

MCHB/DHSPS
June 2005 Webcast

“More than Just a Number”: Realities
of Women and HIV/AIDS



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Women and HIV/AIDS

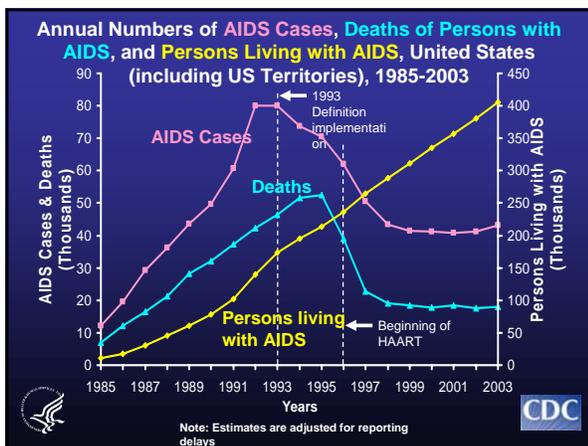
A Perspective from the White Coat

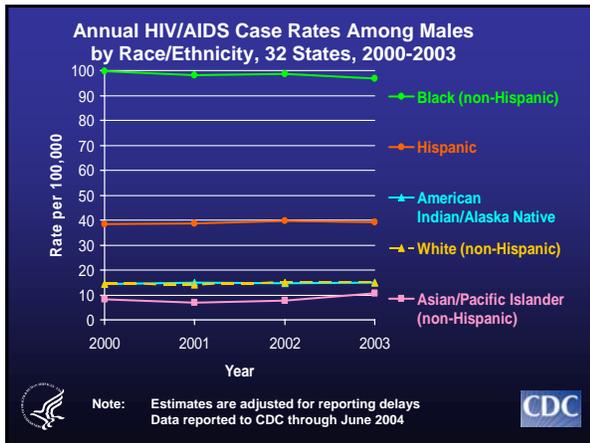
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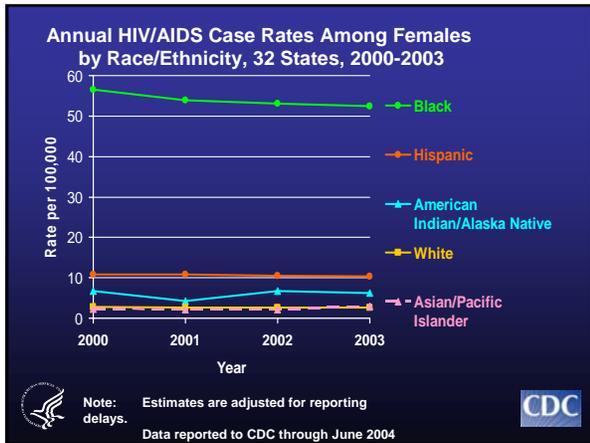
Goals of this Session

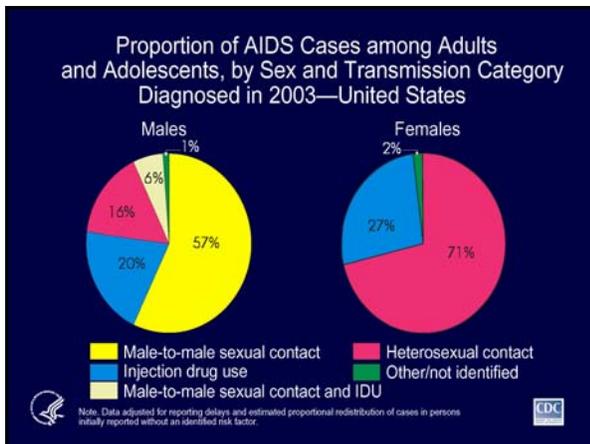
- To identify the impact of HIV upon women, especially women of color
- To identify the difficulties women experience in seeking HIV care and services.
- To identify the factors to be considered when providing services to HIV infected and affected women.

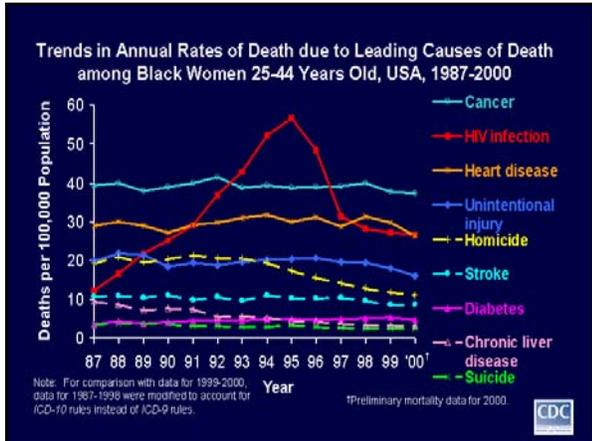


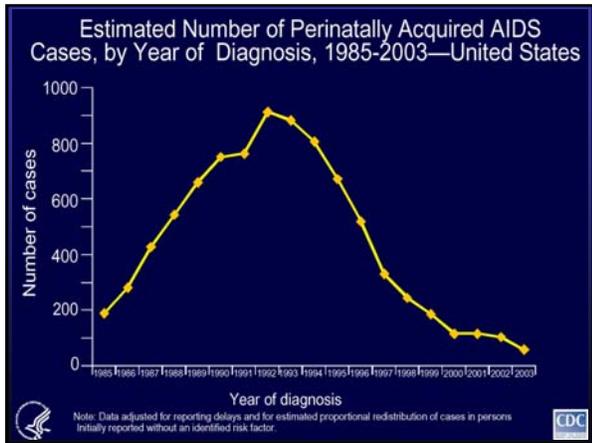












HIV Infection is driven by

- Racism
- Homophobia
- Social apathy
- Health disparities
- Differential access to care
- Substance abuse
- Alcohol abuse
- Immigration issues
- Ageism
- Domestic violence
- Absence of advocacy
- SILENCE

Women are more than numbers

Numbers that have faces.....

Case study 1. 'I need a hit'

- 50 y o AA female
- Long hx of substance abuse: crack, heroin, methamphetamine
- Shows up from other hospital ER after being 'referred' (by cab)
- 7 days of diarrhea
- Kicked out of 5 E.R.s in one day
- Has fever
- Can't stay with friends with diarrhea
- Yelling in the waiting room to be seen
- Demanding \$\$ from social worker



What's failed....

- E.R. #1 insisted upon drug treatment before seeing her
- E.R. visit #2 patient walked out because the wait was too long
- Social worker note from ER #3 states language "foul"
- Found stealing oxygen masks in ER #4
- ER#5 bypassed all problems by sending patient to HIV Clinic at a teaching hospital via cab.....



The other side of the desk...

- Patient had done drug treatment on her own and was satisfied with results
- ER walk out prompted by an episode of incontinence
- Social worker had asked about children
- Oxygen masks would have given \$\$ for a room at the Y when fenced (tubes = tourniquets)
- Doc in ER #5 told patient HIV was 'not urgent' when there was a gunshot wound



Small victories...

- Diarrhea linked to patient eating from trash
- IV fluids and simple remedy stopped diarrhea
- Emergency housing found
- Treatment discussed
- A contract was negotiated between patient and provider
- Son's death had driven a downward spiral
- Patient lived for 5 years and died of her crack lung, not HIV



Case 2. We don't want you....

- 15 yo Latina female in juvenile detention
- PE shows she has 3 STDs: chlamydia, warts and herpes
- HIV test returns as +
- Mother is contacted and advised of results with the client
- She is discharged from detention the same day



The trouble begins....

- Connie becomes truant.
- School nurse says she doesn't belong in school
- Mother feels she is 'unruly'
- Connie feels mother doesn't care
- Visits missed with pediatrician
- Admits to unprotected sex
- Declines treatment: "I don't need no damn drugs"



From the other side.....

- Why go to school, no one wants me there.
- I have to live with HIV, I don't want to be bossed around.
- My mother won't listen – her boyfriend tried to rape me.
- I won't see a baby doctor – how can he help me with HIV?
- Why take those drugs? I don't feel sick.....
- I wake up every day thinking: Will I die today?



The human face....not numbers

- A Latino youth worker is added to our team; he learns there's lots of abuse at home
- The school nurse gets a personal visit for some AIDS 101
- Connie moves to her grandmother's
- We settle on a jelly bean trial before pursuing meds (she loves it!)
- Case manager persuades HMO to pay for adult provider
- Adherence is an issue, but Connie is living with HIV, not dying



Case 3. "...A white girl with HIV

- 32 y o white female
- Employed as manager of a transcription service
- Has an 9 y o son from a prior marriage. Husband died from "hepatitis"
- Has new partner, and she is pregnant
- Read about HIV, asks Ob for an HIV test who dismisses her
- Test finally done and is +
- Ob calls her at WORK with result saying



"I've never seen a white girl with HIV before,

But don't worry I'll still deliver your baby."



HIV+ women are caregivers

- She asks OB to test her son, he declines
- Test for son done by internist partner of Ob
- Test is +
- Same OB calls at work AGAIN with results
- Says counseling is not his "thing"
- Pediatrician refers her to HIV/AACTG practice
- Former mother-in-law calls to tell her that her husband really died of AIDS
- Partner due home that night after long trip**



Points of reference

- **ADVOCACY:** ditch the OB
- **REALITY:** keep the pediatrician
- **INFORMATION:** teach about HIV and pregnancy, and what can be done
- **LINKAGE:** pedi with HIV specialist for son
- **SAFETY:** ways to introduce sexual safety or delay sexual contact
- **AVAILABILITY:** talk with partner together in our offices w/ support



Take Home Points....

- Every number has a face
- HIV is not the whole woman, but it can swallow the woman whole.
- Push for greater access to treatment, knowledge of treatment and advocacy for women.
- Don't take no for an answer. NO food, NO care, NO money kills women every day.



Take Home Points

- HIV is more than the person before you – it is sucking the life blood out of every person who cares for them.
- HIV work is hard, rest often, fight hard, stay focused and never give up.
- Use EVERY teachable moment. You may save more people than you know.



Remain Informed and Involved

- Learn as much as possible about female controlled methods and how these can be used in a number of contexts
- Several microbicides are in clinical trials, including Phase III
- Provide encouragement and support to women for the broader context of their lives OUTSIDE of HIV infection



Wisdom is like a baobab tree

No one person can embrace it.
-African proverb



CIRCLE OF CARE



CIRCLE OF CARE: A Model Program

Department of Health and Human Services
Office of Women's Health
Women's Health Coordinating Committee (WHCC)
June 7, 2005

Alicia Beatty, Director
Circle of Care

Philadelphia, Pennsylvania

CIRCLE OF CARE



- Designated Ryan White Title IV Grantee for the Philadelphia area
- Founded 1989 to provide integrated and consumer-centered services responsive to the priorities of individuals and families infected and affected by HIV
- Project of the Family Planning Council

Our Mission

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The Circle of Care is committed to the provision of quality comprehensive family-centered care and services for HIV affected women, children, adolescents, and their families and to the prevention of HIV disease in these populations.



Presentation will Cover

CIRCLE OF CARE

- Overview of Circle of Care network
- Integration of Family Planning and HIV Care
- Perinatal Services



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Who We Serve: Demographic Information

In 2003, the Circle of Care provided services to **1100 Families, 1776 individuals** in total

- 239 infants
- 507 children
- 260 adolescents (13-24)
- 770 adults (25+)

- 76% Black or African American
- 15% Hispanic
- 8% White
- 1% Other



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Provider Network

- Action AIDS
- AIDS Care Group-Chester, PA
- BEBASHI
- The Children's Hospital of Philadelphia (CHOP)
- CHOP Adolescent Project
- Philadelphia Department of Health- Strawberry Mansion Care Plus
- Congreso de Latinos Unidos
- Drexel University/Partnership Comprehensive Care Practice
- Friends Rehabilitation Program
- Germantown Settlement
- Mazzone Center (formerly PCHA)
- St. Christopher's Hospital for Children
- St. Mary's Family Respite Center
- Women's Anonymous Testing Site (WATS)

AFFILIATED PROVIDERS

Temple University Women's Health Center
Hospital of the University of Pennsylvania
Philadelphia Department of Health - Health Center 9
Presbyterian Medical Center



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Program Funding

- Title I \$138,041
- Title II \$14,000
- Title IV \$2,320,869
- State of PA \$225,837
- CDC Perinatal \$185,400
- HUD \$130,169

- Need for diverse resources to change with community needs
- Links to care and prevention through coordinated planning and resource prioritization
- Provides more flexibility in placement of both care and prevention services in the areas of greatest need



Network Roles/Functions

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- Inter-agency networking
- Facilitate linkages between providers
- Facilitate linkages with other systems
- Provider training
- Program development
- Program evaluation
- Development of network-wide standards
- Needs assessment and planning
- Continuous quality improvement (CQI)
- Peer counseling (outstationed)
- Consumer education
- Fund for Families

♥ Advocacy

Array of Services

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- Primary care
- Case management/Case manager assistants
- Outreach & Case Finding
- Perinatal services
- Adolescent services
- Behavioral Health
- Supportive housing program
- Fund for Families (Emergency Needs)
- Transportation assistance
- Food vouchers
- Peer counseling
- Project Empower

Building and Maintaining A Network

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- Continually assess the environment for change
- Coordinate regular communication with health care providers, larger service system
- Listen, respond to consumer comments; value consumer input
- Circle of Care network exemplifies **DIVERSITY** of
- Services
- Communities
- Service Providers

Integration of Family Planning in HIV

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- Background
 - Analyses of the extensive Perinatal Database revealed that an excessive proportion of women were using tubal ligations as a contraceptive method
 - In Fall 1999, the Circle began to link family planning services to the HIV clinical care services at the four major HIV care sites in Philadelphia

Family Planning Services

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- Family Clinics
 - Provide family planning and GYN care, offer HIV counseling and testing services
- HIV Testing Sites
 - Given pregnancy testing kits to ensure the prevention of perinatal HIV transmission
 - Provide direct referral to family planning clinic
- Information Hotlines
 - Hotline that coordinates information and referrals for HIV testing, family planning services, and other provider referrals

Key Role of Peers

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- Act as part of the interdisciplinary care team
- Aid provider in working with consumers on complex issues
 - Adherence
 - Disclosure
- Provide resources and support through health care providers for newly diagnosed individuals

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Integrating Peer Counselors in Family Planning and OB Services

HIV Positive Women can serve as educators, counselors, and support persons in the family planning setting providing:

- Education to women
- Encouragement for HIV testing
- Member of the disclosure team
- Emotional support



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Care of HIV+ Pregnant Women

- **Standards of care**
 - Continuing education for clinical and support staff
 - Integration of HIV/AIDS information into family planning services
- **Combining HIV & Prenatal care**
 - Inclusive specialty medical services for both mother and unborn child
- **Intensive perinatal case management**
 - Clinic-based case management appointments increase adherence



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Linkages

- Linkage with sentinel prenatal clinics. Onsite HIV testing, Nurse CM for HIV positive pregnant women and peer counseling services. Post delivery FP linkage.
- Perinatal Transmission Review Panel. One outcome is to develop program of services for providing pre-conceptual counseling, linking family planning and HIV providers.



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“The Partnership” Program

Drexel University, College of Medicine, Division of HIV/AIDS, Partnership Comprehensive Care Practice (PCCP)

- Largest Provider of HIV Clinical Services for Women in Philadelphia, Family Planning:
 - 20-45 years (half are 30-39)
 - 69% female; 34% male
 - Most medical assistance
 - 77% condom users; 21% Depo-Provera users

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St. Christopher’s Hospital for Children

- “One Stop Shopping” model: Co-location of OB/GYN and FP at pediatric immunology clinic. Clinicians are from Hahnemann HIV clinic and St. Chris Adolescent Medicine.
- Serves HIV affected and infected children, youth, and their families
- Circle Funds the Family Clinic through R.W. Title IV & Title I, and FPC Title X
- Family Clinic serves 140 adult women, 21 men, 100 HIV+ children, 40 youth.

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Lessons Learned

- Network concept to facilitate linkages between providers
- Integration of peers as link between care team and support services
- Employ Assistant Case Managers as in home support
- Integration of HIV Family Planning and OB/GYN in one-stop services

Future Challenges

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- Increased focus of prevention and care of target groups
 - Adolescents
 - New Immigrants
- Early identification and treatment of pregnant women who are out of the mainstream
- Continued responsiveness to the changes in the environment and the disease