

## Referral Follow Up: The Missing Link Between Prevention and Care

Jack Carrel and  
Jyaphia Christos-Rodgers  
Louisiana Office of Public Health  
HIV/AIDS Program



1

---

---

---

---

---

---

---

---

## The Challenge

- ❑ As Prevention workers labor to encourage people with high risk to know their HIV status, they can also play an important role when a result is positive, assisting the newly identified person living with HIV to quickly enter HIV medical care.

2

---

---

---

---

---

---

---

---

## Ensuring Access to Care: Good Care is Good Prevention *(and vice versa)*

- ❑ Late testing/entry into care result in greater chance of AIDS diagnosis and of death.
- ❑ People who are in medical care are more likely to have safer sex/drug using behaviors.
- ❑ Reduction in viral load among people in care also leads to less HIV transmission in the population when there is unprotected sex or needle sharing.
- ❑ In a recent study in Louisiana, having a medical appointment set by a counselor at a confirmatory post test counseling visit more than doubled the chances of a client entering care within 6 months of diagnosis (Wendell, 2008).

3

---

---

---

---

---

---

---

---

## From Prevention to HIV Medical Care

- ❑ In Louisiana, the state's HIV Prevention Unit prioritizes making quality referrals to a wide range of health and social services.
- ❑ Quality referrals are referrals that provide detailed information on where and how to access a service and then include follow up to confirm that a service actually has been accessed.
- ❑ In this presentation we will examine Prevention Referrals with special attention paid to Referrals to HIV Medical Care.

4

---

---

---

---

---

---

---

---



### Introduction Louisiana Office of Public Health HIV/AIDS Program



A cluster of 3 program units:

- A Prevention Unit designed to thwart the spread of HIV,
- A Services Unit designed to ensure the availability of quality medical and social services for people who are HIV infected and affected, and
- A Surveillance Unit to track the impact of the epidemic in Louisiana.

5

---

---

---

---

---

---

---

---

## Systems that can Facilitate Access to HIV Medical Care

Three main sources of referrals to care

- ❑ Part B Case Management
- ❑ Medical Providers at Diagnosis
- ❑ Prevention Providers at CTRS

6

---

---

---

---

---

---

---

---

## Louisiana's Systemic Resources to Ensure Links to Care

- Case Management
- Prevention Referrals
- Surveillance Data for Confirmation

7

---

---

---

---

---

---

---

---

## Surveillance Data

Louisiana collects:

- name-based HIV/AIDS case data (started 1993)
- mandatory lab data for all HIV related labs (started 1999)

8

---

---

---

---

---

---

---

---

## Case Management

□ In 2004 Louisiana participated in ARTAS II\* demonstration project, which focused on ensuring that new positives were connected to medical care:

- 2 case managers trained to use Strengths Based Case Management (SBCM)
- New positives referred from STD Clinics, CTRS sites and Hospitals to SBCM
- Over course of project, 76.4% had accessed medical care within six months, an improvement compared to pre-ARTAS II data (61.7%).

\*Described in greater detail at session by Dr. DeAnn Gruber from LA OPH-HAP

9

---

---

---

---

---

---

---

---

## Prevention Referrals

- In 2007, Hap's Prevention Program instituted required follow up for all referrals made by prevention contractors as they deliver interventions.
- The majority of prevention referrals to HIV medical care are through Counseling, Testing and Referral Services, when new positives are identified; but, there is a subset from other interventions.
- Outcomes of Referrals to HIV Medical Care are validated using surveillance data from lab reports. The CDC standard is that if a patient has a single lab report show up in a 12 month period they may be considered "in care"

10

---

---

---

---

---

---

---

---

## HAP's Prevention Program



- HIV counseling, testing, and referral
- Prevention with HIV positive individuals,
- Outreach and referral
- Prevention materials (Condom Availability)
- Partner services,
- Behavioral interventions, and
- Statewide info-line for HIV, STD, hepatitis, and TB-related information
- Follow up on all referrals

11

---

---

---

---

---

---

---

---

## How Prevention Works



- Louisiana is divided into 9 Public Health Regions.
- HAP coordinates a statewide planning process.
- Community-based organizations are contracted in each region to provide services.
- A HAP regional coordinator oversees the CBOs and monitors their progress in meeting contract objectives.

12

---

---

---

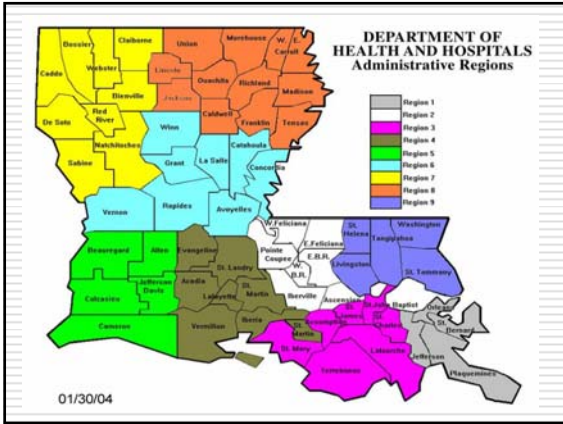
---

---

---

---

---




---

---

---


---

---

---

---

---



### Genesis of the Referral System Idea

- HAP first explored the idea of Referral Tracking as the program prepared to implement PEMS.
- Early versions of the PEMS variables indicated follow up would eventually be required for all referrals to and from prevention programs.
- However, as the PEMS project unfolded, CDC backed away from this requirement.

---

---

---

---

---


---

---

---

### Then Came Katrina and Rita...

- Hurricane Recovery
- Upheaval across the state
- Limited Services with no clear links
- HAP began looking for ways to strengthen its impact by
  - integrating services
  - building a more holistic model preventive health




---

---

---

---

---

---

---

---

## Learning from CBO Best Practices

- ❑ HAP knew referrals were being made by the CBOs during their different interventions, but there was no mechanism to report and track the outcomes.
- ❑ One CBO, Metro Health in Baton Rouge, on their own, instituted a referral program that was producing clear results.

**BRBAC Metro Health  
Organization**

<http://www.brbac-metrohealth.org/index.html>



16

---

---

---

---

---

---

---

---

### Metro Health HIV Prevention Referrals Issued 4/4/2006 to 6/22/2006

#### Results of All Referrals Made

Referral Outcome	#	%
Confirmed not accessed	12	24%
Confirmed accessed	16	33%
Refused/did not provide contact information	3	6%
Contact information not good	2	4%
Left message/no return call	9	18%
No follow up	5	14%
Total	47	100%



#### Referrals with Confirmed Results

Referral Outcome	#	%
Confirmed not accessed	12	43%
Confirmed accessed	16	57%
Total	28	100%

17

---

---

---

---

---

---

---

---



## Five Main Priorities

Soon, HAP developed a referral tracking pilot driven by five main priorities

- To connect people with needed services
- To remove barriers to reducing risk & making healthy decisions
- To increase the communities awareness of resources
- To ensure people get the services they need
- To document the capacity of prevention programs to make successful referrals.

18

---

---

---

---

---

---

---

---

## Pilot Projects

- Piloted in three regions
  - New Orleans (Large Urban Area)
  - Baton Rouge (Smaller Urban Area)
  - Lafayette (Rural Area)
- Wide base of referral outcomes needed



19

---

---

---

---

---

---

---

---

Referral Outcomes in the Pilot Phase N=94

CBO	Pending	Confirmed Accessed	Confirmed- Did not Access	No Follow up	Total
CBO A n=14	21%	0%	0%	79%	100%
CBO B n=64	22%	72%	3%	3%	100%
CBO C n=3	0%	0%	100%	0%	100%
CBO D n=13	8%	15%	0%	77%	100%
<b>Total</b>	<b>19%</b>	<b>51%</b>	<b>5%</b>	<b>24%</b>	<b>100%</b>



20

---

---

---

---

---

---

---

---

## Learnings from the Pilot

- CBOs met the idea of referral follow up with a lot of concern. For example:
  - Will we be penalized?
  - Is this one more way to burden and judge contractors?
  - Will clients agree to provide information or permission for follow up?
- The word "tracking" to refer to Referral Follow up adds to the discomfort. It's a "loaded" word that has not historically meant good things.

21

---

---

---

---

---

---

---

---

## Learnings Continued...

- CBOs face two challenges to be ready to create a referral system:
  - Time to build the relationships with Agencies and Clients
  - Knowing what resources are available in their community and bringing some coordination to the network of agencies that provide different services.



---

---

---

---

---

---

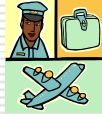
---

---

## Pilot Learnings...again

The Health Department had a clear set of roles to fill:

- Supporting relationship building with state programs
  - Office of Addictive Disorders,
  - Public Health Units,
  - the Office of Mental Health,
  - STD Clinics, and
  - Family Planning Clinics.
- Helping local service provider networks to address information sharing and especially HIPAA concerns.



23

---

---

---

---

---

---

---

---

## Full Implementation Begins



- In July 2007 the program was implemented statewide with 18 CBO contractors.
- HAP conducted training sessions with every CBO in which referral tools were distributed and reviewed.
- Some CBOs expressed many of the same concerns raised in the pilot phase.
- HAP held strong, this wasn't about the CDC; it was about strengthening the service delivery to clients and the program's capacity to show results.

24

---

---

---

---

---

---

---

---

## Looking at the Data



- The next few slides display data from the first 3 quarters of full implementation.
  - 2 slides on Prevention Referrals overall
  - 2 slides on Referrals to HIV Medical Care
- Taking the tables one at a time, use a few moments to review the data
- Circle anything you would like to ask about or comment about. We will hear and discuss what people notice. Then we will do the same with the next table.

25

---

---

---

---

---

---

---

---

---

---

Referral Outcomes Over Three Quarters- All Referrals Made

Referral Outcome	July-September		October-December		January-March		Total	
	#	%	#	%	#	%	#	%
Pending	55	5%	95	8%	210	18%	360	10%
Confirmed, accessed	560	48%	525	44%	858	74%	1943	55%
Confirmed, did not access	23	2%	56	5%	67	6%	146	4%
Lost to follow-up	16	1%	68	6%	26	2%	110	3%
No follow-up	512	44%	462	38%	1	0%	975	28%
<b>Total</b>	<b>1166</b>	<b>100%</b>	<b>1206</b>	<b>100%</b>	<b>1162</b>	<b>100%</b>	<b>3534</b>	<b>100%</b>

26

---

---

---

---

---

---

---

---

---

---

Types of Referrals Made July 2007- March 2008

Types	#	%
HIV Testing	2593	73.9%
HIV Confirmatory Testing	66	1.9%
HIV Medical Care	57	1.5%
STD Screening and Treatment	353	10.1%
General Medical Care	108	3.1%
IDU Related Services	13	0.4%
Prevention Case Management	22	0.6%
Other HIV Prevention Services	35	1.0%
Substance Abuse Services	64	1.8%
Partner Counseling and Referral Services	34	1.0%
Mental Health Services	16	0.5%
Housing Services	31	0.9%
Prenatal or other Reproductive Health Services	18	0.5%
Viral Hepatitis Screening and Treatment	15	0.4%
Tuberculosis Testing	2	0.1%
Other Services	87	2.5%

---

---

---

---

---

---

---

---

---

---

### Prevention Referrals to HIV Medical Care

Referring Intervention	Pending		Confirmed - accessed		Confirmed - did not access		Total	
	#	%	#	%	#	%	#	%
CTRS	4	10%	38	88%	1	2%	43	100%
Outreach	0	0%	1	100%	0	0%	1	100%
RM*	1	8%	12	92%	0	0%	13	100%
<b>Total</b>	<b>5</b>	<b>9%</b>	<b>51</b>	<b>89%</b>	<b>1</b>	<b>2%</b>	<b>57</b>	<b>100%</b>

\* RM is Risk Management, Louisiana's version of Comprehensive Risk Counseling Services (CRCS) for persons who are HIV Positive.

28

---

---

---

---

---

---

---

---

---

---

---

---

### Confirming Referral Follow Up Results

- In the next slide you will see a discrepancy between results reported by Prevention Teams and EHARS data.
- A variety of factors may be driving this, such as:
  - Reporting lag of data into EHARS
  - Inaccurate self reports from clients
  - Data entry error
- Next step will include further follow up on those recorded as "confirmed Successful but not confirmable in EHARS.

29

---

---

---

---

---

---

---

---

---

---

---

---

Referral Outcome	Client in HIV Medical Care? (as confirmed through EHARS)					
	NO		YES		Total	
	#	%	#	%	#	%
Pending	1	20%	4	80%	<b>5</b>	<b>100%</b>
Confirmed Successful	10	19%	43	81%	<b>53</b>	<b>100%</b>
Confirmed Unsuccessful	0	0%	1	100%	<b>1</b>	<b>100%</b>
<b>Total</b>	<b>12</b>	<b>20%</b>	<b>47</b>	<b>80%</b>	<b>59*</b>	<b>100%</b>

\* This includes 2 cases with Intervention not reported that are omitted from previous table.

30

---

---

---

---

---

---

---

---

---

---

---

---

## Dialogue: Benefits and Challenges of Referral Follow-Up

- On the next slide you will find a list of questions and concerns raised by CBOs as we built the referral program.
- Divide into groups of 4 and, as a group, choose 3-4 of the questions to discuss.
- Share ideas of how you might respond to the questions.
- Afterward we'll hear a sample of your ideas.



31

---

---

---

---

---

---

---

---

## Questions to Discuss

- Won't this take too much time?
- Why follow up on referrals?
- Why is this our job?
- How much time do I need to spend on referral follow-up ?
- What does the client gain?
- How does this make our job easier?
- What if the client doesn't want a referral?
- What do we as outreach workers gain from making referrals?
- If we do follow up, our encounter numbers will go down.



32

---

---

---

---

---

---

---

---

## Building Referral Networks

- Helping contractors work with local networks of service providers to build relationships and agreements related to referrals is an important strategy.
- This is where Links 2 Prevention comes in.



33

---

---

---

---

---

---

---

---

## What is Links 2 Prevention?

- A model of Service Network Provider Collaboration shared by CBA provider CHOW\*
- A coalition formed with the sole purpose of linking clients into necessary services.
- The Baton Rouge Louisiana Links coalition is called the Compassionate Care Referral Network (CCRN). It is 2 years old and was the first one to be formalized.



\*Community Health Outreach Workers <http://chowlinks2.org/>

34

---

---

---

---

---

---

---

---

## Coalition Stakeholders & Partners

- Consumers
- CBOs
- Local Businesses
- Churches
- Media
- Public Agencies including:
  - Office of Addictive Disorders,
  - Public Health Units,
  - Office of Mental Health,
  - STD Clinics, and
  - Family Planning Clinics.



35

---

---

---

---

---

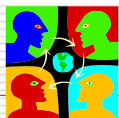
---

---

---

## Why Collaborate?

- Increases Community Involvement
- Addresses Clients' Access to Services
- Helps with Prevention of Positives
- Reduces Duplication of Services
- Increases Cost Effectiveness
- Directs Service



36

---

---

---

---

---

---

---

---

### Collaboration: Its Benefits and Challenges

---

<p><b>Benefits</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Increases Effective Referrals</li> <li><input type="checkbox"/> Increases Cost Effectiveness</li> <li><input type="checkbox"/> Puts Everyone at the Same Table</li> <li><input type="checkbox"/> Increases Funding Opportunities</li> </ul>	<p><b>Challenges</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Reluctance of Organizations</li> <li><input type="checkbox"/> Funding</li> <li><input type="checkbox"/> Recruiting</li> <li><input type="checkbox"/> Multiple Organizations</li> <li><input type="checkbox"/> Diversity</li> </ul>
--	---



37

---

---

---

---

---

---

---

---

### Keys to Linkages Between Agencies

---

- Communication
- Participation
- Keep an Open Mind
- Make Necessary Referrals Appropriately
- Listen



38

---

---

---

---

---

---

---

---

### What's Needed to Build Your Coalition?

---

<ul style="list-style-type: none"> <li><input type="checkbox"/> Recruitment Process</li> <li><input type="checkbox"/> Network Development</li> <li><input type="checkbox"/> Governance Policies</li> <li><input type="checkbox"/> Community Capital Assessment</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Strategic Planning</li> <li><input type="checkbox"/> Referral Development</li> <li><input type="checkbox"/> Leadership Development</li> <li><input type="checkbox"/> Information Dissemination</li> <li><input type="checkbox"/> Marketing</li> </ul>
---	---



39

---

---

---

---

---


---

---

---

### Steps in Referral System Development

- Asset Mapping
- Resource Directory
- Referral Networking
- Referral Activity Protocol
- Data Collection/Analysis



40

---

---

---

---

---


---

---

---

### Making Referrals to Medical Care:

- In the post test counseling session you help the client recognize the benefit of entering HIV Medical Care ASAP
- Offer the referral, letting the client know you would like to follow up to make sure they get what they need.
- Each worker must develop the art of referral making in the counseling session so they are prepared to follow up and confirm that the client accesses the service



41

---

---

---

---

---

---

---


---

### Three Ways to Confirm a Referral

Client phone contact - Obtain a phone number from the client and call them after they have had time to access the referral.

Client in-person contact - Let the person know you will check in with them in person once they have had a chance to access the service. Then look for the person the next time you are doing outreach at that location.

Agency contact - With the clients permission, you contact the "receiving agency" to find out whether the client came in for the service. This is where the formalized network plays a key role.



42

---

---

---

---

---

---

---

---

## Nuts and Bolts for Documenting Referral Activity



HAP has developed three instruments for data collection and reporting.

- An optional and editable Referral Card
- A required Referral Follow Up Form
- A Quarterly Referral Summary Form

43

---

---

---

---

---

---

---

---

## Nuts and Bolts Dialogue

Look over the three forms in your packet. What are your questions or comments?



44

---

---

---

---

---

---

---

---

## Community Sound Bites....in the beginning

□ "Why would they talk to us about their personal needs? If they have a problem with alcohol or drugs – they're not going to share it."

■ Venita Grimes – GO CARE

□ "Or any personal problems. Personal pride won't let them tell us if they're homeless or hungry."

■ Cedrick Jackson – GO CARE



45

---

---

---

---


---

---


---

---

## Community Sound Bites...



- ❑ "Now we ask those questions. 'Are you homeless?' 'Are you hungry?' 'Do you have a problem with alcohol or drugs?' 'Are you worried about an STD?' Now we ask. We don't wait for them to tell us."
  - Venita Grimes – GO CARE
- ❑ "We didn't realize how comfortable they'd be talking to us about these personal issues."
  - Cedrick Jackson – GO CARE



46

---

---

---

---


---

---

---

---

## Key Concluding Insight #1



Providing information on where to get a service does not, alone, stand as a "referral"

- First, providing a referral should mean that the client has said they will go to the service.
- Then, following up to ensure that the client got to the service completes the referral.

47

---

---

---

---


---

---

---

---

## Key Concluding Insight #2



- ❑ CBOs were concerned that documenting referrals would get in the way of delivering prevention services.
- ❑ The point of prevention is to chisel away at barriers to behavior change and to service access/utilization.
- ❑ Referral follow-up should support, not interfere with it.
- ❑ There is a learning curve here that each agency will need to master. Believing that its possible is half the battle!

48

---

---

---

---

---

---

---

---

## Next Steps...



- Continue to build the confidence in and commitment to this prevention and care strategy among CBOs
- Broaden and strengthen the links among agencies in each region
- Add a measure of client satisfaction with services to the client follow up part of the protocol.

49

---

---

---

---

---

---

---

---

## References

- Lessons Learned During and After ARTAS II: Louisiana's Experience. Ryan White 2008 conference presentation. DeAnn Gruber, PhD, LCSW, Louisiana Office of Public Health-HIV/AIDS Program, August 25, 2008,
- Late Diagnosis and Entry into Medical Care Among Persons Newly Diagnosed with HIV in Louisiana, Presentation to colleagues. Debbie Wendell, PHD. 2008.

50

---

---

---

---

---

---

---

---