access to HIV care and services were best organized around the rights of the individual. They felt the government had no role in regulating seat belt use and so felt personal sexual and needle sharing behavior was outside the purview of regulation.

In a subsequent publication, *Balancing Individual Rights and the Common Good*, Etzioni (1997) addresses a key issue in the current HIV debate: universal testing of all blood samples for HIV and the notification of at-risk sexual and needle-sharing partners. The essential question posed frames the entire debate: Will a move to a Communitarian position and application of the "Golden Rule" promote the well being of the community

or cause it harm?

It has long been held that the individual is the ultimate locus of control of HIV-related information. This control encompasses all aspects of the HIV experience: counseling, testing, test results, partner notification, treatment, management of medical information and risk reduction activity. This position cast the community in the position to protect the rights and responsibilities of the individual, subjugating the protection of the community, including the gay community, to a secondary position. This perspective developed as a result of limited protections against discrimination toward PWA and the political strength of the gay white male community with which the disease process was first publicized.

Gay men experienced a revolution in the years following the June 1969 Stonewall riots. The individual and community expression of their sexuality was unbridled. A community norm developed that placed the rights of the individual far above responsibility to the community and some would say in many cases to their own body. Sexually transmitted diseases were commonplace and readily-treated. Traditional public health measures such as the notification of the at-risk partners of the index case became impossible as index cases were reticent to reveal the names of their partners and as anonymous sex became widespread (Coppola, West, & Huck, 1983).

To many AIDS activists and leaders in the gay rights movement at the onset of the HIV epidemic, this and other standard public health measures intensified their fear that community forces would use the control of the epidemic to strip the individual of newfound rights and freedoms. In the book, *And the Band Played On*, Shilts (1987) chronicles the resistance of the gay community in San Francisco to the closing of the bathhouses in which an individual might have in excess of 100 sexual contacts in a weekend. Public health epidemiological investigation identified the baths as the locus for the spread of new infection. The individual right to expression shaped the policy that

allowed the baths to remain open in San Francisco and established the norms for HIV policy to this day. The individual in isolation made decisions for him/herself. Individuals were instructed to act as though "everyone had HIV", and the responsibility for determining if an encounter was going to be "safe" rested with an inquiry of the other party rather than disclosure by the index partner.

Times have changed and the issues that Etzioni identified as minimal for a communitarian approach to HIV have come to be the norm. As described by the Communitarian Network, a communitarian perspective:

- Recognizes both individual human dignity and the social dimension of human existence.
- Recognizes that the preservation of individual liberty depends on the active maintenance of the institutions of civil society where citizens learn respect for others as well as self-respect; where we acquire a lively sense of our personal and civic responsibilities, along with an appreciation of our own rights and the rights of others; where we develop the skills of self-government as well as the habit of governing ourselves, and learn to serve others – not just self.
- Recognizes that communities and polities, too, have obligations – including the duty to be responsive to their members and to foster participation and deliberation in social and political life.

The rise of the communitarian position has, however, limited the voice of the individual. As a result of professionalization of AIDS care, federal funding guidelines, and increased access to care, the voice of the individual has been subsumed into a collective position. This homogenized position presents a generalized, often broad-based statement of goals and objectives, to which input is restricted to professional surveys and studies. Direct action and political input are extremely curtailed.

Background

"I Fear That I Would Come Home One Day…"

On June 4, 1981, the United States Centers for Disease Control and Prevention (CDC) released a report of an outbreak of pneumocystis carinii pneumonia (PCP), a disease ordinarily found in populations of older men of Mediterranean descent, in Los Angles. The epidemiologic report of this rare cancer was identified in a cohort of gay men in Los Angeles. PCP, known to be an opportunistic infection which advances in patients with compromised immune systems, was identified as the harbinger of an unidentified infectious agent. Identification of PCP was the gateway to the identification of a collection of disease processes that had an immune compromised host as their underlying commonality. This unique collection of diseases was common to those identified. As a result, the 1981 report was subsequently classified as the Acquired Immunodeficiency Syndrome (AIDS). AIDS was universally fatal.

In the absence of referential diagnostic tools like serologic screening, the single common factor among these men was their sexual activity with men. Common exposure to and infection with cytomegalovirus[2] (CMV) mirrored seroprevalence surveys of CMV in the gay male population. However, the immune suppression observed in the five index cases was atypical for CMV infection and CMV was not considered a factor in immune suppression but a potential marker for identifying future immune-compromised individuals (Friedman-Kien et al., 1981).

As a result of the CDC report by Friedman-Kien et al. (1981), epidemiological research was undertaken to understand the transmission routes and modes of the unknown infectious agent responsible for the outbreak of PCP in Los Angeles. The absence of a serologic screening test and the resulting epidemiological study, which identified the single common factor among the men as their sexual activity with men, was the set point

for a resulting focus on *Men Who Have Sex with Men* (MSM), known in the public as gay men. This magnified the overall societal stigma against gay men. Fear of a new disease was linked with a profoundly stigmatized lifestyle. This mutually reinforcing dynamic has colored the public's response to AIDS to this day. In response, leaders in the gay community advocated protection of the individual rights of People with AIDS (PWA). The individual's need for confidentiality, legal protections against discrimination, and pervasive social stigma was magnified by a lack of medical information and treatment options. Concerns for protections of individual rights were addressed through the development of policy and legal protections.

In September 1983, *Lymphadeopathy associated virus* (LAV) was identified as the etiologic agent causing AIDS by Luc Montagnier and his associates at the Pasteur Institute, Paris (Barre-Sinoussi et al., 1983). Subsequently, Robert Gallo, researcher at the National Institutes of Health, announced in May of 1984 his discovery of HTLV-III which he determined to be the infectious agent that caused the destruction of the immune system, resulting in AIDS (Gallo et al., 1983). Ultimately, the Committee for Retroviral adopted the nomenclature of Human Immunodeficiency Virus (HIV) as the standard by which the virus would be identified (Palca, n.d.; Brown, 1986).

Diagnostic Tools for Detecting HIV Infection

"…has turned the pain into reality"

Discovery of HIV made it possible for the development of diagnostic tools to test for HIV infection. In 1985, the Food and Drug Administration (FDA) approved and subsequently required testing of the blood supply for HIV antibody tests using an enzyme-linked immunosorbent assay (ELISA) and confirmatory Western Blot. This test was licensed and released in 1987 for use by the general public. The release was limited initially only to professional clinical settings. A commercially available test kit available

for purchase was subsequently released. The release of the test to the general public created levels of concern in the community and raised concerns for privacy and discrimination (United States Food and Drug Administration, n.d.).

Scientific studies of the sexual behavior of gay men proliferated in the first decade of the epidemic as an outgrowth of the early identification of immunocompromised men who have sex with men. With the identification of HIV and reliable diagnostic serologic tools, behavioral studies were initiated. The risk factors for infection were defined by Darrow et al. (1987). A sample of 492 participants was studied, selected from a random sample of a cohort of 785 homosexual men. This particular cohort of men was unique. They participated in earlier studies of Hepatitis B in San Francisco in 1970-80 and have provided a benchmark group frequently referenced by researchers throughout the HIV epidemic. Two hundred and forty (67%) had developed antibodies to HIV as measured by ELISA. These were compared with 119 who remained seronegative. Using multivariate analysis, receptive anal intercourse with ejaculation by non-steady sexual partners, many sexual partners per month, and other indicators of high levels of sexual partners per month were highly associated with seroconversion.[3] These co-factors included partners from cities in which there was a high incidence of HIV infection, medical history of parasites, bleeding with intercourse, seromarkers for Hepatitis B, and treatment for sexually transmitted infections. Only 4 of 18 men (22%) who had not engaged in receptive anal intercourse since entering the cohort had developed HIV antibodies. Men reporting five or more sexual partners per month, sexual exposures in a bathhouse, sexual exposure with someone who subsequently was diagnosed with AIDS, “fisting” by or from a non steady partner, and receptive intercourse with either a steady or non-steady partner were more likely to have seroconverted. The authors concluded that “HIV is transmitted during sexual activities between homosexual men. No sexual activities involving exposure to the semen, blood, or excretions of infected persons have been shown to be safe” (Darrow et

al., 1987, p. 482).

HIV Counseling and Testing

"What will I do…"

Release of the HIV antibody test, behavioral studies and epidemiological studies created a focus on HIV counseling and testing as the locus for HIV-related interventions. Developed as a diagnostic tool, administration of the HIV antibody test became the centerpiece of an intervention model that partnered serologic testing with extended pre- and post- counseling. The counseling sessions were federally mandated, and, as required by individual state statue, included personal risk assessment, suicide assessment, screening for domestic violence, risk reduction counseling, collection and reporting of high risk contacts, and, as indicated, disclosure to potentially infected partners. Testing was offered anonymously[4] by units of the federal and state governments. Non-governmental units provided HIV testing confidentially.[5]

The availability of reliable serologic HIV antibody screening increased the capacity of public health officials to engage in behavioral and epidemiologic research. In September 1999, Weinhardt, Carey, Johnson, and Bickham (1999) published a meta-analysis of the literature focused on the effects of HIV counseling and testing on sexual risk behavior. The authors' results indicate that after counseling and testing, HIV-positive participants and HIV-serodiscordant couples reduced unprotected intercourse and increased condom use more than HIV-negative and untested participants. HIV-negative participants did not modify their behavior more than untested participants. Participants' age, volition for testing, and injection drug use treatment status, as well as the sample seroprevalence and length of the follow-up, explained the variance in results. They concluded that HIV counseling and testing appeared to provide an effective means of secondary prevention for HIV-positive individuals (Weinhardt et al., 1999, p. 1152).

McCusker et al. (1988) followed 270 men who received HIV-antibody testing at a community health center in Boston, 21% of whom were unaware of their HIV antibody status. At intervals of 6 months and 1 year, participants completed a self-administered questionnaire, a physical examination and an HIV antibody test. The levels of sexual activity in study participants declined over time. No effects of the test awareness were found on protective behavior for receptive anogenital contact. Elimination of unprotected insertive anogenital contact was reported somewhat more often among seropositive men who became aware of their test result. The finding suggests some behavioral impact of HIV antibody test knowledge in this cohort. The researchers conclude that the results of the study do not support the use of HIV antibody testing by itself as an informational aid to risk reduction. The authors conclude findings of the study are not generalizable to the other study populations.

Confidential Nature of HIV Test Findings

"I am past the point of going quietly insane…"

Testing, no matter the setting, was regulated by confidentiality laws developed on a state-by-state basis, each state adopting policies based upon core principles defined by the CDC. A system for the release of HIV-related information was developed to manage the transfer of information among providers in health care, drug treatment, social service and corrections systems. The New York State Department of Health was a leader in this area of policy development. In 1985, when Article 27F of the New York State Health Code addressed issues of HIV confidentiality and privacy, 32% of all identified HIV cases in the United States was found in the New York City metropolitan area (the next city of high incidence was San Francisco at 11%). Based on recommendations promulgated by the CDC, detailed regulations were developed to address every aspect of the release and control of HIV-related information. HIV information was a carve-out from existing laws

regulating medical information. The privacy of the HIV-infected individual and their control of their personal health-related information were the standards upon which the regulation was based. Penalties for violations were clearly defined. Similar regulations were developed on a state-by-state basis.

Social Stigma

"The neighbors must think I'm mad."

Legal safeguards adopted to maintain HIV confidentiality were not enough to provide homosexual men with the assurances necessary to consistently receive the results of the HIV antibody test. Lyter, Valdiserri, Kingsley, Amoroso, and Rinaldo Jr (1987) invited by mail 2,047 gay and bisexual men enrolled in the Pittsburgh cohort of the Multicenter AIDS Cohort Study (MACS) to learn the results of their antibody test for HIV infection – human immunodeficiency. "The most frequent reason chosen by 48% of the 188 men who declined results was the belief that the test is not predictive of AIDS. This was also the most important reason for 16% of these men. The next three most commonly cited reasons reflect concern about the potentially harmful psychological impact if the antibody results were positive. Forty-eight percent indicated that a positive test result would be 'too worrisome', 31% felt they would be 'unable to cope' with a positive result, and 28% believed that if their results were positive they would be 'afraid to have sex'. Eighteen percent of the men believed the test was inaccurate and 19% were concerned about confidentiality. Nine percent declined because they were 'not promiscuous' and believed, therefore, that they were not exposed to HIV" (Lyter et al., 1987, p. 471).

Response of the Gay Community

"I'm getting quite noisy about it."

Gabriel Rotello (1997) describes the experience of gay men in New York City in his book *Sexual Ecology*:

> Then I watched with horror as a plague descended and much of my world sickened and died. It is almost impossible to overstate the impact of the AIDS epidemic on gay men, to exaggerate what happened when a group of people deeply stigmatized for the way they made love finally emerged from the shadows, proclaimed that Gay is Good, and then were struck down by a disease spread through the very behavior that was the focus of their stigma. The overwhelming shock of this was something many gay men could scarcely deal with, but then we scarcely had time. We had work to do. We had to discover and fix whatever was causing the epidemic; a task we thought was quickly accomplished with the invention of safer sex. We had to aid the stricken, which we did with the creation of a vast network of personal and institutional care giving and volunteerism. And we had to fight for a cure, which we did with everything from inside-the-Beltway lobbying to tenacious street activism. (Rotello, 1997, p. 2-3)

In August 1981, 80 men gathered in New York writer Larry Kramer's apartment to address the "gay cancer" and to raise money for research. This informal meeting provided the foundation for what soon became Gay Men's Health Crisis (GMHC). In 1982, Nathan Fain, Larry Kramer, Larry Mass, Paul Popham, Paul Rapoport, and Edmund White officially established GMHC. An answering machine in the home of GMHC volunteer Rodger McFarlane became the world's first AIDS hotline, receiving over 100 calls the first night (Gay Men's Health Crisis, n.d.).

Policy Response

As previously discussed, within the gay community, conflict and concern for individual liberties also played a role in developing a policy response. Gay men experienced a revolution in the years following the Stonewall riots of June 1969. Newfound freedom created an atmosphere in which many gay men, in particular those in major urban centers, openly expressed their sexuality, often engaging in sex with multiple partners, frequently under the influence of a wide array of mind altering substances. A community norm developed that placed the rights of the individual above responsibility to the community, and, in many cases, to their own bodies. Sexually transmitted diseases were commonplace and readily-treated leading many of those with these diseases to prioritize their privacy over notifying their at-risk partners. Traditional public health measures such as the notification of the at-risk partners of the index[6] case became impossible, as the index case was reticent to reveal the names of their partners and anonymous sex became widespread (Coppola et al., 1983).

When We No Longer Touch

"The layers I have put around your going are thin. . ."

The extended choral composition *When We No Longer Touch,* by Kristopher Anthony, provides the artistic framework for analyzing the impact of these social conditions on political process of policy development. *When We No Longer Touch* is uniquely suited for this project in that the composition and text were composed by People Living with AIDS. Anthony uses traditional requiem texts juxtaposed with poetry written by Peter McWilliams and based on the stages of death and dying as described by Elizabeth Kübler-Ross. Using interdisciplinary research, the following links are established between specific stages of death and dying as used in the choral work, key policy actions and the key leaders of this era.

Policy Represented

The accompanying documentary video, produced in cooperation with Richard Diefenbach, chronicles the struggles and history of People Living with AIDS, caregivers, family and advocates during the first ten years of the epidemic, 1981-1991. Fear and social stigma, coupled with the untimely death of friends and neighbors galvanized a movement that shaped social policy at an unprecedented rate. These policies continue to shape the global response to HIV/AIDS and influence the development of health policy in the United States.

The video specifically explores four movements of the work as examples of the scope of possible analysis:

1. Fear: Using the movement entitled, "What Will I Do If It Happens," social issues of homosexuality, the role of public health in regulating private activity, the role of government in the regulating of the blood supply and the responsibility of first responders (as a surrogate for all medical providers) are raised. Personal fears that impact the public discourse are identified by fear of HIV transmission by casual contact and limited personal intimacy. We are reminded of the many prominent cultural and political personalities whose lives were impacted by HIV disease.

These aspects of fear provide the underpinning for the

- Testing of the blood supply for HIV and Hepatitis B.
- Reestablishment of universal precautions.

2. Anger: Using the movement, "I Am Past the Point," we experience the rage that fueled the protests of the direct action movement AIDS Coalition to Unleash Power (ACT-UP). With them, we are enveloped by the anger of friends and family at the revelation of a loved one's diagnosis. The subsequent rejection by family and friends as a result of that diagnosis fans the flame of outrage.

These expressions of anger created the climate in which

- Treatment advocacy became the norm and federal officials relied upon the advocates to advance their internal agenda.
- The FDA streamlined and restructured the approval process for pharmaceuticals making drugs available more rapidly to the marketplace.
- By statute, People Living with AIDS are involved in health planning related to HIV/AIDS.
- The AIDS Drug Assistance Program (ADAP) was developed to make essential pharmaceuticals available free to all HIV infected persons. It also helps people with partial insurance or who have a Medicaid spend-down requirement.
- The roots of legal protections against discrimination based on sexual orientation are linked to this expression of anger.

3. Isolation: The segment draws upon the movements "The Layers I Have Put Around My Pain" and "I Am Missing You" as the basis for this exploration. We learn about the personal loathing and isolation common among People With AIDS, the rejection they have experienced from family and friends, the deep sense of abandonment and the troubling lack of access to hospital rooms for 'non-family' members, no matter the depth of their relationship.

These experiences of intense isolation lead to the creation of community-based solutions to the endemic issues of the day:

- The development of extensive buddy programs that provided social support, respite care and informal care throughout the community.
- The adoption of the San Francisco Model of Care, where volunteers were used extensively to supplement traditional medical and social care. Ultimately, this led to the basic mode for the delivery of care as being the community-based organization. Today, these organizations (e.g. Gay Men's Health Crisis) are the backbone of community care

and advocacy networks.

- Organized food delivery and home-based collateral services became essential elements of the continuum of care.
- The social model of care became the norm, supplanting the medical model.

4. Acceptance: We experience the impact of acceptance in the music of "I Shall Miss Loving You." Acceptance enabled a sense of focused action and acts of memorialization to emerge. In acceptance, we see promotion of safer sex practices, syringe and needle exchange programs, programs that support active deathing, and programs that celebrate life. The Quilt Project, candle light memorials, and community remembrances like World AIDS Day become possible.

Acceptance brought into being:

- Film and television productions that focused public attention on the reality that AIDS was a part of the social fabric of the United States.
- The Red Ribbon Campaign, created by Frank Moore, that became the most widely recognized and pervasively used symbol of the AIDS epidemic.
- Programs like Camp Viva came into being to celebrate the living experience of People with AIDS, decrease their sense of isolation and increase skills for living with the virus.
- Memorial activities like the Quilt Project became a routine part of the American folk art tradition to memorialize those lost.

Hope: "I Have Loved" opens the door to the signs that there is a hopeful horizon. The voice of the entertainment industry first expressed by Elizabeth Taylor, one of the earliest and most vocal AIDS activists in the entertainment industry, and continued here through Bono, a contemporary AIDS activist who has a particular focus on the pandemic in Africa who continues to bring hope to a hopeless situation. The transformation of Senator Jesse Helms, fostered in part by Bono, from anti-AIDS activist to a supporter of AIDS assistance programs is a hopeful transformation. The development of medical

interventions, legislative protections and the desire to be alive for the cure are presented here as representations of the possibilities for the future.

Hope is driven by

- the President's Emergency Plan for AIDS Relief (PEPFAR) legislation initiated by President George W. Bush which provides funding to the global fight against AIDS.
- Medical advances in HIV treatment, diagnostic procedures, health monitoring and vaccine research.
- American With Disabilities Act (ADA) providing protections to People With AIDS.
- Fair Housing Amendments Act providing protection against discrimination in all housing with limited exceptions.
- Federal Rehabilitation Act of 1973, Section 504, provided protections against work place discrimination and discrimination in federal employment for People With AIDS.

The Text

"I shall miss, missing loving you." The poet, Peter McWilliams makes this keen observation. Composed by Kristopher Anthony using poetry by McWilliams, *When We No Longer Touch* leads us through the stages of death and dying. Although McWilliams does not attribute the structure of the poetry to the influence of Elizabeth Kübler-Ross, I have followed the example of many who have written about the poems using the Kübler-Ross framework. We are reminded in each phrase that the AIDS epidemic is about people who struggle yesterday, today, and every day to make sense of their personal experience. In the end, it is this experience that drives the engine of effective policy development, community response, and the delivery of care.

A native of LaCrosse, Wisconsin, Kristopher Jon Anthony received degrees in music at the University of Wisconsin and composition at the University of Miami, and pursued doctoral studies in composition at the University of North Texas.

Anthony joined the Turtle Creek Choral in Dallas, and remained a member until his death of AIDS-related complications at the age of 38 on June 26, 1992. He served as composer-in-residence and assistant director of the Choral from 1989 to 1992. *When We No Longer Touch* was commissioned by the Choral and premiered under the direction of Timothy Seelig at Meyerson Symphony Center in Dallas in October 1991.

In 1996 the work was presented by the Gay and Lesbian Association of Choruses at Constitution Hall in Washington, DC, a venue which in earlier years denied the Black soprano Marion Anderson an opportunity to sing, as part of "Music for Life: A Choral Tribute to the Quilt in the Capital." The performance drew these comments from Judy Gruber of the Washington Post: "*When We No Longer Touch: A Cycle of Songs for Survival* was one of the finest musical events of the season. This is a large dramatic work for soprano, baritone, men's chorus and orchestra, with music by Kristopher Jon Anthony and lyrics by Peter McWilliams. Anthony's haunting score calls for violin, viola, cello, bass, harp, flute, English horn, piano and percussion, and he has woven McWilliams's lyrics with text from the Latin Requiem Mass. The result is very effective but never maudlin. The piece touches on grief, despair, regret, denial and anger, yet it also incorporates hope, acceptance and salvation. The poignancy of 'I Shall Miss Loving You' lingered long after the concert was over."

Poet Peter McWilliams was a best-selling author of self-help books who fought for the medicinal use of marijuana. He died June 14, 2000 at his home in Los Angeles. He was 50 and had AIDS and AIDS-related non-Hodgkin's lymphoma. At his death, Mr. McWilliams was waiting to be sentenced in federal court after being convicted of having conspired to possess, manufacture and sell marijuana. At 17 he wrote his first book, "Come Love with Me and Be My Life," a collection of romantic poems published by his own Versemonger Press. Among the better known of the nearly 40 books that followed were "Surviving the Loss of a Love" published in 1971 from which the poems

for the current work are taken (Lehmann-Haupt, 2000).

As a PWA, McWilliams would have been well known to Anthony. I can find no evidence, however, that they actually met or collaborated on the development of this work.

Anthony uses the poetry of McWilliams and places it in dialogue with traditional Requiem texts, the traditional texts of the Mass of the Dead in the Tridentine Rite of the Roman Catholic Church. He juxtaposes these as a reminder that his struggle is not with the material world alone. He struggles to make sense of his experience as a Person with AIDS in the context of God. By using a traditional Requiem text, he places his struggle in the context of Mozart, Brahms, Faure, Britten and other notable composers who, using their individual musical idiom, open a dialogue with God and seek comfort, peace and understanding. This is in keeping with his training as a professional musician.

I have based my comments in the context of that musical tradition and have drawn upon the funeral liturgy of the Roman Rite to bring the poetic and liturgical texts together.

Prologue/Requiem in aeternum.

The stage is set for the feelings that are presented in the poems that follow (see Table 1). McWilliams immediately connects with the fear of the reader for loneliness and links it to pain, a physical hurt that is carried in the body. The immediacy of that moment is brought to the reader, as the future thought of "What will happen?" is recast as a present reality, "It has."

The opening harp chords are a call to worship. The English horn is the faint sounds of the organ inside the sanctuary that greets the casket at the door. We are the loved ones following the casket in the human dialogue between the earthly shock of death and the otherworldly call of Jerusalem, as the choir sings the Latin introit.

Denial.

The denial of the reader is focused on the planning of lifetimes, eternity (see Table

2). Denial in the description of this Kübler-Ross identified stage can be described as the experience of "It can't be happening!" The time of physical knowing and the time of knowing in the heart are challenged as the announcement of impending death is made. These have allowed for the imagination to create emotional experiences that were not possible when confronted with the daily reality of the other. The common aggravations of daily interaction fade and the romantic ideal is expressed. The words are formed in the mind and take on a life creating an image of a parent looking for a lost child. The child is the innocence of self, calling to be reunited with the self. This is evident when the voice of the poem is placed with the lover who survives the death of a beloved. The image of the Good Shepherd from the New Testament also seems to be involved. Endless wandering throughout eternity to find the lost and create the imaginary life has taken shape to guard the living from the loss of the beloved.

The composer presents us with a halting rhythm in the low strings and piano. We hear the irregular tick of a heartbeat, an internal clock. The singers move us to an alternative reality as the elongated notes of their opening stretch time. Ultimately, both instrumentalists and singers are consumed by the throbbing rhythm of anxiety and yearning.

There is no requiem text presented with this poem. By this structural variation, Anthony takes us out of the public events of grieving and allows us moment with the bereaved. These are the musings of the heart wounded and confused. The requiem, focused on the future life, distracts from this deeply personal moment lived in the present.

Isolation.

"Isolation" is not an explicit stage identified by Kübler-Ross (see Table 3). Rather, this poem continues the exploration of denial. The grieving lover cannot escape the essential pain of the loss, even as the wandering to create an eternal life continues. To be

isolated and in denial requires the mind to create distance from the events that bring pain. These layers are added naturally by the mind on a daily basis. There is a tenderness that is concomitant with this process. “The spin of the first layer of life” and the “night in death” create for us a scene we do not remember from our birthing; those last, painful hours as contractions begin in the womb and we are about to be expelled into the first breaths of life outside the womb. The images of the eternal search, the sunrise, the calling end and the reality of the birthing/deathing pain become real. No one gives birth silently. The paradox that we give life to death and find the thin layer of the amniotic sac is broken and the pushing begins in earnest.

Death, like birth, is a painful experience. In the final words of the poem, we are left with the hope that in the sunrise the weaving of the new eternal life will take hold and the infiltrates of reality will stop creating fissures in the warmth of the womb created by the layers of self-protective denial.

The thick choral writing is a stark contrast to the single line melody of the English horn. We hear the bass voices of the choir rattling the bedrock to crack the surface, while singing “Exaudi orationem meam.”

Anger/Dies irae, dies illa.

Anger asks the question, “How dare you do this to me?” a stinging question addressed to God, the deceased and oneself (see Tables 4, 5 and 6). Again, the poet creates a paradox. The narrator is quite noisy about being quietly insane. We get a glimpse into the life of the narrator and the neighbors. They have thought him mad in past situations. One would read the poem to understand that in the past it was without reason. The current state of madness is expressive and appropriately recognized by the neighbors.

The use of 5/4 meter, moving from three beats to two, drives the rage of insanity. Nothing is regular; nothing is predictable in this rhythmic pattern. Anthony uses one of

the most commonly quoted melodic phrases by using Dies Irae. Like Berlioz, insanity is joined to the rages of hell.

Bargaining/Quid.

The direct simplicity of this poem is its strongest metaphor (see Table 7). A clear, direct question. I wonder if before our birth, we ask the same question of our mother. The reader easily understands the bargain between the narrator and God, the narrator and the lost love, the narrator and his lost self.

This hymn-like setting brings the living in direct conversation with the Divine. The melody of the soprano reminds us of angels, the traditional messengers of God, mediating the time and space between heaven and earth.

Depression/Lacrimosa dies illa.

The idea that one can love more intensely in death than in life is a poignant reminder of the life lost (see Table 8). Depression is marked by lack of verbal communication. Short, truncated sentences and phrases. The poet uses this condition in constructing the text. Missing includes all the good and bad memories that have been accumulated. Love is only one among them. Missing becomes a more complete experience than loving.

This is a moving duet between the voices of angels who call the living to prepare of the dead and the human who can never be prepared for the depression and sadness of death.

Acceptance/Agnus Dei.

There is an element of convincing the self that comes with this acceptance (see Table 9). The poet gives the emotions personhood by using a capitalized statement of the emotion making it a name. These characters are players in the development of the plot, which moves from missing the past of loving to the future thoughts that will be marked by the decline of the strong feelings of loss. This immediacy of the loss is connected to the

eventual experience that even a feeling of loss is finite. Comfort, Loneliness, Joy, and Pain are identified and acknowledged. The good and the bad are remembered and a composite of the relationship emerges. In the end, it is missing that matters; and, even missing comes to an end.

We can imagine the final incensing of the casket and the song in our heart as the choir pleads for the eternal rest of the deceased. We hear their voices and accept that this too is our prayer, for their eternal repose.

Hope.

This postlude to the set provides a secondary level of understanding and acceptance that grows from the previous poem (see Table 10).

There is no requiem text to focus us on the deceased. The composer looks to the triumph of life over death. The bereaved lives on in hope. The understanding that hope is born of acceptance completes the healing process. Many people directly impacted by the AIDS epidemic felt that the illness brought communities closer together and created a new context for love. The love that was post-Stonewall and pre-AIDS focused on genital sexual activity. A transformation in the social awareness began with the epidemic that gave birth to the current struggle for gay marriage, gay adoptions and civil unions.

The dead live on in the memory and actions of the living. The perpetual light of eternity becomes intermingled with the song of the living. Ultimately, the conclusion is that “I have loved” is the expression of “Music in Catholic Worship” (Catholic Church, 1983): “People in love make signs of love, not only to express their love but also to deepen it. Love never expressed dies. Christians’ faith in Christ and in each other must be expressed in the signs and symbols of celebration, or it will die.”

Essay II – Personal Process and Personal Reflection

On December 6, 2008, I presented a full length recital/choral concert at the Maryknoll Fathers and Brothers, Ossining New York. The concert was scheduled to be a commemoration of the annual World AIDS Day on the first of December each year. The tri-part concert included an opening movement which was a musical reflection on my work in the HIV/AIDS epidemic, a presentation of my policy analysis delivered in the form of a documentary video, and a concert performance of *When We No Longer Touch.*

This performance became an element of the public rituals of World AIDS Day consistent with the definition of Etzioni in "Toward a theory of public ritual" (Etzioni, 2000). Building upon the work of Durkheim, Etzioni identifies the importance of public ritual in defining the individual and community response to an event. This concert/video event looks to the past to memorialize and commemorate events essential to the socialization of new members of the AIDS community. The musical selections capture the tension between the public and private commemoration of local and global events. Ultimately, this event marks the unity, diversity and relations among the parts of the community impacted by AIDS.

The performers were drawn from the professional ranks of New York City musicians. Faithful to the score, I was able to use a full male chorus, soprano soloist, and complete instrumental ensemble. In addition, I was honored to have Sandra Proctor, internationally known concert organist, and David Broome, innovative concert pianist, join the ensemble.

The setting, the Queen of the Apostles Chapel at Maryknoll, NY, provided a suitable acoustic and elegant setting. This hall was selected after a long search for a hall that would accommodate the forces required for the performance and not be a space too large that the audience would feel apart from the experience. In addition to the performance

space, the Maryknoll venue provided an adjacent hall for viewing the video.

In order to create a context for the listeners, I programmed a first movement for the evening that offered some insight into my work in and passion for HIV/AIDS issues. The selections lay the groundwork for and understanding of how and why I would consider addressing HIV policy using a musical composition.

This first movement also allowed the listener to be engaged in the process of experiencing the policy analysis. As addressed earlier, the conductor is a transformational leader and as such leads both the performer and listener in a process that moves them to a new level of understanding (Armstrong & Armstrong, 1996). The works in this section set the stage for that transformation.

The documentary video followed. Designed to provide links between the social conditions in the first ten years of the epidemic and the development of social policy, this 22 minute educational piece used clips from news footage, made-for-TV movies, popular media and Hollywood produced motion pictures to build its case. The musical soundtrack comprised selections from *When We No Longer Touch.* At the conclusion of each section, a silent screen was used to identify the policy activity associated with the social context presented in the previous video section. The viewer experienced the pathos of the time. They were also engaged in a subliminal experience of the musical composition that linked the music to this pathos.

A full concert presentation of *When We No Longer Touch* completed the program. Anecdotal comments from the audience identified the impact in which they were engaged by attending the concert.

The Concert – Movement I

I began the concert as I have begun each AIDS presentation I give. A quiet reflection on Veni Creator Spiritus is my personal centering activity: “Come Holy Spirit, fill the

hearts of your faithful. . . veni Creator Spiritus. . . " (see Table 11, "Veni Creator Spiritus").

"You are more a G-clef than a Red Ribbon,' a friend once told me. He was referring to my dual career in music and as a full-time HIV/AIDS policy wonk. I have carried this sentiment closely as I evaluate my daily experiences living at the intersection of two such diverse yet profound disciplines.

I have come to appreciate only now the statement is not quite right. Rather, I am the embodiment of that fluid ribbon that makes both the G-clef and the Red Ribbon different expressions of the same form. Indeed, the flexibility of the ribbon allows for distinct expressions of music and of HIV concern. The wonder is that this also allows the interconnection of many life experiences within the insights of these two, primary worlds.

Oddly, my entry to the world of HIV/AIDS was as a musician. With no background or training in HIV I relied on my skills as a performer to initiate many AIDS education programs in 1986 and beyond. My personal truth is clear: If you can live through music school and the associated pressures, you can live through anything. It was my training as a conductor that has had the greatest continuing impact on my work. When developing programs and working with groups, I draw upon my skill as a professional conductor, engaging performers and exploiting their unique talent, and, in the framework of trust, building up the individual within the cohesive ensemble and ultimately producing excellence in performance. As the conductor, I create the vision together with the performers and sustain it for them as the goal towards which the ensemble moves. Here, the G-clef becomes the living Red Ribbon.

This skill is guided by my theological prism, the Gospel call to building community. At the beginning of my music ministry, I was struck by this excerpt from "Music in Catholic Worship":

"People in love make signs of love, not only to express their love but also to deepen it. Love never expressed dies. Christians' faith in Christ and in each other, must be

expressed in the signs and symbols of celebration, or it will die" (Catholic Church, 1983, p. 4).

It is this love, the love of God, continually imposed on our past as well as our present, which keeps me in this commitment. In these days before Christmas, it is particularly clear to me that Incarnation is a continual process of acceptance and expression (see Table 12, "O Magnum Mysterium").

This expression of love in symbol and in community is not uniquely the prevue of the worship space. It pervades all that we do and is, for me, deeply rooted in the symbols of the G-clef and the Red Ribbon.

The AIDS community is not without its symbols and expressions. Red ribbons, quilt panels, public celebrations and memorial services are symbolic gestures that express the depth of feeling engendered by engagement in the AIDS community at any level.

So, as I reflect on my involvement in the AIDS epidemic, my life is inextricably linked to these primary symbols, all composed of the same fabric of and vision for all people (see Table 13, "'People' from Funny Girl").

The development of my AIDS expertise followed a winding path. Beginning with my work at the American Red Cross, I quickly became involved in AIDS issues that had a national perspective. I moved from this education and policy position to be the founding administrator of the Westchester County Medical Center Designated AIDS Program. This was an immersion experience in the delivery of health care and hospital administration. Subsequently, I was hired by the Westchester County Commissioner of Health to be an AIDS policy advisor, an exciting position that placed me in a very public role as executive director of the Westchester AIDS council, County AIDS spokesperson and policy wonk – always with an eye to the end of creating a system of prevention and care that addressed the emergent and continuing needs of those infected and at risk.

Through the National Catholic AIDS Conference, I met leaders in the fight against

AIDS from within and outside the church. I remember being an attendee at the first meeting of the conference in 1984. So little about the disease was known in those early days. So many projects were being developed. Such pain was in the air that you could not help but weep. It was at this first meeting that I had my first deeply personal encounter with God. It was anything but the warm, embracing, comforting God of Psalm 23. Surrounded by a cold flash in the University of Notre Dame Basilica of the Sacred Heart, I came to know the mantra of my work: "The Lord is my light and my salvation, whom should I fear" (Psalm 121). The power of this psalm is magnified by the trust that is evidenced in the subsequent psalm. We have no fear because life is a journey to Jerusalem, building a kingdom of peace. People with AIDS are my companions on this journey, teaching me a depth of understanding that comes from the pain of struggle.

In that basilica, in the cold of that lonely moment, I was searching for peace. That moment was the beginning of many glimpses of the new and eternal Jerusalem radiant in the eyes of the People with AIDS I have been privileged to know. Truth itself provides permission to search for peace (see Table 14, "Psaume 121").

Among the training, public appearances, policy work and care giving, I have always maintained work in the religious sphere. Funerals, memorial services, quilt showings and World AIDS Day remembrances have been abundant. Working with the dying, grieving families, lovers, friends and care staff, I was witness to the very real struggle to gain understanding of AIDS and death. As a musician, I was challenged to assist in making musical selections that were not always 'traditional' or 'appropriate.' However, understanding that God is immediately present to us, and within all of creation, who am I to question where and how the Spirit speaks? Standard popular songs became part of the expression of life often performed at these gatherings. They are themselves the expression of a G-clef as Red Ribbon: surrounding pain, expressing the culture of affliction and suffering, ultimately offering hope (see Table 15, "Danny Boy"; Table 16, "Amazing

Grace"; and Table 17, "Over the Rainbow").

Hope, ever present to the human spirit, was the fuel that kept all of us, those living with and affected by AIDS, moving forward. In those early days of the epidemic, the devastating ferocity of a living, relentless and resourceful particle, a virus, made hope the only medication available. For a generation of AIDS caregivers and advocates, the Red Ribbon gave life to the belief that a cure would be found. The Red Ribbon was the symbol of local efforts filled with compassion and care. The Red Ribbon is the symbol of unity and diversity, an understanding of which is an act of continuing socialization.

I have been fortunate in these years of AIDS work to have used the flexible expression of the ribbon to directly and indirectly better the lives of many and support their embrace of hope. Camp Viva was one of those efforts. Born of frustration with the clinic system and legal statutes that imposed isolation on individuals with AIDS, I worked to establish a collaborative that would provide a fun-filled opportunity for socialization and respite to families (very loosely defined) and individuals with AIDS. Camp Viva continues today as an opportunity for those people at the fringe to come to the center and be welcomed, surrounded by the ribbon of friendship and fun.

Camp Viva, the work with the Red Cross, the AIDS Care Center, countless families who grieve the loss of so many friends and the hundreds of talks given to groups across the country are all an experience that has given me access to the Divine. The mystery of the Incarnation brings my life into focus as I have seen the light of the Divine in the faces of the people I have met and with whom I have worked. They have given me laughter and healing. This is the mystery of the Incarnation.

This reflection closes as it opened, melding the G-clef with the Red Ribbon in an expression of community and trust. The two aspects of a ribbon, AIDS symbol and G-clef are that river of life, flexible, creative and always moving us all toward the goal of moving from the margins to a full life at the center (see Table 18, "Blessed Assurance").

The Concert – Movement II and III

The program notes and description of these movements are embedded in the first essay above.

Analytic Methods – Interdisciplinarity

Drawing upon my experiences in AIDS as a background, I adopted an interdisciplinary approach for discussing the relationship between the musical composition and the social conditions that were the underlying forces that drove the development of AIDS-related policy from 1981 to 1991. The National Academy of Sciences, National Academy of Engineering and Institute of Medicine of the National Academies developed the following working definition of interdisciplinary research in 2005:

> Interdisciplinary research (IDR) is a mode of research by teams or individuals that integrates information, data, techniques, tools, perspectives, concepts, and/or theories from two or more disciplines or bodies of specialized knowledge to advance fundamental understanding or to solve problems whose solutions are beyond the scope of a single discipline or field of practice. (Committee on Facilitating Interdisciplinary Research & Committee on Science, Engineering, and Public Policy, 2005)

The authors posit that at the heart of interdisciplinarity is communication – "the conversations, connections, and combinations that bring new insights to virtually every kind of scientist and engineer. . . without sustained and intense discussion of such possibilities and without special effort by researchers to learning the languages and cultures of participants in other traditions, the potential interdisciplinary research might not be realized and might have no lasting effect" (Committee on Facilitating

Interdisciplinary Research & Committee on Science, Engineering, and Public Policy, 2005, p. 20-21).

Veselinovic-Hofman (2005, p. 9-27) develops an interdisciplinary approach systematic understanding of musicology and related ethnomusicology that reflects this definition. Using examples from contemporary Serbian music, she addresses the communication between the interrelated nature of the mixed media involved in the music and the social context of the work's creation and the role of the listener.

The interdisciplinary process includes analysis and synthesis. Working with the composition *When We No Longer Touch,* analytic processes common to thanatology,[7] sociology, public policy and ethnomusicology, presented through the vehicle of a choral conductor were employed. These were synthesized in a process developed by Mary McGann (2002), RSCJ, and published in her essay "Exploring Music as Worship and Theology: Research in Liturgical Practice." She lays an interdisciplinary foundation for the research process and interpretive strategies that draws from liturgical studies, ethnomusicology and ritual studies that are understood as starting points for exploring what takes place when an assembly makes music. I adopted McGann's approach after reading Etzioni (2000) in *Toward a Theory of Public Ritual*, Berezin (1997) in *Politics and Culture: A Less Fissured Terrain* and Gusfield and Michalowicz (1984) in *Secular Symbolism: Studies of Ritual, Ceremony, and the Symbolic Order in Modern Life*. These authors analyze contemporary observance of holidays, procedures embedded in the political process and the development of an institutional order as secular rituals; that is, public rites in which the community engages to form community. This is the secular equivalent of McGann's premise that "persons and communities who make music in culturally distinct ways, and through their music express their existence…" (McGann, 2002, p. 7).

Although the discrete disciplines are different, there are similarities between liturgical practice, thanatology and sociology, and public policy and ritual studies to make her approach easily modified to the analysis I completed, from which the documentary video and performance were derived.

A necessary focus on thanatology is well described by Gabriel Rotello. The experience described by Rotello can be understood in terms of the stages of death and dying as described in the seminal classic *On Death and Dying* (1969), by Elizabeth Kübler-Ross, MD. These stages are particularly notable in this research as both the composer and poet chose the Kübler-Ross model as the focus of their work to express their point-of-view.

In response to the HIV/AIDS epidemic, Kübler-Ross refocused her discussion of death and dying in light of her experiences with People With AIDS and their families in the book *AIDS: The Ultimate Challenge* (1987). In this she creates in the late twentieth century what the *Ars moriendi* achieved in the Middle Ages, an approach to understanding the ritual process of dying in response to the contemporary plagues of their day (O'Connor, 1942). Each text articulates a social process that approaches death by creating a ritual process in which the patient and the family can identify benchmarks and from which they find comfort.

Ultimately, she links the stages of death and dying as described in her earlier works with the patient dying of HIV infection, the caregiver to the patient, and the community in which the patient lives. She argues that the ongoing stress of the possibility of HIV infection for each individual and the continuing deaths of a significant number in the community is itself a form of dying.

Morrison (1996) graphically describes the relationship between the arts and HIV/AIDS and alludes to the grief process described by Kübler-Ross. "In the midst of AIDS-related death and dismay, art has depicted the devastation, spread hope for the

future, and promoted democratization. Worldwide, the cultural world is being decimated by AIDS" (Morrison, 1996, p. 118). A reciprocal relationship also exists, as the author notes that draw upon the arts as a "bearing witness, affirmation, and galvanization." The analysis of *When We No Longer Touch* draws upon the key roles identified by these authors. "Bearing witness involves the testimonies of mourning, remembrance, and reverence, and includes elements ranging from red ribbons to elegy. Affirmation is part of a general process of moving the traditional boundaries from prevention to promotion. Finally, galvanization is the essence of activism. Whether used to confront authorities, to articulate desires, or to challenge beliefs, art and AIDS embody partnerships and community action."

The development of public policy in the AIDS epidemic follows from the engagement of the public rituals described above. Policy was developed that insured the rights of the individual as primary, compelling the government to a position of "reasoning" or "persuading" them to engage in HIV risk reduction behavior, seek HIV counseling and testing, share HIV-related information, and seek HIV treatment. Community support of gay men of this position was unquestioning. In the book, *And the Band Played On* (1987), Randy Shilts chronicles the resistance of the gay community to efforts of the San Francisco Department of Public Hygiene to the closing of the bathhouses, in which an individual might have upwards of 100 sexual contacts in a weekend. This despite clear epidemiological evidence that the baths was the locus for the spread of new infection. The individual right to expression shaped the policy that allowed the baths to remain open in San Francisco and established the norms for HIV policy to this day. The individual in isolation made decisions for himself. Individuals were instructed to act as though "everyone had HIV" and the responsibility for determining if an encounter was going to be "safe" rested with an inquiry of the other party rather than disclosure by the index partner. It is hoped that disclosure will happen as a matter of course and that the

sense of doing no harm to another will lead to disclosure.

To engage these phenomenon ethnomusicological research tools were used to bring the social context of the early years of the AIDS epidemic into dialogue with the selected musical composition. Ethnomusicological analysis engages the place of music in a culture or society. This approach is well suited for the exploration of the socio-political issues of AIDS in a musical context. Conceptually, ethnomusicologists "have drawn from a variety of theories or approaches, and the boundaries between them are treated as porous and permeable" (Stone, 2008, p. 10).

Further interdisciplinary research on the AIDS epidemic is required to gain further understanding of the human experience and the policy results given rise by that experience. Etzioni (2006) outlines the *Unique Methodology of Policy Research*. He describes malleability, scope of analysis, private and confidential research, and communication as key elements of policy research. He draws upon his philosophical position as a communitarian to develop these themes.

The Conductor as Transformational Leader

As a choral conductor, I engage this body of data, apply it to the interpretation of *When We No Longer Touch,* produce a performance and reflect on the experience of the process.

Henry Coward in *Choral Technique and Interpretation* (2007) outlines the conductor's charge. In chapter eight, he focuses specifically on the choral conductor. The first thing a conductor requires is self-reliance, born of mastery of the subject he has to inspire the performers and guide them to a common vision. The conductor must have power to inspire, incite, and command.

His focus on leadership is echoed in *The Conductor as Transformational Leader* (Armstrong & Armstrong, 1996). They present an analysis of the conductor as a model for

understanding transformational leadership and enabling a generalized application of these characteristics to a broad audience. They develop the thesis that there is more to successful leadership than producing a worthy product. Conductors can and should have a transforming impact on the musicians in their ensemble. Although I did not study this phenomenon specifically, there was a great deal of anecdotal evidence that the performers and the listeners of the December 6, 2008 concert were transformed by the experience.

The ability to forge a shared vision is a characteristic of a transformational leader. Transformational leaders inspire belief and trust, which allow those they lead to look beyond their doubts and make a commitment to the common vision. This is easily applied to conductors' need to have a vision for their performing organization, for their music program, and for themselves.

Through positive modeling, the transformational leader models the way he or she desires his or her followers to act. Scott notes that this "characteristic of the transformational leader has also been described as the 'management of trust'." The group learns very quickly that it can rely on the leader, who is exactly what he or she appears to be. "The transformational leader is not a dictator, but an enabler. When conductors show their enthusiasm, share their vision, produce through people, model the way, empower, and encourage, the result will be students who have a vision and the strength and ability to make it come true" (Armstrong & Armstrong, 1996). As a conductor and transformational leader, my responsibility was to be thoroughly conversant in the background material and analysis, musical structure and performance practice suitable for a successful performance of the composition. The ability to lead and create a vision is essential in this process.

The performance of this work became a metaphor of the AIDS grieving process and a public ritual as described above. The choir and orchestra become a community. As such, they developed a lived experience of the work by drawing on their personal experience of the AIDS epidemic and the impact of the musical work in their lives. This experience is a

shared, community experience as the performers meld to achieve the common vision of performance.

Performance as Ritual

This performance becomes a part of the public ritual of the AIDS epidemic by its performance on December 6, to coincide with World AIDS Day commemorated on December 1. World AIDS Day was first recognized on December 1 in 1988 by the World Health Organization to focus global attention on the HIV/AIDS pandemic (National Institute of Allergy and Infectious Diseases, 2001).

From the start, the World AIDS Day commemoration has included 3 key elements: memorial of those who have died from the complications of HIV infection, public education and awareness campaign to increase awareness of the global spread of HIV, and local activities to engage the public in action that has a local impact.

Etzioni develops a theory of public ritual expanding on the work of Emile Durkheim. He begins with a summary of Durkheim's relevant points:

1. Profane (secular), routine, daily life, the conduct of instrumental activities at work, and carrying out household chores, tend to weaken shared commitments to beliefs and social bonds, and to enhance centrifugal individualism. For societies to survive these centrifugal, individualistic tendencies, they must continuously "recreate" themselves, by shoring up commitments to one shared ("common") set of beliefs and practices.

2. Rituals provide one major mechanism for the recreation of society, one in which the members of a society worship shared objects and in which they share expe-riences that help form and sustain deep emotional bonds among the members.

3. The specifics of the ritual, and the objects that are being worshipped or celebrated in these rituals, be they colored stones or woodcuts or practically anything else, have no intrinsic value or meaning. It is the society that imbues these objects with significance,

and, thus endowed, they become the cornerstones of the integrative rituals built around them (p. 45).

Commemorations of World AIDS Day fall within the overarching rubric of the Durkheim/Etzioni construct. Following the articulation developed by Etzioni, World AIDS Day holidays can be understood from the perspective of global indicators (p. 45), socialization agents (p. 47), an expression of unity, diversity, and relations among the parts (p. 49); maintaining a tension between public and private commemoration (p. 52); the cyclic nature of subordinate commemorations that have emerged from the December 1 event (p. 53); the key elements of design and tradition (p. 55); and the impact of World AIDS Day celebrations focusing on the past and lagging behind the future.

The concert/documentary format provides for the presentation of information, analysis and reflection structured in the format of McGann (2002). McGann describes three research tasks. First, the researcher must "come to know the music as we come to know the community." Here the researcher "learns the complex relationships that are mediated in the community's life and in it liturgical-musical performance" (McGann, 2002, p. 39). The second task is to make the learnings available for further reflection within the field. McGann proposes that these two activities are best accomplished through the third task, an ethnographic study rooted in the understandings and categories of those who perform.

Participants in this concert, the researcher/conductor, performers and audience were transformed by their role in the concert. The transformation provided them with memory of the events of their personal and/or communal past, insight into the impact of those historical events and offered them an opportunity to bring this experience to life in their interaction.

Essay III – Changing HIV Epidemic

The creative work of this dissertation is a first attempt to draw upon this understanding of public ritual as applied to World AIDS Day and expands upon them to form the vehicle to engage the participant in a new level of action.

Embedded in the performance, video and essays are the memorialization of the HIV infected – living, dead, and their life partners, segments of public education to describe the spread of HIV infection locally and globally, and as a local performance is a local activity that engages the public in an action that has local impact.

To date, the literature discussing World AIDS Day describes the ritual action of World AIDS Day and makes suggestions for concrete local action. This dissertation draws these rituals into a context and uses them to analyze the impact of these past actions on policy and assessment of the future course of this impact.

In particular, this dissertation addresses the limited scholarly literature assessing the impact on the experience of People With AIDS living in the first 10 years of the epidemic, the years preceding the release of protease inhibitors, on the development of public policy and the rituals of World AIDS Day.

This is the first work that uses an interdisciplinary method and a creative media performance medium to express such findings to a public that has a wide range of experience with and background in the epidemic.

Further interdisciplinary research on the AIDS epidemic is important to gain understanding in the human experience and the policy results given rise in the experience. In the *Unique Methodology of Policy Research*, Etzioni (2006) describes malleability, scope of analysis, private and confidential research, and communication as key elements of policy research. He draws upon his philosophical position as a communitarian to develop these themes. This emergent philosophical position requires new leadership that

will, at its best, draw from the lessons learned in the first ten years of the epidemic.

Medical and Technological Advances

In 1996, the understanding of HIV disease and the delivery of HIV care changed. The ability to inhibit the replication of HIV by blocking the functioning of protease in cell division through the use of protease inhibitors had dramatically reduced the number of deaths due to AIDS and progress of disease in HIV infected individuals. HIV infection and disease progression was widely discussed as a "long-term chronic illness" like diabetes (Beaudin & Chambre, 1996). The progression of scientific opinion from the plague model to the chronic disease model was begun in June 1989 when Samuel Broder, then head of the National Cancer Institute, declared that AIDS was "Like Cancer" and should be treated in the same way (Scandlyn, 2000).

New therapies were developed to supplement the effectiveness of AZT. The first of these was Saquinavir. The therapeutic benefits were immediately identified in clinical trials of the drug Saquinavir, a protease inhibitor. Over 16 weeks of treatment, CD4 cell[8] counts increased on average for 30 to 40 cells above entry level in patients on saquinavir in combination with other antiretroviral drugs (United States Food and Drug Administration, 1995). The introduction of protease inhibitors, administered in combination with previously available HIV antiretrovirals brought a precipitous decline in deaths among People With AIDS (see Figure 1).

The release of protease inhibitors dropped the number of deaths from AIDS in the United States from a high of 51,297 in 1996 to less than 20,000 by mid-1997.

This drop in AIDS-related deaths brought treatment optimism to the community of HIV providers, People with AIDS, and the community at large. Pharmaceutical companies began intensive campaigns showing robust models portraying HIV infected individuals living healthy, active lives as a result of combination drug therapy (Kumbier, 2001).

Beginning August 1, 1999, the New York State Department of Health implemented a comprehensive newborn HIV screening program. This program mandated that all newborns in New York State be screened for HIV as a standard of care. This screening may happen during the mother's prenatal care or immediately postpartum. The mother must receive the test result during the initial newborn pediatric visit. This policy change was made in response to the findings of the clinical trial commonly known in the industry as 076. The trial tested administration of zidovudine (AZT) during labor and delivery. The treatment resulted in the reduction in the rate of HIV infection from a mother to the newborn from approximately 33% to less than 8% (New York State Department of Health, 1999). This practice posits the concern for the well being of the fetus over the rights of the mother. As a result of the implementation of the testing policy and treatment intervention, Westchester County, a New York suburban county of approximately 1 million residents, has seen a drop from a high of 12 cases of HIV in newborns annually to zero (Westchester County Department of Health, 2005).

Technology further fueled a change in the HIV delivery system with the development of laboratory tests that made geno-typing and phenol-typing of the virus in the blood of the infected individual. This diagnostic test was approved by the FDA in 1999. This advance allowed clinicians to identify the specific nature of the HIV with which the individual was infected and the drug resistance of the virus. This allowed clinicians to prescribe medication in a combination that most efficiently worked to control the specific virus in each individual (Hwang, n.d.).

The most recent technological advance to impact the HIV care system is the approval of a serologic screening test for HIV, which provides a test result in 20 minutes. Approved in June 2004, this assay-screening test provides a non-invasive, oral swab method of determining if the client is reactive or non-reactive to HIV antibody reagents. Those who are non-reactive are not infected with HIV at the time of the test (95%

confidence interval). Those who are reactive are referred for confirmatory testing of their HIV status, generally accommodated through seroscreening with the Western blot test.

Public Opinion

As a result of these technological and medical advances, policy addressing the HIV epidemic is at a crossroads. At issue is the continued "exceptional" treatment of HIV infection as a unique disease process requiring discrete policy and practice, maintaining the delivery of HIV care, prevention and funding through a system that parallels the delivery of routine medical care. This dialogue is influenced by the voices of many communities, participants in many of which share multiple memberships. These include but not exclusively the public-at-large, medical providers, consumers/People Living with HIV, medical and social researchers, funders, and health care advocates. At issue are policies that have been the bedrock of HIV policy and care: HIV confidentiality, delivery of HIV counseling and testing, partner and contact tracing, names reporting to governmental units, integration of HIV primary care into the general primary care setting, discrete funding for HIV social service programs, risk reduction strategies focused on HIV infected individuals, and managed care for HIV infected patients.

Government sponsored public education campaigns have been the focus of study. Of particular note is research exploring the impact of the October 1997 United States government sponsored public education campaign. This campaign was designed to reach every household in the United States. The Gallup Organization conducted public opinion surveys before and after the campaign. The data were reviewed and analyzed by Singer, Rogers, and Glassman (1991). Their findings addressed changes in public information and misinformation about transmission, in concern about AIDS as an epidemic, and in reported behavior to avoid exposure to AIDS. The authors determined that some changes could be identified over the time studied. They concluded, however, that these were

consistent with the trends for change which had begun before the campaign and continued long after the campaign had ended (Singer et al., 1991, p. 161).

Among the many factors fueling this debate is the perception of the public at large on the direction and progress of the epidemic. The sense of urgency for the HIV epidemic among the public-at-large continues to decline. The 2006 Kaiser Family Foundation Survey of Americans on HIV/AIDS, published in May 2006, found that 17% of respondents ranked HIV the most urgent health problem in the United States, ranking it third behind cancer and heart disease. This is a drop in ranking from first place in 1995 and second, behind cancer, in 1997 (see Figures 2 and 3).

The survey further identified a drop in concern among respondents that they were personally very concerned about becoming HIV-infected, falling from a high of 24% in October 1997 to a low of 15% in March 2006, the time during which the data for the survey was collected. This trend is even more pronounced when addressing issues of concern of parent for their children. In October 1997, 53% responded that they were "very concerned" about a son or daughter becoming infected with HIV. In March 2006 the percentage had fallen to 32% (see Figure 4).

This trend toward decreased personal concern is mirrored in the perception of respondents most likely to be infected. When asked in an open ended question: "Which groups of people do you think of first as those who are most likely to be infected?", respondents reported the following result shown in Figure 5.

These responses do not reflect the current epidemiology of HIV infection. Today, about one-third of new infections are transmitted heterosexually, up from 3% in 1989, as reported by Centers for Disease Control and Prevention (2004). More than half of those diagnosed with HIV are black, up from 25% in 1986, though blacks account for about 12% of the US population (Centers for Disease Control and Prevention, 2005). Black women and black gay men are especially at risk.

Infection rates among black women in the USA are 20 times higher than for white women and five times higher than among Hispanic women. Two-thirds of HIV infections in young women result from unsafe sex with infected partners as reported by the CDC. “More than half the women we treat had one sexual partner and no idea he was HIV positive,” says Donna Futterman, director of Adolescent AIDS care at Montefiore Medical Center in New York (Centers for Disease Control and Prevention, 2003). This is the story typically heard by HIV/AIDS care practitioners.

Heterosexual sex has now become a major transmission route for HIV and is a leading cause of infection among women, especially within minority communities. In fact, the proportion of total AIDS cases attributed to heterosexual transmission has increased six-fold since 1989, from 5% to 31% (Espinoza, Hall, Campsmith, & Lee, 2005).

In the face of this, the 2006 Kaiser Family Foundation findings among African Americans are instructive. When asked: “Bearing in mind the different ways people can be infected with HIV, how concerned are you personally about becoming infected with HIV?”, 45% responded either “not too concerned” or “not at all concerned.” This follows a trend among African American respondents who responded that they were personally “very concerned” at 55% on November 1995 to a low of 34% in March 2006 (see Figures 6 and 7).

Media coverage and the role of the media were studied by Brodie, Hamel, Brady, and Altman (2004) for the Princeton Survey Research Associates International and the Kaiser Family Foundation in October 2003. The findings of the survey mirror the findings of the 2006 Family Survey. The decline in personal concern has followed the decline of total media coverage of HIV/AIDS which has decreased since the late 1980’s when total coverage peaked at over 5,000 stories in 1987. International AIDS conferences have received greater coverage by the media. This has mirrored the increase of the focus on global issues as presented in the news stories. Over time, the study concludes, fewer

stories contained information related to consumer education (Brodie et al., 2004, p. 1).

Stigma

Stigma towards People Living with HIV has shaped the HIV policy debate since the earliest days of the epidemic. During August-September 2000, the Research Triangle Institute (Lentine et al., 2000) conducted an internet-based, household study of 7493 adults aged 18 years or greater. The reported findings were based on an analysis of 5641 respondents (75.3%) who answered the question considered to be a proxy indicator for a stigmatizing attitude. The findings suggest that most adults in the United States do not hold stigmatizing views about persons with HIV infection or AIDS. Significantly more of the respondents misinformed about HIV transmission gave a stigmatizing response, suggesting that increasing understanding about behaviors related to HIV transmission may result in lower levels of stigmatizing beliefs about infected persons (Lentine et al., 2000, p. 1).

An integral participant in any conversation about HIV/AIDS is the physician-provider. The attitudes and beliefs of the physician can have a profound impact on the service delivered, both its quality and its quantity. Yedidia, Barr, and Berry (1993) surveyed house staff, faculty and applicants at six residency programs in internal medicine and six in surgery. House staff had more negative outlooks than senior medical students and faculty. They reported greater fear of exposure to AIDS and greater unwillingness to treat AIDS patients. Comparing the two areas of training, surgeons expressed more negative outlooks than internists. For all groups, concern expressed about possible negative educational consequences of treating AIDS patients was a function of their amount of contact with AIDS patients. Comparing willingness to treat AIDS and nine other conditions, AIDS consistently ranked low, along with Alzheimer's disease, alcoholism, and drug dependency (Yedidia et al., 1993, p. 273).

As a result of the 1993 study, the authors subsequently studied and authored *Changes in physicians' attitudes toward AIDS during residency training: a longitudinal study of medical school graduates* published in 1996. This prospective panel study collected data on 383 physicians at two stages: as fourth year medical students and third-year residents. Aspects of residency training were the most powerful predictors of increase in willingness to treat People With AIDS. Decline in willingness was primarily a product of negative social attitudes, for example homophobia and aversion to injection drug users. Cynicism toward patient care acted as a trigger (Yedidia et al., 1996, p. 1).

AIDS Exceptionalism

The current HIV policy debate centers on changes in the fundamental understandings of confidentiality and access to care. The dialogue is framed in the social context of American exceptionalism. The American ideal of ruggedness, the shining city on the hill, the ever hopeful conquering nation set to right the world's ills. Kohut and Stokes (2006) observe, "American's self-confidence breeds indifference and inertia toward dealing with problems. . . Americans tend to minimize challenges even as they acknowledge them." Citing major polls conducted by Pew in mid-1999, the authors note that eight in ten Americans described themselves as hopeful. Majorities predicted that AIDS would be eradicated in the 21st century, cancer would be curable, and ordinary people would travel in space.

The changes in the landscape of HIV care and delivery include key areas of concern to policy makers. Increased access to screening for infection, effective pharmacological therapies and diagnostic tools to maximize treatment have had an impact on health policy both in the realm of public opinion and in the financing of care. No longer was AIDS the untreatable disease. Rather, the possibility of treatment and long-term survival with the virus has become a reality.

Traditional AIDS advocates spoke in support of these measures and struggled to determine their position in this new landscape. Public health professionals long in support of primary prevention to combat the HIV epidemic began advocating a return to standard public health models for medical interventions. They cited the following statistics:

1. The number of new infections of HIV has been stable at 40,000 cases per year since 1990 (see Figure 8).

2. After 15 years of decline, the number of new cases of AIDS has begun to climb steadily since 1999 (see Figure 9).

3. HIV is moving into the heterosexual population (see Figure 10).

4. Women are increasingly part of the case mix (see Figure 11).

As a result of these technological changes and data, on September 21, 2006, the CDC issued *Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings* (Branson et al., 2006). These recommendations were developed in response to the continuing rate of HIV infection of 40,000 new cases of HIV infection per year and advances in the treatment of HIV disease. By issuing these guidelines, the CDC continued the policy shift from the individual rights enshrined in public policy from the earliest days of the HIV epidemic to a communitarian, public health approach. Heralded as the end of "AIDS exceptionalism," the guidelines reframed HIV testing as a routine diagnostic test.

The discrimination and stigma of the early years of the AIDS epidemic fostered the development of complex regulation of HIV-related activity. Principal among these was the requirement that all HIV diagnostic testing be preceded by an exhaustive pretest counseling session, authorized by specific consent, and followed by test results delivered in a structured, face-to-face encounter with a health care provider. These regulations were necessary to focus the locus of control on the individual as the sole authority in control of the dissemination and use of HIV-related status.

Policy Shift

The release of the 2006 guidelines seeks to end this practice. HIV testing will be provided without pretest counseling and specific, written informed consent. Patients will have the option to "opt out" of the test on an individual basis. The anticipated outcome of this shift includes a belief that new cases of HIV will be identified that would have otherwise been unidentified by the current system. This early identification will enable these clients to be referred for treatment and social services (Branson et al., 2006). These anticipated outcomes are informed by current understanding of HIV epidemiology.

As noted earlier, treatment has improved survival rates for people with HIV disease dramatically. Today a person treated for HIV can have a life expectancy of 24 years post-infection. This improvement is due in large part to the introduction of highly active antiretroviral therapy (HAART) in 1995 (see Palella et al., 2003). This advance in treatment is not reflected in a parallel improvement in early diagnosis. During 1990-1992, the proportion of persons who first tested positive for HIV one year before receiving a diagnosis of AIDS was 51% (Wortley et al., 1995); during 1993-2004, this proportion declined only modestly, to 39% in 2004 (Centers for Disease Control and Prevention, 2004). Persons tested late in the course of their infection were more likely to be black or Hispanic and to have been exposed through heterosexual contact; 87% received their first positive HIV test result at an acute or referral medical care setting and 65% were tested for HIV antibody because of illness.

These results are often cited in conjunction with an estimate that one quarter of the 252,000 to 312,000 persons infected with HIV are unaware of their infection and therefore unable to benefit from clinical care to reduce morbidity and mortality (Glynn & Rhodes, 2005). A number of these persons are likely to have transmitted HIV unknowingly (Marks, Crepaz, Senterfitt, & Janssen, 2005).

These data have further driven a move to erode a focus on individual rights and redouble efforts to engage a communitarian, public health approach to protect the community by balancing the rights and responsibilities of the infected and uninfected in light of the total health and well-being of the community.

A number of issues related to the "end of AIDS exceptionalism" have been raised as reasons to approach changes in HIV policy with care and study. I have identified some of the issues and tried to frame some fundamental questions that can spark further dialogue and research. Among these questions: "How does one define 'exceptional'?" A reading of the literature leads one to believe that what we are ultimately considering is universal access to HIV testing. Few authors have posited the notion that all HIV care be mainstreamed. Greater clarity in this definition is necessary to develop a comprehensive plan. As the plan develops, will differences in populations at risk be discreetly funded for enhanced service and outreach?

Implementation of this recommendation of universal testing will be uneven across the US. Each state and the District of Columbia have adopted statues and policies that interpret HIV practice for their jurisdiction. Federal guidelines set a national standard of care for HIV and virtually every other medical condition and disease process. Local jurisdictions are, nevertheless, free to legislate to address the concerns of their constituents. For example, in order to implement the federal HIV testing guidance in New York State, legislative authority must be given to change Article 27-F of the Public Health Law, the statute which delineates the legal scope and application of HIV confidentiality. Long regarded as the nation's most comprehensive and stringent statues of its kind, it was designed in the earliest days of the epidemic when civil rights protections were essential.

Today, states like New York are revisiting these statutes. Nationwide a battle line has been drawn between the "individual rights" proponents and the "communitarian" advocates. Again using New York as an example, a number of New York State legislators

have publicly expressed reticence for adopting the federal guidelines. The state's public health professionals are strongly advocating for change. The voice most often overlooked in the debate is the unfiltered voice of those living with HIV on a day-to-day basis.

Practical Outcomes of Policy Shifts

Change in policy is not an abstraction made without practical impact, both on the life of individuals in society and on the activity of the health care system. This policy conundrum has implications for medical malpractice. Federal guidelines have long been the standard against which quality of care has been measured. Can the practitioner be held liable for malpractice if the federal standard is not met due to compliance with local statutes? Will this concern drive practitioners away from providing HIV services and, in effect, create a net loss of HIV case finding? (see Gostin, 2006)

The uneven application of the federal recommendations mirrors the attempts by states to implement pre-marital HIV testing. In Illinois, pre-marital HIV testing was mandated as a condition for obtaining a marriage license. Ultimately, Illinois state health officials said the law had been an expensive and ineffective way to identify carriers of the AIDS virus. Out of the 155,458 newly betrothed people tested for the virus in 1988, tests indicated that only 26 were infected with the virus, and health officials suspected that half a dozen of those results may be false. $5.4 million was spent on the testing initiative, costing $30 to $125 for each person tested, depending on whether testing was done in clinics or in doctors' offices and whether follow-up testing was required. The total cost for Illinois couples was at least $5.4 million last year, or about $209,000 to find a single infection with the AIDS virus.

Because of the law, health officials say marriages in Illinois fell by nearly a quarter, from 99,212 in 1987, the last year for which data is available, to 77,729 as about 40,000 people left the state to marry. Others, particularly low-income couples who could not

afford the test, put off marriage altogether (Wilkerson, 1989). Americans are mobile, and if uneven application of the federal regulations becomes the norm, they are likely to find locales where they feel their best interests are served.

A second significant area of concern is for the quality of care administered to the patient. The scope of HIV services has evolved into a complex matrix of highly specialized care. Surveys by the New York State Department of Health have made a link between high volume HIV providers and better outcomes for the patient. Post HIV diagnosis, geno-typing and phenol-typing of the virus carried by each individual are done to tailor treatment for each patient to be specific to the virus with which they have been infected. Treatments are designed and managed in asymptomatic and symptomatic patients using a matrix of lab values and techniques for the management of side effects. Effective HIV care requires comfort on the part of the provider with issues of sex and substance use.

Central to the communitarian approach to management of HIV infection in the community is the development of partnerships for care with HIV infected individuals. People living with HIV infection must be engaged in the process of HIV prevention. CDC recognized this and instituted the Advancing HIV Prevention campaign in April 2003. This campaign set as its goal providing HIV prevention counseling and risk reduction skill building to all HIV infected individuals in care. These interventions are to be provided in the medical setting by physicians and mid-level practitioners.

Research data continue to demonstrate that medical providers seldom engage patients by talking about a sexual and/or substance use history, discussing sexual risk reduction or managing substance use issues in their patients. Fewer than 25% of patients report their provider discussing sexual risk reduction at their last appointment; 5.8% recall a specific discussion of sexual activities (Morin et al., 2004; Abrahmson, Bennet, & Stehling, 2004). These results were gathered from clients who received care from HIV

specialists. What level of care can be expected from non-HIV focused providers? Is it reasonable to expect every primary care provider to manage the medical care of their patients and be skilled in discussing HIV risk reduction? At what point in care does specialty or exceptional care begin?

Social setting, geography, community norms, and social structures are important in the delivery of all health care. The provision of HIV care and services continues to highlight the differences embedded in American life. Consistent with the communitarian argument, the family and community resources for each patient are important. It is my concern that a false assumption is made that all medical facilities are staffed by HIV savvy providers – professional and support staff – and that stigma has been removed from the equation. In urban areas, there is a significantly higher concentration of experienced HIV providers. However, as you move to rural areas, there are far fewer experienced providers.

Conclusion

Leadership by a few visionary pioneers shaped the initial policy response to the HIV epidemic. Exploration of the work of two iconic figures of that era; Larry Kramer, founder of Gay Men's Health Crisis (GMHV) and C. Everett Koop, MD, MPH, former Surgeon General of the United States, provides insight into the impact of that leadership.

In June of 1981, what we now know as Acquired Immune Deficiency Syndrome (AIDS) was announced on the world scene by the United States Centers for Disease Control and the United States Public Health Service. A small cohort of gay men in New York and San Francisco were identified as having an unusual cancer followed by a rapid post-diagnosis death. C. Everett Koop, MD, Surgeon General of the United States at that time issued the Surgeon General's Report on Acquired Immune Deficiency Syndrome ("The Report") in October 1986. "The Report" details the epidemiology, modes of transmission, and current treatment and prevention recommendations for AIDS.

Koop acted as the leader of the public health and larger medical community, a key population of professionals who influenced the development of HIV policy. The public health community was the first to recognize the clusters of outbreak in 1981 and publish the notification of the previously unseen constellation of symptoms in the Morbidity and Mortality Weekly (MMWR). A great deal has been written about the leadership of the homosexual community in fashioning and influencing public policy for HIV/AIDS. This largely heterosexual cadre of professionals in a government agency was the first and consistent leaders in HIV/AIDS policy. Koop is representative of this constituency.

Koop moved the conversation of AIDS from the corridors of the public health community and the associated fledgling community-based organizations (CBO) instituted to address the physical and psychosocial needs of People with AIDS (PWA) to an open public discourse. In 1985, President Ronald Reagan first spoke of AIDS in a public address. In that year, he asked Koop to prepare a report to the American people on AIDS. The delay in "The Report's" release to October 1986 is an indication of how reticent the Reagan administration was to address the AIDS issue. Ultimately, Koop reported that he "was never informed why the Surgeon General was not to discuss AIDS at any public forum" (United States Public Heath Service, 2007).

"The Report" was produced with goals broader than simply providing education to the American people. In an unusual distribution scheme, "The Report" was mailed to every household in America. It used basic medical information to educate the public about their personal risk, reduce the rates of new infection, and minimize discrimination against People With AIDS. This was groundbreaking. The blanket distribution of "The Report" forced the AIDS debate from the halls of the immunology laboratories and hospitals of the world into the public realm. Koop's approach was replicated throughout the industrialized world. "The Report" was translated and distributed by the governments of France and Australia. Health ministries of other nations reacted to Koop's public health agenda by

initiating high profile national campaigns (United States Public Heath Service, 2007).

Koop brought the weight of being "America's doctor" to the debate. "The Report" was constructed in such a way that the reader identified with Koop as an extension of their local provider. With him, he brought the full weight and authority of the federal government's reputation as the final arbiter in the development of standards of medical care, his position in the United States Public Health Service which is emphasized by his photograph in full dress uniform in the document, and a vast network of local, regional and state public health administrators who shared a similar vision to stop the spread of an infectious disease that was transmitted through a virus.

Larry Kramer was a second powerful voice in the AIDS policy dialogue. A gay man, Kramer gave voice to the fears and frustrations of a generation of gay men. Kramer was an accidental leader, thrown into action in the earliest days of the AIDS epidemic when his friends began getting infected. "I was just a New York faggot like everyone else who was gay then," he said. "I didn't march in Pride. We used to be at Fire Island and make fun of all that" (Vargas, 2005).

Americans were concerned about AIDS and casual contact in 1981. Gay men were, by contrast, frightened by the sudden sickness and death of their friends. News reports, film documentaries, play and educational videos all depict the terror that consumed gay men each time an unidentified dermatitis or blemish appeared on their body. As AIDS threatened the lives of his friends, and fueled by anger at government and policy inaction against the epidemic, Kramer co-founded Gay Men's Health Crisis, the first and the world's largest service provider to people with AIDS in 1981. In 1987, he launched the AIDS Coalition to Unleash Power – ACT UP. This grassroots effort focused on establishing an accelerated approval process for drugs to treat AIDS. At its height from the late-1980s to the mid-1990s, ACT UP boasted 140 chapters nationwide (Potier, 2003).

Tony Kushner, Pulitzer Prize winning playwright who explores the AIDS epidemic

in his play “Angles in America”, discusses the impact of Kramer who is a playwright in his own right. “How many gorgeous passages are there in ‘Faggots’? How many beautiful pages of prose?” Kushner adds. He wonders, as do others, “Who knows what Kramer might have written had he not taken it upon himself to shape a whole movement – a whole movement – in response to the epidemic?”

“There wasn’t a casting call for Larry. When AIDS began, before we even knew to call it AIDS, he recognized a historic opportunity and he had the courage to speak the truth,” says Rodger McFarlane, a longtime friend. He met Kramer in 1981; in the same Greenwich Village apartment Kramer now shares with his lover of 10 years, David Webster, the same apartment where Kramer started GMHC (Vargas, 2005).

The management of HIV prevention, disease and policy development is a study in the impact of difference on the evolution of societal response. Recent advances in technology and treatment have made possible a reassessment of the social framework by which public health policy has developed to address the needs of the American public. Initially, in the absence of treatment and the social need for confidentiality, legal protections against discrimination and profound social stigma were addressed through policy and systems that focused on the individual (Bayer, 1997). These drew upon the framework developed by Rawls (1971) in *A Theory of Justice*. As reassessment continues, a communitarian approach as detailed by Etzioni (1993) in *The Spirit of Community* is increasing the norm. Each addresses core needs of the individual and the population. Careful consideration and planning is required as this evolution continues.

Leadership in this time of change is reflective of the strength of the shift from a focus on individual rights to a communitarian approach. Public health physicians like Dr. Koop remain central to the debate. Thomas Freiden, MD, MPH, Commissioner of Health for the New York City Department of Health is at the forefront of articulating policies and interventions, reflecting this shift. Lacking is a strong voice from the communities

impacted by HIV and AIDS. Leaders of AIDS organizations have not captured the attention of the press in the way that Larry Kramer did in the early days of the epidemic nor are they insistent on being integral to the development of a vision for the future shaped by the results of this shift.

It is ironic that the period that primarily focused on the rights of the individual saw the greatest input and impact of the community most deeply affected. As Communitarian ideals have emerged, the direct input of members of the HIV community has been minimized. Activism by groups such as ACT-UP has been replaced by scientific studies. The voice of the individual has been subjected to responses on formal questionnaires that provide homogenized data to a planning committee. This may be the greatest indication of the strength and lasting impact of this shift.

Epilogue to the Dissertation

The HIV epidemic continues as does my personal journey living and working in it. The poetry and music discussed in this series of essays and related public performance brings to mind the words of Edmund White in *Loss Within Loss: Artists in the Age of AIDS*:

> . . . I can feel the heat rising off them – the intense, baked terra-cotta heat of longing and desire, or the headachy, sobbing heat of grief writhing on the mattress, pounding like a defeated wrestler. And I can felt the simple, blunt fact of the head of human presence – of eyelashes brushing the pillowcase, of breath held, heart bursting, of another head on the pillow, drinking it all in, a bit stunned by such voluminous and cruel information but observant nonetheless, memorizing the moment. (White, 2001, p. 3)

Using an interdisciplinary approach, I have employed elements of traditional policy, metaphoric, and ethnomusicological analysis to identify key links among policy, poetic

text and music. Leadership studies, ritual studies, thanatology and the use of memoir have provided an understanding of the development of social policy in the HIV epidemic.

The important work of Etzioni by the application of Durkheim's work under girds this creative dissertation. World AIDS Day is a public ritual into which a unique interdisciplinary synthesis has been introduced.

In *When We No Longer Touch* Anthony gives the listener a first hand account of the experience of a PWA. This has provided a unique canvass for exploring social commentary, memorialization of life's events, grappling with giving meaning to tragedy and developing a framework for hope for the future.

As the journey continues, the pain of death continues worldwide. The use of protease inhibitors has slowed the devastation and distracted many in North America as the mortality decreased. The worldwide epidemic continues to escalate without moderation. From this global epidemic, new voices and new leaders are emerging. Their experience expressed in their music continues to give life to the "longing, grieving, observing" (White, 2001, p. 3) of the current age.

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Appendix A

Credits for Accompanying Video Documentary

Anthony, K. J., McWilliams, P., & Seelig, T. (1990). *When we no longer touch* [Musical score]. Dallas, TX: Turtle Creek Chorale.

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Appendix B

Program: Recital/choral concert at the Maryknoll Fathers and Brothers, Ossining New York

World AIDS Day 2008

Our History and Our Hope

123 Main Street

December 6, 2008
7:30 p.m.
Maryknoll Center
Ossining, New York

Owen M. Borda

Conductor

World AIDS Day 2008
Our History and Our Hope

This evening's program is designed to inspire your active participation in the program. Together, with the performers,we hope to be enlightened by the experience of the presentation.

On this occassiion, we ask you to reflect on the history of the AIDS epidemic, your personal journey and experience during these times, and to consider the impact of the social conditions in the early days of the epidemic within which profound social change and policy development occurred. A fuller comprehension of the initial phase of the AIDS epidemic will help us draw upon the successes and failures of this ten year period to develop tools that can be used to assist organizations meet the changing HIV/AIDS funding environment to be even more succesful in the future.

Consider the following:
What are the lessons learned?
How do these lessons impact the current situation?
How do we use these lessons to craft a future in the epidemic?

Part I -- A Personal Reflection

I begin my work this evening as I have begun every AIDS presentation I have made over the past 20 years of presentations. "Come Holy Spirit, fill the hearts of your faithful…..veni Creator Spiritus…."

Veni Creator Spiritus ***Chant***

Prelude and Variations on Veni Creator Spiritus ***Maurice Duruflé***

"You are more a G-clef than a Red Ribbon," a friend once told me. He was referring to my dual career in music and as a full-time HIV/AIDS policy wonk. I have carried this sentiment closely as I evaluate my daily experiences living at the intersection of two such diverse yet profound disciplines.

I have come to appreciate only now the statement is not quite right. Rather, I am the embodiment of that fluid ribbon that makes both the G-clef and the Red Ribbon different expressions of the same form. Indeed, the flexibility of the ribbon allows for distinct expressions of music and of HIV concern. The wonder is that this also allows the interconnection of many life experiences within the insights of these two, primary worlds.

Oddly, my entry to the world of HIV/AIDS was as a musician. With no background or training in HIV I relied on my skills as a performer to initiate many AIDS education

programs in 1986 and beyond. My personal truth is clear: if you can live through music school and the associated pressures, you can live through anything. It was my training as a conductor that has had the greatest continuing impact on my work. When developing programs and working with groups, I draw upon my skill as a professional conductor, engaging performers and exploiting their unique talent, and, in the framework of trust, builds up the individual within cohesive ensemble and, ultimately, produce excellence in performance. As the conductor, I create the vision together with the performers and sustains it for them as the goal to which the ensemble moves. Here, the G-clef becomes the living Red Ribbon.

This skill is guided by my theological prism, the Gospel call to building community. At the beginning of my music ministry, I was struck by this excerpt from *Music in Catholic Worship:*

> "People in love make signs of love, not only to express their love but also to deepen it. Love never expressed dies. Christians' faith in Christ and in each other, must be expressed in the signs and symbols of celebration, or it will die." (no. 4)

It is this love, the love of God, continually imposed on our past as well as our present, that keeps me in this commitment. In these days before Christmas, it is particularly clear to me that Incarnation is a continual process of acceptance and expression.

O Magnum Mysterium **Morten Lauridensen**

O Magnum Mysterium
O most awesome mystery
and sacrament divine and most wondrous:

that animals should look and see the Lord a babe newborn
beside them in a manger laid.
O how truly blessed is the Virgin whose womb was worthy
to bear and bring forth the Lord Christ Jesus.
Alleluia!

This expression of love in symbol and in community is not uniquely the prevue of the worship space. It pervades all that we do and for me, is deeply rooted in the symbols of the G-clef and the Red Ribbon.

The AIDS community is not without its symbols and expressions. Red ribbons, quilt panels, public celebrations and memorial services are symbolic gestures that express the depth of feeling engendered by engagement in the AIDS community at any level.

So, as I reflect on my involvement in the AIDS epidemic, my life is inextricably linked to these primary symbols, all composed of the same fabric of and vision for all people.

"People" from *Funny Girl* **Julie Styne**
Tim Takach, arr.

People--people who need people
Are the luckiest people in the world,
We're children, needing other children
And yet letting our grown-up pride
Hide all the need inside,
Acting more like children
Than children.

Lovers are very special people,
They're the luckiest people
In the world.
With one person, one very special person
A feeling deep in your soul
Says you were half,
Now you're whole.
No more hunger and thirst
But first be a person
Who needs people.
People who need people
Are the luckiest people
In the world!

The development of my AIDS expertise followed a winding path. Beginning with my work at the American Red Cross, I quickly became involved in AIDS issues that had a national perspective. I moved from this education and policy position to be the founding administrator of the Westchester County Medical Center Designated AIDS Program. This was an immersion experience in the delivery of health care and hospital administration. Subsequently, I was hired by the Westchester County Commissioner of Health to be an AIDS policy advisor, an exciting position that placed me a very public role as executive director of the Westchester AIDS council, County AIDS spokesperson and policy wonk -- always with an eye to the end of creating a system of prevention and care that addressed the emergent and continuing needs of those infected and at risk.

Through the National Catholic AIDS Conference, I met leaders in the fight against AIDS from within and outside the church. I remember being an attendee at the first meeting of the conference in 1984. So little about the disease was known at that time. So many projects were being developed. Such pain was in the air that you could not help but weep. It was at this first meeting that I had my first deeply personal encounter with God. It was anything but the warm, embracing, comforting

God of Psalm 23. Surrounded by a cold flash in the University of Notre Dame Basilica of the Sacred Heart, I came to know the mantra of my work "The Lord is my light and My Salvation, whom should I fear." (Psalm 121) The power of this psalm is magnified by the trust that is evidenced in the subsequent psalm. We have no fear because life is a journey to Jerusalem, building kingdom of peace. People With AIDS are my companions on this journey, teaching me a depth of understanding that comes of the pain of struggle.

In that basilica, in the cold of that lonely moment, I was searching for peace. That moment was the beginning of many glimpses of the new and eternal Jerusalem radiant in the eyes of the People with AIDS I have been privileged to know. Truth itself provides permission to search for peace.

Psaume 121 **Darius Milhaud**

I rejoiced when I heard them say:
"Let us go to God's house."
And now our feet are standing
within your gates, O Jerusalem.

Jerusalem is built as a city
strongly compact.
It is there that the tribes go up,
the tribes of the Lord.

For Israel's law it is,
there to praise the Lord's name.
There were set the thrones of judgment
of the house of David.

For the peace of Jerusalem pray:

"Peace be to your homes!
May peace reign in your walls,
in your palaces, peace!"

For love of my brethren and friends
I say: "Peace upon you."
For love of the house of the Lord
I will ask for your good.

Among the trainings, public appearances, policy work and care giving, I have always maintained work in the religious sphere. Funerals, memorial services, quilt showings and World AIDS Day remembrances have been abundant. Working with the dying, grieving families, lovers, friends and care staff, I was witness to the very real struggle to gain understanding of AIDS and death. As a musician, I was challenged to assist in making musical selections that were not always "traditional" or "appropriate." However, understanding that God is immediately present to us, and within all of creation, who am I to question where and how the Spirit speaks? Standard popular songs became part of the expression of life often performed at these gatherings. They are themselves the expression of a G-clef as Red Ribbon: surrounding pain, expressing the culture of affliction and suffering, ultimately offering hope.

Danny Boy **Traditional**
Steve Bishop, Patrick Rose, arr.

Oh Danny boy, the pipes, the pipes are calling
From glen to glen, and down the mountain side
The summer's gone, and all the flowers are dying
'Tis you, 'tis you must go and I must bide.

But come ye back when summer's in the meadow
Or when the valley's hushed and white with snow
'Tis I'll be here in sunshine or in shadow
Oh Danny boy, oh Danny boy, I love you so.

And if you come, when all the flowers are dying
And I am dead, as dead I well may be
You'll come and find the place where I am lying
And kneel and say an "Ave" there for me.

And I shall hear, tho' soft you tread above me
And all my dreams will warm and sweeter be
If you'll not fail to tell me that you love me
I'll simply sleep in peace until you come to me.

I'll simply sleep in peace until you come to me.

Amazing Grace **American Traditional**
Stephen Hatfield, arr.

Amazing grace! How sweet the sound
That saved a wretch like me!
I once was lost but now am found,
Was blind but now I see.

'Twas grace that taught my heart to fear,
And grace my fears relieved;
How precious did that grace appear
The hour I first believed!

Through many dangers, toils, and snares,
I have already come;
'Tis grace hath brought me safe thus far,
And grace will lead me home.

When we've been there ten thousand years,
Bright shining as the sun,
We've no less days to sing God's praise
Than when we'd first begun.

Over the Rainbow **Harold Arlen**
Mark Hayes, arr.

When all the world is a hopeless jumble,
And the raindrops tumble all around,
Heaven opens a magic lane.
When all the clouds darken up the skyway
Theres a rainbow highway to be found
Leading from your window pane
To a place behind the sun
Just a step beyond the rain

Somewhere over the rainbow,
Way up high
Theres a land that I heard of once,
In a lullaby.
Somewhere over the rainbow,
Skies are blue.
And the dreams that you dare to dream
Really do come true.

Someday I'll wish upon a star
And wake up where the clouds are far behind me...
Where troubles melt like lemon drops,
Way above the chimney tops,
Thats where youll find me...

Somewhere...
Over the rainbow
Bluebirds fly,
Birds fly over the rainbow
Why then oh why cant i?
If all those little bluebirds fly
Beyond the rainbow...
Why .. oh .. why .. can't I

Hope, ever present to the human spirit, was the fuel that kept all of us, those living with and affected by AIDS, moving forward. In those early days of the epidemic, the devastating

ferocity of a living , relentless and resourceful particle, a virus, made hope the only medication available. It was the Red Ribbon that gave life to the belief that a cure would be found. The Red Ribbon was the symbol of local efforts filled with compassion and care.

I have been fortunate in these years of AIDS work to have used the flexible expression of the ribbon to directly and indirectly better the lives of many and support their embrace of hope. *Camp Viva* is one of those efforts. Born of frustration with the clinic system and legal statutes that imposed isolation on individuals with AIDS, I worked to establish a collaborative that would provide a fun-filled opportunity for socialization and respite to families (very loosely defined) and individuals with AIDS. *Camp Viva* continues today as an opportunity for those people at the fringe to come to the center and be welcome, surrounded by the ribbon of friendship and fun.

Camp Viva, the work with the Red Cross, the AIDS Care Center, countless families who grieve, the loss of so many friends and the hundreds of talks given to groups across the country are all an experience that has given me access to the Divine. The mystery of the Incarnation brings my life into focus as I have seen the light of the Divine in the faces of the people I have met and with whom I have worked. They have given me laughter and healing. This is the mystery of the Incarnation

This reflection closes as it opened, melding the G-clef with the Red Ribbon in an expression of community and trust. The two aspects of a ribbon, AIDS symbol and G-clef are that river of life, flexible, creative and always moving us all toward the goal of moving from the margins to a full life at the center.

What is your personal story of HIV / AIDS advocacy and service delivery?

Blessed Assurance **Phoebe Knapp**
Nancy Wertsch, arr.

Blessed assurance, Jesus is mine!
O what a foretaste of glory divine!
Heir of salvation, purchase of God,
born of his Spirit, washed in his blood.

Refrain
This is my story, this is my song,
praising my Savior all the day long;
this is my story, this is my song,
praising my Savior all the day long.

Perfect submission, perfect delight,
visions of rapture now burst on my sight;
angels descending bring from above
echoes of mercy, whispers of love.

Perfect submission, all is at rest;
I in my Savior am happy and blest,
watching and waiting, looking above,
filled with his goodness, lost in his love.

☒☒☒☒☒☒☒☒☒☒☒☒

Please move to Spellman Hall for the video presentation.

Part 2 -- A History of HIV Policy Development

Using a video documentary produced in cooperation with Richard Diefenbach, the struggles and history of People Living with AIDS, the caregivers, family and advocates during the first ten years of the epidemic, 1981-1991, are documented. Fear and social stigma, coupled with the untimely death of friends and neighbors galvanized a movement that shaped social policy at an unprecedented rate. These policies continue to shape the global response to HIV/AIDS and influence the development of health policy in the United States.

The extended choral composition *When We No Longer Touch,* by Kristopher Anthony, provides the artistic framework for this analysis. *When We No Longer Touch* is uniquely suited for this project in that the composition and text were composed by People Living with AIDS. The composition uses traditional requiem texts juxtaposed with poetry based on the stages of death and dying as described by Elizabeth Kübler-Ross. Using interdisciplinary research, the following links are established between specific stages of death and dying as used in the choral work, key policy actions and the key leaders of this era.

The video specifically explores four movements of the work as examples of the scope of possible analysis

1. **Fear**: Using the movement entitled, , social issues of homosexuality, the role of public health in regulating private activity, the role of government in the regulating the blood supply and the responsibility of first responders (as a surrogate for all medical providers) are

raised. Personal fears that impact the public discourse are identified by fear of HIV transmission by casual contact, limited personal intimacy. We are reminded of the many prominent cultural and political personalities whose lives were impacted by HIV disease.

These aspects of fear provide the underpinning for the

- Testing of the blood supply for HIV and Hepatitis B
- Reestablishment of universal precautions

2. Anger: Using the movement, *I Am Past the Point*, we experience the rage that fuel the protest movement ACT-UP, are confronted by the anger of friends and family at the revelation of a loved one's diagnosis, and the subsequent rejection by family and friends as a result of that diagnosis.

These expressions of anger created the climate in which

- Treatment advocacy became the norm and federal officials relied upon the advocates to advance their internal agenda.
- The FDA streamlined and restructured the approval process for pharmaceuticals making drugs available more quickly to the marketplace.
- By statue, People Living With AIDS are involved in health planning related to HIV/AIDS.
- The AIDS Drug Assistance Program (ADAP) was developed to make essential pharmaceuticals available free to all HIV infected. It also helps people with partial insurance or who have a Medicaid spenddown requirement.
- The roots of legal protections against discrimination based on sexual orientation are linked to these expression of anger.

3. **Isolation**: The movements *The Layers I Have Put Around My Pain* and *I Am Missing You* is the basis for this exploration. We learn about the personal loathing and isolation common among People Wit AIDS, the rejection they have experienced from family and friends, the deep sense of abandonment and the troubling lack of access to hospital rooms for non-"family" members, no matter the depth of their relationship.

These experiences of intense isolation lead to the creation of community-based solutions to the endemic issues of the day.

- The development of extensive buddy programs that provided social support, respite care and informal care throughout the community.
- The adoption of the San Francisco Model of Care, where volunteers were used extensively to supplement traditional medical and social care. Ultimately, this lead to the basic mode for the delivery of care as being the community-based organization. Today, these organizations (eg. Gay Men's Health Crisis) are the backbone of the community care and advocacy network.
- Organized food delivery and home-based collateral services became essential elements of the continuum of care.
- The social model of care became the norm, supplanting the medical model.

4. **Acceptance**: We experience the impact of acceptance in the music of, *I Shall Miss Loving You.* Acceptance enabled a sense of focused action and acts of memorialization to emerge. In acceptance, we see promotion of safer sex practices, syringe and needle exchange programs, programs that support active deathing, and programs that celebrate life. The Quilt Project, candle light

memorials, and community remembrances like World AIDS Day become possible.

Acceptance brought into being

- Film and television productions that focused public attention on the reality that AIDS was a party of the social fabric of the United States.
- The Red Ribbon Campaign, created by Frank Moore, became the most widely recognized and pervasively used symbol of the AIDS epidemic.
- Program like *Camp Viva* came into being to celebrate the living experience of People with AIDS, decrease their sense of isolation and increase skills for living with the virus.
- Memorial activities like the Quilt Project became a routine part of the American folk art tradition and memorialize the memory of those lost.

5. **Hope**: *I Have Loved* opens the door to the signs that there is hopeful horizon. The voice of entertainment industry, first expressed by Elizabeth Taylor and continued here through Bono, continues to bring hope to a hopeless situation. The transformation of Jesse Helms from anti-AIDS to a support is a hopeful transformation. The development of medical interventions, legislative protections and the desire to be alive for the cure are presented here as representations of the possibilities for the future.

Hope is driven by

- President's Emergency Plan for AIDS Relief (PEPFAR) providing funding to the gobal fight against AIDS
- Medical advances in HIV treatment, diagnostic procedures, health monitoring and vaccine research

- American With Disabilities Act (ADA) providing protections to People With AIDS
- Fair Housing Amendments Act provides protection against discrimination in all housing with limited exceptions.
- Federal Rehabilitation Act of 1973, Section 504, provided protections against work place discrimination and discrimination in federal housing for People With AIDS

☒☒☒☒☒☒

Please return to the chapel for the conclusion of the program.

Part 3 -- When We No Longer Touch

"I shall miss, missing loving you." The poet, Peter McWilliams makes this keen observation. Composed by Kristopher Anthony using poetry by McWilliams, *When We No Longer Touch* leads us thru the stages of death and dying. We are reminded in each phrase that the AIDS epidemic is about people who struggle, yesterday, today and every day to make sense of their personal experience. In the end, it is this experience that drives the engine of effective policy development, community response and the delivery of care.

As a duet with this text, Anthony uses traditional Requiem texts, the traditional texts of the Mass of the Dead in the Tridentine Rite of the Roman Catholic Church. He juxtaposes these as a reminder that his struggle is not with the material world alone. He struggles to make sense of his experience as a Person With AIDS in the context of God. By using a traditional Requiem text, he places his struggle in the context of Mozart, Brahms, Faure, Britten and other notable composers who, using their individual musical idiom, open a dialogue with God and

seek comfort, peace and understanding. This is in keeping with his training as a professional musician.

I have based my comments in the context of that musical tradition and draw upon the funeral liturgy of the Roman Rite to bring the poetic and liturgical texts together.
The key question remains to be answered: "How does my personal experience fuel my commitment to the development of future HIV/AIDS policy?

Prologue

The fear that I would
come home one day and find you gone has turned
into the pain of the
reality.
What will I do if it happens?
What will I do now
that it
has?

The stage is set for the feelings that are presented in the poems that follow. McWilliams immediately connects with the fear of the reader for loneliness and links it to pain, a physical hurt that is carried in the body. The immediacy of that moment is brought to the reader as the future though of "what will happen?" is recast as a present reality, "It has."

The opening harp chords are a call to worship. The english horn is the faint sounds of th eorgan inside the snactuary that casket greets the casket at the door. We are the loved ones following the casket in the human dialogue between the earthly shock of death and the otherworldly call of Jerusalem, as the choir sings the latin introit

Requiem in aeternum
Rest eternal grant them, O Lord,

and let perpetual light shine on them.
To thee praise is due, O God, in Zion,
and to thee vows are recited in Jerusalem.

Denial

I know our time together
is no more.
Then why do words
come to mind that call you back?
Why do I plan lifetimes
that include you?
Why do I torture myself
with love
I never felt while you were here?

The denial of the reader is focused on the planning of lifetimes, eternity. Denial in the description of this Kübler Ross identified stage can be described as the experience of "It can't be happening!" The time of physical knowing and the time of knowing in the heart are challenged as the announcement of impending death is made. These have allowed for the imagination to create emotional experiences that where not possible when confronted with the daily reality of the other. The common aggravations of daily interaction fade and the romantic ideal is expressed. The words are formed in the mind and take on life creating an image of a parent looking for a lost child. The child is the innocence of self, calling to be reunited with the self. A second look at the child can be related to the child of relationship with another. This is evident when the voice of the poem is placed with the lover who survives the dead of a beloved. The image of the Good Shepherd from the New Testament also seems to be involved. Endless wandering throughout eternity to find the lost and create the imaginary life is taken shape to guard the living from the loss of the beloved.

The composer presents us with a halting rhythm in the low strings and piano. We hear the irregular tick of a hearbeat, an internal clock. The singers move us to an alternative reality as the elongaed notes of their opening stretch time. Ultimately, both instrumentalists and singers are consumed by the throbbing rhythm of anxiety and yearning.

Isolation

The layers I have put
around the pain of your going are thin.
I walk softly through life, adding thickness each day.
A thought or a feeling
of you cracks the surface;
a call to you shatters it all.
I spend that night in death
and spin the first layer of life
with the sunrise.

"Isolation" is not an explicit stage identified by Kübler Ross. Rather, this poem continues the exploration of denial. The grieving lover cannot escape the essential pain of the loss, even as the wandering to create an eternal life continues. To be isolated and in denial requires the mind to create distance from the events that bring pain. These layers are added naturally by the mind on a daily basis. There is a tenderness that is concomitant with this process. This author "The spin of the first layer of life" and the "night in death" creates a scene we do not remember from our birthing; those last, painful hours as contractions begin in the womb and we are about to be expelled into the first breaths of life outside the womb. The images of the eternal search, the sunrise, the calling end and the reality of the birthing/deathing pain become real. No one gives birth silently. The paradox that we give life to death and find the thin layer of the amniotic sac is broken and the pushing begins in earnest.

Death, like birth, is a painful experience. In the final word of the poem, we are left with the hope that in the sunrise the weaving of the new eternal life will take hold and the infiltrates of reality will stop creating fissures in the warmth of the womb created by the layers of self-protective denial

The thick choral writing is a stark contrast to the single line melody of the english horn. We hear the bass voices of the choir rattling the bedrock to crack the surface, while singing

Exaudi orationem
hear my prayer;
unto thee all flesh shall come

Anger
I'm past the point of going quietly insane.
I'm getting quite noisy about it.
The neighbors must think I'm mad.
The neighbors,
for once,
think right.

Anger asks the question, "How dare you do this to me?" referring wither to God, the deceased or oneself. Again, the poet creates a paradox. The narrator is quite noisy about being quietly insane. We get a glimpse into the life of the narrator and the neighbors. They have thought him mad in past situations. One would read the poem to understand that in the past it was without reason. The current state of madness is expressive and appropriately recognized by the neighbors.

The use of 5/4 meter, moving from three beats to two, drives the rage of insanity. Nothing is regular, nothing is predicable in this ryhtmic pattern. Anthony uses one of the

most commonly quoted meodic phrases by using Dies Irae. Like Berlioz, insanity is joined to the rages of hell

Dies irae, dies illa

The day of wrath, that day

which will reduce the world to ashes,

as foretold by David and the Sybil.

What terror there will be,

when the Lord will come

to judge all rigorously!

The trumpet, scattering a wondrous sound

among the graves of all the lands,

will assemble all before the Throne.

Death and Nature will be astounded

when they see a creature rise again

to answer to the Judge.

The book will be brought forth

in which all deeds are noted,

for which humanity will answer.

When the judge will be seated,

all that is hidden will appear,

and nothing will go unpunished.

Alas, what will I then say?

To what advocate shall I appeal,

when even the just tremble?

O king of redoutable majesty,

who freely saves the elect,

save me, o fount of piety!

Remember, merciful Jesus,

that I am the cause of your journey,

do not lose me on that day.

You wearied yourself in finding me.

You have redeemed me through the cross.

Let not such great efforts be in vain.

O judge of vengeance, justly

make a gift of your forgiveness

before the day of reckoning.

I lament like a guilty one.

My faults cause me to blush,

I beg you, spare me.

You who have absolved Mary,

and have heard the thief's prayer,

have also given me hope.

My prayers are not worthy,

but you, o Good One, please grant freely

that I do not burn in the eternal fire.

Give me a place among the sheep,

separate me from the goats

by placing me at your right.

Having destroyed the accursed,

condemned them to the fierce flames,

Count me among the blessed.

I prostrate myself, supplicating,

my heart in ashes, repentant;

take good care of my last moment!

Bargaining

I know, I know it was time for us to part
but today?
I know I had much pain to go through,
but tonight?

The direct simplicity of this poem is it's strongest metaphor. A clear, direct question. I wonder if before out birth, we ask the same question of our mother? The read easily understands the bargain between the narrator and God, the narrator and the lost love, the narrator and his lost self.

This hymn like settingbrings the living in direct conversation with the Divine. The melody of the soprano reminds of of angels mediating the time and space betweenheaven and earth, the traditional messengers of God.

Quid
What shall I, frail man, be pleading?
Who for me be interceding,
when the just are mercy needing?

Depression
I am missing you
far better than
I ever loved you.

The idea that one can love more intensely in death than in life is a poignant reminder of the life lost. Depression is marked by lack of verbal communication. Short, truncated sentences and phrases. The poet uses this condition in constructing the text. Missing includes all the good and bad memories that have been accumulated. Love is only one among them. Missing becomes a more complete experience than loving.

This is a moving duet between the voices of angels who call the living to prepare of the dead and the human who can never be prepared for the depression and saddness of death.

Lacrimosa dies illa,
Ah! that day of tears and mourning!
From the dust of earth returning
man for judgment must prepare him

Acceptance
I shall miss loving you.
I shall miss the Comfort of your embrace.
I shall miss the
Loneliness of waiting for the
calls that never came.

I shall miss the Joy of your comings,
and the Pain of your goings
and,
after a time,
I shall miss
Missing
loving
you.

There is an element of convincing the self that comes with this acceptance. The poet gives the emotions personhood by using a capitalized statement of the emotion making it a name. These characters are players in the development of the plot, which moves from missing the past of loving to the future thoughts that will be marked by the decline of the strong feelings of loss. This immediacy of the loss is connected to the eventual experience that even a feeling of loss is finite. Comfort, Loneliness, Joy, and Pain are identified and acknowledged. The good and the bad are remembered and a composite of the relationship emerges. In the end, it is missing that matters; and, even missing comes to an end.

We can imagine the final incensing of the casket and the song in our heart as the choir pleasds for the eternal rest of the deceased. We hear thier voices and accept that this too is our prayer, for their eternal repose.

Agnus Dei
Lamb of God who takes away the sins of the world
Grant them rest, Grant them eternal rest

Hope
And through all the tears
and the sadness
and the pain

comes the one thought
that can make me
internally smile again:
I have
loved.

This postlude to the set provides a secondary level of understanding and acceptance that grows from the previous poem. The understanding that hope is born of acceptance completes the healing process. Many people directly impacted by the AIDS epidemic felt that the illness brought communities closer together and created a created a new context for love. The love that was post-Stonewall and pre-AIDS focused on genital sexual activity. A transformation in the social awareness began with the epidemic that gave birth to the current struggle for gay marriage, gay adoptions and civil unions.

The dead live on in the memory and actions of the living. The perpetual light of eternity become intermigled with the song of the living. Ultimately, the conclusion is that "I have loved" is the expression of *Music in Catholic Worship:*

> "People in love make signs of love, not only to express their love but also to deepen it. Love never expressed dies. Christians' faith in Christ and in each other, must be expressed in the signs and symbols of celebration, or it will die." (no. 4)

Owen Borda
Conductor

David Broome
Pianist

Sondra Goldsmith Proctor
Organist

Lielle Berman
Soprano

Choristers

Keith Dunn
Larry Long*
David Morrow
Paul Daniel Murphy
Michael O'Hearn
Caleb Stokes
Alexander Tall*
Jason Thoms+
Sorab Wadi+
Erik Nelson Werner + #
Avid Williams

*soloist in *When We No Longer Touch*
+soloist in *Danny Boy*
#soloist in *Veni Creator Spiritus*

Instrumentalists

Maryanne Meade	violin
Kiku Enomoto	violin
Christiana Liberis	viola
Allison Seidner	Cello
Matt Smallcomb	percussion
Jessica Schmitz	flute
Joy Plaisted	harp

Author Note

A creative work is not developed in a vacuum. I offer my most sincere gratitude to my family and friends who, with patient understanding and care, have supported me throughout my life. Their generosity and support are tireless. I am deeply grateful for the lives of the many People with AIDS and their caregivers with whom I have had the privilege to share a portion of life's journey. They continue to teach me the profound lessons of life, love, and hope. Finally, a special thank you to Richard Diefenbach and Kyle Spitzfaden for their excellent collaboration in the preparation of the accompanying documentary video and to Joshua Wong for the ever thankless job of editing and formatting this text.

Notes

[1]Human Immunodeficiency virus, the infectious agent that weakens the human immune system leading to Immunodeficiency Syndrome (AIDS).

[2] CMV (cytomegalovirus) is found throughout the world in all geographic and socioeconomic groups, but, in general, it is more widespread in developing countries and in areas of lower socioeconomic conditions . It is a member of the herpes virus family, which includes the herpes simplex viruses and the viruses that cause chicken pox (varicella-zoster virus) and infectious mononucleosis (Epstein-Barr virus). It's found in body fluids, including urine, saliva (spit), breast milk, blood, tears, semen, and vaginal fluids. Once CMV is in a person's body, it stays there for life. Most CMV infections are "silent", meaning they cause no signs or symptoms in an infected person. CMV can cause disease in unborn babies and in people with a weakened immune system (United States Centers for Disease Control and Prevention, 2008).

[3] Seroconversion is the process during which a person infected with HIV develops a measurable concentration of HIV antibodies in their blood. The Elysa-Western Blot test combination identifies these antibodies in the blood of the HIV-infected person. Once antibodies are detected, the individual is diagnosed as "HIV positive." Seroconversion describes the process the immune system undergoes as it produces HIV antibodies and the individual moves from "HIV negative" to "HIV positive."

[4] Anonymous testing does not require the patient to reveal any personally identifying information. No individual medical record is created; only epidemiologic data is collected.

[5] Confidential testing requires a client reveal their name and other identifying data. A medical record is created.

[6] The first case of a contagious disease in a group or population that serves to call attention to the presence of the disease.

[7] The study of death and dying.

[8] White blood cells used as a marker for the health of the immune system.

Table 1

Prologue/Requiem in aeternum

Prologue	Requiem in aeternum
The fear that I would come home one day and find you gone has turned into the pain of the reality. What will I do if it happens? What will I do now that if has?	Rest eternal grant them, O Lord, and let perpetual light shine on them. To thee praise is due, O God, in Zion, and to thee vows are recited in Jerusalem.

Note. From *How to survive the loss of a love*, by Colgrove, M., Bloomfield, H. H., and McWilliams, P., 1967-1996, Los Angeles: Prelude Press. Used with permission. All right reserved. Reprinted with permission. Retrieved from `http://www.mcwilliams.com/books/books`

Table 2

Denial

Denial	(no requiem overlay)
I know our time together is no more. Then why do words come to mind that call you back? Why do I plan lifetimes that include you? Why do I torture myself with love I never felt while you were here?	

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Table 3

Isolation

Isolation	Exaudi orationem
The layers I have put around the pain of your going are thin. I walk softly through life, adding thickness each day. A thought or a feeling of you cracks the surface; a call to you shatters it all. I spend that night in death and spin the first layer of life with the sunrise.	hear my prayer; unto thee all flesh shall come

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Table 4

Anger/Dies irae, dies illa

Anger	Dies irae, dies illa
I'm past the point of going quietly insane.	The day of wrath, that day
I'm getting quite noisy about it.	which will reduce the world to ashes,
The neighbors must think I'm mad.	as foretold by David and the Sybil.
The neighbors,	What terror there will be,
for once,	when the Lord will come
think right,	to judge all rigorously!
	The trumpet, scattering a wondrous sound
	among the graves of all the lands,
	will assemble all before the Throne.
	Death and Nature will be astounded
	when they see a creature rise again
	to answer to the Judge.
	The book will be brought forth
	in which all deeds are noted,
	for which humanity will answer.
	When the judge will be seated,
	all that is hidden will appear,
	and nothing will go unpunished.

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Table 5

Anger/Dies irae, dies illa (continued)

Anger	Dies irae, dies illa
	Alas, what will I then say?
	To what advocate shall I appeal,
	when even the just tremble?
	O king of redoutable majesty,
	who freely saves the elect,
	save me, o fount of piety!
	Remember, merciful Jesus,
	that I am the cause of your journey,
	do not lose me on that day.
	You wearied yourself in finding me.
	You have redeemed me through the cross.
	Let not such great efforts be in vain.
	O judge of vengeance, justly
	make a gift of your forgiveness
	before the day of reckoning.
	I lament like a guilty one.
	My faults cause me to blush,
	I beg you, spare me.

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Table 6

Anger/Dies irae, dies illa (continued)

Anger	Dies irae, dies illa
	You who have absolved Mary, and have heard the thief's prayer, have also given me hope. My prayers are not worthy, but you, o Good One, please grant freely that I do not burn in the eternal fire. Give me a place among the sheep, separate me from the goats by placing me at your right. Having destroyed the accursed, take good care of my last moment!

Note. From *How to survive the loss of a love*, by Colgrove, M., Bloomfield, H. H., and McWilliams, P., 1967-1996, Los Angeles: Prelude Press. Used with permission. All right reserved. Reprinted with permission. Retrieved from `http://www.mcwilliams.com/books/books`

Table 7

Bargaining/Quid

Bargaining	Quid
I know, I know it was time for us to part but today? I know I had much pain to go through, but tonight?	What shall I, frail man, be pleading? Who for me be interceding, when the just are mercy needing?

Note. From *How to survive the loss of a love*, by Colgrove, M., Bloomfield, H. H., and McWilliams, P., 1967-1996, Los Angeles: Prelude Press. Used with permission. All right reserved. Reprinted with permission. Retrieved from `http://www.mcwilliams.com/books/books`

Table 8

Depression/Lacrimosa dies illa

Depression	Lacrimosa dies illa
I am missing you	Ah! that day of tears and mourning!
far better than	From the dust of earth returning
I ever loved you.	man for judgment must prepare him

Note. From *How to survive the loss of a love*, by Colgrove, M., Bloomfield, H. H., and McWilliams, P., 1967-1996, Los Angeles: Prelude Press. Used with permission. All right reserved. Reprinted with permission. Retrieved from `http://www.mcwilliams.com/books/books`

Table 9

Acceptance/Agnus Dei

Acceptance	Agnus Dei
I shall miss loving you. I shall miss the Comfort of your embrace. I shall miss the Loneliness of waiting for the calls that never came. I shall miss the Joy of your comings, and the Pain of your goings and, after a time, I shall miss Missing loving you.	Lamb of God who takes away the sins of the world Grant them rest, Grant them eternal rest

Note. From *How to survive the loss of a love*, by Colgrove, M., Bloomfield, H. H., and McWilliams, P., 1967-1996, Los Angeles: Prelude Press. Used with permission. All right reserved. Reprinted with permission. Retrieved from `http://www.mcwilliams.com/books/books`

Table 10

Hope

Hope	(no requiem overlay)
And through all the tears and the sadness and the pain comes the one thought that can make me internally smile again: I have loved.	

Note. From *How to survive the loss of a love*, by Colgrove, M., Bloomfield, H. H., and McWilliams, P., 1967-1996, Los Angeles: Prelude Press. Used with permission. All right reserved. Reprinted with permission. Retrieved from `http://www.mcwilliams.com/books/books`

Table 11

Veni Creator Spiritus

Veni Creator Spiritus	Chant
Prelude and Variations on Veni Creator Spiritus	Maurice Duruflé

Note. Public Domain

Table 12

O Magnum Mysterium

O Magnum Mysterium	Morten Lauridensen

O Magnum Mysterium

O most awesome mystery

and sacrament divine and most wondrous:

that animals should look and see the Lord a babe newborn

beside them in a manger laid.

O how truly blessed is the Virgin whose womb was worthy

to bear and bring forth the Lord Christ Jesus.

Alleluia!

Note. Public Domain

Table 13

'People' from Funny Girl

"'People' from Funny Girl" — Julie Styne

Tim Takach, arr.

People – people who need people
Are the luckiest people in the world,
We're children, needing other children
And yet letting our grown-up pride
Hide all the need inside,
Acting more like children
Than children.
Lovers are very special people,
They're the luckiest people
In the world.

With one person, one very special person
A feeling deep in your soul
Says you were half,
Now you're whole.
No more hunger and thirst
But first be a person
Who needs people.
People who need people
Are the luckiest people
In the world!

Note. From *People*, lyrics by Bob Merrill, Los Angeles, CA: Warner Chappell. Copyright 1964. All rights reserved. Reprinted with permission.

Table 14

Psaume 121

Psaume 121 Darius Milhaud

I rejoiced when I heard them say:
"Let us go to God's house."
And now our feet are standing
within your gates, O Jerusalem.
Jerusalem is built as a city
strongly compact.
It is there that the tribes go up,
the tribes of the Lord.
For Israel's law it is,
there to praise the Lord's name.

There were set the thrones of judgment
of the house of David.
For the peace of Jerusalem pray:
"Peace be to your homes!
May peace reign in your walls,
in your palaces, peace!"
For love of my brethren and friends
I say: "Peace upon you."
For love of the house of the Lord
I will ask for your good.

Note. From *The Psalms : a new translation*, by Gelineau, J., & Schuon, G., 1963, Philadelphia: Westminster Press. Reprinted with permission.

Table 15

Danny Boy

Danny Boy — Traditional

Steve Bishop, Patrick Rose, arr.

Oh Danny boy, the pipes, the pipes are calling
From glen to glen, and down the mountain side
The summer's gone, and all the flowers are dying
'Tis you, 'tis you must go and I must bide.
But come ye back when summer's in the meadow
Or when the valley's hushed and white with snow
'Tis I'll be here in sunshine or in shadow
Oh Danny boy, oh Danny boy, I love you so.
And if you come, when all the flowers are dying
And I am dead, as dead I well may be
You'll come and find the place where I am lying
And kneel and say an "Ave" there for me.
And I shall hear, tho' soft you tread above me
And all my dreams will warm and sweeter be
If you'll not fail to tell me that you love me
I'll simply sleep in peace until you come to me.
I'll simply sleep in peace until you come to me.

Note. Public Domain

Table 16

Amazing Grace

Amazing Grace	American Traditional Stephen Hatfield, arr.

Amazing grace! How sweet the sound
That saved a wretch like me!
I once was lost but now am found,
Was blind but now I see.
'Twas grace that taught my heart to fear,
And grace my fears relieved;
How precious did that grace appear
The hour I first believed!
Through many dangers, toils, and snares,
I have already come;
'Tis grace hath brought me safe thus far,
And grace will lead me home.
When we've been there ten thousand years,
Bright shining as the sun,
We've no less days to sing God's praise
Than when we'd first begun.

Note. Public Domain

Table 17

Over the Rainbow

Over the Rainbow — Music, Harold Arlen; Lyrics, E.Y. Harburg

Mark Hayes, arr.

When all the world is a hopeless jumble,
And the raindrops tumble all around,
Heaven opens a magic lane.
When all the clouds darken up the skyway
There's a rainbow highway to be found
Leading from your window pane
To a place behind the sun
Just a step beyond the rain
Somewhere over the rainbow,
Way up high
There's a land that I heard of once,
In a lullaby.
Somewhere over the rainbow,
Skies are blue.
And the dreams that you dare to dream
Really do come true.
Someday I'll wish upon a star
And wake up where the clouds are far
behind me…
Where troubles melt like lemon drops,
Way above the chimney tops,
That's where you'll find me …
Somewhere…
Over the rainbow
Bluebirds fly,
Birds fly over the rainbow
Why then oh why can't I?
If all those little bluebirds fly
Beyond the rainbow…
Why…oh…why…can't I?

Table 18

Blessed Assurance

Blessed Assurance — Phoebe Knapp

Nancy Wertsch, arr.

Blessed assurance, Jesus is mine!
O what a foretaste of glory divine!
Heir of salvation, purchase of God,
born of his Spirit, washed in his blood.

Refrain:

This is my story, this is my song,
praising my Savior all the day long;
this is my story, this is my song,
praising my Savior all the day long.

Perfect submission, perfect delight,
visions of rapture now burst on my sight;
angels descending bring from above
echoes of mercy, whispers of love.

Perfect submission, all is at rest;
I in my Savior am happy and blest,
watching and waiting, looking above,
filled with his goodness, lost in his love.

Note. Lyrics by Fanny J. Crosby, 1820-1915. Reprinted with permission.

Figure Captions

Figure 1. Deaths among people with AIDS, 1985-2004. *Note*. From "Selected Findings on the New Medicare Drug Law AIDS at 25: An Overview of Major Trends in the U.S. Epidemic, p. 7" by Kaiser Family Foundation, 2006. Copyright June 2006 by Kaiser Family Foundation. Reprinted with permission.

Figure 2. Most urgent health problem facing the nation. *Note*. From "2006 Kaiser Family Foundation Survey of Americans on HIV/AIDS, p. 17," by Kaiser Family Foundation, 2006. Copyright May 2006 by Kaiser Family Foundation. Reprinted with permission.

Figure 3. Trend in share naming HIV/AIDS as the most urgent health problem facing the nation/world. *Note*. From "2006 Kaiser Family Foundation Survey of Americans on HIV/AIDS, p. 18," by Kaiser Family Foundation, 2006. Copyright May 2006 by Kaiser Family Foundation. Reprinted with permission.

Figure 4. Trend in personal and parental concern about becoming infected with HIV. *Note*. From "2006 Kaiser Family Foundation Survey of Americans on HIV/AIDS, p. 33," by Kaiser Family Foundation, 2006. Copyright May 2006 by Kaiser Family Foundation. Reprinted with permission.

Figure 5. Perceptions of groups most likely to be infected. *Note*. From "2006 Kaiser Family Foundation Survey of Americans on HIV/AIDS, p. 31," by Kaiser Family Foundation, 2006. Copyright May 2006 by Kaiser Family Foundation. Reprinted with permission.

Figure 6. Personal concern about becoming infected. *Note*. From "2006 Kaiser Family Foundation Survey of Americans on HIV/AIDS, p. 41," by Kaiser Family Foundation, 2006. Copyright May 2006 by Kaiser Family Foundation. Reprinted with permission.

Figure 7. Trend in personal concern about becoming infected. *Note*. From "2006 Kaiser Family Foundation Survey of Americans on HIV/AIDS, p. 42," by Kaiser Family Foundation, 2006. Copyright May 2006 by Kaiser Family Foundation. Reprinted with permission.

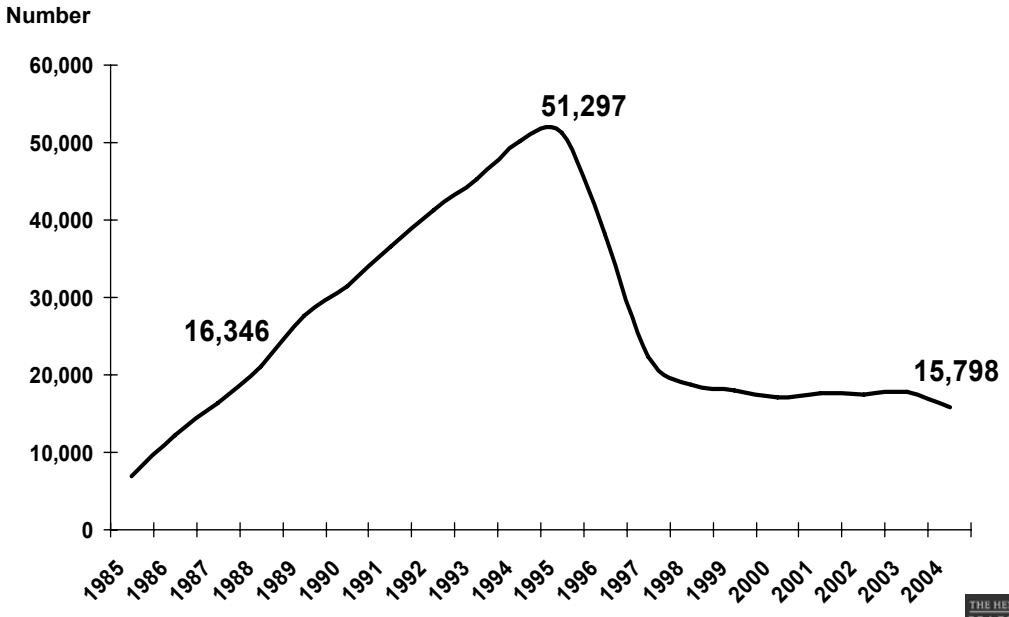
Figure 8. Estimated number of new HIV infections in the United States, 1980-2005. *Note*. From "Selected Findings on the New Medicare Drug Law AIDS at 25: An Overview of Major Trends in the U.S. Epidemic, p. 5," by Kaiser Family Foundation, 2006. Copyright June 2006 by Kaiser Family Foundation. Reprinted with permission.

Figure 9. New AIDS Cases, 1985-2004. *Note*. From "Selected Findings on the New Medicare Drug Law AIDS at 25: An Overview of Major Trends in the U.S. Epidemic, p. 6," by Kaiser Family Foundation, 2006. Copyright June 2006 by Kaiser Family Foundation. Reprinted with permission.

Figure 10. Trends in HIV Transmission, 1985-2004. *Note*. From "Selected Findings on the New Medicare Drug Law AIDS at 25: An Overview of Major Trends in the U.S. Epidemic, p. 17," by Kaiser Family Foundation, 2006. Copyright June 2006 by Kaiser Family Foundation. Reprinted with permission.

Figure 11. Women as a share of new AIDS cases. *Note*. From "Selected Findings on the New Medicare Drug Law AIDS at 25: An Overview of Major Trends in the U.S. Epidemic, p. 15," by Kaiser Family Foundation, 2006. Copyright June 2006 by Kaiser Family Foundation. Reprinted with permission.

Deaths Among People with AIDS, 1985-2004

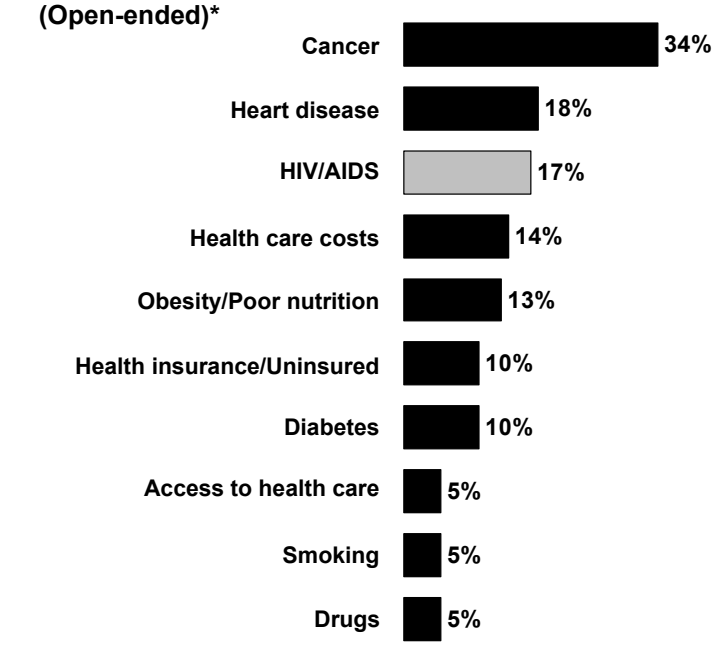


Source: CDC, Special Data Request for the Kaiser Family Foundation, 2006.

THE HENRY J. KAISER FAMILY FOUNDATION

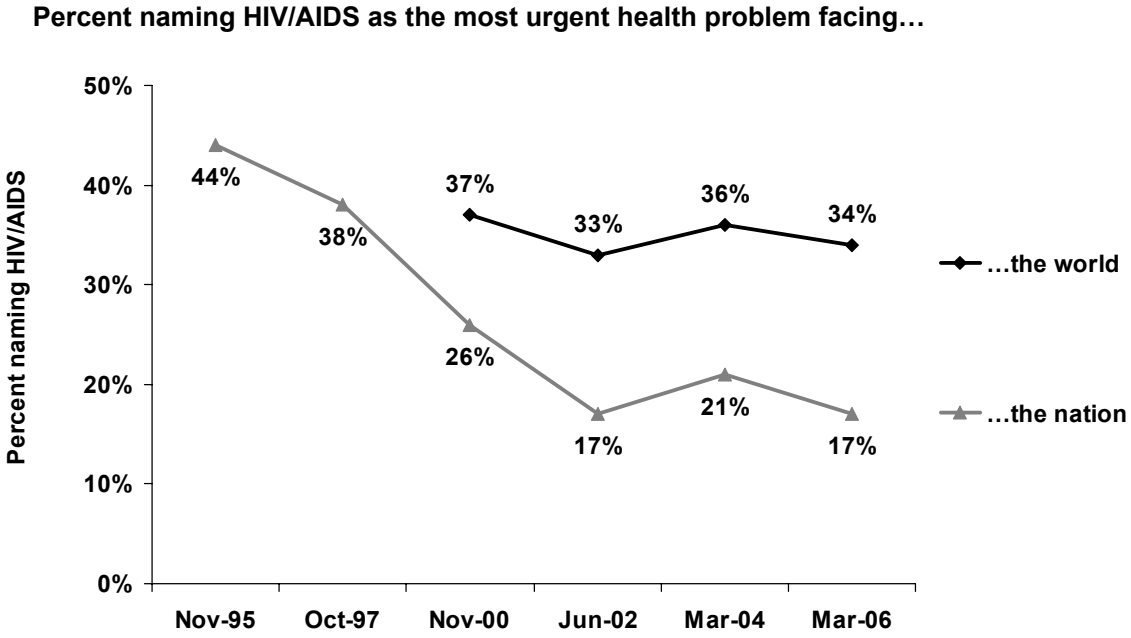
Most Urgent Health Problem Facing the Nation

What do you think is the MOST urgent health problem facing THIS NATION today? (Open-ended)*

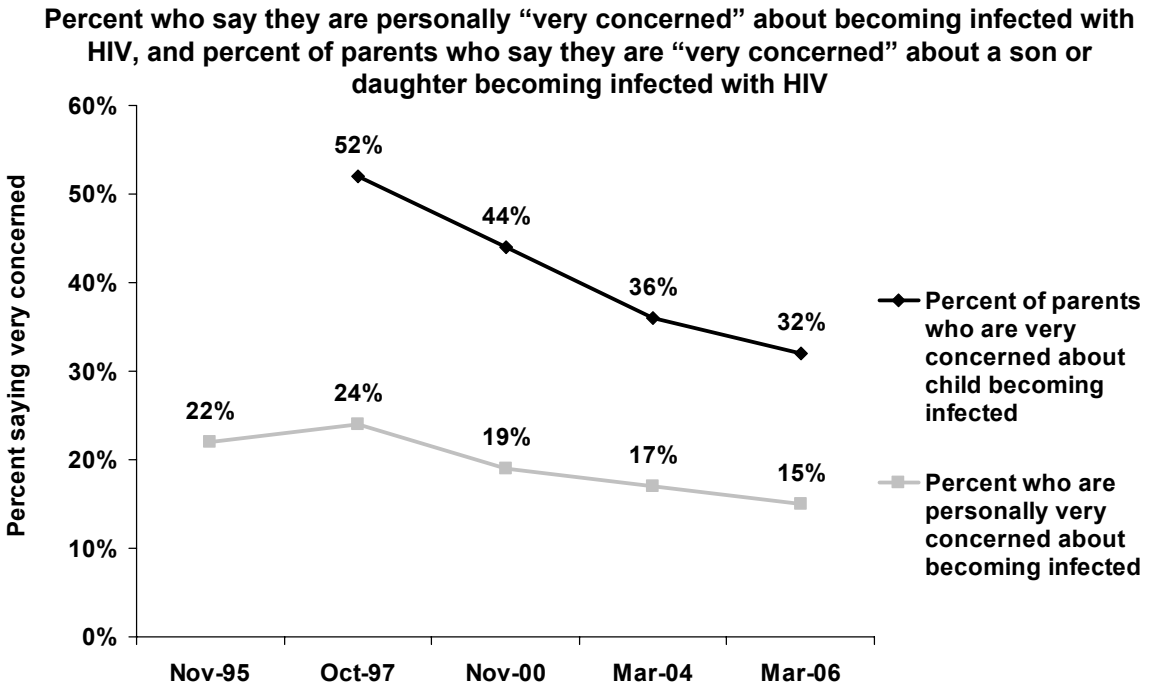


* Note: Adds up to more than 100% because of multiple responses.

Trend in Share Naming HIV/AIDS as the Most Urgent Health Problem Facing the Nation/World

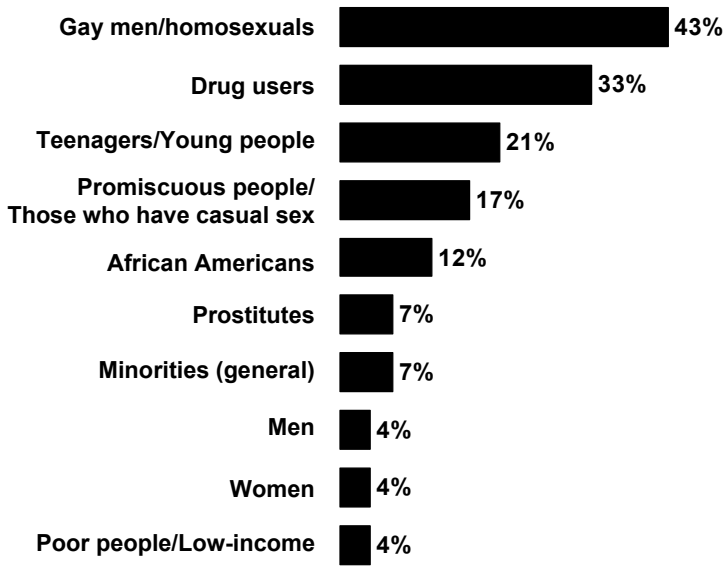


Trend in Personal and Parental Concern About Becoming Infected With HIV



Perceptions of Groups Most Likely to Be Infected

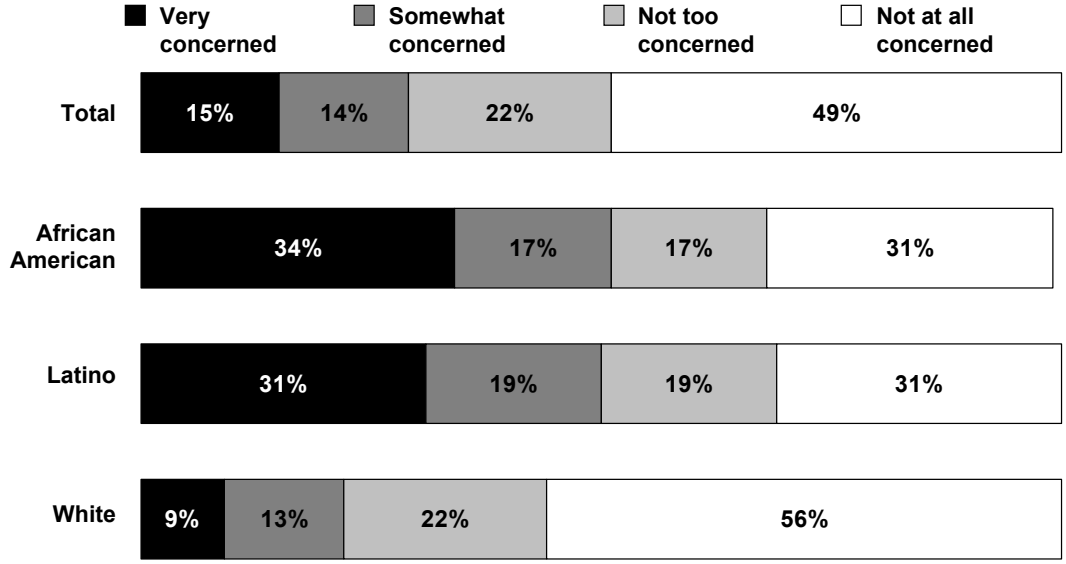
When you think about HIV/AIDS, which group of people do you think of first as those who are most likely to be infected? (Open-ended)*



* Note: Adds up to more than 100% because of multiple responses.

Personal Concern About Becoming Infected

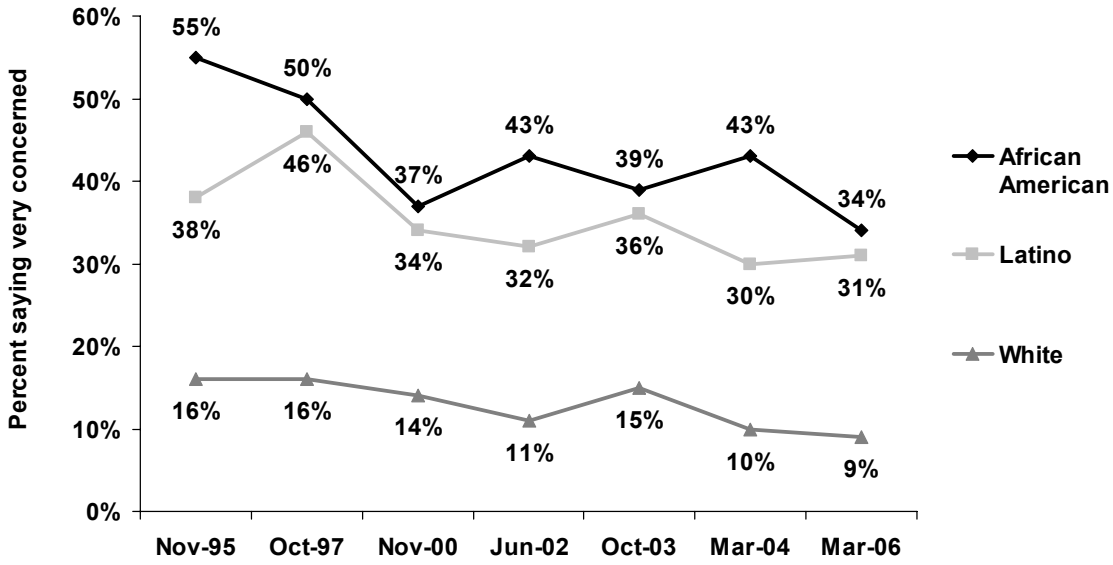
Bearing in mind the different ways people can be infected with HIV, how concerned are you personally about becoming infected with HIV?



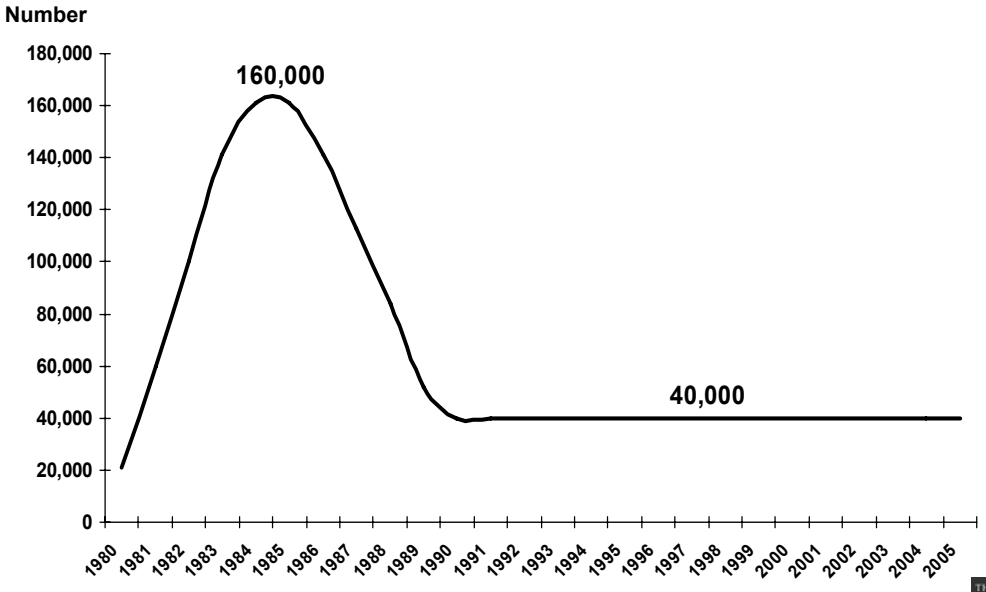
Note: Don't know responses not shown.

Trend in Personal Concern About Becoming Infected

Percent who say they are personally "very concerned" about becoming infected with HIV



Estimated Number of New HIV Infections in the United States, 1980-2005



Note: Data are estimates only. Sources: Kaiser Family Foundation analysis of data from: Holtgrave DR., Pinkerton SD. "Implications of Economic Evaluation for National HIV Prevention Policy Makers" In Kaplan and Brookmeyer (Eds.), *Quantitative Evaluation of HIV Prevention Programs*. New Haven, CT: Yale University Press, 2002; Brookmeyer R. "Reconstruction and Future Trends of the AIDS Epidemic in the United States" *Science*, Vol. 253, 1991; CDC, *A Glance at the HIV Epidemic*, 2006.

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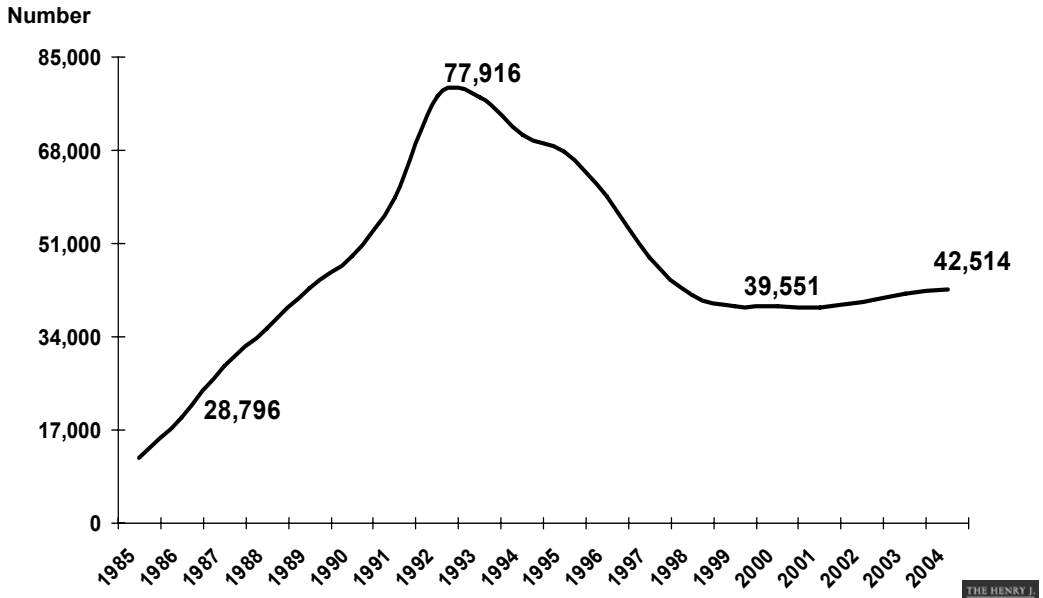
New AIDS Cases, 1985-2004



Note: Cases are by year of diagnosis.
Source: CDC, Special Data Request for the Kaiser Family Foundation, 2006.

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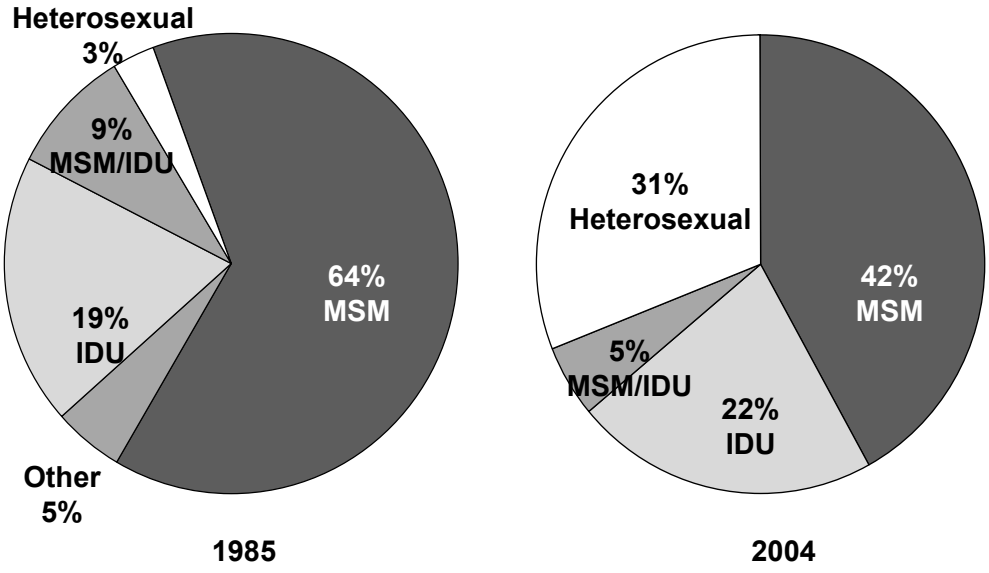
Trends in HIV Transmission, 1985-2004



Source: CDC, Special Data Request for the Kaiser Family Foundation, 2006.

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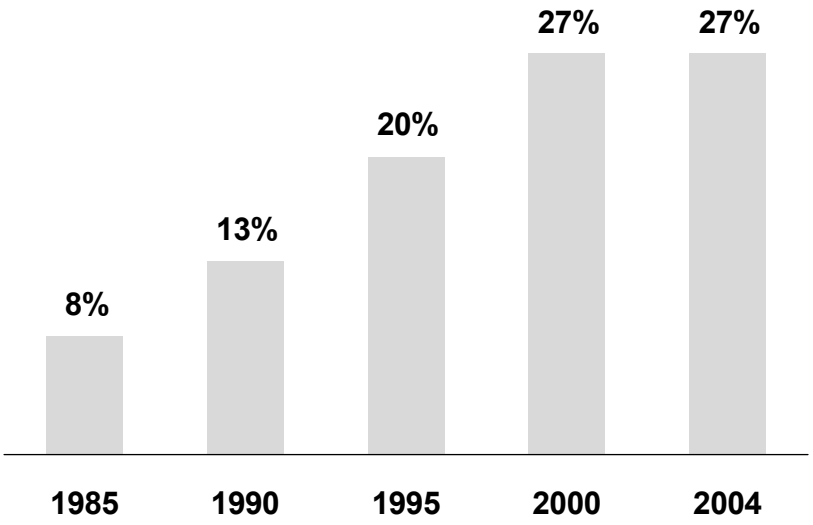
Women as a Share of New AIDS Cases, 1985 - 2004



Note: AIDS cases are by year of diagnosis.
Source: CDC, Special Data Request for the Kaiser Family Foundation, 2006.

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