

**EVALUATING LINKAGES
BETWEEN HIV PREVENTION,
COUNSELING AND TESTING,
AND CARE**

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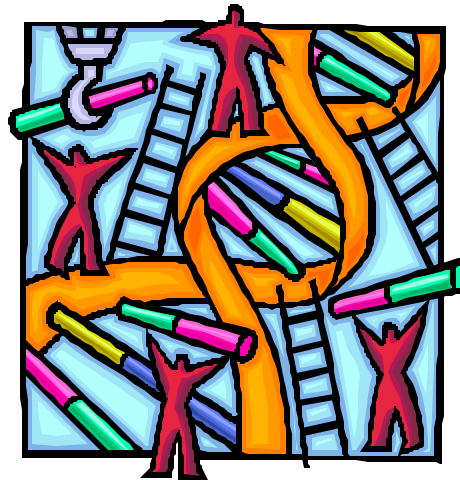
Today we will review...

- **Evaluation approaches taken in the past**
- **A conceptual framework for evaluating service linkages and integration**
- **Challenges encountered in evaluating linkages and integration**
- **Evaluation strategies that might be adopted**

MOVING TOWARDS AN INTEGRATED SYSTEM



**Current
System**



**Linked
System**



**Integrated
System**



INTEGRATING HIV PREVENTION, COUNSELING AND TESTING, AND CARE

- **Integration is already underway**
 - **47% of CARE Act providers are engaged in prevention services**
- **Only 37% of those agencies receive CDC funding**
- **Minority providers are more likely to offer prevention services than other agencies (42% versus 35%)**
- **Only 37% of agencies providing prevention participate in community prevention planning activities**

PREVIOUS EVALUATION APPROACHES

- **Uniform administrative reporting systems required by CDC, HAB, or State or local government for programmatic accountability**
 - **Data collection systems may not be designed explicitly for evaluation purposes**
 - **The volume of prevention services provided by CARE Act funds may not be fully accounted for by CDC**

PREVIOUS EVALUATION APPROACHES

- **Cross-sectional data collected at the “point of service”**
 - **Often not accurately linkable to create person-based records**
 - **Outgoing referrals may not be linked to completed referrals**
 - **Repeat testing inflates counseling and testing site data**
 - **Use of multiple agencies inflates service population data**
- **Use of actors to assess content of pre- and post-test counseling and other services, including referrals made**

PREVIOUS EVALUATION APPROACHES

■ HIV/AIDS surveillance system

- Staff tend to focus on collecting data required to document the case**
- High rates of missing data because surveillance staff may not have access to a complete longitudinal set of medical charts or insurance records**
- Not all states participate in HIV reporting**
- Variability in completeness of HIV and AIDS reporting**

PREVIOUS EVALUATION APPROACHES

- **Use of interviews with HIV/AIDS “cases” to review their experiences with HIV testing, entrance into care, and service use (e.g., SHAS, HCSUS, ACSUS)**
 - **Not all states are represented in surveillance follow-back studies**
 - **The “active” medical chart or chart of the reporting physician is the focus of data collection**
 - **Recall is likely to bias the data**
 - **Validation via insurance claims has been done on only a limited basis: service use is under-reported**

PREVIOUS EVALUATION APPROACHES

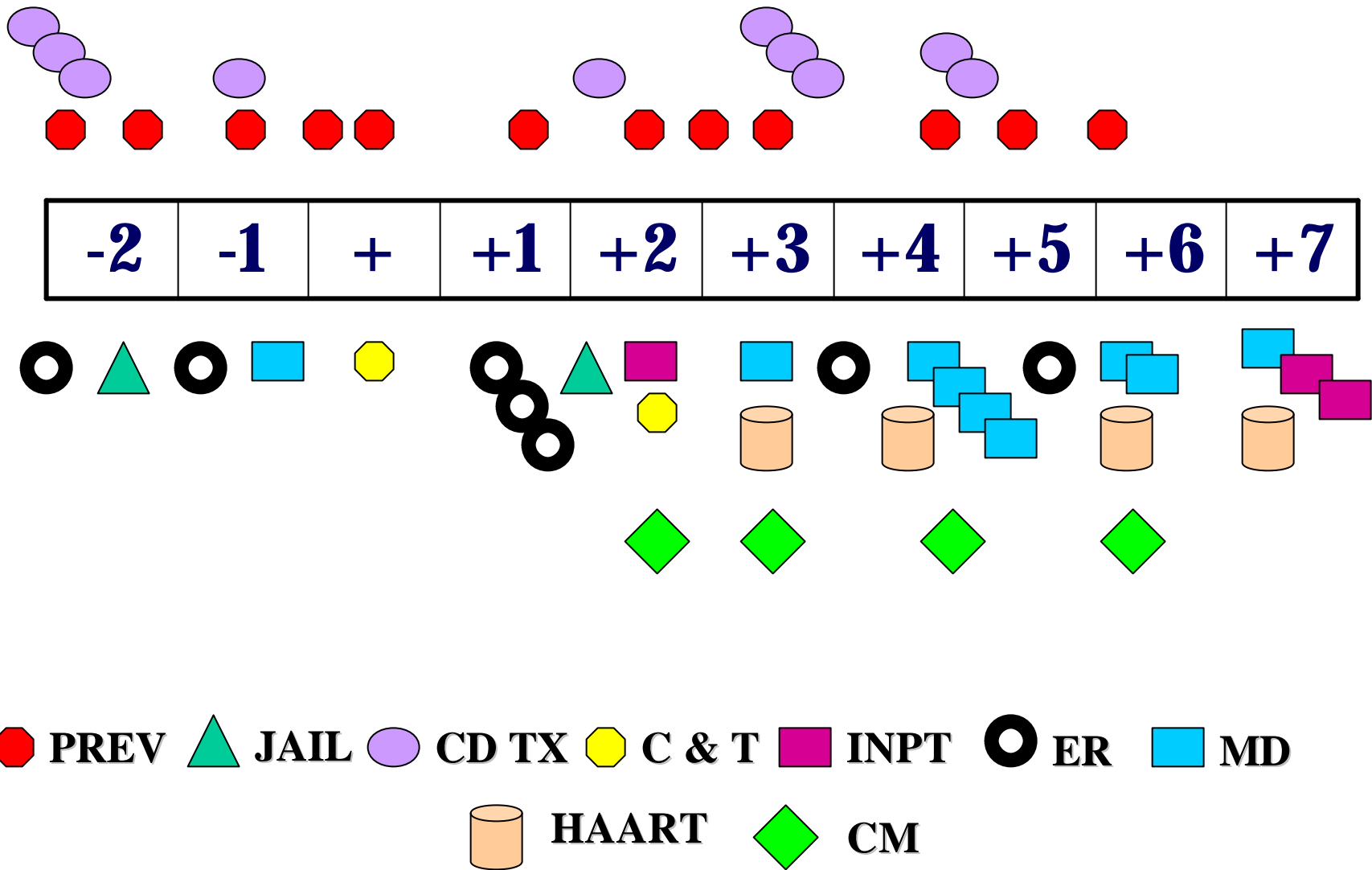
■ Use of insurance claims records

- ◆ Enrollment changes over time, with gaps in enrollment**
- ◆ Prepaid managed care systems use encounter-based data**
 - Little incentive for providers to fully apply coding systems to record diagnostic and procedural data**
- ◆ Large complex data systems that are often not readily accessible to researchers**
- ◆ Confidentiality**
- ◆ Institutional barriers and use of different coding systems have thwarted efforts to link publicly funded data systems**
- ◆ Geographic comparisons increasingly difficult as State programs apply different eligibility and coverage policies**

PREVIOUS EVALUATION APPROACHES

- **Few formal studies of referral systems**
 - **Studies use network theory to develop theoretical framework**
 - **Studies may be complex, depending on the number and nature of referral relationships**
 - **Respondents may under-report the number of agencies they commonly receive referrals from or refer to**
 - **Study have tended not to assess the actual flow of clients or patients and the impact of the referral relationships**

TRANSITION FROM HIV PREVENTION TO CARE: ONE PERSON'S ODYSSEY



CHALLENGES

- @ Entrance into the HIV service system frequently is commonly outside the network funded by the CDC or HRSA (e.g., office-based MDs, managed care plans, corrections systems)**
- @ Consumers may receive a large share of their services outside the HIV prevention and care system; making it appear that essential services were not provided**

CHALLENGES

- Ⓢ HIV service systems are increasingly complex due to the diverse needs of consumers**
 - Ⓢ It may be difficult to define local systems and the relationships of member agencies and other providers**
- Ⓢ Systems may be difficult to compare:**
 - Ⓢ Variable commitment to HIV prevention and care among local / State government, CBOs, safety net programs, and hospitals**
 - Ⓢ Differences in service demand**
 - Ⓢ Differences in priority areas and targeting of funds**
 - Ⓢ Other public funds may support HIV care in varying degrees**

CHALLENGES

- ④ **Additional data collection may burden an already overwhelmed system of HIV prevention, counseling and testing, and care**
 - ④ **About one-half of CARE Act providers report insufficient direct service staff and physical space to meet *current* demand**
 - ④ **Two-thirds of CARE Act providers report that they need more funds to meet *current* demand**
 - ④ **One-fourth of CARE Act providers report that they need TA in evaluation**
- ④ **Consumers' self-reported data regarding risk behaviors, referrals, and adherence to treatment may be inaccurate**

CHALLENGES

- ② **Moving from descriptive studies to outcomes studies is desirable but difficult to accomplish because it may be hard to:**
 - ② **Achieve sufficiently large sample sizes and follow cohorts over time**
 - ② **Measure the cumulative effect of different interventions**
 - ② **Account for the impact of other factors**
 - ② **Interpret the results**

CHALLENGES

- ② **The state of the art of HIV treatment is changing, making “interventions” difficult to distinctly define and measure over time across sites**
- ② **Self-determination by consumers may significantly impact the order and frequency of services**
- ② **The most meaningful initial HIV early intervention services may be drug treatment and mental health services**

EVALUATION DESIGN

- ④ **Use a multi-disciplinary approach in which epidemiologists, behaviorists, health services researchers, and operations researchers join forces**
- ④ **Focus on a balance of process and outcomes measures applied in cross-sectional and longitudinal studies**
- ④ **Link epidemiologic, administrative, insurance, program performance, and clinical data**
- ④ **Apply realistic approaches that do not result in further unfunded mandates for grantees and service providers**
- ④ **Meaningful partnerships with prevention, counseling and testing, care providers, and consumers to design studies**

MULTI-PRONGED EVALUATION STRATEGY

Consumer behavioral studies




-  **HIV risk behaviors**
-  **Test *and* result seeking**
-  **Initial and longitudinal care seeking,**
-  **Adherence to harm reduction practices and treatment**
-  **Referral follow-up**
-  **Appointment initiation and keeping**

Individual provider behavioral and performance studies

-  **Prevention workers**
-  **HIV counselors**
-  **Clinicians**
-  **Case managers**
-  **CD and mental health program staff**
-  **Mental health workers and social support providers**

MULTI-PRONGED EVALUATION STRATEGY

Agency studies

-  **Program design**
-  **Service models**
-  **Outreach and case finding strategies**
-  **Referral relationships**
-  **Accessibility assessments**
-  **Performance measures**
-  **Quality measures**
-  **Consumer satisfaction**

Delivery system studies

-  **Planning mechanisms**
-  **Defining roles and responsibilities**
-  **Referral mechanisms and relationships**
-  **Extent of integration**
-  **Role of substance abuse and mental health providers**
-  **Co-location of services**

MULTI-PRONGED EVALUATION STRATEGY

- **Planning systems studies focusing on Planning Councils, consortia, and Community Prevention Planning Groups:**
 - **Their effectiveness in identifying and filling service gaps,**
 - **Integrating high quality services, and**
 - **Allocating funds to this end**

IMPLEMENTATION STRATEGY

- + Evaluations should be launched prior to reengineering of systems to obtain baseline data**
- + Demonstration projects might be used to develop conceptual frameworks and instrumentation**