

Can You Feel Their Pain?

Society, Community, Family and Individual Loss

In Presence of HIV/AIDS

FAMILIES SURVIVING LOSS
16th Annual Conference
Mid-Atlantic Council on Family Relations
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ABOUT THE DISEASE



HIV/AIDS BASICS



Human
Immuno-Deficiency
Virus

Acquired
Immuno-
Deficiency
Syndrome

FLUIDS & HIV TRANSMISSION



- Blood
- Vaginal Fluid
- Semen
- Breast Milk

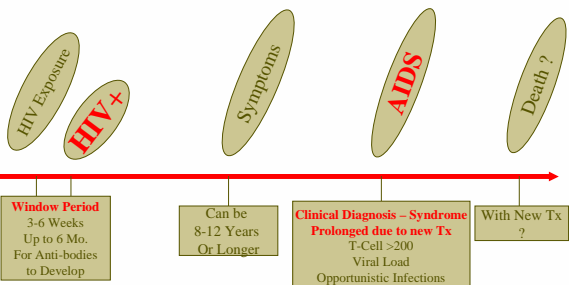


BEHAVIORS that Transmit HIV



- **UNPROTECTED SEX**
 - Anal
 - Vaginal
 - Oral
- **SHARING INJECTION EQUIPMENT**
 - All Components (spoon, cooker, syringe, needle)
- **RECEIVING UNSCREENED BLOOD**
- **IN-UTERO, BIRTHING, BREAST FEEDING**

HIV-DISEASE PROGRESSION



How It Was/Is....



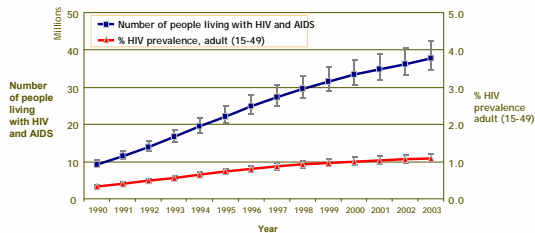
- Hid Behind Our Personal Sense of Security
- Viewed as Morality vs. Public Health Issue
- Blamed Those Impacted
- Denied it Would Affect Us
- Responded "Too Little Too Late"



A CALL TO ACTION



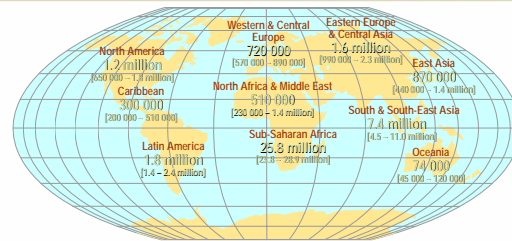
GLOBAL AIDS EPIDEMIC 1990-2003



Source: UNAIDS/WHO, 2004
2004 Report on the Global AIDS Epidemic (Fig 1)

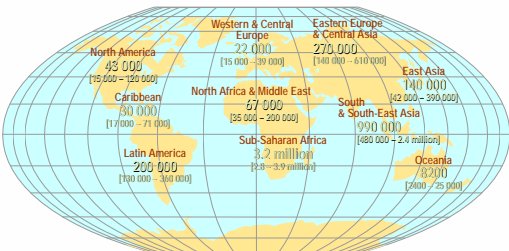
Adults/Children Living with HIV

(End 2005)



Total: 40.3 (36.7 – 45.3) million

NEW HIV Infections During 2005 (Adults & Children)



Total: 4.9 (4.3 – 6.6) million

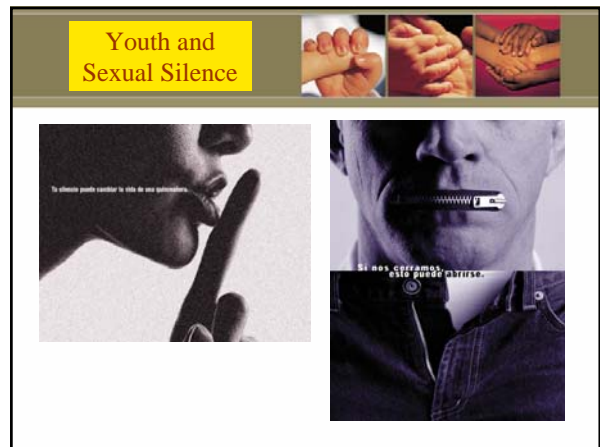
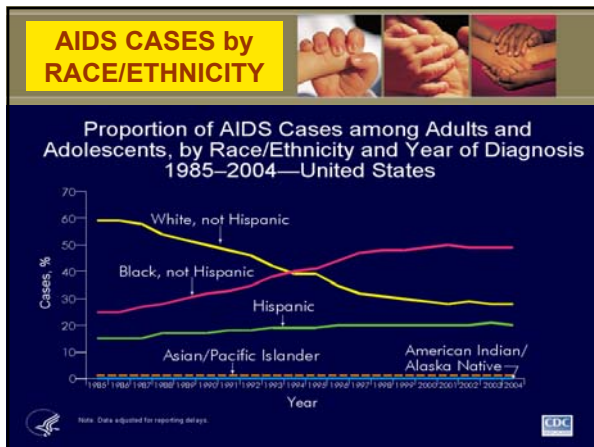
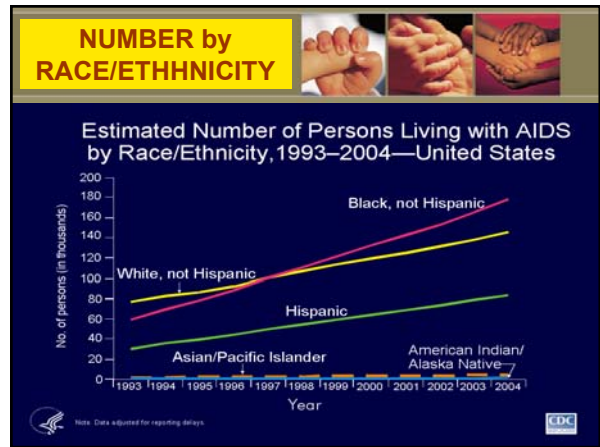
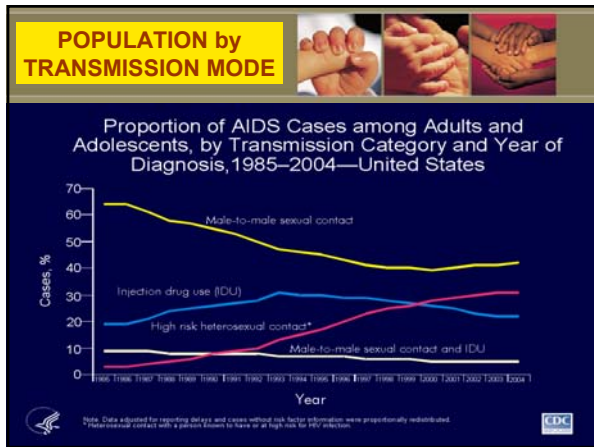
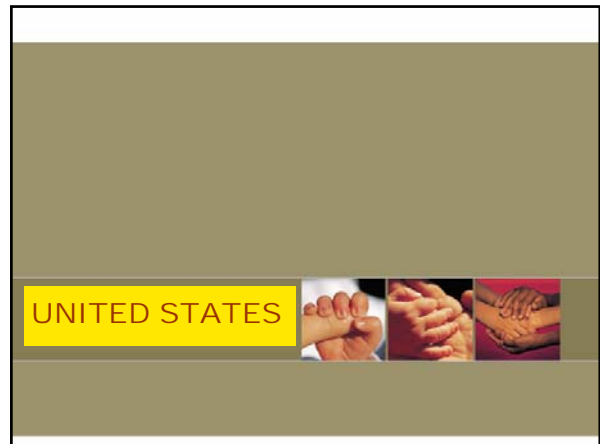
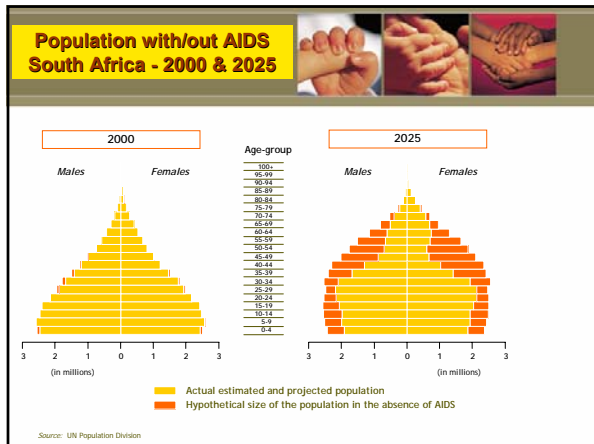
Regional HIV/AIDS

(End 2005)



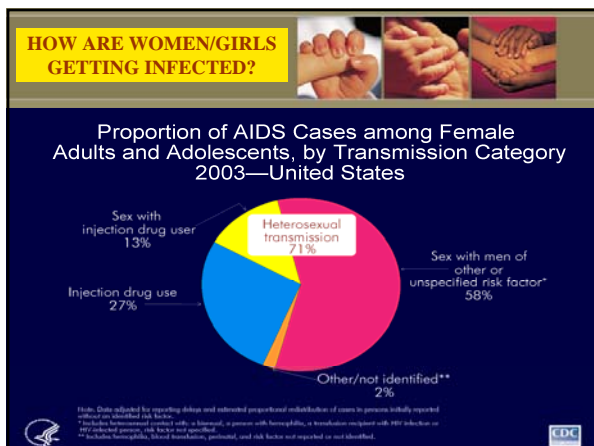
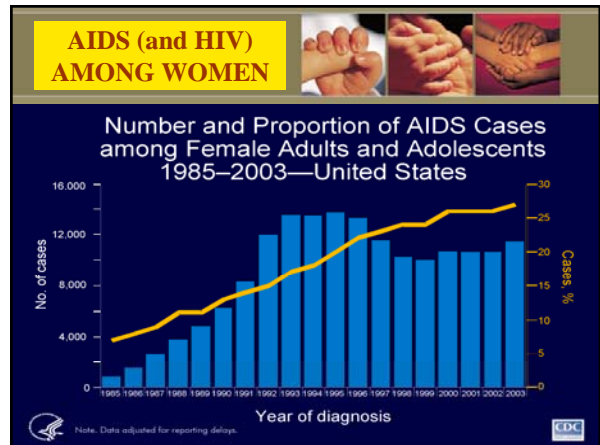
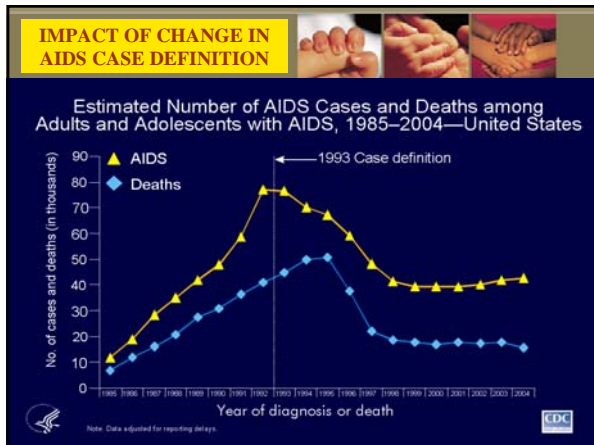
Region	Adults & children living with HIV	Adults & children newly infected with HIV	Adult prevalence [%]	Adult & child deaths due to AIDS
Sub-Saharan Africa	25.8 million	3.3 million	7.2 (6.1 - 8.3)	2.4 million
North Africa & Middle East	510 000	67 000	0.2 (0.1 - 0.3)	58 000
South and South-East Asia	7.4 million	990 000	0.7 (0.4 - 1.0)	460 000
East Asia	870 000	140 000	0.1 (0.05 - 0.2)	41 000
Latin America	1.8 million	200 000	0.6 (0.5 - 0.8)	66 000
Caribbean	300 000	30 000	1.6 (1.1 - 2.1)	24 000
Eastern Europe & Central Asia	1.6 million	270 000	0.9 (0.4 - 1.3)	62 000
Western & Central Europe	720 000	22 000	0.3 (0.2 - 0.4)	12 000
North America	1.2 million	45 000	0.7 (0.4 - 1.0)	19 000
Oceania	74 000	8 200	0.5 (0.2 - 0.7)	3 600
TOTAL	40.3 million	4.9 million	1.1 %	3.1 million

* The proportion of adults (15 to 49 years of age) living with HIV in 2005, using 2005 population numbers
The ranges around the estimates in this table define the boundaries within which the actual numbers lie, based on the best available information.



Young MSM Men of Color

WOMEN and GIRLS



HIV & AGING

GENERATION GAP

THE GENERATION GAP

LONG-TERM SURVIVORS

- Sustaining Relationships
- Side effects of the Treatments
- Physiology of Aging
- Prevention "Burnout"
- New Strategy - Prevention for Positives

NEWLY "AT RISK"

- Don't think they are at risk for HIV
- "Viagra-effect"
- Physiology of Women
- Not familiar with using Condoms
- Not informed about HIV/STIs
- FEW Services targeted to HIV+ Elders

Older Adults

Shandor

"Don't worry — I'm on the pill."

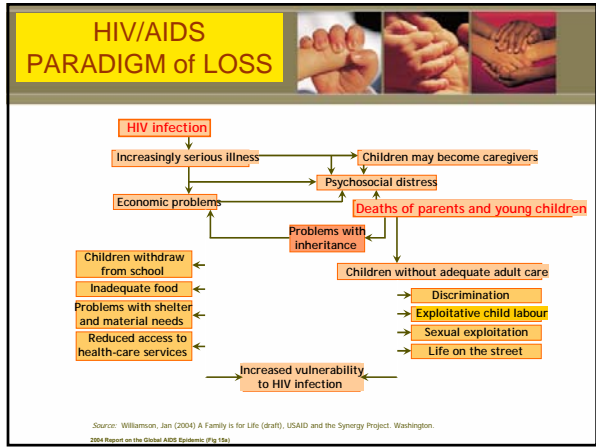
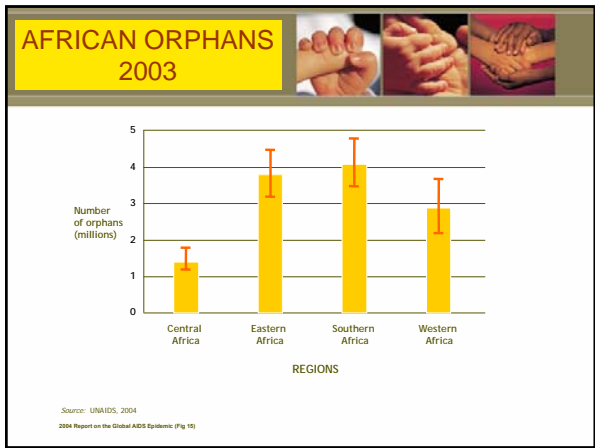
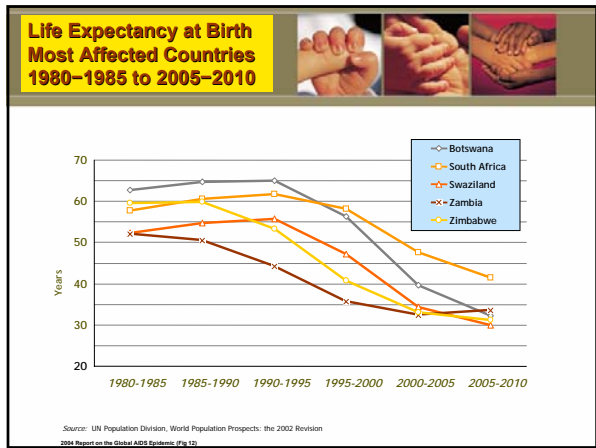
TIME, MAY 4, 1998

CONSEQUENCES OF LATE OR NO ACTION

Risk, Vulnerability and Impact Reduction

Source: UNAIDS. The Global Strategy Framework on HIV/AIDS (Reinforcing strategies of risk, vulnerability and impact reduction: The expanded response to the epidemic), 2007

2004 Report on the Global AIDS Epidemic (Pg 16)



Personal Stories


Loss: Diagnosis and Disclosure

"Just today I learned that my favorite uncle is HIV positive. I am 15 years old and my mother decided that today was the appropriate to spit out that my uncle has AIDS. I don't know any details or for how long he has had [it], and only my mother knows that I am aware of his infection. Since finding this out, I have kept to myself and have been falling deeper into depression. I don't know what I should do at all. I don't feel comfortable talking to him about it, and I don't know how to cheer myself up. Everything I do and see makes me think about him and want to cry because I don't know how long he as left. I have never been aware of this and it has come as quite a shock. I am scared and have no idea what to do at all and I just want to be happy again. Please help me."

Relationship Dynamics: Grief & Secrecy

"I was infected in Africa after an affair with a married man when I was working there. We continued the relationship and were making plans to reunite in my country. He was mid-divorce and looking into a student visa, etc. Last weekend, he died suddenly while still in Africa. I am very sad about my lost future with him but also very confused about what to do about the knowledge that I alone had of his HIV – like whether I have a responsibility to tell his family (who are very confused about his sudden death) and his wife who may or may not know and/or have been tested. I know he did not want to tell his family, and while I encouraged him to talk to his wife, I don't know whether he did or not before his death. The stigma associated with HIV in this part of Africa is very serious (complete social isolation, etc) and I don't want to "out" him (or even his memory for family) or his wife carelessly. But I also want her to be well and seek treatment if she is also infected which I suspect she may well be."

Loss of Body & Spirit



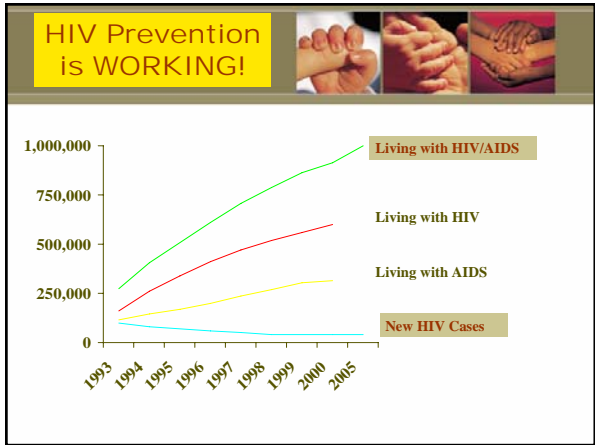
“AIDS is a lonely thing. The body is alone and fearful when one awakens at three in the morning, sheets drenched with night sweats. AIDS is a despairing thing. It is a slow decomposition rather than a mercifully sudden surcease; it’s a way of wearing down moral resistance, the devotion of friends, funds, resolutions to be optimistic. AIDS may be opportunistic, but it usually comes inopportunistly to cut short lives that have yet to be fulfilled.”

LOSS OF URGENCY





- Treatment Advances
- Prevention Successes
- Perception that HIV/AIDS is “Over” in US
- Increased Complacency
- Abandonment of HIV/AIDS as Domestic Funding Priority

THE POWER OF ACTION






LOSING TIME....

- While WE are here today - 14,000 NEW individuals will become HIV+
- More than 95% are in low and middle income countries (communities)
- Almost 2,000 are children under 15 years of age
- About 12,000 are persons aged 15 to 49 years, of whom:
 - almost 50% are women
 - about 50% are 15–24 year olds

Who Has The Most To Lose?

YOUTH
COMMUNITIES OF COLOR
WOMEN
YOUNG MSM
POOR PEOPLE EVERYWHERE
OLDER ADULTS

BUT IT CAN BE DIFFERENT!!!!




<ul style="list-style-type: none"> • Hid Behind Our Personal Sense of Security • Viewed as Morality Issue • Blamed Those Impacted • Refused to Act • Denied it Would Affect Us • Responded - Late 	<ul style="list-style-type: none"> • Walk the Walk • View as Public Health Issue • Serve the Impacted • Act with Compassion • Acknowledge: We are ALL in this Together • Be Proactive!
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Both at home and abroad, there may now be a temptation to relax. For the road has been long, the burden heavy and the pace consistently urgent. But we cannot be satisfied to rest here. This is the side of the hill, not the top.... We have made a beginning, but we have only begun.

Now the time has come to make the most of our gains – to translate the renewal of our national strength into the achievement of our national purpose."

January 14, 1963
President John F. Kennedy
State of the Union Address



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THANK YOU!

