**Exploring participatory HIV prevention strategies** for youth through a community-based participatory research partnership

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### Acknowledgments

Safe Horizon, Bronx AIDS Services, Citizens Advice Bureau, Project Reach Youth, New York State Department of Health AIDS Institute Adolescent HIV Prevention Services Unit, Cornell University Family Life Development Center

Youth involved in pilot study – Spring 2006

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#### Issues

- Engaging young people in HIV prevention efforts is crucial to stemming the global epidemic.
- Many programs have developed innovative participatory strategies for involving youth.
  Few studies have researched the relationship between youth engagement in participatory HIV prevention programs and HIV risk reduction.

#### Youth in New York State: Too many becoming infected with HIV, too few accessing care

Estimated number of new infections each year in people aged <25 in New York State

*New HIV/AIDS diagnoses reported during 2004 in people aged <25 in NYS* 

Percentage of estimated number of new HIV infections in people aged <25 in NYS that are diagnosed

*Estimated number of new infections not diagnosed if projections are accurate* 

3,600

US total: 40,000 NYS share: 18% Percentage in youth: 50%

716

(includes 34 diagnoses in children <13)

*20%* (one in five)

2,884

# **Complementary Strengths:**

Our goal is to examine whether specific characteristics of highly engaged program participation (e.g., youth voice/choice/influence on program decision-making, opportunities for individual development, quality of linkages between the program and other key social contexts, and program climate) influence young people's connectedness to family and the larger community, and their HIV risk reduction practices.

## Brief history of our partnership

- 2004 New York State Department of Health AIDS Institute Adolescent HIV Prevention Services worked to expand strength-based approaches
- 2005 Foundation for the partnership (main question: how do strength-based, positive youth development approaches affect HIV risk reduction?)...Developed initial proposal to NIH (May)...IRB approval (August)...Formed steering committee (October)....Planned pilot study

 2006 – Pilot study engaged 98 young people: Youth program participants between the ages of 13 and 24 piloted a survey regarding program participation characteristics, social connectedness, and HIV risk reduction. (February-March)...April and October data discussion sessions with youth

 2007 – Expanded partnership to involve NYC Department of Youth and Community Development and five additional community-based programs (Spring)...Funded for larger exploratory study (September)

## Supporting engagement

- Fast tempo –worked to reduce lag time between data collection and data interpretation
- Group discussions enabled youth to discuss issues addressed in the survey and to give feedback on the survey contents and format
- Rapid preliminary data analysis
- Data interpretation sessions sought to promote youth voice and adult-youth dialogue
- Aggregate data reports to programs

#### Recommendations

- Provide tangible incentives to youth participants at the same time as fostering their intrinsic interest in the research process
- Develop infrastructure to allow rapid preliminary data analysis
- Organize timely community-based data interpretation sessions
- Develop processes for translation of research findings into program activities
- Encourage understanding and appropriation of the research process by participants
- Design flexible modes of participation for youth and frontline staff
- Create opportunities for working sessions that spark dialogue among stakeholder groups

### Next steps

- Larger exploratory study supported by the National Institute of Nursing Research (1R21NR9764-01A1 - Longitudinal design: Baseline, 6-month and 12-month surveys of 300 13-17 year olds in 8 NYC programs)
- Possibly develop proposal for longer term intervention research
- Continue to emphasize dissemination and utilization of findings
- Continuing to build the partnership

## Discussion of participation scale

HIV prevention and participatory program strategies for youth: Are voice, choice, decision-making, and opportunities for personal development linked to risk reduction practices?

> (Abstract #155680) Tuesday, November 6, 2007 12:30 PM-2:00 PM

Panel on Methodological Considerations for Recruitment, Data Collection, and Assessment in HIV Research

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