

Linkage, Retention, and Adherence to Care in Florida

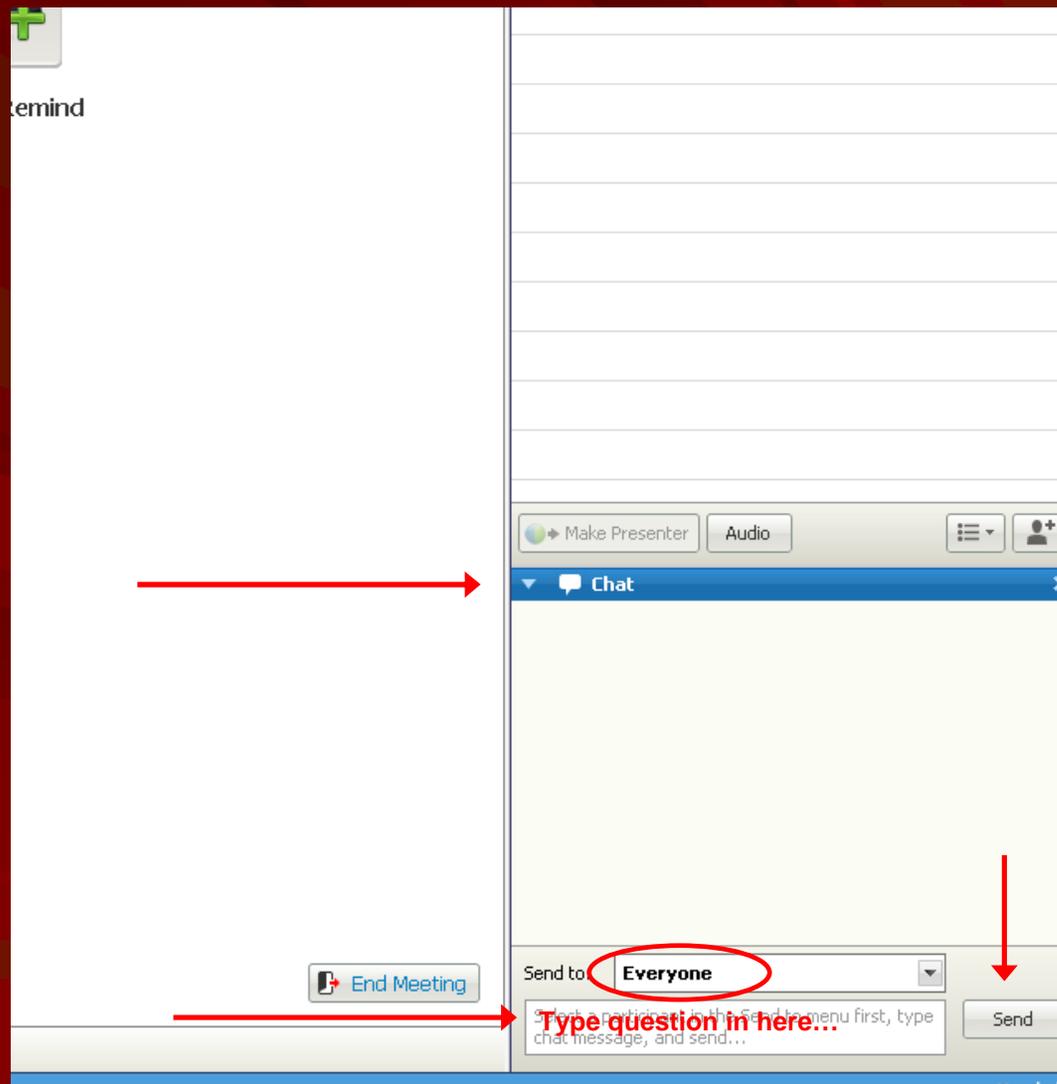
May 2012



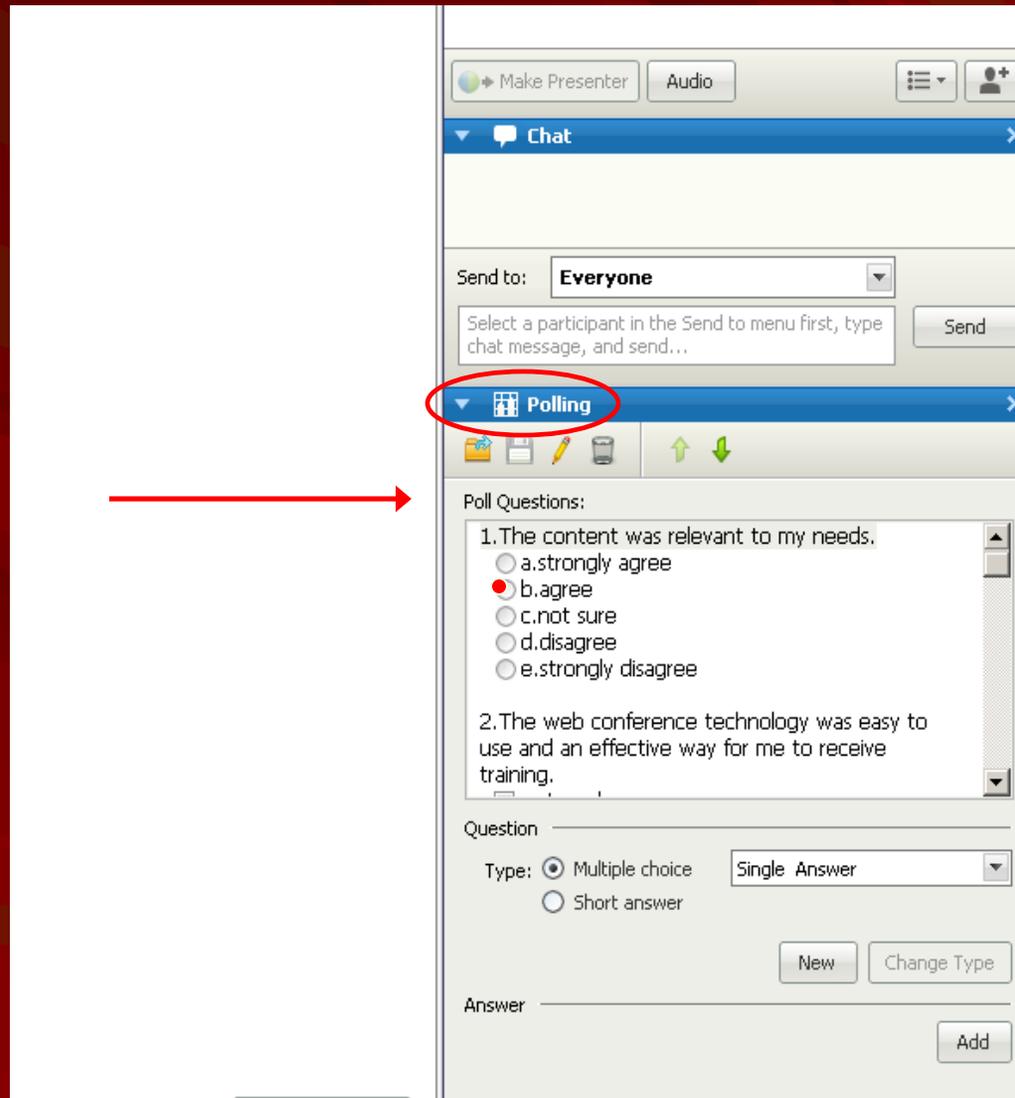
Bureau of HIV/AIDS
Prevention Section



Typing a Question in the Chat Box



Completing the Webinar Evaluation (opened at end of webinar)



The screenshot shows a webinar control panel with the following elements:

- Buttons: Make Presenter, Audio, and a user icon.
- Chat panel: A blue header with a close button.
- Send to: A dropdown menu set to "Everyone" and a "Send" button.
- Send message: A text input field with the placeholder "Select a participant in the Send to menu first, type chat message, and send..."
- Polling panel: A blue header with a close button, circled in red. A red arrow points to it from the left. Below the header are icons for a folder, document, pencil, and mobile device, along with up and down arrows.
- Poll Questions: A list of two questions with radio button options:
 - 1. The content was relevant to my needs.
 - a.strongly agree
 - b.agree
 - c.not sure
 - d.disagree
 - e.strongly disagree
 - 2. The web conference technology was easy to use and an effective way for me to receive training.
- Question: A text input field.
- Type: Radio buttons for "Multiple choice" (selected) and "Short answer". A dropdown menu is set to "Single Answer".
- Buttons: "New" and "Change Type".
- Answer: A text input field with an "Add" button.

Objectives:

- To learn what role linkage and retention play in the National AIDS Strategy
- To learn about impact of linkage, retention, and adherence on your clients
- To help you evaluate your work in the context of the larger service delivery system
- To learn best practices

NATIONAL HIV/AIDS STRATEGY FOR THE UNITED STATES

Vision for the National HIV/AIDS Strategy:

“The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination”

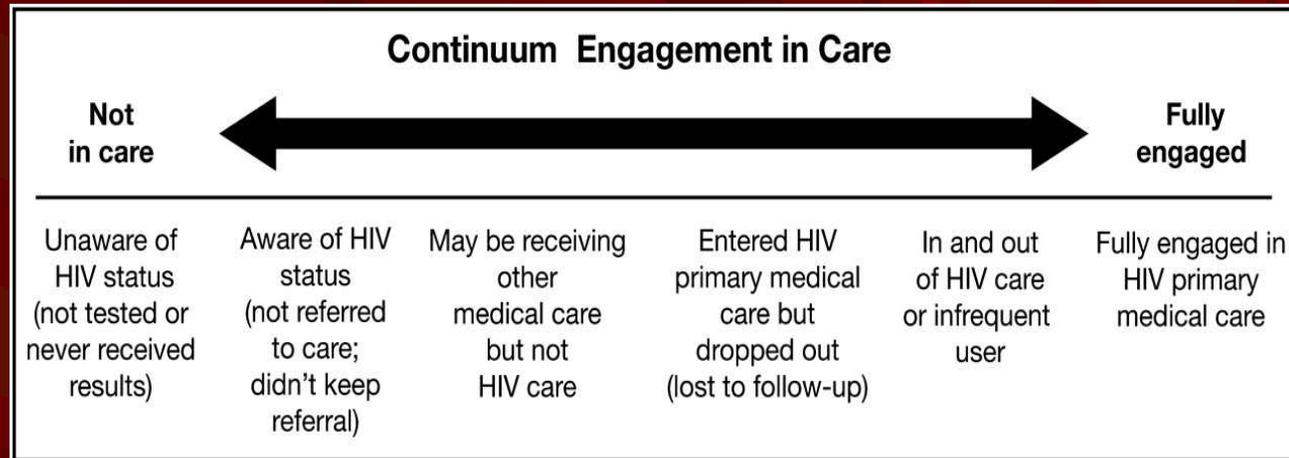
The 3 Goals of the National AIDS Strategy

- Reduce the number of people who become infected with HIV
- Increase access to care and optimize health outcomes for people living with HIV, and
- Reduce HIV-related health disparities

Scope of Florida Epidemic

- It is estimated that 130,000 persons are living with HIV in Florida,
- Of those, **approximately 20%** are not aware of their positive HIV status (26,000 people undiagnosed) and
- Approximately 40,000 individuals **ARE AWARE** of their HIV infection and are **NOT** in care

Continuum of Engagement in Care



- The concept of “in care” encompasses relationships with the care system that may vary in their level of consistency and durability and that may change over time.
- The terms linkage to care, engagement/retention, and re-engagement in care and re-entry to care reflect the degrees of relationship with the care system.
- Each step requires different intervention activities.

Figure adapted from Cheever LW. Engaging HIV-infected patients in care: Their lives depend on it. Clin Infect Dis 2007; 44: 1500-1502.

Common Barriers to Seeking and Maintaining Care

- Denial of one's HIV status
- Concern that others will find out their HIV diagnosis
- Stigma of HIV, particularly in rural areas
- Awareness of and access to HIV care
- Cost of care
- Lack of education about the benefits of adherence
- Side effects of medication

Self-Reported Barriers to Entering Care (ARTAS-2)

| Frequently reported barriers* | Not entered HIV care (n = 60) | Entered care, missed ≥ 1 appt (n = 117) |
|--|--|--|
| Felt well or had no symptoms | 70% | 58% |
| Lacked transportation to the clinic | 37% | 39% |
| Not ready to start taking HIV meds | 37% | 33% |
| Takes too long to get appointment | 20% | 38% |
| No insurance/could not afford cost | 33% | 31% |
| Could not take time off of work | 25% | 33% |

*Respondents could choose more than 1 barrier

Feeling Well is a Risk Factor for Not Entering Care (ARTAS-1)

% with care visits in 2 consecutive 6-month periods

Felt well

| | | |
|-------|---------------|----------|
| – Yes | 39% (29/74) | |
| – No | 63% (125/199) | P < .005 |

The Health Literacy of American Adults

2003 National Assessment of Adult Literacy

Definition: The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. People in America have health literacy that is:



| | |
|----------------|-----|
| ■ Below basic | 14% |
| ■ Basic | 22% |
| ■ Intermediate | 53% |
| ■ Proficient | 12% |

Some Examples of Sources of Confusion

- Take one tablet 2 times a day
- Take with food
- Take one hour before meals
- Take a teaspoon
- Apply to affected area
- Take half a tablet
- Why take the rest if I feel better now



Linkage is More Than a Referral

Linkage

Ask the client for their preference in care providers, make the appointment with them, and if possible, assist the client in attending the appointment. Follow-up to ensure the client attended their first appointment.

Referral

Involves giving the client the contact information for the care provider and leaving it up to them to call, get the date and time, and attend the initial appointment. No follow-up is expected.

Systems, Structural, and Organizational Factors Associated with Care Entry

- ❑ Rapid HIV testing (vs. traditional)
- ❑ HIV testing site is co-located with primary care site
- ❑ HIV counselor cross-trained as linkage facilitator
- ❑ Partnerships/processes established between testing sites and HIV care facilities
- ❑ Active assistance (e.g., identifying provider, making appt)
- ❑ Getting newly diagnosed “in the door” ASAP
- ❑ Follow-up contacts

Working With Your DIS

- When a person tests HIV positive in Florida, the Disease Intervention Specialists (DIS) are notified immediately.
- In Florida, only a DIS can provide partner services to a newly diagnosed person.
- Make sure you let your local DIS know that your agency is available to assist newly diagnosed persons in accessing medical care and treatment.

Success Checklist:

Implementing a Linkage to Care Program

- ↔ Existing, strong working relationships with
 - ↔ County/State Health Departments
 - ↔ Disease Intervention Specialists and C & T Services
 - ↔ HIV Case Management Systems
 - ↔ Medical Care Facilities
 - ↔ Ryan White Funded Agencies
- ↔ Reciprocal Referral Relationships with the Above
- ↔ Experienced staff, strong in understanding the system of care
- ↔ Major networking skills!
- ↔ Customer Service (view professionals as **secondary client**)

The ARTAS Model

- Antiretroviral Treatment Access to Services (ARTAS)
- CDC driven evidence-based intervention
- Most successful in areas with high prevalence
- Short-term case management
- Limited to 5 face-to-face visits

ARTAS is Rooted in Strengths-Based Case Management Principles

1. Encourage clients to identify and use their own strengths and abilities
2. Support client control over goal-setting
3. Work as a team with the client
4. Identify informal sources of support (family members, friends, and neighbors)
5. Case management as a community-based activity

Linkage



"That Information is CONFIDENTIAL"

How do you share client-level
data between entities??

- ✓ The “Gold Standard” is a signed consent from the client
- ✓ The linkage program can be co-located as an additional service of the medical provider
- ✓ The linkage program can become a Business Associate of the medical provider

HIPAA BUSINESS ASSOCIATE AGREEMENT

The _____, hereinafter Covered Entity, and _____, hereinafter Business Associate, agree to the following terms and conditions in addition to an existing agreement to perform services that involve the temporary possession of protected health information to develop a product for the use and possession of Business Associate. After completion of the contracted work all protected health information is returned to the Covered Entity or destroyed as directed by the Covered Entity.

- This form allows for the establishment of a relationship between the Covered Entity and the Business Associate.
- The Covered Entity (medical provider) can disclose the contact information for clients who have fallen out of care to the Business Associate (linkage program.)
- The agreement allows the linkage program to bring the client back to that medical provider only.

Peer Programs Work

- Someone who has “been there” has a more powerful message than others
- Someone who shares the same gender, sexual orientation, or stage of life can make a stronger impact



Peers use their own experiences with HIV to mentor, advocate for, and support PLWHA.

Peer support programs play four important roles:

1. Provide information and support through shared experiences with the system of care.
2. Model adherence skills.
3. Offer emotional support, including encouragement, reinforcement, and decreased isolation.
4. Bring mutual reciprocity through shared problem solving and by giving and receiving help on a shared medical issue.

Retention in Care Over Time

- Peers can play an important role in helping people understand the importance of maintaining medical care.
- HIV clinics and medical providers also have a responsibility to assist clients in keeping their appointments.
 - Reminder phone calls/texts
 - A welcoming atmosphere in the clinical setting
 - Respecting client as member of the health care team
 - Follow-up and reschedule no-shows
 - After an extended absence, refer client to linkage program

Treatment is Prevention

By keeping clients linked to care and **ADHERENT** to their medications, they are much less likely to transmit the virus to others. - Not to mention their own health and well-being.

It is important that people understand that taking HIV meds only some of the time is more harmful than not taking any meds at all.



VIRAL RESISTANCE

Preparing for Adherence Before Starting HIV Treatment

Tips for Success:

- Use a 7-day pill box
- Use a timer, alarm clock, or cell phone as a reminder
- Keep a backup dose in purse or pocket
- Plan for medication refills a week before you run out
- Keep all medical appointments

**Make
sure your
client understands
what they are
“getting
into”**

A Word About Ex-Offenders

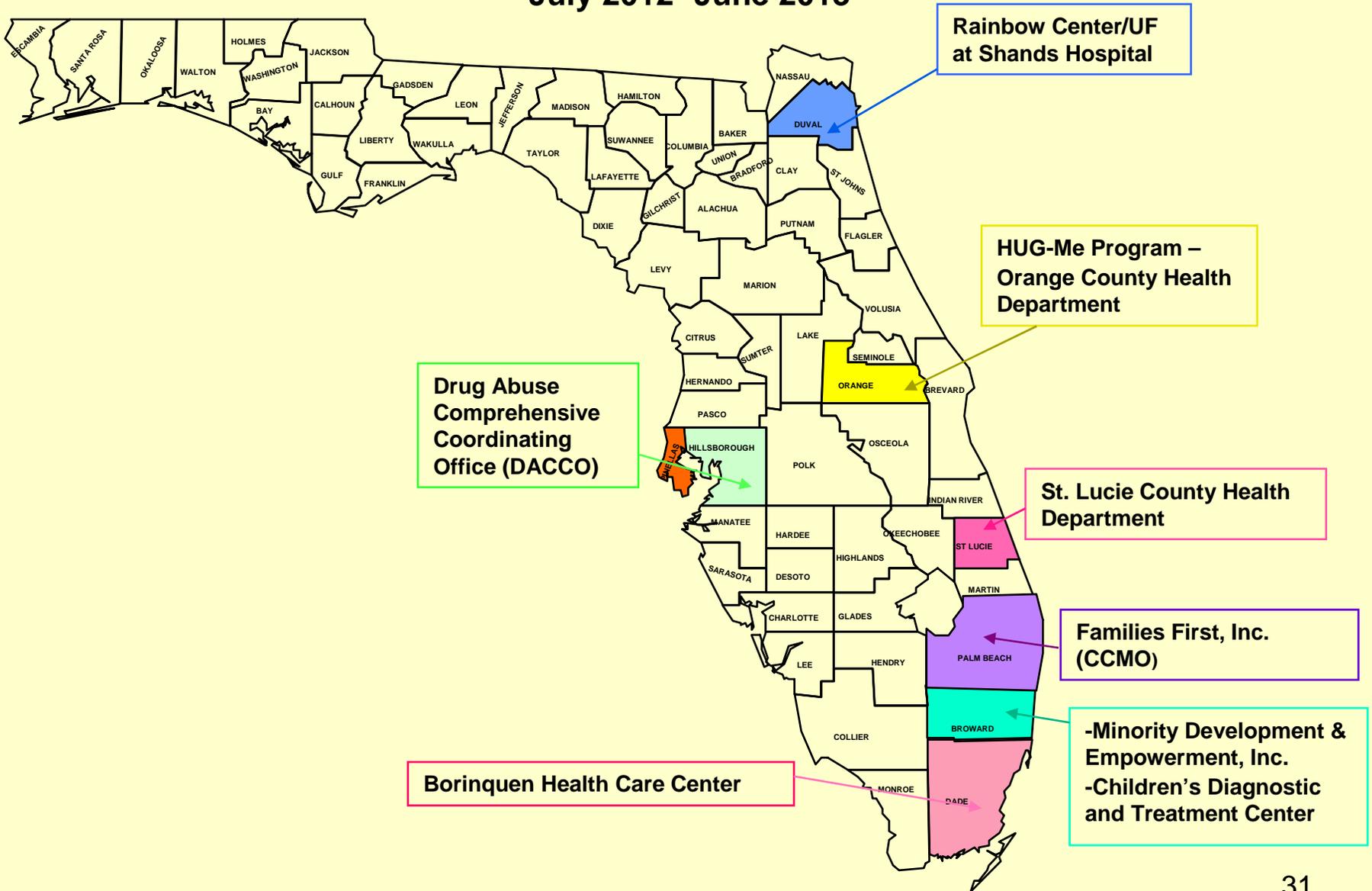
- Florida has a Pre-Release Planning Program for HIV-infected inmates leaving the Department of Corrections (prison) and Jail Linkage Programs
- Each individual is provided with an appointment for medical care a few days after release
- If your program wants to assist these clients in linking to and maintaining care, please contact the bureau corrections coordinator, Kathy McLaughlin: kathryn_mclaughlin@doh.state.fl

A Word About Pregnant Women

We can lower the risk of HIV transmission from the mother to the baby to $< 2\%$!



Targeted Outreach for Pregnant Women Act (TOPWA) Contract Providers July 2012- June 2013



Webinar Evaluation

- **Before you leave the webinar**, please take a moment to complete the evaluation in the polling section (to the right of your screen)
- Your feedback is extremely important to us and will help improve on current and future trainings
- The more feedback the better!



Resources

National Institutes of Health, HIV Treatment Guidelines

<http://www.aidsinfo.nih.gov/guidelines>

HIV Prevention Section Website (slides from today's webinar will be available here, under Resources & Materials) <http://www.preventhivflorida.org/>

Linkage Team Page, HIV Prevention Section Website

<http://www.preventhivflorida.org/Linkage.html>

Bureau of HIV/AIDS and Hepatitis Website

<http://www.floridaaids.org/>

National HIV/AIDS Strategy

<http://www.cdc.gov/hiv/strategy/>

Guidelines for Traditional and Internet-based HIV Prevention Outreach (Bureau of HIV/AIDS, Prevention)

http://www.preventhivflorida.org/Interventions/Outreach_Guidance_FINAL_01_2012.pdf

Questions/Comments

Did I Understand You To Say...

But What About...

HUH?

What Did You Mean By...

Contact Information

Nita Harrelle

Linkage Team Lead

Nita_Harrelle@doh.state.fl.us

Bureau of HIV/AIDS, Prevention Section

Florida Department of Health

4052 Bald Cypress Way, Bin A-09

Tallahassee, FL 32399

(850) 245-4336



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