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

Julia Hidalgo

George Washington University &

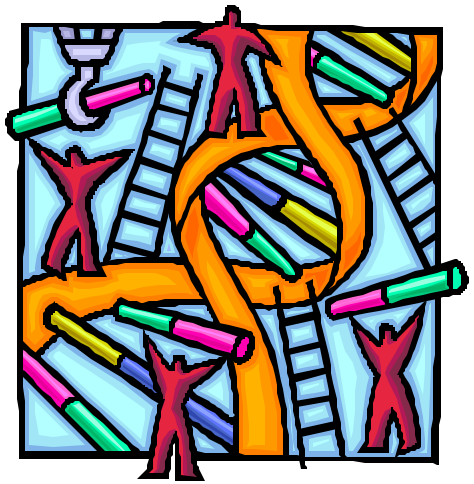
Positive Outcomes, Inc.

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**

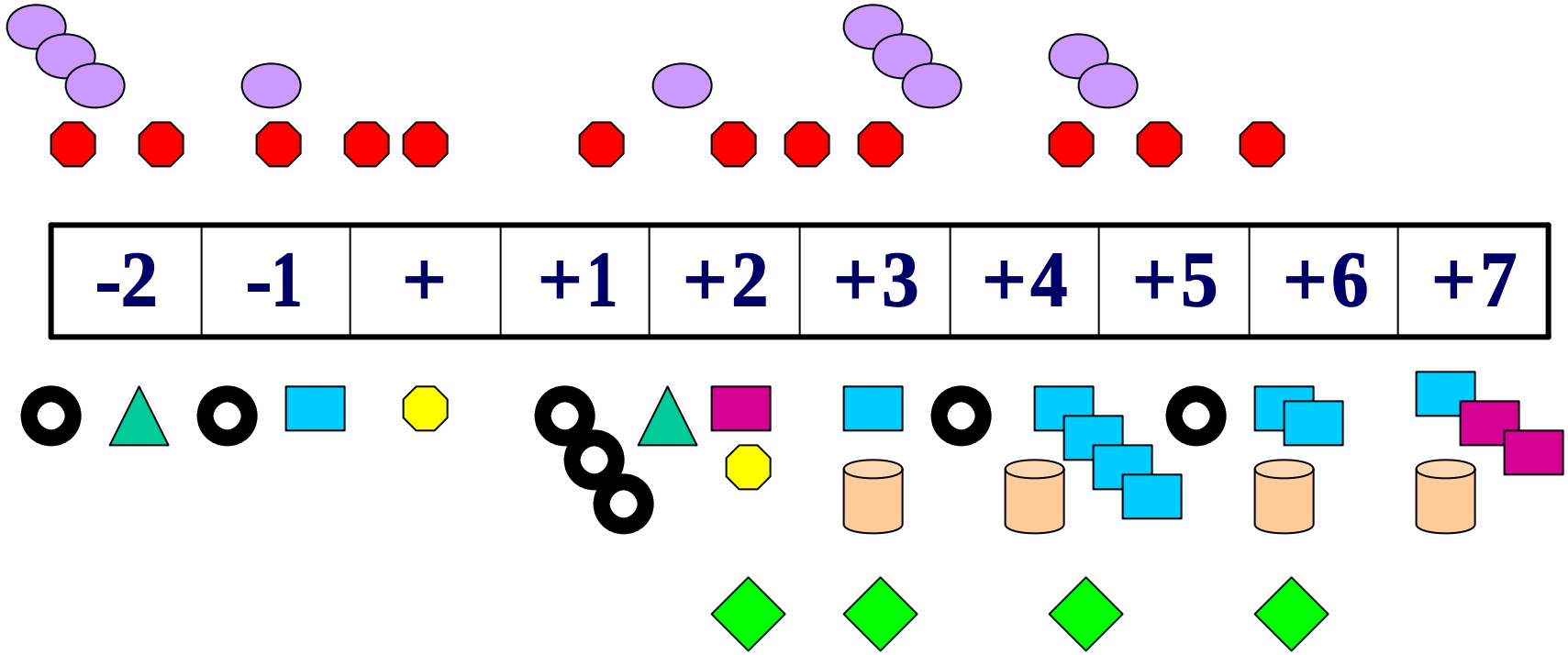
PREVIOUS EVALUATION APPROACHES

- **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



PREV JAIL CD TX C & T INPT ER MD

HAART CM

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

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

CHALLENGES

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

CHALLENGES

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

EVALUATION DESIGN

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