

SILENCE IS THE VOICE OF COMPLICITY

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Editor's Note: The impact of HIV/AIDS on people's lives has led to a greater urgency to speak openly about denial, fear, death, and the pain of keeping silent. Fear surrounding public disclosure about HIV/AIDS remains a painful issue for affected loved ones as well as those with HIV/AIDS. We hope that these articles will motivate and encourage the rest of us to speak out whenever possible.

Is the silence broken? I speak from anger that has grown from grief. When I hear the name Magic Johnson and read the news stories telling us that AIDS has finally hit someone to whom we can all relate, that HIV/AIDS research and services must now be paid attention to, and that the public and particularly young people will realize that they too are vulnerable, I am filled with a paradox of emotions. I appreciate Magic's courageous act of openness and I admire his commitment to making his life as an HIV-positive person public in order to educate as many people as possible, especially in light of the discrimination and fear surrounding HIV/AIDS. But I am overwhelmed with anger when I think about the thousands of lives ravaged by HIV/AIDS, and the families, partners, and friends who have suffered in silence because of the stigma associated with the illness. I am angered at the years of battling for legislation, to protect individuals from discrimination, and to finance medical research, drug availability, and services for those infected. I am angered at the years lost to inadequate HIV/AIDS education of the young due to personal and institutional homophobia and fear of dealing with issues of sexuality, illness, and death.

I am a parent with three sons and a daughter, and three grandchildren, and I live in a small Midwestern city. My oldest son lives in California, is gay, and is

HIV-positive. I learned of his serostatus when he first became aware of it some time ago. I had been fearful of his being infected for a long time before that, and I was able to translate my fear into constructive action by working for policy change and education about HIV. For eight years, I have been involved with Parents FLAG, the Federation of Parents and Friends of Lesbians and Gays, as a networker, a speaker, an organizer, a resource and information and referral person, and a facilitator of others' involvement in these same areas. Parents FLAG was founded in 1981 to bring together a number of local self-help groups which had sprung up around the nation. In their support groups, parents and family members had discovered the value of sharing their stories to support one another, and the need to become empowered to speak out against discrimination based on homophobia.

At our Parents FLAG meetings, a small group is designated to support those dealing with HIV/AIDS in any way and that is why a few family members have come, but still the numbers of families with members who have HIV/AIDS that I am aware of are not represented at Parents FLAG regularly. My work has largely involved speaking with individuals over both the AIDS Support Line and the Parents FLAG Helpline — two telephones that sit side-by-side on my kitchen desk. The AIDS line, supported by a small grant to Parents FLAG from our local county, is for people concerned about HIV/AIDS who might not be as likely to seek support or help from the Parents FLAG line because of its connection with homosexuality. Both lines are well used. There have not been any abusive calls on the AIDS line, whereas the Parents FLAG line has received some virulent ones. Prior to my involvement with Parents FLAG, I was not aware of how much bigotry, and concomitant fear, exists about homosexuality.

I am one of only a few parents in this region who are willing or able to be a public person. My gay son

and his partner are open and have enabled me to be open as well. With that choice I believe I have the responsibility to be a spokesperson for all those family members who are forced to remain silent. It is my way of dealing with HIV/AIDS, an unbearable situation. My choice is right for me, but others must live by what is right for them. My hope is that by sharing my feelings and experiences here, a few of those people living with loss and potential loss will know that there is support, understanding, and even the confidentiality they may need — they have only to reach out from the silence.

Although my son was able to share the knowledge of his HIV status with me, silence was imposed for his partner's family. They were not to know that both our sons are HIV-positive, not from a fear of rejection, but from a sense of protecting them. Workplace and insurance discrimination issues were also a part of the decision for silence to be justifiably imposed.

Silence is the voice of complicity. I wear a pin with that motto on it and I am delighted to be asked about it. As a society, we have been complicit in silence that discourages us from openly talking to each other and educating ourselves about sexuality, illness, and death — and HIV/AIDS integrates them all. Sex can be chortled and giggled about, and used to sell products, but human sexuality cannot be taught comfortably — for students and teachers alike — in most schools. Illness of any kind is a part of life, yet even the common cold is blamed on the sufferer. In delivering the messages of HIV prevention, we somehow imply that we are masters of our fate and that if we but live a healthy lifestyle we will never get sick, and if we do, it is probably our own fault. Death is the most difficult one of all, even though it confronts every human being. And so, these topics are not allowed to be a part of our natural growing up process. Instead, a child's natural curiosity about them is turned into fear very early on by the silence and discomfort that surrounds them.

Anger and grief are two edges of the same sword and the cuts are deep for any loss, but when those cuts must be hidden and denied, normal grief is stifled. A woman and her brother attended a support group for family members in a Midwestern city, having driven 50 miles from their small town because they had no one with whom to talk. Her brother, I will call him Jim, had died of an AIDS-related illness. He had come home to visit his sister while he was still able to travel. She and her husband had wanted him to move in with them and their children, but her parents gave her an ultimatum: if Jim comes to live with you, we will never speak to you again. Jim chose to leave rather than put his sister in the position of having to make that choice. When he died, he was half a continent away from his loving sister's home. She had no one to talk with about shared memories of childhood experiences and escapades. The threat of rejection by the family still hangs over her head. If she breaks the silence her parents have imposed, her children will lose their grandparents. With this kind of silence comes immense guilt to compound the grief and anger.

A mother came to our Parents FLAG meeting long before we had an AIDS Family Support Group. Her son and daughter-in-law were now providing a home for her HIV-positive son because he could no longer live alone. She and her husband had been caring for him in their small town over 150 miles away, but now the son required more frequent medical treatment and needed to be in the city. This mother had told three people in her small town about her son's illness: her

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PARENTS FLAG FAMILY AIDS SUPPORT PROJECT

A nationwide program to assist parents and other family members of persons with AIDS has been undertaken by an organization composed largely of parents of gay and lesbian children. "Grief, compounded by a climate of fear and discrimination, threatens to isolate millions of family members affected by AIDS," said Paulette Goodman, president of the Federation of Parents and Friends of Lesbians and Gays, or Parents FLAG. "We want to provide them with guidance and information, plus the kind of strength that can only come from others who have been through the same trials."

The *Parents FLAG Family AIDS Support Notebook* contains basic information for family members, including sections on medical and treatment information, psychosocial, education, legal, and legislative issues, religious and spiritual support, and bereavement matters, and is available from local Parents FLAG contacts or from the Federation offices. The directors of the Federation's Family AIDS Support Project say it is one of a few that specifically targets the needs of family members. The Project is described in the introduction of the *Notebook*, "The Project's mission is to provide support for the special needs of members whose children are living with HIV infection, as well as to serve those outside the Parents FLAG network. Included in our definition of family are: spouses, offspring, siblings, as well as close friends, lovers, and life partners who may or may not be blood relatives."

One unique aspect of Parents FLAG is the nationwide network which can connect family members with support services in different parts of the country. "These are people who have to contend not only with the debilitating illness of their loved ones, but also with the twin scourges of stigma and ostracism," Goodman said. Thus, the project aims to help families and friends of persons with HIV infection to find both emotional support and necessary technical information about care and treatment. Working through the Federation's regional offices and local chapters, it offers individual and group support counseling, packets of regularly updated informational material, and assistance in locating local service resources. The Federation comprises more than 200 chapters and contacts throughout the country. Its principal function, in Goodman's words, is that of "keeping families in loving relationships." To that end, Parents FLAG sponsors local support groups to help families and friends understand and accept their gay loved ones. It also promotes education on the nature of homosexuality, and advocates the full human and civil rights of gays and lesbians.

Parents FLAG, Federation Office, PO Box 27605, Central Station, Washington, DC 20048-7605; 202/638-4200. Parents FLAG Family and Chapter Support Office, PO Box 20308, Denver, CO 80220, 303/321-2270. Copies of the Notebook may be ordered for a suggested tax-deductible donation of \$12 each.

physician, who said he never wanted to hear about it again; her pastor, who said it was God's judgement; and a friend, who was supportive. She never dared tell anyone else and her husband was simply unable to deal with the issues at all, beyond loving and caring for his son. The son died soon after and the mother died within three years of her son. She was in her early sixties.

I have talked with too many people who have lost a dear friend or family member to AIDS. Recently, I sat across the lunch table at a restaurant with a mother who, with tears streaming down her cheeks, told me that no one in her office has even acknowledged her son's death. She had spent the last six months commuting to a larger city to care for him and had sent word when he died. She posted a copy of her son's memorial service, a life-affirming tribute with pink triangles* on it, at her workstation. She told me that she would love to be able to talk with her coworkers about her son. Although her close friends reacted to the news with sadness, they cannot open the door to

share her and her husband's grief. She does not want to stand on a soapbox; she just wants to be able to talk openly about her experience. This silence goes far beyond our usual discomfort with death. This silence is grief denied.

Denial of death in general must also be acknowledged as part of the issue. How can a person share grief when they have to first teach their listeners to be comfortable with the whole idea of death, HIV/AIDS, and perhaps sexuality as well? A young woman who came to our Parents FLAG Family Support group recently used the word *silenced* several times to describe how she feels around other people. In our sharing we came to the recognition that, although we do not feel that hiding is necessary for us, in some way our mouths are stopped.

While I was writing this article, my brother was diagnosed with a condition that required surgery. I was able to discuss this situation freely with my friends and coworkers, and share the reasons for my concern and the need to travel to be with him before his surgery. If

* The pink triangle has become a rallying symbol for the gay community. Different colored triangles were originally used by the Nazis to identify categories of prisoners in concentration camps. Prisoners were

forced to wear these labels whether or not the category was accurate for them. A yellow Star of David was used to identify Jews. A pink triangle was used to identify homosexuals.

the diagnosis had been AIDS related, such openness might not have been possible. To share the fact that someone you love has an AIDS-related illness, is to expose oneself to the stigma that society associates with HIV/AIDS. One senses that some people react with sympathy for one's involvement with a stigma, instead of sympathy for one's pain and anxiety. Or worse, that they might be condemnatory of the person with HIV/AIDS. During times of grief and stress it is enough to simply deal with our own feelings *without having to educate others.*

My anger moves in waves, back and forth between the pain of grief and the rage that comes from feeling impotent in the face of denial, apathy, and ignorance shared by institutions and individuals alike. The same mother in the restaurant told me that the medicine prescribed for her son was not permitted to be administered, except for a specific condition under the experimental protocols, even though it had been found effective for another one of her son's AIDS-related illnesses.

These stories are not unique to the Midwest; I know that the same personal stories occur in all parts of the country. The incidence of HIV/AIDS is lower in the sparsely populated areas of mid-America, which means that the availability of care and support is much less. Another family wants their son to come home, but their town is many miles from a medical center and their local physician has advised them that their son would not have the same level of care that he can receive where he now lives. The inability to be with their dying son haunts them and compounds their pain. The nearest support group is 60 miles away.

A young woman who is HIV-positive returned home to be with her family. Only her sister has troubled to learn about HIV disease; the rest of her family sees her as well and denies the reality of the illness their daughter faces. The sister is her mainstay of support and a sharer of her grief. She writes poetry about the losses of her friends in the support group, one after another, over the short year she has been home.

A young woman in college decided to do a paper on homosexuality and called the Parents FLAG Helpline for information. When she came to pick up the materials, I asked her how she happened to become interested in the subject. Tears welled up. Her uncle had died of an AIDS-related illness the month before and her father, his brother, was not dealing with it well, and she had no one to talk with about it. We hugged. Sometimes hugging is all you can do. Then we talked. The *Names Quilt* was coming to town the following month, and I urged her to invite her father to see it with her. I later learned that she did convince him to come, and he was moved by the seeing the patchwork tributes to people who had died of AIDS. He requested information about how to make a panel and where the next display would be so he could present his brother's quilt piece. We must be able to affirm the lives of our loved ones, not only privately, but openly and proudly. We need new rituals for expressing our grief, not silence.

Funerals happen so often that caregivers related to

this disease often say to one another, "We'll have to get together for something other than a funeral soon." And then the next funeral or memorial service happens, too soon, and we meet again. There are people who, when they hear my voice on the other end of the telephone, assume that I am calling because there has been another death. Although I try to call at other times just to say hello, the initial expectation of bad news is still there.

We need to move HIV/AIDS into the mainstream of grief. There has been a tendency to form isolated groups for support around HIV issues, including grief. Individuals need to be connected with groups and other individuals on a wider scale — in order to reduce their isolation, and to make the subject of grieving AIDS a part of the public's awareness that death from AIDS-related illnesses is very much a part of our lives. Parents FLAG has a Family AIDS Education project that seeks not only to support people, but to bring them together around these issues. This can be facilitated by dovetailing services with other local resources, such as grief centers. Interacting with the board members of groups can bring us into the sphere of other groups, as people who are on one board are frequently on several. Through the sharing of resources with other organizations, networks of support and assistance can grow. This will serve both to acknowledge the validity of these families' experiences of grief and preserve their confidentiality to the extent they wish.

Our school district has invited people living with HIV/AIDS to be a part of the educational process by speaking to the students. One speaker was a friend of mine who told me of a young man who stayed behind after the presentation and started talking about his own mother who had a terminal illness and how a lot of the things my friend had said were things he knew about — how difficult it was to be sick, and how hard it was to find people to talk with about her illness. My friend died a few months later. I wondered if any of the teachers who had invited him to visit their classrooms had been able to extend his message as an affirmation of his death as well as his life. I called one of the school counselors who had frequently arranged for my friend to speak to his students, particularly the Peer Helpers, who told me that his school was the only one in the district which publicly acknowledged his death. An announcement was made to the students and they were invited to sign a card for him, or to send their own cards and letters to his partner, and a moment of silence was observed. I was glad that at least one school had been able to experience and share the loss openly. My friend was proud of the opportunity he provided for them during his life, and he would have welcomed their acknowledgment of his death. I miss him.

Homophobia impacts on HIV/AIDS education. How can we educate about HIV/AIDS in the face of the homophobia and ignorance which lead people to believe that this is a shameful disease *others* get, and probably deserve for the kind of sexual activities or drug using habits *they* engage in? Teachers in the

SIECUS received the following letter which helped inspire these articles' development.

Why does the gay and lesbian community say Silence=Death? AIDS activists created it to say: If we remain silent, waiting for the government to take action against AIDS people will die. Likewise, we as family must raise our voices to end the silence about our members who are at risk for AIDS, who carry the virus, or who have died, so that the larger society around us can know we are all family...so that our gay and lesbian members are not *them*.

In all stories of AIDS told though our news and entertainment media, something has always been missing: the real stories of the millions of people who are the families and friends of gay people with AIDS. Underreported and under-represented are the mothers, fathers, sons, daughters, husbands, wives, lovers, aunts, uncles, nieces, nephews, cousins, brothers, sisters, grandmothers, grandfathers, and friends: the family.

As a gay man from the Midwest living in New York City, I have lost family and many friends to AIDS. I know of so many who, out of fear of rejection, did not tell their families they were gay and/or ill. So they did not get some of the support they needed. And worse, they did not seek medical care when it could have helped. Their silence equalled death.

We, as family, must not let people with AIDS and HIV die of our embarrassment. You may be involved in some aspect of our society which helps create the images of gay men and lesbians that our nation comes to know and believe. It is because you are family, the core of American life, that you are listened to when you speak. Parents, siblings, relatives, and friends of gay men and lesbians and especially people with AIDS can make a difference. We can let American know AIDS is not going away because the family has arrived. We are *all* family. We will not be silent!

Midwest, even at the college level, run scared of discussing homosexuality, although this is not much different from what occurs in the rest of the country. Talking with students about adopting safer sexual behaviors, and the option of abstaining from sexual involvement, means acknowledging that we need to be communicating with them and with each other about sexuality, and that we are sexual beings from an early age.

A woman who is a caregiver and has been involved in the AIDS education and policy effort since 1984, was asked "What are you doing these days?" by a fellow parishioner at her liberal church one Sunday morning. She said that she was involved in facilitating

an AIDS support group. The person responded, "I thought you'd have been through with all that by now," and turned away as though to dismiss a distasteful subject.

Our AIDS support group had outgrown the living room where it was being held. I asked a minister if he could arrange for the group to meet in his church's parlor. Although he was sure the church board would approve, he was new to the parish, and decided to run it past them. When I met him later, his subdued demeanor told me before he spoke that the response had been negative. I happened to share this problem with an attorney who is involved in developing HIV/AIDS policies, and I discovered that he was a member of that congregation. His intervention with the board, a good example of breaking silence without pointing a finger, led to the reconsideration of the request and approval by the board. The temporary furor this created actually opened the door to providing HIV/AIDS education within the church's adult Sunday school program. The church members who helped with our meeting room arrangements were helpful and concerned. Their frame of reference as a group had expanded as a result of the controversy. Suspicion and fear gave way to understanding and compassion — once someone had broken the silence, others were empowered to keep the effort alive.

A silence that seems to remain unbroken is that of caregivers and service providers who face deaths, and persistent apathy and resistance. A group of caregivers responded affirmatively to a colleague who recognized and acted on her need to take a leave of absence because she was experiencing the warning signs of burnout. In their discussions, each one shared with the group, for the first time, their feelings that their needs were seldom recognized as they faced cumulative deaths and service demands. And sadly, even their respective partners in good caring relationships did not, perhaps could not, fully understand the toll that such cumulative grief takes. This particular silence, that of caregivers, is a silence that also needs to be broken. This work has no end in our lifetimes.

There are many manuals, workshops, and other resources available for educating and assisting all members of various communities, but we often struggle with the unwillingness of these audiences to open the doors to us. Once again, the silence, which stems from fear and avoidance of dealing with controversial issues either in a public forum or on a personal level, shuts us out. The temptation to break the door down and to beat our way in is great. In the long run we will gain most by being invited in as guests so that we can work together. The door has opened for Magic Johnson. How difficult that role is to develop. *Breaking the silence, as often as possible, and with as many people as possible, is essential.* This applies on personal, local, and legislative levels. Those who are tired of waiting, who must for their own sanity beat on the doors, frequently pave our way. Surely silence does equal death. Awareness about HIV/AIDS must happen in every place and in every heart. Those who can be open, must be.

A MOTHER'S STORY

The following story, by a mother whose daughter is HIV-positive, describes the very real need to speak out at a time when, ironically, the threat of repercussions or discrimination against her daughter prohibits the author from revealing their identities. Thus, certain details in this personal account have been changed in order to protect their privacy.

I want to share what it is like for me to be facing the probable loss of my child from a cause that involves severe debilitation and grim details, that is laden with discrimination and ignorance, and is perceived as a burdensome plight of the times. My daughter has HIV/AIDS.

As an adolescent, Lucinda was curious about sexuality, and naturally, along with most of her friends, she experimented sexually. Her questions to me about sexuality were knowledgeable and often challenging, and I rarely felt unable to openly discuss her concerns. There were some behavioral problems during high school, often a result of mood swings, but nothing too difficult for us to deal with at the time. She left home with high hopes of finding her niche in world.

When Lucinda decided to enroll in the army, I was quite disappointed. My vision of her in cap and gown in three years dissolved. She had spent an unhappy year in college, and she felt unmotivated to enter the job market. We discussed her plans to enlist, and I began to adjust. I assumed she would pass the numerous tests and go off to boot camp.

Three days later, I received a phone call at 9 am from the enlistment officer at the Army Headquarters calling about a problem with my daughter. I was confused. What kind of problem could possibly cause the army to call me, her mother, at work? He informed me that I had to call the medical director for the region who had some very important information for me. As I dialed the number, I felt increasing anxiety. Was she alright? Had something happened?

And then I learned, *over the telephone from a stranger*, that my daughter had taken the HIV-antibody test for entrance into the army and that her test result had been positive — which meant that she was infected with HIV, the virus that invariably leads to AIDS. My first thought was that it must be a mistake. How could my daughter have HIV? I methodically posed a dozen questions to the compassionate medical expert on the other end of the line to verify the accuracy of this statement.

When I was finally able to stop analyzing and take in the truth of this news, it was as if I had been shot. I felt sheer fright followed by numbness. Sitting at my desk, I knew this news would change our lives irrevo-

cably, but I couldn't begin to imagine the impact this would have for myself and my daughter, for our relationships with family and friends, and our relationship with each other.

After the initial period of shock and rage that this had happened, I was constantly thinking about how and when did this happen. Lucinda returned home and moved in with me. We began to reestablish normal lives, however, the stressful situation of living with HIV led to much tension between us.

My sister was getting married in Florida, and I made the difficult decision not to bring Lucinda along with me to attend the wedding, as her moods were severely erratic and I was feeling panicked about this HIV issue. She was annoyed, but agreed to stay behind, and like many other families who live with *the secret* that one of their family is HIV-positive or has AIDS, I went to the family event carrying this enormous personal burden *in silence*. Looking back, I regret that I did not have the courage to share the truth with my family and bring Lucinda with me to attend the wedding. Here I was, at a time of great need for personal support for both Lucinda and myself, and instead of seeking support from my family, I opted for silence. Perhaps I was protecting my family of origin, however, I suspected that bringing this news to the wedding would add tension and only spoil the whole occasion for everyone involved, and I grinned falsely throughout the event. At that time, Lucinda was awaiting the results from a second HIV-antibody test. When I phoned her on my last day in Florida, I learned that her test result was negative. Imagine my relief to learn that the first test must have been incorrect.

After this second test, Lucinda began to have recurrent bouts of flu-like symptoms, which disturbed me. After weeks of prodding, she finally agreed to retest at a local anonymous HIV testing site. Waiting two weeks for the result, especially after two conflicting results in less than a year, seemed eternal. One of my coworkers offered support and took a personal interest in befriending Lucinda and lending a helpful and informed ear. Lucinda and I went to the testing site together, but the nurse insisted on speaking with her confidentially at first. The nurse then allowed me to come speak with her and Lucinda, and informed me

that there was no equivocation — the test result was positive.

Lucinda and I began to work together to find ongoing support for both of us. A few months after the positive test result, it became clear that Lucinda needed her own place to live, hopefully with other supportive people. We visited the local AIDS project, renowned for its progressive educational and clinical care services. They assisted us greatly in having a place to talk about this, and in finding suitable housing. Knowing that there were support groups available was crucial to our staying healthy and sane, although most of the groups we contacted initially were comprised of gay men, which we have found to be the case throughout our explorations for support. After weeks of paperwork and phonecalls, Lucinda was offered a room in a new facility, which served her well for several months.

During that time the next step was to access medical care. Many physicians and other health care providers are not adequately prepared to deal with, much less treat, symptoms in women infected with HIV. Lucinda seems to have manifested a chronic spectrum of skin disorders, which at one time was diagnosed as measles. The medication for this treatment caused an allergic reaction that landed her in the hospital emergency room one Friday night, which allowed us to see just how ignorant some of the medical profession is when diagnosing and treating HIV-positive females. Had we not gone to the emergency room that night, Lucinda would probably have died within days.

Eventually we located a physician with vast experience in treatment of HIV-related disorders, who was equally as caring and humane as he was competent. That was a welcome relief, at a time when my fears were beginning to escalate about the course of events ahead of us, as symptoms were already presenting in her body. And, as are the daily themes for all families, I lived with the terror of not knowing the future, not having a sense of control, and the critical need to be able to rely on medical professionals for the type of support that only they can provide.

The next challenge came related to telling the rest of the family. As Lucinda gained some balance in taking charge of her life, I increasingly began to feel that this was bigger than I could handle alone. I became aware that this is a matter for whole families to deal with. I decided to "come out" and tell the family. I have made some strategic blunders along the way as the mom in this process, but it is difficult to navigate on racing and choppy waters with no maps to guide you. The idea occurred to me that a visit to the family in Florida would be a good idea, while Lucinda was relatively healthy and could do so. I wrote a letter to the whole family telling them the truth — that Lucinda was HIV-positive and what that might mean to us as a family. I told them how much we would like to visit them over the Christmas holidays. What a wrenching disappointment it was to learn that not only were they afraid of contracting a disease from her staying with them, *they did not even want to breathe the same*

air, for fear of those remote possibilities that might exist. I was devastated. I felt rejected by my own flesh and blood. I sensed their terror and panic, I understood their concerns, but I was enraged at their inability to accept. I tried to find a way to hide the truth from Lucinda, and I realized that honestly facing reality is part of the journey of living with HIV/AIDS.

When I told Lucinda the truth about our family's reaction, it was a hard blow for her. Yet it bonded us in a new way. I explained that they loved her and that in their ignorance they simply did not understand. I reassured her that in time things would change — and they have. I mounted a personal campaign to educate all of our family members with pamphlets, books, phonecalls, and letters citing the facts and the compelling call to band together and fight this thing as a family. I told them that Lucinda and I needed their support, and that they needed *us*. And gradually, our family members, in their own ways, began to open their hearts and minds. Two of them are finally ready to open their doors to us. That has led to Lucinda's and my own acceptance of family ties as an integral part of coping with HIV disease.

That was one and a half years ago. Life since then is sometimes unbearable, sometimes exquisitely joyful in the moments Lucinda and I spend together, as I gradually embrace the reality that this young woman in her early twenties may not be here for her thirtieth birthday. Sometimes I feel so overwhelmed by the enormous burden which this petite and increasingly frail young person is carrying, symbolized for me by a little blue mother-of-pearl pill case I gave her for her birthday. Other times I feel so powerless that as a mother I cannot "make it better," something that moms are supposed to be able to do for their children, and this hurts. My daughter is presently unable to face and accept being diagnosed with AIDS. Despite her taking AZT regularly, she has wavering T-cell counts and chronic herpes simplex II. Although we choose not to say the "A-word" at home, she now qualifies as having AIDS.

We have all learned in this process — mother, daughter, and our circle of family and friends — and what we have found is this: families living with HIV/AIDS need support. We need airtime and permission to tell our story — all parts of it. We need to speak of the burden that we carry and to talk about our fears, and guilt, and sadness. We need to acknowledge that it is natural to never know from one minute to the next what is the right thing to do, and to walk the razor's edge about living our own lives at what may look like the expense of our HIV-infected children. What we must remember especially is that we are doing the best we can, that we must preserve our own lives and live each day consciously, with joy, and with commitment. My daughter remains steady, her conditions do not improve, nor have they worsened. My healthy denial tells me that maybe the next drug on the market will be the one to keep her alive and healthy. That maybe she can turn this around. What I can affirm is that we are family, that we are there for each other, that this tragedy has opened the floodgate for loving, genuine communication.

POLITICS AND PRACTICE

HIV/AIDS Education Including

Condom Availability

In New York City Public Schools

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On February 27th, 1991, the New York City Board of Education, in a four to three vote, broke new ground in its adoption of the most far-reaching HIV/AIDS education initiative in the country — a program that includes the availability of condoms at the high school level, without parental notification or consent, for all students enrolled in the school. This bold and challenging program is not only unique because of its component parts; it speaks to the need to raise consciousness and demands that controversial issues be discussed in public, that the opposition reveal itself, and that the community-at-large take responsibility. What makes the New York City Public Schools HIV/AIDS Education Program Including Condom Availability special is that it required a public debate and a public vote. It demanded accountability from all sectors of the community, from the Mayor to the Commissioner of Health.

Development of New York City's Program

What is the context for New York City's program? In 1987, the New York State Education Commissioner required that every Board of Education in the state form an advisory council on HIV/AIDS education. In addition, the regulations called for a kindergarten through twelfth grade (K-12) instructional program on HIV/AIDS.

The Board of Education in New York City never formally convened an advisory council on HIV/AIDS education. In the absence of formal action, the central Office of Health convened an Ad Hoc Advisory Council on AIDS. The council, a loosely knit group comprised people from the advocacy community who cared deeply about the issue, lacked student or faculty involvement. In fact, the Board of Education never conferred with it, and the Chancellor's office did not participate on it. In the years of the Advisory Council's operation, many of its members became disillusioned and angry. The advocates felt that the staff from the central Office of Health did not care, and the staff felt that the advocates did not understand the constraints under which they operated.

The New York City Public School system had never formally adopted an HIV/AIDS curriculum. There was a pilot document in place, and in 1989, then Schools

Chancellor Richard Green issued a memorandum mandating that students in grades seven through 12 receive a minimum of six lessons per grade of HIV/AIDS instruction. At the time, the New York City Schools did not have an official HIV/AIDS curriculum that could be used to implement this mandate, so a pilot curriculum was used. This curriculum, still in use, has not been officially revised or adopted.

In the Spring of 1990, a subcommittee of the HIV/AIDS Advisory Council wrote a letter to Chancellor Fernandez requesting a meeting. The Chancellor, unaware of the history of the Advisory Council, scheduled a meeting to discuss their concerns. The subcommittee presented evidence of neglect by the school system and a lack of commitment by the administration on this issue, and presented the Chancellor with a call for a high quality curriculum, an upgraded Advisory Council with broad representation, and condoms in the schools. They presented statistics and they spoke of children with whom they had worked, whose lives had been decimated by HIV disease, and of adolescents who reported being HIV-positive. They spoke of young people who were not educated about their own risk of infection, and who had no access to information about HIV/AIDS prevention.

On August 30, 1990, the AIDS Advisory Council met with the Chancellor. This was the first time in its history that the Chancellor had met with the council, and as a result, there was a record turnout, with representatives from the Catholic Church as well as advocates and activists. The Chancellor discussed their recommendations and stated his intention to adopt every recommendation with the exception of condom availability — which he would have to investigate and present to the members of the board. Staff members, with assistance from the New York City Department of Health, collected materials and reviewed the statistics on adolescent sexuality and unintended pregnancy. In September, the Chancellor expressed his personal support of the availability of condoms and on September 26, 1990, the headline in *New York Newsday* read: "Chancellor: Schools Should Hand Out Condoms; Fernandez Pushes AIDS Education Plan."

Members of the New York City Board of Education requested that the Chancellor present them with a

comprehensive plan for K-12 on HIV/AIDS education. The plan was developed over several months, beginning in early October 1990, when an extraordinary advocacy coalition came together from a broad spectrum of educators, health professionals, and HIV/AIDS activists to strategize and organize an education initiative with the goal of helping to protect New York City's youth from a deadly epidemic.

By November 15th, a draft plan had been written. Meetings were scheduled with labor unions, the Federation of Parent Associations, district and high school superintendents and principals, members of locally elected community school boards, clerical leaders, and advocacy organizations. The consultation process for an issue of this kind requires affirmative outreach. If you simply put out a call for comment, and wait for a reply, you are vulnerable to criticism for selective consultation. The development of the Chancellor's plan included a range of actions and activities, from updating and developing a K-12 HIV/AIDS curriculum to organizing HIV/AIDS Education Teams comprised of parents, students, and faculty at every high school in the City. The plan was revised a half dozen times, as a result of the consultation process, prior to its presentation to the Board of Education. Though the changes were relatively minor, the process proved helpful both in generating support for the Chancellor's initiative and in broadly disseminating the content of the plan.

In early December, a memo was issued to more than 1,000 individuals and institutions inviting written comment on the plan. Four public sessions were scheduled on Saturdays and weekday evenings, with the Chancellor's staff available for comments and questions. At the same time, there were other forums for public debate. To demonstrate the interest generated by this issue, when the Board of Education presented its budget proposal for the school system, a \$6.5 billion plan for school expenditures, only a handful of citizens came to comment on the proposed budget. Yet, from October to February, more than 500 people signed up to speak on HIV/AIDS education in the schools. One session lasted six hours. Eventually the Board of Education scheduled a 12-hour Public Hearing to allow all parties to be heard. The hall of the board was crowded with spectators and speakers, with television cameras from as far away as Australia.

Citizens spoke about adolescent sexuality and family morals, about religious conviction and the risk of disease, about the breakdown of society and the crime of ignorance. Some speakers asserted that children were dying, and others called those people who are infected, deviants. There were protests and prayer vigils. The newspapers and television news reported the sometimes hysterical and chaotic atmosphere that pervaded the public sessions of the board. But beyond the anger and the outrage, there were moments of gripping emotion.

Joey DiPaolo, a student who attends a New York City elementary school and is HIV-positive, stood on a chair to reach the microphone and spoke of his own illness, of his friends' ignorance about the infection,

the lack of information, and the importance of the program. Joey's voice cracked as he pleaded with those present to "please, educate the children."

Condom Availability — The Differences That Matter

Since Chancellor Fernandez launched his campaign more than a year ago to promote comprehensive HIV/AIDS education including condom availability, many school districts across the country have begun to discuss the issue and examine the need for new pedagogic strategies to effect adolescent knowledge and behavior. The public debate aspect of the New York City program has been critical to its success, not only in New York, where significant dialogue has been generated among young people and adults about HIV, but across the nation where New York City's program has been the subject of heated debate. It is, in fact, these discussions which can raise public awareness of the issues of HIV/AIDS education and prevention that will impact on the HIV/AIDS epidemic.

In addition to public awareness, there are other critical program components, and very important distinctions that must be made as this issue is further discussed and new program designs are developed. Not all condom availability initiatives are alike, and in order to assess the objectives and effectiveness of different models, we must be able to cite the differences. The following represents a sampling of what I consider to be the most important distinctions that should be understood.

Clinic-Based Versus School-Based. Clinic-based programs usually require some form of parental consent, either affirmative or passive, and are designed as a medical intervention model — not as a component of education and counseling about HIV/AIDS for adolescents.

Parental Consent Versus Non-Consent. The New York City program is the only school-based program using faculty volunteers that has no consent requirement of any kind. A parental consent requirement, by definition, inhibits open communication between the young person and the adult school professional in discussing issues of adolescent sexuality and HIV/AIDS.

Comprehensive Versus Compartmentalized. This distinction, again, ties into a clinic-based program versus a school-based program. The New York City model is a comprehensive HIV/AIDS education program for K-12. The program includes a curriculum that is designed in collaboration with health professionals, staff development for curriculum implementation, and training — specific to the implementation of condom availability — for parents, students, and faculty who volunteer to participate on the HIV/AIDS Education Teams.

This is the only program we offer where training is provided to all members of the school community — parents, students, and faculty — in the same environment. The response to this strategy has been overwhelmingly positive. The training includes three sections:

- Orientation (one half day, for all HIV/AIDS Education Team members): an informational and motivational seminar;
- Tier I (one full day, for all HIV/AIDS Education Team members): Team building, understanding adolescence, and basic factual overview of HIV infection and related health topics via small group exercises;
- Tier II (two full days, for faculty only): learning to reinforce abstinence as the most effective method of prevention of sexual transmission of HIV and other STDs, emphasizing resistance to peer pressure; understanding the risks of use and misuse of condoms; understanding adolescent sexuality within the context of broader developmental issues; clarifying roles and responsibilities; using referrals effectively; and communication skills building.

After schools successfully complete all three training components, they are visited by a health educator and a licensed school supervisor. This team observes a lesson in HIV, visits the health resource sites identified by the school as condom availability sites, and meets with the faculty members who have volunteered to make condoms available. This site visit represents the last step in the review process prior to implementation.

Community Organizing Initiative Versus School-Based Initiative. Some school districts pride themselves on being able to implement HIV/AIDS education programs without controversy. In truth, one of the most effective aspects of any HIV/AIDS education initiative is the degree to which it raises community consciousness and generates public debate. Whether people agree or disagree, it is critical that the community at large become engaged in a dialogue to address this issue.

Implementation

Since February 27, 1991, when the New York City program was adopted by the Board of Education, the following has occurred:

- *Implementation Guidelines** were developed.
- High schools were offered technical assistance in developing their condom availability plans.
- A training committee of outside experts was established to design the training for our high schools in HIV and condom availability.
- A K-6 curriculum was written and shared with national readers, and is about to be submitted to the board for adoption.
- \$195,000 was donated by private corporations and foundations to establish a small grants program for high school students on student-developed HIV/AIDS education projects.
- \$510,000 was provided privately to hire staff to assist with the implementation of condom availability in the high schools.

- 500,000 condoms were donated by Carter-Wallace and London International, leading condom manufacturers.
- Sixteen high schools began their training in June 1991.
- On November 26, two of those 16 schools began condom availability.
- More than 100 of the city's high schools are in the process of completing or have completed their training.
- As of January 10, 1992, 15 of the 16 high schools were making condoms available, reaching more than 35,000 students in communities across the city.

This chronology gives the impression that things have gone smoothly since February 27, 1991. However, a lawsuit has been filed by a member of the board and four parents against the Chancellor and the Board of Education for violating parental rights, and charges are pending before the State Education Commissioner against the Chancellor.

Conclusion

Our faculty, administrators, students, and parents have performed admirably under a great deal of pressure and public scrutiny. Every Thursday from 8:30 am until 10 am, an internal working group comprised of HIV/AIDS educators, technical assistance providers, special education supervisors, substance abuse prevention faculty, and high school division guidance staff reviews the program's progress and provides ongoing direction and assistance to the HIV/AIDS education campaign that has been launched in the New York City Public Schools.

At John Dewey High School, one of the first of the two schools that launched the New York City initiative, the program began with frenzied activity as students converged on the health resource sites in large numbers for the first day or so. However, after the program had been in place for a week, students were quietly lining up their chairs and waiting outside the health resource sites to meet with the faculty volunteer and talk about issues of concern. Students were asking to see a condom, some for the first time, and to learn about STDs, HIV, and pregnancy prevention. The health resource sites were being used as sources of information, support and guidance — just as we had hoped they would when we designed the initiative.

We continue to receive letters from people who oppose the program, many on religious and moral grounds. And we continue to argue that HIV/AIDS education is mandated by our State Education Department and that condom availability is a voluntary component — no student is required to receive a condom. The intention of the New York City program is to convey a message, not simply to provide a condom. The message is that we care about the lives

* To obtain a free copy of the Implementation Guidelines, send a stamped, self-addressed, manila envelope to: HIV/AIDS

Implementation Guidelines, New York City Public Schools, 110 Livingston Street, Brooklyn, NY 11201.

of youth, that we are paying attention to the crisis at hand.

I had the privilege of visiting the AIDS and Adolescent Clinic at Montefiore Hospital in the Bronx, where nearly every young person enrolled in the clinic is either now or has been a student of the New York City Public Schools. I asked the young people with whom I spoke, what they learned in school about HIV/AIDS, and they replied, "Not enough." I have met parents, who have described their own HIV infection and their concerns for the future of their children, and children, who were grieving from the loss of a school-aged friend, a parent, or a sibling to AIDS.

Ongoing HIV/AIDS education in public schools is absolutely critical if we are to make a dent in the spread of HIV infection among young people. For too long, some schools have neglected or ignored this issue, and hoped it would go away. And in other cases, their approach has been so timid, that the instructional programs reflect society's self-consciousness about human sexuality, and fail to present a well-developed instructional program on HIV/AIDS. Public schools need to work in tandem with local health departments and community-based organizations providing services and information about HIV/AIDS. Parents must also be educated, and the political battles must be public. In order for schools to meet the challenge of implementing an aggressive HIV/AIDS prevention initiative, we need to be courageous in our various professions and communities, and share our conviction and resources.

This article was adapted from a speech presented at the Association for Public Policy Analysis Management Conference in Bethesda, Maryland, October 26, 1991, with information on the different types of condom availability programs and an update on the implementation of the New York City program added subsequently.

We Won't Go Back...

MARCH FOR WOMEN'S LIVES

April 5, 1992 in Washington, DC

SIECUS is sponsoring a delegation to this march and demonstration in support of reproductive freedom for all women. We urge you to show your support for our Constitutional rights and we invite you to march under a SIECUS banner. For more information or to register for the SIECUS delegation, please call Joanne Pereira at 212/819-9770 by March 13, 1992.

Guidelines For Comprehensive Sexuality Education Kindergarten Through Twelfth Grade

NOW AVAILABLE

Guidelines for Comprehensive Sexuality Education, Kindergarten Through Twelfth Grade have been developed by a National Task Force of 20 leading health, education, and sexuality experts. The Task Force was initially convened by SIECUS in 1990 in response to findings from a SIECUS study of programs for school sexuality and HIV/AIDS education. The Guidelines represent the first national consensus about what should be taught in a comprehensive sexuality education program, and have been endorsed by the following organizations: Association of Reproductive Health Professionals, Center for Population Options, National Education Association Health Information Network, National Network of Runaway and Youth Services, Planned Parenthood Federation of America, and SIECUS.

The *Guidelines* are not a curriculum; they are a framework for communities to create new or improve existing sexuality education programs. It is the responsibility of each local community to determine how best to develop and implement these guidelines. Parents, teachers, students, administrators, community and religious leaders all need to be involved.

The *Guidelines* are based on the premise that the primary goal of sexuality education is the promotion of adult sexual health and that sexuality education is a lifelong process of acquiring information and forming attitudes, beliefs, and values about identity, relationships, and intimacy. Based on the understanding that sexuality education is not simply education about reproduction and anatomy, this framework encompasses sexual development, reproductive health, interpersonal relationships, affection, intimacy, pleasure, body image, and gender roles.

Response to the *Guidelines* has been overwhelmingly positive, with more than 3,000 copies distributed within its first three months of publication. SIECUS invites you to be part of this groundswell of interest in comprehensive sexuality education.

The Guidelines are available for \$5 per copy, with bulk rates available, from SIECUS, 130 West 42nd Street, Suite 2500, New York, NY 10036, 212/819-9770. All orders must be prepaid.

SIECUS Fact Sheet #1

On Comprehensive Sexuality Education

CONDOM AVAILABILITY PROGRAMS

"Not that being HIV-positive has been easy to accept. Not when I could easily have avoided being infected at all. All I had to do was wear condoms."

— Magic Johnson, *Sports Illustrated*, November 18, 1991

"What kids plainly need is straight talk about sex."

— *New York Times* editorial, October 18, 1991

Many communities across the United States have begun to investigate the possibility of increasing adolescents' access to condoms as one strategy in HIV/AIDS prevention. Several communities have begun to explore condom availability programs in schools as a component of HIV/AIDS education.

YOUNG PEOPLE ARE AT RISK OF CONTRACTING HIV

- At the end of the first decade of the AIDS epidemic, more than 200,000 men, women, and children in the United States have been diagnosed with AIDS, and 65% of those, more than 130,000, have died of AIDS-related illnesses. One in five individuals diagnosed with AIDS are in their twenties. Because the incubation period of the virus averages 10 years, most of these people probably became infected as adolescents. Reported cases of AIDS among adolescents increased 25% for 13 to 19 year olds and 23% for 20 to 24 year olds, between November 1990 and November 1991.¹
- One million people in the United States are seropositive for HIV.²
- Although there are no national studies of HIV prevalence among the nation's youth, several studies indicate that HIV is spreading among teenagers. A recent national study of Job Corps applicants, ages 16 to 21 during 1987-1991, indicated that 3.6 per 1,000 were HIV-positive upon testing, a rate 10 times that of military applicants of the same ages. In the older males, rates were greater than for females; among 16 to 17-year-old females rates were higher than for males (2.3 per 1,000 vs 1.5 per 1,000). One in 40 black and Hispanic 21-year-old applicants were HIV-positive.³
- In a major, 4-year, hospital-based study of patients ages 13 to 19, the HIV-positive rate was 4.07 per 1,000. Since 1987, according to this study, seropositive rates among males have escalated from 2.47 to 18.35 per 1,000. Once again, older teenagers were infected at greater rates than their younger peers.⁴
- A study of 19 college campuses found that one in 500 college students was found to be infected with HIV.⁵
- HIV infection is not the only risk teenagers face from unprotected sexual intercourse. Over one million teenaged women become pregnant annually.⁶
- In 1990, three million teenagers became infected with a sexually transmitted disease (STD).⁷

MANY YOUNG PEOPLE ARE NOT PROTECTING THEMSELVES AGAINST HIV AND OTHER STDs

- Although abstinence is the best method of preventing pregnancy and STDs, including HIV, 50% of females ages 15 to 19,⁸ and 60% of males ages 15 to 19,⁹ have engaged in sexual intercourse.
- Condom use has increased among teenagers. In a national study of 17 to 19-year-old urban males, condom use at last intercourse increased from 21% to 58% between 1979 and 1988.⁹
- Many young people report that they are not using condoms because they find them difficult to obtain. Feelings of embarrassment, and fear of public exposure and admitting to strangers that they are having sexual intercourse, limit young people's willingness to obtain condoms in drug stores and supermarkets.
- Although most teenagers have some knowledge about HIV and AIDS, the majority of young people do not appear to be making effective

changes in their sexual behaviors. One recent survey indicated that more than 50% of adolescents did not perceive themselves to be at risk for HIV infection.¹⁰ Although 85% of teenagers know that condoms are an effective way to decrease the risk of HIV infection, nearly one-half of almost 2,000 sexually active teenaged men surveyed in 1988 did not use a condom during the last time they had sexual intercourse.⁹

- In a recent study of 112 incarcerated adolescents, those who perceived peer norms to be supportive of condom use were significantly more likely to be consistent condom users.¹¹
- A 1987 study of 16,000 females attending family planning clinics in Pennsylvania shows an alarmingly low rate of condom use. Among these patients, more than one-third of whom were adolescents, only 10% with regular partners and only 14% with casual partners reported that they had used condoms.¹²

YOUNG PEOPLE NEED EDUCATION ABOUT CONDOMS

- Teenagers are more likely to use condoms if they think that their friends are using them, if they allow for spontaneity, and if they are easy to use.¹³
- Although 33 states require HIV/AIDS education, the vast majority are not providing young people with a comprehensive base of information. Although 85% of states with HIV/AIDS curriculum guidelines present the important topic of abstinence, only 9% present a balanced picture of safer sexual behaviors and only 12% place HIV/AIDS education and information in the context of positive sexuality. Although 74% mention condoms, only 9% tell young people how to use them.¹⁴
- 96% of adolescents in a recent survey believed that students should receive HIV/AIDS instruction in the school curriculum.¹⁰ 64% of adults in a national poll believe that such education for high school students should be explicit about condoms and safer sexual practices.¹⁵
- Only one television network, Fox Broadcasting Company, currently allows condoms advertisements to be aired. These advertisements are for disease prevention only; they may not mention that condoms can be used for pregnancy prevention.
- Condom breakage and slippage can often be avoided with proper use. Instruction about effective ways to place or wear condoms without creating "user failure" requires frank education. Young men and women must be educated about how to use and where/how to obtain condoms, other latex barriers such as dental or rubber dams, and the lubricants or nonoxynol-9-based products that enhance their reliability. Condom education is best handled as an integrated part of an existing HIV/AIDS education program. And, as always, the most effective of such programs must be founded on a basis of comprehensive sexuality education which is gender-neutral and unbiased in its language and teaching approaches.

CONDOM AVAILABILITY PROGRAMS ARE ONE PART OF THE ANSWER

- Condom availability programs are designed to make condoms more accessible to high school students. Condoms are made available through specially designated resource rooms, health clinics, health education classes, or school nurses. Students request condoms from specially trained personnel.
- Programs for condom availability are beginning in several areas of the United States. The oldest condom availability program is in Commerce City, Colorado, in a rural school district.¹⁶
- New York City has the single largest school district in the world with 261,000 students in 120 high schools, 3% of all 13 to 21 year olds in the United States, and 20% of AIDS-related cases among this same population.¹⁷ The New York City Board of Education has implemented a condom availability program as a component of an in-depth integrated HIV/AIDS curriculum. Trained staff volunteers dispense the condoms along with a card on proper condom use, and the schools also offer sexuality and HIV-related counseling.
- Other cities whose school districts are beginning to investigate or plan condom availability programs include San Francisco, Berkeley, Los Angeles, and Philadelphia.
- Many school systems with school-based clinics make condoms available to students as part of their services. Schools in Los Angeles, Miami, Baltimore, Houston, and Chicago have made condoms available to students at clinic sites.¹⁸
- The Governors Advisory Council on HIV/AIDS in Washington State has recommended condom availability programs for junior and senior high schools, including access to lubricants and dental dams.¹⁶
- The Massachusetts Department of Education has recently issued guidelines for comprehensive HIV/AIDS education, including recommendations for condom availability programs. The guidelines suggest that schools consider placing condom vending machines on school grounds.¹⁹ In Falmouth, Massachusetts, school officials voted to install condom vending machines in high schools, and students in junior high schools will be able to obtain condoms from the school nurse.¹⁶
- Almost two-thirds of adults support condom availability programs in high schools, and almost half support such programs at the junior high level.¹⁵
- Numerous national organizations support condom availability programs.²⁰

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SIECUS acknowledges the Center for Population Options for providing useful background information in the development of this fact sheet, written by Patti O. Britton, deputy director, Program Services. It may be reproduced in its entirety without permission, provided that credit is given to SIECUS.

The National Coalition to Support Sexuality Education (NCSSE) is a group of more than 50 national non-profit organizations, many of which are noted role models and initiators in promoting the health, education, and social concerns for our nation's youth. The Coalition is committed to the mission of assuring that comprehensive sexuality education is provided for all children and youth in the United States by the year 2000. Among that leadership coalition, 19 organizations have endorsed the following statement in support of condom availability programs.

THE NATIONAL COALITION TO SUPPORT SEXUALITY EDUCATION

Statement in Support of Condom Availability Programs In Public Schools

More than half of American teenagers have had sexual intercourse and face significant sexual health risks. Each year, over one million teenagers become pregnant, one in seven teenagers contract a STD, and one in five hundred students on college campuses are infected with HIV.

Schools have an essential role to play in providing young people with sexuality education. Teenagers need accurate information and education about sexuality, opportunities to explore their values in supportive environments, and encouragement for responsible decision making. Education, about abstinence, alternatives to intercourse, sexual limit setting, and resisting peer pressure, should support adolescents in delaying sexual intercourse until they are ready for mature sexual relationships. Young people who choose to be involved in sexual relationships need ready access to prescription and nonprescription contraceptive and prophylactic methods.

Condom availability programs have been proposed in many communities in order to help protect the health of sexually active adolescents. The following members of the National Coalition To Support Sexuality Education support and encourage the development of condom availability programs in high schools. These programs must be coordinated with sexuality and HIV/AIDS education programs in order to provide sexually experienced young people with the information and motivation they need.

Parental and community involvement in the design of these programs is encouraged. It is generally desirable for parents to be involved with their children's sexual and contraceptive decisions. However, the right of every individual to confidentiality and privacy, regardless of age or gender, in receiving such information, counseling, and services, should be paramount.

**American Association for Counseling and Development
American Association of Sex Educators, Counselors and Therapists
American Home Economics Association
American Social Health Association
Association of Reproductive Health Professionals
Center for Population Options
Child Welfare League of America
Coalition on Sexuality and Disability, Inc.
Hetrick-Martin Institute for Lesbian and Gay Youth
National Education Association Health Information Network
National Family Planning and Reproductive Health Association, Inc.
National Gay and Lesbian Task Force
National Lesbian and Gay Health Foundation
National Network of Runaway and Youth Services
Planned Parenthood Federation of America
Sex Information and Education Council of the U.S.
Society for Behavioral Pediatrics
U.S. Conference of Local Health Officers
University of Pennsylvania**

For more information about NCSSE, contact: SIECUS, 130 West 42nd Street, Suite 2500, New York, NY 10036, 212/819-9770, fax 212/819-9776.

WE NEED MORE THAN MAGIC

Debra W. Haffner

On November 7th, when basketball player Magic Johnson announced that he had tested positive for the human immunodeficiency virus, I felt compassion for yet another individual infected with HIV, and admiration for his courage in publicly announcing his illness. However, I also experienced a deep seated feeling of rage that this announcement was what was needed to bring about such an incredible renewal of media attention and public and political response to this decade-old epidemic.

Following Magic Johnson's disclosure, George Bush spoke publicly about AIDS *for only the third time*. The media's coverage of HIV/AIDS suddenly increased, with stories in *Newsweek*, *Sports Illustrated*, *US News and World Report*, and *USA Today*, hundreds of television reports and sports page articles, and a barrage of misinformation, including the claim by two radio sportscasters that HIV can be transmitted between players on the basketball court. Condom ads were accepted for the first time on one television network, but only for disease prevention.

Yet, on November 6th, the day *before* Magic Johnson made his announcement, 195,000 Americans had been diagnosed with AIDS and 122,000 Americans had died of AIDS-related illnesses.

We have witnessed how deep our homophobia runs. When Magic Johnson announced on Arsenio Hall's television talk show, "You know I'm far from homosexual," the audience cheered, presumably in relief. If he had admitted to having sexual relationships with men, it is difficult to believe that he would have been lauded by the president.

We have also witnessed the double standard about the sexual activities of women and men that persists in our culture. The fact that professional athletes have no shortage of available female companions is taken for granted, yet the women who seek sexual relationships with them have been portrayed as *the* potential sources of infection. *All* sexually active individuals need to be concerned about the risk of HIV transmission, and the responsibility to use condoms to protect oneself against HIV and other STDs must be shared by *both* partners.

Tennis player Martina Navratilova commented that if she had announced that she was HIV-positive, the public would not be sympathetic, and would say that she contracted HIV because she is gay. Moreover, Navratilova pointed out that if a heterosexual female athlete admitted to having sexual intercourse with hundreds of male partners, she would be instantly vilified, and that corporations would be likely to cancel her promotion of their products.

SIECUS was deluged with media calls about HIV/AIDS education and Magic Johnson during the weeks following his disclosure. Here is a sampling of the questions I was asked:

Reporter's question: Because Magic Johnson has made this announcement, do we need AIDS education in schools?

My answer: No, we have needed it for years.

Reporter's question: Do parents need to provide information about AIDS to their children?

My answer: Yes, parents need to provide them with information about how HIV is and is not transmitted, and how they can protect themselves from possible exposure to HIV.

Reporter's question: Will Magic Johnson's being on the National AIDS Commission make a difference in their effectiveness?

My answer: The work of the commission has been excellent. The Administration needs to pay attention to its reports.

Reporter's question: Shouldn't Magic Johnson tell young people to just say no to all sex?

My answer: Abstinence from sexual intercourse is the most effective method of preventing unwanted pregnancies and STDs, including HIV, and there are many sexual behaviors that do not put one at risk of pregnancy or disease. It seems to me that Magic Johnson is a much more credible role model for safer sex than he is for abstinence.

There are a variety of questions I have asked myself as well. What is needed for this surge in public awareness of the AIDS epidemic to continue to grow? Will the message that behavior places one at risk, not what group you belong to, finally be heard? Is Magic Johnson going to advocate only for prevention, or will he speak out on the needs of people living with HIV/AIDS for treatment, research, and services?

The theme of World AIDS Day on December 1, 1991 was "Sharing the Commitment." Let us each actively renew our commitment to provide comprehensive services and treatment for people living with HIV/AIDS, to ensure easily accessible counseling and testing with assurances of confidentiality, to provide honest and explicit education about HIV transmission and prevention, to advocate for increased funding for research and clinical trials, and to end the discrimination and panic that has, for too long, been associated with this epidemic.

CURRENT RESOURCES FOR HIV/AIDS EDUCATION

A SIECUS Annotated Bibliography

This annotated bibliography profiles materials that can be used in HIV/AIDS education for a wide range of audiences. These resources have recently become available or have not been listed in a previous SIECUS bibliography. Although SIECUS does not distribute any of the materials listed in the bibliography, they are available for use within our reference library.

POLICY GUIDELINES AND CURRICULA

AIDS AIDS: HIV PREVENTION EDUCATION FOR PUBERTY-AGE YOUTH — LESSON PLANS AND RESOURCE GUIDE

Sue Monfort, et al

A valuable collection of available guidelines for curriculum evaluation, teaching manuals, and lesson plans that includes audiovisual resources and other teaching aids, background resources, and bibliographies most likely to be useful to educators of grades 4 through 9. Also included are activities successfully used by PPNNJ's health educators. 1990, 79 pp., \$23.90.

Center for Family Life Education,
Planned Parenthood of Greater Northern
New Jersey, Inc., 575 Main Street,
Hackensack, NJ 07601; 201/489-1265.

AIDS/HIV AND CONFIDENTIALITY: MODEL POLICY AND PROCEDURES

American Bar Association

The purpose of this resource is to assist programs and agencies, especially those serving persons with developmental disabilities, in formulating their own confidentiality policies. By providing a model for adaptation and adoption, as well as a full discussion of each individual policy, the authors hope to help programs understand their legal obligations and provide them with procedures and standards for fulfilling these obligations. This model policy is intended for use by various types of programs and agencies, including health care facilities, residential programs and group homes, day care centers, social service programs, schools, and government agencies. 1991, 122 pp., \$28.95.

American Bar Association Commission on the Mentally Disabled and Center on Children and the Law, 1800 M Street NW, Washington, DC, 20036; 202/331-2282.

AIDS, HIV, AND SCHOOL HEALTH EDUCATION: STATE POLICIES AND PROGRAMS 1990

National Association of State Boards of
Education, Council of Chief State School
Officers

This resource is the result of a survey conducted in 1990 and the findings are very useful for policy-makers and program developers in their efforts. Organized in two major sections: summary results from the 50 states, Washington DC, Puerto Rico, American Samoa, Guam and the Virgin Islands; and a profile of each education agency's HIV/AIDS education and school health policies and programs. 1991, 142 pp., free.

CCSSO, 379 Hall of the States, 400
North Capitol Street NW, Washington, DC
20001; 202/393-8159 or NASBE Publications
Department, 1012 Cameron Street,
Alexandria, VA 22314; 703/684-4000.

ENDING THE HIV EPIDEMIC: COMMUNITY STRATEGIES IN DISEASE PREVENTION AND HEALTH PROMOTION

Steven Petrow with Pat Franks & Timothy
Wolfred, editors

Provides detailed information and expert thought on developing prevention strategies to reduce the spread of HIV in communities throughout the nation. Composed of three sections: Understanding the HIV Epidemic; The San Francisco Response; and Preventing the Spread of HIV in Your Community. A book that encourages people to take an active involvement and share their work with others. 1990, 164 pp., \$24.95.

Network Publications, PO Box 1830,
Santa Cruz, CA 95061; 800/321-4407.

EPIDEMIC OF FEAR: A SURVEY OF AIDS DISCRIMINATION IN THE 1980s AND POLICY RECOMMENDATIONS FOR THE 1990s

American Civil Liberties Union/ACLU
AIDS Project

This bibliography has been prepared by Carolyn Patierno, director of SIECUS' National AIDS Initiative, and is funded through a cooperative agreement with the U.S. Centers for Disease Control. A single copy can be obtained, free upon request, with a self-addressed, stamped, business envelope by writing to: SIECUS, 130 West 42nd Street, Suite 2500, New York, NY 10036.

The ACLU sent questionnaires to more than 600 legal and advocacy organizations throughout the country in order to document discrimination related to HIV/AIDS. The report contains three sections: Section One provides the key findings of the study, along with an analysis of the results; Section Two highlights gaps and inconsistencies in anti-discrimination protections; and Section Three identifies priority areas for combatting HIV-related discrimination, and presents recommendations for future anti-discrimination efforts. 1990, 146 pp., \$10.

ACLU AIDS Project, 132 West 43rd
Street, New York, NY 10036; 212/944-
9800.

LATINA AIDS ACTION PLAN AND RESOURCE GUIDE

National Hispanic Education and
Communications Projects (HDI)

Covers the critical issues that must be addressed in order to implement successful HIV/AIDS prevention programs and to develop policies that will empower women and support women's leadership in public health decision making. Contains a resource guide which covers model programs, a bibliography targeting Latinas and children, and a listing of HIV/AIDS testing and counseling sites and organizations providing HIV/AIDS services to Latinas. Spanish translations of the major sections are provided. 1990, 195 pp., \$15.

HDI Projects, 1000 16th Street NW,
Room 504, Washington, DC 20036; 202/
452-0092.

SAFE CHOICES: AIDS AND HIV POLICIES AND PREVENTION PROGRAMS FOR HIGH-RISK YOUTH

National Network of Runaway and Youth
Services

A guide which provides relevant HIV/AIDS prevention materials to community-based shelters and programs serving runaway, homeless, and high-risk adolescents. Contains seven modules that

outline organizational policies, staff training, youth training, individual and family counseling, outreach to street youth, AIDS hotline materials, and foster care. Additional vital information is found in 16 appendices at the end of the guide. 1990, 252 pp., \$30.

National Resource Center for Youth Services, The University of Oklahoma, 202 West Eighth, Tulsa, OK 74119; 918/585-2986.

TALKING WITH KIDS ABOUT AIDS: A PROGRAM FOR PARENTS AND OTHER ADULTS WHO CARE

Jennifer Tiffany, Donald Tobias, Arzeymah Raqib, & Jerome Ziegler, Illustrations by Marcia Quackenbush

This resource is actually a training manual that includes a resource manual and a teaching guide. This three-session training will better prepare parents and other adults who care for young people "to work as a group to clarify any confusion they have felt about AIDS and to learn to offer AIDS information to young persons in increasingly effective ways." The resource manual is provided to participants of this workshop. The material is well-organized and beautifully illustrated and the information is clearly and sensitively presented. 1991, Resource Manual: 86 pp., Teaching Guide: 47 pp., \$9.50.

Parent AIDS Education Project, Department of Human Service Studies, Cornell Cooperative Extension, Cornell University Resource Center, 7 Business and Technology Park, Ithaca, NY 14850; 607/255-1942.

TEACHING AIDS: A RESOURCE GUIDE ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

Marcia Quackenbush & Pamela Sargent

An updated version of this curriculum for educators to use with teenagers that provides seven teaching plans, ready-to-use worksheets, teacher background information, and a 10-question quiz about HIV transmission and prevention. New sections added to the third edition include: a preface about the evolving language of the AIDS epidemic, new information on the changing patterns of high-risk behavior among teens, practical recommendations for more effective HIV/AIDS prevention education, and a glossary expanded with new terminology. Third edition 1990, 163 pp., \$19.95.

Network Publications, PO Box 1830, Santa Cruz, CA 95061; 800/321-4407.

TRAINING EDUCATORS IN HIV PREVENTION: AN INSERVICE MANUAL

Janet Collins, PhD & Patti O. Britton

This inservice manual reviews the knowledge, skills, and attitudes that contribute to preventing HIV transmission and presents practical activities to prepare teachers for their role as effective HIV prevention educators. Activities center around the following topics: teaching the facts, feelings about HIV infection and AIDS, perceiving oneself at risk, and risk-

reduction skills. Helpful tips are provided for each activity. 1990, 155 pp., \$39.95.

Network Publications, PO Box 1830, Santa Cruz, CA 95061; 800/321-4407.

BOOKS

AIDS AND ALCOHOL/DRUG ABUSE: PSYCHOSOCIAL RESEARCH

Dennis Fisher, PhD, editor

The relationship between HIV and substance abuse is considered in this collection of papers by drug abuse researchers. Also examined are the issues involved in conducting HIV/AIDS research with various racial and ethnic communities. The book focuses on aspects of HIV infection that have received little attention elsewhere such as injection drug use in Alaska, little-known facts that relate substance use to HIV infection in the American Indian/Alaskan Native population, and the transmission of HIV by gay men who are alcoholic and by injection drug users. 1991, 97 pp., \$19.95 hc, \$9.95 pb.

The Harrington Park Press, 10 Alice Street, Binghamton, NY 13904; 800/342-9678.

AIDS DEMO GRAPHICS

Douglas Crimp with Adam Rolston

"This book is intended as a demonstration, in both senses of the word. It is meant as direct action, putting the power of representation in the hands of as many people as possible. And it is presented as a do-it-yourself manual, showing how to make propaganda work in the fight against AIDS." This is a valuable resource as it is the only collection of graphic materials that captures the history of the HIV/AIDS movement. 1990, 141 pp., \$16.95.

InBook, PO Box 120470, East Haven, CT 06512; 800/253-3605.

AIDS AND THE HOSPICE COMMUNITY

Madalon O'Rauke Amenta & Claire Teban

Documents facts and addresses issues of concern in current AIDS hospice care and presents an authoritative commentary on many common misperceptions about HIV/AIDS. Describes research projects and findings that detail these and other effective barriers to AIDS hospice care. Gives examples of hospices that have entered into AIDS patient care and shows that such programs can be extremely successful for everyone involved. Will help agency administrators plan AIDS policies and programs and promotes further research by identifying specific areas in need of study. 1992, 196 pp., \$14.95.

The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904; 800/342-9678.

AIDS AND WOMEN: A SOURCEBOOK

Sarah Watstein & Robert Laurich

A reference of information and data on all aspects of HIV/AIDS and women that provides facts, recommended policy ac-

tions, fully annotated references, and statistics. Chapters include: Transmission Through Intravenous Drug Use, Transmission Through Blood and Blood Products, Risk for the Sexual Partners of Hemophiliacs, Perinatal Transmission, Lesbians and AIDS, Imprisoned Women and AIDS, and Women of Color and AIDS. 1991, 176 pp., \$39.95.

Oryx Press, 4041 North Central at Indian School Road, Phoenix, AZ 85012; 800/279-ORYX.

CIRCLE OF HOPE: OUR STORIES OF AIDS, ADDICTION, AND RECOVERY

Perry Tilleraas

Twenty-four powerful stories of people living with HIV/AIDS and recovering from addiction. Revealing the links between chemical dependency and HIV/AIDS, these stories outline a process of recovery that can play a pivotal role in living with HIV/AIDS. 1990, 364 pp., \$10.95.

A Hazelden Book, Harper and Row Publishers, Inc., 10 East 53rd Street, New York, NY 10022; 800/242-7737.

EARLY CARE FOR HIV DISEASE

Ronald Baker, PhD, Jeffrey Moulton, PhD, & John Charles Tighe

Written for people who are HIV-positive, this book offers vital medical information about HIV infection and HIV disease and suggests ways to maintain and improve psychological health. Divided into three parts, Early Medical Care, Your Psychological Well-Being, and Resources and Glossary, which have been expanded for the second edition. This is an extremely helpful resource for those who have just learned they are HIV-positive antibody status. Second edition 1992, 180 pp., \$13.95.

Impact AIDS, 3692 18th Street, San Francisco, CA 94110; 415/861-3397.

THE ESSENTIAL AIDS FACT BOOK

Paul Harding Douglas & Laura Pinsky in cooperation with the Columbia University Health Service

Provides readers with essential facts regarding biological, medical, psychological, social, and legal issues. A concise reference work with easy-to-access information chapters on Causes, Characteristics and Transmission, Observed Patterns of Illness, Prevention, HIV Antibody Testing, Health Care, Insurance, and Discrimination and Confidentiality. A Resource Guide is also included. 1989, 126 pp., \$6.

Pocket Books, 1230 Avenue of the Americas, New York, NY 10020; 800/223-2348.

GETTING THE WORD OUT: A PRACTICAL GUIDE TO AIDS MATERIALS DEVELOPMENT

Ana Consuelo Matiella, editor

Provides a practical guide for developing effective HIV/AIDS education materials as well as insights and recommendations on

how to develop culturally sensitive and relevant HIV/AIDS education materials for the diverse communities they are intended to reach. Chapters include: Using Focus Group Interviews to Design Materials; Developing Low-Literacy Materials; Adapting and Translating Materials; Producing Comic Books and Photovideos; and Developing Relevant Materials on a Low Budget. 1990, 232 pp., \$19.95.

Network Publications, PO Box 1830, Santa Cruz, CA 95061; 800/321-4407.

HANDLE WITH CARE: CARE TEAMS SERVING PEOPLE WITH AIDS

Ronald Sunderland & Earl Shelp

A step-by-step guide for religious congregations that wish to organize care teams to serve people living with AIDS. Lays the foundation for an interfaith response in areas such as: how to organize a care team, how to minister to the psychosocial, social, and emotional needs of people living with HIV/AIDS, and how to assist in the activities of daily living. 1990, 144 pp., \$7.95.

Abingdon Press, 201 Fifth Avenue South, Nashville, TN 37202; 800/251-3320.

HOW TO FIND INFORMATION ABOUT AIDS

Virginia Lingle, MLS & M. Sandra Wood, MLS, MBA

This resource assists in the effort to access HIV/AIDS information by providing key access points such as government agencies, community hotlines, organizational resources, funding sources, major publications, and informational databases. 1988, 130 pp., \$9.95.

Harrington Park Press, 12 West 32nd Street, New York, NY 10001; 800/342-9678.

INVENTING AIDS

Cindy Patton

An analysis of the discourses of HIV/AIDS and "the AIDS service industry" which emerged in the 1980s. Using literary and social theory techniques, her critique reveals that AIDS discourse is not only about people, but about power, homophobia, and discrimination as well. Patton considers the critical relationship between how individuals think about HIV/AIDS and how institutions need to formulate public policy and political strategies that will combat all forms of oppression accompanying the epidemic. 1990, 176 pp., \$13.95.

Routledge, Chapman and Hall, Inc., 29 West 35th Street, New York, NY 10001; 212/244-3336.

WOMEN, AIDS AND ACTIVISM

The ACT-UP/New York Women and AIDS Book Group

This resource advances research by and about women involved with the HIV/AIDS crisis, provides information about women's particular needs, analyzes the impact of

AIDS on women's lives from a feminist perspective, and promotes grassroots activism. Includes articles on a wide range of topics including: Testing and Legal Issues for HIV-Positive People; Unique Aspects of HIV Infection in Women; Race, Women and AIDS; Lesbians in the AIDS Crisis; Teenagers; Reproductive Rights and AIDS; Bisexual Women and AIDS; and Prostitution and HIV Infection. 1990, 295 pp., \$9.

South End Press, 116 St. Botolph Street, Boston, MA 02115; 800/533-8474.

FOR YOUNGER READERS

COME SIT BY ME

Margaret Merrifield, MD and Heather Collins

A book about understanding and dealing with HIV/AIDS that is written for children ages four to eight and their caregivers. The story concerns a young girl who finds out that one of her school mates is living with AIDS. Beautifully illustrated, sensitive, and realistic. 1990, 30 pp., \$6.95.

Women's Press, 517 College Street, Suite 233, Toronto, Ontario M6G 4A2, Canada; 416/921-2425.

YOUR DECISION

Neal Starkman

This realistic and interesting story, accompanied by terrific illustrations, is designed for teenagers who are learning decision-making skills in the areas of relationships, drug use, and sexuality. The reader makes decisions based on the information provided and determines the outcome of the story. There are separate sections for males and females. 1988, 116 pp., \$9.95.

Comprehensive Health Education Foundation, 22323 Pacific Highway South, Seattle, WA 98198; 800/323-2433.

RYAN WHITE: MY OWN STORY

Ryan White & Ann Marie Cunningham

A personal account of this outstanding young man's life, both joyous and difficult, told with much humor. It is amazing, interesting, and moving, and many photographs are included. Although enjoyable for people of all ages, this autobiography is especially useful for teenagers learning about HIV/AIDS. 1991, 277 pp., \$16.95.

Dial Books, 375 Hudson Street, New York, NY 10014; 800/526-0275.

Z'S GIFT

Neal Starkman

This book tells the story of how a young boy responds to the news that his teacher is living with AIDS, and how he teaches the adults and children around him the meaning of compassion and rationality. Written for eight to 12 year olds, this beautiful story

has lovely and simple illustrations and characters with diverse racial and ethnic backgrounds. 1988, 52 pp., \$5.95.

Comprehensive Health Education Foundation, 22323 Pacific Highway South, Seattle, WA 98198; 800/323-2433.

FOR MORE INFORMATION

American Red Cross
AIDS Public Education Program
1730 D Street NW
Washington, DC 20003
202/726-6554

California AIDS Clearinghouse
PO Box 1830
Santa Cruz, CA 95061-1830
804/438-4822

Children in AIDS Families Project
Beth Israel Medical Center
First Avenue at 16th Street
New York, NY 10003

Gay Men's Health Crisis
129 West 20th Street
New York, NY 10011
212/807-6655

Mothers of AIDS Patients
PO Box 1763
Los Angeles, CA 90717
213/541-3134

National Association of
People with AIDS (NAPWA)
PO Box 18345
Washington, DC 20036
202/429-2856

National Leadership Coalition on AIDS
1150 17th Street NW #202
Washington, DC 20036
202/429-0930

National Lesbian and Gay
Health Foundation
1638 R Street NW #2
Washington, DC 20009
202/797-3708

Parents and Friends of Lesbians and Gays
Federation Office
PO Box 27605
Central Station
Washington, DC 20038

People With AIDS Coalition, Inc.
263A West 19th Street, Room 125
New York, NY 10011
212/627-1810

Sex Information and Education
Council of the U.S.
130 West 42nd Street, Suite 2500
New York, NY 10036

National AIDS Hotline
800/342-AIDS

National AIDS Information
Clearinghouse
800/458-5231

HIV/AIDS AUDIOVISUAL REVIEWS

HER GIVEAWAY: A Spiritual Journey with AIDS

Skyman-Smith. Distributed by Women Make Movies, 212/925-0606, 1/2" and 3/4" video, rental \$50, purchase \$195. Discounts available for Native Americans.

Carol LeFavor is a woman living with HIV/AIDS. She is also an American Indian, mother, lesbian, and recovered injection drug user. All of these voices contribute to the spiritual and medical approach she takes to her life. *Her Giveaway* documents her journey with HIV/AIDS.

HIV/AIDS education becomes most relevant when those who are struggling with the disease come forward and share their stories. LeFavor is a shining example of why this way of educating is so effective. She explains that, according to American Indian culture, a giveaway is a way "to express to other people that you care about them and that your home is open to them and what you have, you'll share with them." What she shares is her story as a woman living with AIDS out of the belief that it may be a way to prevent others from becoming infected with HIV. She states, "My vocation is that if I can in any way prevent even one more person from becoming infected with this virus, everything I do, as tired as I get...it'll all be worth it." She is honest about her life and the pain and happiness to which she bears witness. She is frank about the disappointment she feels and hopeful that her efforts in speaking out will perhaps save lives.

The video attempts to dispel the damaging myths that HIV/AIDS is a white man's disease and that American Indians don't use injection drugs. LeFavor unequivocally states that the two highest risk behaviors are hysteria and ignorance — due to ignorance, people may engage in unprotected sexual activities and through hysteria, people will alienate those who are living with this disease. The video concludes on this note and its effect is inspiring.

LeFavor's story is interspersed with basic information on HIV/AIDS throughout the video. This is sometimes distracting because viewers easily become engrossed in her personal story; however, for audiences with little or no knowledge of HIV/AIDS, this information is vital. The video is an important resource for all people learning about HIV/AIDS, and is especially useful for American Indian and Alaskan Native audiences.

MENDING HEARTS

Carle Medical Communications, 212/384-4838, 1/2" video, rental: \$75/3 days, \$100/5 days, purchase: \$295.

In *Mending Hearts*, five people who are living with AIDS share their lives. Witnessing the stories of people who are living with HIV/AIDS is a powerful, moving, and important means of educating. This video is compelling and sensitive and will help viewers understand the enormous challenge of living with this disease. It is an important testament to the fact that more and more people are *living* with HIV/AIDS.

The video is narrated by Christopher Reeves, which lends a bit of credibility to an issue that apparently does better when well known celebrities speak out. Reeves' narration weaves the individual stories together, and provides insightful commentary to the story.

With a running time of 59 minutes, the video is rather long, but can certainly be used in sections. One of the most interesting aspects of this video is that the viewer follows the long-term life story of each person profiled. After having seen the video in its entirety, it is disappointing to imagine experiencing only part of each of these stories. Despite its length, the story moves along at a comfortable pace, allowing time for involvement as well as reflection.

This resource would be important in communities where it would be more difficult for people living with AIDS to come forth and share their stories. As it is vital for their voices to be heard, *Mending Hearts* is an excellent alternative.

TOO CLOSE FOR COMFORT

Wild Ginger Productions. Distributed by ETR Associates/Network Publications, 800/321-4407, 1/2" video, \$189.

This video tells the story of Nick, a young man who is fired from his job at the local video store when his employer learns — by accident — that he is HIV-positive. As his friends learn the news, Nick becomes the victim of discrimination not only on the basis of his serostatus, but also because he is perceived as gay. The audience witnesses the effects this has not only on Nick, but on his friends as well.

The strongest HIV/AIDS education message heard throughout the story is the distinction between HIV infection and an AIDS diagnosis. This point is driven home quite effectively. Issues such as testing and confidentiality, discrimination, and trust are covered more honestly than in most HIV/AIDS videos. However, the most valuable aspect of this video is that it clearly points out the link between homophobia and AIDSphobia. This link is rarely discussed in HIV/AIDS education resources, yet, it may be one of the greatest barriers in the delivery of effective HIV/AIDS education. Many of Nick's friends refuse to speak with him after they learn he is HIV positive, not only because they are misinformed about HIV/AIDS, but also because they now consider him a "faggot." The manner in which Nick is treated not only by this circle of friends, but also by his basketball teammates, his employer, and coworkers offers a wealth of discussion opportunities about gay men and lesbians and homophobia. There is somewhat of a surprise twist at the conclusion of the video that would certainly add a different dimension to a discussion among young people.

There are various ethnic and racial communities represented in this story that takes place in a middle-class suburban community. In addition, gay men and lesbians are portrayed in a sensitive and positive light. As a person living with HIV, Nick is portrayed as a young man who takes control of his life, honestly and clearly expresses his emotional needs, is in good health, and is accessible as a source of information to his friends.

Too Close for Comfort also includes a Discussion Guide that reinforces and extends the important information presented in this video.

Reviewed by Carolyn Patierno, director, National AIDS Initiative.

HIV/AIDS RECOMMENDED RESOURCES

CONSUMER ADVISORY: AIDS & OTHER BLOOD-BORNE DISEASES (3x4½ wallet-size card) is a consumer advisory card that explains patients' rights to protection against infection from the human immunodeficiency virus (HIV) and the hepatitis B virus (HBV) in the hospital or health care setting, and outlines standard infection control procedures that health care workers are required to follow. The card is a facilitative tool produced by the Consumer Advisory on AIDS, which was developed by the American Nurses Association (ANA) to express nurses' and other health care professionals' advocacy for protecting their patients, and to respond to public concern about the issue of HIV-antibody testing of health care workers. This consumer advisory is based on the U.S. Centers for Disease Control's 1991 recommendations for protection against infectious diseases. Intended for use during hospital admission, or any time a patient has questions about practices or procedures that inhibit the risk of infection, the card underscores the need for patients to communicate their HIV status with their health care providers. Written in concise lay language, the card outlines modes of transmission of HIV and HBV as well as the important fact that they are *not* transmitted by casual contact. Two colorful posters are also available as part of this set of facilitators for consumers and patients. *American Nurses Association, 2420 Pershing Road, Kansas City, MO 64108; 202/789-1800, fax 202/842-4375, to order 800/637-0323.* Price: \$6 for 100 cards, \$25/500, \$35/1,000; 8½x11 poster, \$4 each, \$9/12; 23x20 poster \$6 each, \$30/10.

THE HIV/AIDS BOOK: INFORMATION FOR WORKERS

(Fourth edition 1991, 88 pp., 8½x8½ spiral bound book) and **HIV/AIDS AND THE HEALTH-CARE WORKER**

(Sixth edition 1991, 12 pp., 7x7 booklet) are produced by the Occupational Health and Safety Department, Service Employees International Union (SEIU), of the AFL-CIO. *HIV/AIDS and the Health Care Worker* answers basic questions about HIV and how it is transmitted, the HIV-antibody test, and how to minimize the risks of exposure to HIV and hepatitis B (HBV) in the workplace. This information is expanded in *The HIV/AIDS Book: Information for Workers*, which includes an extensive resources directory; chapters on Questions and Answers about HIV/AIDS, The Union's Role, and Guidelines for Worker Protection, which detail information on those health care workers who are potentially at risk and what protective procedures they need to follow, those workers in health care settings who are not at risk, and other workers who are potentially at risk such as police and correctional services workers. Recommended model language and samples of nondiscrimination statements used in negotiations are described in a section on Using Law, Negotiations and Policy. This well-documented resource contains checklists on HIV-antibody testing, safer sex, a plan for infection control, and topics to cover in developing HIV/AIDS training. Fact sheets included are: *Counseling After an Occupational Exposure, Some Facts on Occupational*

Exposure and Zidovudine (AZT), and Responding to AIDS: Ten Principles for the Workplace, which was developed by the Citizens Commission on AIDS for New York City and Northern New Jersey. Appendices with sections on Environmental Considerations for HIV Transmission, Implementation of Recommended Precautions, Management of Exposures, Precautions for Other Body Fluids in Special Settings, and Use of Protective Barriers are also included. The first edition of this resource, *The AIDS Book*, was produced in 1986 in response to local union members' requests for information and assistance in dealing with HIV/AIDS. The introduction to the fourth edition states, "Workers who routinely come into direct contact with blood at their jobs, such as health care workers, emergency responders, and public safety personnel, may be at risk of occupational exposure to HIV. Training about HIV transmission is needed so that these workers understand their occupational risk in its proper perspective. With the correct information, workers can avoid having either irrational fears or insufficient concern over workplace exposure to HIV and AIDS....Fear creates additional stress for workers and may result in less compassionate and professional care of patients with HIV disease. Insufficient concern, on the other hand, may lead a worker to neglect basic universal precautions, thereby increasing the risk of exposure to HIV and to other more common infections such as hepatitis B." *HIV/AIDS and the Health Care Worker* contains a perforated wallet-size card which outlines what to do if you get stuck with a needle or splashed with blood, and steps to prevent needlestick injuries, and lists the SEIU Health and Safety Department's telephone number for further information. These inexpensive publications are indispensable sources of information and guidance about HIV/AIDS and the workplace. *SEIU, 1313 L Street NW, Washington, DC 20005; 202/898-3446.* Price: *The HIV/AIDS Book*, \$3 each; *HIV/AIDS and the Health Care Worker*, \$.50 each.

THE POSITIVE WOMAN (Volume 1, Issue 1, October 1990; Volume 1, Issue 2, December 1990, 12pp., 8½x2½ newsletter) a bimonthly newsletter by, for, and about the HIV positive woman, was first conceived when the members of a Women's HIV Support Group discovered how little information for women with HIV/AIDS was available. The premier issue contains articles on HIV protocols, legal issues and HIV, food facts and HIV, personal perspectives, and a listing of Washington, DC area resources. The lead article, "Who is At Risk? Why Know?" by Mary Agnes Young, MD, presents basic information about exposure to HIV, the HIV antibody test, and the compelling reasons for knowing one's serostatus. The editor of *The Positive Woman* introduces herself and explains her reasons for using a pseudonym: "[Women] are unique, our bodies are unique. As mothers with children, our legal concerns are complicated. Because we are women, many of us are economically disadvantaged and we all know medical care is expensive. And so often we are invisible. We fear losing children, family, friends, medical insurance, etc. if our virus becomes public knowledge....I am the mother of a child who is school age; I have a job in the greater Washington, DC area where I am not open with my HIV status and fear losing

my health insurance; my parents do not know about my HIV status and though this newsletter will probably never reach their hands, word of mouth might....I do not like hiding my identity. I know that it takes away from my personal power and at this point I need all the power I have to fight this disease." The second issue includes articles on ways in which HIV-related conditions faced by women are different from those faced by men and why, discrimination based on HIV status in the workplace, early symptoms of HIV disease, intimacy and passion after being diagnosed, and comments from readers on this new and valuable resource for women who are HIV-positive. *The Positive Woman* is mailed in an unmarked envelope in order to protect readers' privacy. *The Positive Woman, Inc., PO Box 34372, Washington, DC 20043, 202/898-0372.* Prices for annual subscriptions: non-profit organizations/\$55, businesses and institutions/\$90, add \$3 for each additional newsletter; individuals/\$15. A year's subscription is provided at no cost to HIV-positive women who cannot afford to pay.

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Conference and Seminar Calendar

SEX EDUCATION COALITION ANNOUNCES 1991-1992

SKILL-BUILDING WORKSHOPS. Let's Give Away Our Skills: Enabling Parents to Be Effective Sexuality Educators, February 24, 1992; Sex Talk: Skills in Sexual History Taking and Counseling, March 6, 1992; Sexuality Education for the Hispanic Adolescent Immigrant Population, May 4, 1992; Verbal Violence: Dealing with Homophobia and Sex-Role Stereotyping in the Classroom, May 15, 1992; St. Thomas Episcopal Church, Washington, DC. **Sexuality Education for the Developmentally Disabled**, April 3, 1992; Planned Parenthood of Maryland, Baltimore, MD. Contact: Sex Education Coalition, PO Box 3101, Silver Spring, MD 20918, 301/593-8557.

INTERNATIONAL SEMINAR ON SEXUALITY AND DISABILITY, March 2-5, 1992. Sponsored by the Israel Rehabilitation Society, with Rehabilitation International, International Planned Parenthood Federation, and the Disabled Persons Unit, UN Center, Vienna, Austria. Topics will include Sexuality and Locomotor Disability, Sexuality and Developmental Disability, Sexuality and Chronic Mental Illness, and Sexuality and Cancer. Tel-Aviv, Israel. Contact: Dr. E. Chigier, MD, Israel Rehabilitation Society, 18, David Elazar Street, Tel-Aviv, Israel 61909, 972/3-5423446, fax 972/3-263519

SEVENTH ANNUAL TREATMENT CONFERENCE ON SEXUAL ABUSE, "BEYOND SURVIVAL," March 3-6, 1992. Sponsored by the Aiken-Barnwell Mental Health Center and the Aiken County Mental Health Association with the South Carolina Psychological Association. Will present innovative therapeutic techniques and strategies for assessment, prevention, and treatment of sexual abuse for mental health professionals, social service workers, psychologists, and school counselors. Hyatt Regency/Palmetto Dunes, Hilton Head Island, South Carolina. Contact: MHA, PO Box 1074, Aiken, SC 29802, Joy Jay at 803/641-4164, or Susan Jones at 803/642-5007.

SOCIETY FOR THE PSYCHOLOGICAL STUDY OF HUMAN ISSUES THIRD CONFERENCE, "SOCIAL SCIENCE AND HEALTH POLICY: BUILDING BRIDGES BETWEEN RESEARCH AND ACTION," March 4-6, 1992. Cosponsored by Office of AIDS Program/National Institute of Mental Health, Health Psychology Division of the American Psychological Association, and American Psychological Society. Will focus on issues such as access to health care and the equitable distribution of health care resources, the impact of technology on health care, the costs (emotionally and fiscally) of heroic life-sustaining interventions at the beginning and end of the life cycle, and the ethical implications of determining "who gets what care and who pays for it." Hyatt Regency Bethesda Hotel, Bethesda, Maryland. Contact: Sally Shumaker at 919/748-3838 or SPSSI Conference, PO Box 1248, Ann Arbor, MI 48106-1248, 313/662-9130, fax 313/662-5607.

4th ANNUAL CONTRACEPTIVE TECHNOLOGY CONFERENCE, "ISSUES AND OPTIONS IN REPRODUCTIVE HEALTH CARE," March 19-20, 1992, San Diego Princess, San Diego, California; April 10-11, 1992, Omni Shoreham Hotel, Washington, DC. Sponsored by the Association of Reproductive Health Professionals and Contemporary Forums and presented by the authors of *Contraceptive Technology 1990-1992*. "Improvement in diagnostic and therapeutic techniques, new developments in contraception, and ethical dilemmas created by advancing reproductive technology require that we remain current in a wide

variety of issues related to caring for women and their partners as we fulfill our responsibilities as clinicians, educators, counselors, and patient advocates." Contact: Contemporary Forums, 530 La Gonda Way, Suite E, Danville, CA 94526, 510/820-2800.

THE SOCIETY OF BEHAVIORAL MEDICINE'S THIRTEENTH ANNUAL MEETING, "FORGING BRIDGES IN BEHAVIORAL MEDICINE: FROM THE LABORATORY TO THE FIELD,"

March 25-28, 1992. Institutes, workshops, symposia, and paper and poster presentations will explore ways to integrate laboratory work and field work, utilizing knowledge and strategies drawn from both perspectives. Marriott Marquis, New York, New York. Contact: Abby C. King, PhD, 1992 Program Chairperson, The Society of Behavioral Medicine, 103 South Adams Street, Rockville, MD 20850, 301/251-2790.

CHILD WELFARE LEAGUE OF AMERICA NATIONAL CONFERENCE, "CHILDREN '92: IT'S UP TO YOU,"

April 1-3, 1992. Will feature legislative workshops in the areas of child abuse and neglect, family support services, adoption, health care, mental health, substance abuse, child day care, homelessness, HIV/AIDS, developmental disabilities, and juvenile justice; "Electing a Children's President in '92," an invitation for all declared presidential candidates to present their platforms for children; and a two-day training institute of advanced lobbyists, "Framing Child Welfare Issues." Grand Hyatt Washington, Washington, DC. Contact: Children '92, Child Welfare League of America, 440 First Street NW, Suite 310, Washington, DC 20001, 202/638-2952, fax 202/638-4004.

"COMPREHENSIVE SCHOOL HEALTH: A CHALLENGE FOR THE NINETIES AND BEYOND," April 1-4, 1992. Sponsored by the American Health Foundation, National Education Association, and the United States Department of Education. Will provide school health education and health service practitioners, school administrators, and policymakers with a comprehensive approach to health issues facing youth, guidelines for program development, implementation and maintenance of school-based programs, and strategies for improving dialogue between these groups. Washington, DC. Contact: Iris Tropp, Project Coordinator, 404/960-1325, fax 404/960-1528.

INTERNATIONAL FOUNDATION FOR GENDER EDUCATION'S SIXTH ANNUAL CONVENTION, "COMING TOGETHER — WORKING TOGETHER,"

April 6-12, 1992. Will feature eight seminars for newcomers, a three-day program on transsexual issues, a two-day program on female partners' issues, and a variety of educational, leadership, business, and professional programs. IFGE's Educational Resources Committee also sponsors two free seminars for the general public. Hilton Southwest, Houston, Texas. Contact: Coming Together — Working Together Convention, PO Box 367, Wayland, MA 01778, 617/899-2212.

FAMILY RESOURCE COALITION'S FOURTH NATIONAL CONFERENCE, "FAMILY SUPPORT: FRAMEWORK FOR THE FUTURE,"

May 6-9, 1992. Will address family skill-building and empowerment, community based services aimed at the family, culturally relevant services, funding possibilities, family support theory and research, training and program evaluation strategies, and national, state, and local policies. The Palmer House Hotel, Chicago, Illinois. Contact: Stephanie Lubin, FRC, 200 South Michigan, Suite 1520, Chicago, IL 60604, 312/341-0900, fax 3312/341-9361.