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## Creative Avenues to Facilitate Access to Care



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## Marcia Starbecker

Moderator

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## Presenters

- Ann W. Locher, MSN, RN, ACRN
  - UTMC Ryan White Program Coordinator
- Amy Clark, RN, ACRN
  - HIV Nurse Clinician / Database Coordinator
- Christie Clinton
  - Consumer Advocate
- Kennyetta White
  - Financial Counselor / Community Outreach

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## Projects

- Collaboration with DIS
- Dear Friend
- Radio Outreach

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
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## Integrated DIS

- Disease Intervention Specialists
  - Partner notification and referral
  - Case finding
- Integration into Ryan White Clinics

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
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## DIS Referrals

- Partner Notification
  - Outreach HIV Testing
  - Appointment Scheduling
  - Ushering new consumers into care
- HIV Testing
  - Toledo Lucas County Health Department
  - Mobile van
  - Satellite sites

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## Ryan White Referrals

- Newly diagnosed consumers
- Partner testing
- Sexually transmitted infections
- Prevention for Positives

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## The Dear Friend Project

A manifestation of  
successful support  
group work

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## Hello from Ms. R.

Is there anyone listening to a sister like me?  
I am going crazy living with HIV.

I have been hiding for so very long,  
Trying to keep the world from knowing what I  
did wrong.

A couple nights of pleasure, equals a life  
time of pain.  
I end up with something, I hate to even call  
by name.

Ducking and dodging trying so very hard to  
hide,  
Wishing for just one true friend, whom I  
could confide.

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## Patients at the Medical Center

- 20% of 650 patients come to support groups
  - 7% Hispanic
  - 1% more than one race
  - 28% Black or African American
  - 66% White (non Hispanic)
- 14% (80) come to educational groups

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## Therapeutic Factors in Groups

The Theory and Practice of Group Psychotherapy

- Universality
- Imparting information
- Altruism
- Instillation of hope
- Development of socializing techniques

Irvin D. Yalom

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
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## Therapeutic Factors in Groups

The Theory and Practice of Group Psychotherapy

- Imitative behavior
- Group cohesiveness
- Corrective recapitulation of primary family group
- Interpersonal learning
- Catharsis

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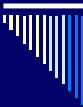
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## History of Groups in NW Ohio

- Men's Group- mid 1980
- Women's Group- early 1990
- Men's and Women's Group- 2004
- Teens- 2006
- Educational meetings: the secret support group

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## Men's Group

- 5-10 men per group
- Lack of diversity
- Largely consumer driven
- Participant sense of ownership
- Information exchange

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## Women's Group 1990's

- 5 women in 1990 / 10-18 in 2008
- Diverse
- Supportive
- Shifting focus of disease from illness to life issues

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## Men and Women's Group

- Designed by request of non-gay men
- Best attended group
- Issues of disclosure, honesty, prevention
- Minimal concerns of boundary issues
- Strong alliances and socialization

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## Teen Group 2006

- Teens infected at birth
- Teens with HIV+ parent(s)
- Facilitators send flyers, call, transport
- Once a month- educational and social
- Group has grown from 1 to 12 members

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
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## The Secret Support Group: Educational Dinners

- "I'd never go to a group and sit around and cry with a bunch of strangers"
- Offers education and socialization w/o stigma of "needing" support
- Not viewed as a group...but it is!
- Clients build bonds and find that meeting with others is not threatening

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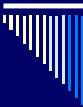
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## Support Breaks Stigmas

- “Support group saved my life”
- “I was not alone anymore.”
- It made me feel better about being an HIV+ woman

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## Why a book?

- **STIGMA**  
*Of 650 plus patients at U.T. Medical Center only 20% have attended a support group*

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## Why a book?

- Provides new patients with info on how others cope with HIV
- Offers support for those who are isolated
- Provides a resource for patients in rural areas with limited support

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**Why a book?**

- Gives the writers the catharsis of telling and preserving stories.
- Empowers writers and encourages involvement
- Gives writers a mutual bond and sense of pride

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*Dear Friend,  
Wise Words and Shared Journeys  
of People Living With HIV*



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**Dear Friends Project**

- Buy in from group members
  - Altruism
  - Their project
- Finding funding
  - Physicians, foundations, agencies, departments, pharmaceutical companies
- Printing
  - Design a cover
  - Local or institutional printing

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## Getting the stories

- Encourage openness and creativity
- Interviewing with recorder
- Few basic questions around a theme
  - Didn't feel like a chore or homework
  - Had to be encouraged that they were important
- Patients have control, editing rights, could stop the process at any time.
- Was a great counseling session

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## Celebrate Success



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## Get the Word Out

- Books are free to all patients at the HIV clinic
- Books are sold to others for \$10
  - Health care providers
  - Family and friends
  - Educators as teaching tools
- Sales support the support groups

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## The Faces and Words



The support groups have been great; mostly because I know I have a safe place to go and talk about what it's like to live with this disease, a place where I will be accepted for who and what I am. I've learned a lot about how to cope, how to deal with the medications, and how to handle the disclosure issue.

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## Mother of 3, active support group member



I go to the groups and listen to the "old timers" tell their story. This helps me. I also find strength in reading the stories in the POZ magazine that the "old timers" write. Seeing that they are surviving this disease and living long lives makes me feel that I will be around to see my children grow up.

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## Support group "Mom"

□ I like having men in group. We should all be together. We find out things through the men's eyes and vice versa. Lots of these women have husbands and kids and so talking to others helps them get a perspective on their own families. It helps both sides. It helps us when we need to deal with a man.



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**Heather**



My first year of support groups all I did was cry through the whole thing and I felt so stupid. But now I see girls coming in like I was and I know where they are coming from and I know how they feel. I try to give them the most support that I can. Outside of the groups, I face many of the same issues that all HIV + people face

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**Her Children**



... my mom started learning more and more about the disease and she started getting involved in things, and that made me feel better. I also have gotten involved with things. I went to World AIDS Day with her and I've gone to her support group with her.

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**Dear Friends and Your Clients**

- Use our book for your clients
- Start your own project
  - Letter of intent
  - Release
  - Tape recorder
  - Funding

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## Outcomes

- Connects to isolated consumers
- Inspires / educates those who can't come
- Becomes a teaching tool for
  - Educators
  - Health care providers
  - General public

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
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## Outcomes

- Sense of pride and accomplishment
- Empowers the writers
- Inspires new writers
- Encourages new activists
  - Volunteers at test site
  - Speakers
  - Drivers
  - Advocates

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
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## Outcomes

The strength I drew from the personal stories laid the groundwork for my own inevitable "self-outing". I haven't detected a noticeable flinch from anybody that realized my positive status. I revealed my status the first time to my sister and I haven't been touch with her for many years."

***Ron from prison***

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## Outcomes for Professionals

- One tape recorder *cheap*
- One release of information *free*
- One client / unlimited time *precious*
- One recorded story

**PRICELESS!**

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
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## Outcomes

“Over the years I've realized I was not helping my health by trying to keep my disease a secret from those who loved and cared about me. Whether it's your partner, parent, friend or support group; sharing your story helps take some of the burden off yourself.

You might not be ready when you are first diagnosed, but please, my friend, when the time feels right, share with those you love and those who care about you. You will be better off for it” **Todd**

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## Chatting up HIV on the Radio

The JUICE Morning Crew  
**Charlie Mack**  
**Tisha Lee**  
**J-Roc**

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## Objectives

- Identify unique avenues to raise awareness of HIV in minority communities.
- Recognize the building blocks to creating partnerships to promote HIV testing.
- Describe how to create an attentive audience with innovative messages.

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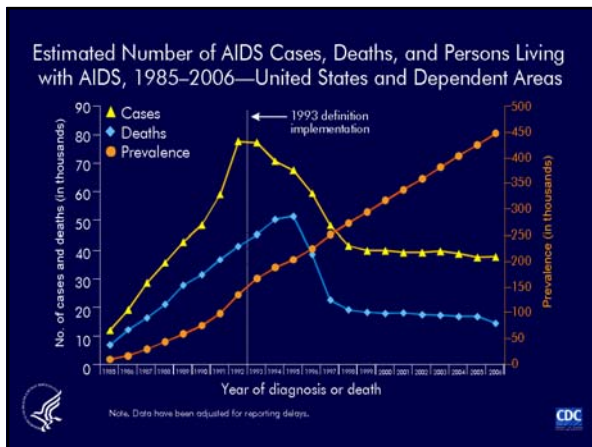
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### Awareness of Serostatus among Persons with HIV & Estimates of Transmission

Estimated: 950,000 PLWH in US      Estimated: 40,000 new infections/year

~25% **unaware** of infection

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~75% **aware** of infection

2/3

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1/3

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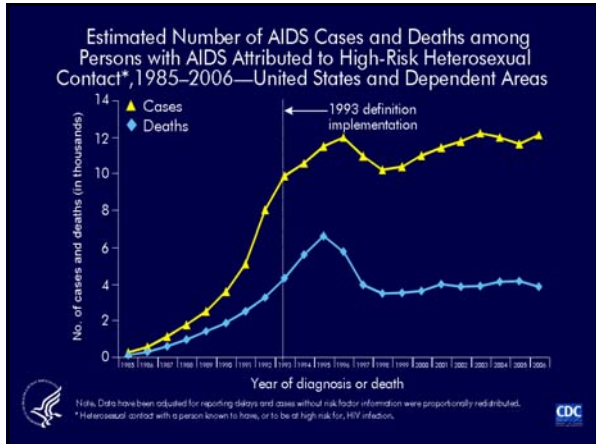
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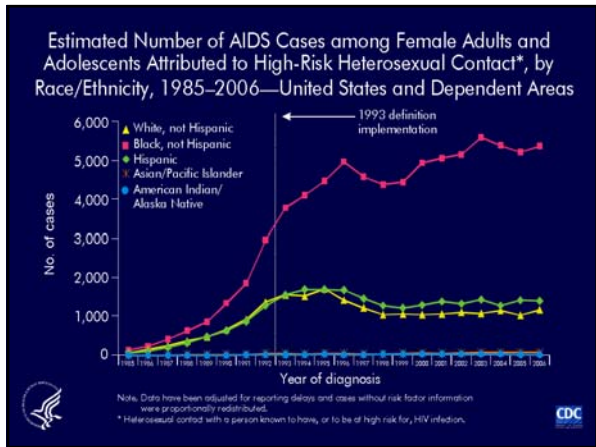
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### AIDS in Blacks

Of the 992,865 AIDS cases reported to CDC through 2006, blacks accounted for

- 40% of total
- 60% of women
- 59% of heterosexual persons at high risk\*
- 59% of children aged <13 years

Of AIDS cases reported during 2006, 48% were in black adults and adolescents.

\* High-risk heterosexual contact with a person known to have, or to be at high risk for, HIV infection.

CDC

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## The Dilemma

- The rising tide
  - Lucas County Population
    - 17% African American
    - 78% White
    - 5% Hispanic
  - Lucas County HIV/AIDS statistics
    - 42% African American
    - 51% White
    - 5% Hispanic

Toledo-Lucas County Health Department HIV/AIDS Statistics (August 2007)

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
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## The Dilemma

- The rising tide
  - Between 1998 and 2005 African Americans were diagnosed with HIV more than any other group.
  - Between 1998 to 2003 the number of African American women diagnosed with AIDS doubled.

Toledo-Lucas County Health Department HIV/AIDS Statistics (August 2007)

- UTMC RW Family Centered Clinic 2005 and 2006 majority of newly diagnosed African American women entered care with an AIDS diagnosis.

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
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## The Conspiracy Theory

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## The Dilemma

- The attitude
  - Testing
    - "It won't happen to me!"
    - "It's better not to know."
    - Misunderstanding that person was tested with routine blood work or prenatal labs.

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
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## The Dilemma

- The attitude
  - Condom Use
    - Fear rejection
    - Fear partner will think they do not trust him/her.
    - Loss of sensation

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
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## The Dilemma

- The attitude
  - Condom Use
    - Don't know how to use condom
    - Don't believe they are at risk
      - Jail
      - Down-Low
      - Married partner not monogamous

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Community Partner



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Testing the Waters

- Getting started
  - Hesitancy to begin
  - Change of mind

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The Show

- A typical day on the radio
  - \*\*\*



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## Creative Commercials

- Commercial Spots
  - The gift of getting tested
  - Played at Christmas, Valentine's Day and the two weeks before HIV National Testing Day



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## Multiple Agency Collaboration

- UTMC
- 107.3 The Juice
- Toledo-Lucas County Health Department
- ARC Ohio
- Planned Parenthood NWO
- Compass (Comprehensive Addiction Services System)
- (SASI) Substance Abuse Services, Inc.
- Ryan White Consortia #5

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
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## Log on to our show!

- [www.thejuice1073.com](http://www.thejuice1073.com)
- Monday's: somewhere between 8:45 and 9:15

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