

**“BUILDING PARTNERSHIPS FOR  
HIV RESEARCH AND EVALUATION WITH THE COMMUNITY”  
October 1, 2004**

**Sponsored by the Community Collaboration Core (CCC),  
the HIV Center for Clinical and Behavioral Studies  
at the New York Psychiatric Institute and Columbia University\***

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Kettering Cancer Center;  
with contributions by Community Collaboration Core Members

**Community Collaboration Core  
Members/ Conference Committee\***

**Partnership Conference October 1, 2004**

Robert H. Remien, PhD	Core Director
Joyce Hunter, DSW	Core Co-Director, Conference Chair
Bruce Rapkin, PhD	Core Co-Director
Sharlene Beckford	HIV Center Post-doctoral Fellow
Jan Baer, MA	Core Coordinator
Laurie J. Bauman, PhD	Albert Einstein College of Medicine
Alma Candelas, MPH	NY State DOH AIDS Institute
Laurie Cullen, MPH	Body Positive
Nabila El-Bassel, DSW	Columbia School of Social Work
Cindy Gordon, PhD	NYC Dept of Health and Mental Hygiene
Soraya Elcock, BA	Harlem United Community AIDS Center
Susan Klein, MS	NY State DOH AIDS Institute
Beatrice J. Krauss, PhD	Hunter Center AIDS/Drugs/ComHealth
David Lounsbury, PhD	Fellow, Memorial Sloan Kettering
Mary McKay, PhD	Mt. Sinai, Psychiatry/Community Med.
Daniel O'Connell, MLS	NY State DOH AIDS Institute
Cassandra Ritas	Hunter Center AIDS/Drugs/ComHealth
Jim Satriano, PhD	New York State Psychiatric Institute
Bill Stackhouse, PhD	NYC Dept. of Health and Mental Hygiene
Russell Westacott	Gay Men's Health Crisis

\*The HIV Center/NYSPI wishes to acknowledge the New York City Department of Health and Mental Health, the New York State Department of Health AIDS Institute, our CBO and research members from many institutions as primary partners of the Community Collaboration Core.

**HIV CENTER FOR CLINICAL AND BEHAVIORAL  
STUDIES/NYSPI**

**PARTNERSHIP CONFERENCE ATTENDEES**

**October 1, 2004, Clark Conference Center  
Columbia Presbyterian Medical Center**

**PROFESSIONAL WORK  
Community/CBO = C**

**Govt/Policy = G**

**Research/Academic=R**

<u>Name</u>	<u>Organization</u>	
Carlos Allende-Ramos, MHS	VIP Community Services, Bronx	C: CCC Member
Maria Alvarez, MPA	Centers for Disease Control and Prevention	G
Heidi Arner	Medical and Health Research Assoc. of NYC - FITA	G: Mgmt Consult
Jan Baer, MA	HIV Center for Clinical & Behavioral Studies/NYSPI	R: CCC Coordinator
Leland Bardsley	CHEST/Hunter College	R: Asst. Project Director
Laurie J. Bauman, PhD	Albert Einstein College of Medicine	R: CCC Member
George Bellinger	Consultant/CBO	C
Alex Caballo-Dieguez, PhD	HIV Center for Clinical & Behavioral Studies/NYSPI	R: Investigator
Alma Candelas, MPH	NY State AIDS Institute	G: CCC Member
Daniel Castellanos, Mphil	Gay Men's Health Crisis	C: CCC Member
Charles Collins, PhD	Centers for Disease Control and Prevention	G: Team Leader
Nathaniel N. Commodore		
Gary Dowsett	HIV Center for Clinical & Behavioral Studies/NYSPI	R: Assoc. Prof.
Shari Dworkin, PhD	HIV Center for Clinical & Behavioral Studies/NYSPI	R: Fellow
Deborah Edwards	Los Vecines SRO (BRC)	C
Soraya Elcock, BA	Harlem United	C: CCC Member
Theresa Exner, PhD	HIV Center for Clinical & Behavioral Studies/NYSPI	R: Investigator
Naomi Fatt	Fiscal Infrastructure Technical Assistance-MHRA	G
Maria Favuzzi	NYC Department of Health & Mental Hygiene	G
Derrick Flowers	Belize Network of People Living with HIV/AIDS (BNP+)	C: VP Advo+clntl
Susan Forlenza	NYC Department of Health & Mental Hygiene	G: Epi Liaison
Rosalyn Galvan	Alianza Dominicana	C
Christopher John Godfrey	Hunter College Center AIDS, Drugs, Com. Health	R: Co-Invest-HIV
Denise Goodman	Project Achieve	C: Com Rel Coord
Alisa Goodwin	Institute for Urban Family Health	C: Soc Serv Coord
Marya Gwadz, PhD	National Development and Research Institutes	R: Investigator
Cindy Gordon, PhD	NYC Department of Health and Mental Hygiene	G: CCC Member
Christian Grov	CHEST/Hunter College	R
Steve Hemraj	Harlem Directors' Group	C: Dr, PWA Initiative
Emily Hollander	Mt. Sinai Medical Center CHAMP Program	R
Joyce Hunter, DSW	HIV Center for Clinical & Behavioral Studies/NYSPI	R: CCC Co-Director
Brian Jacobson	Columbia Presbyterian Medical Ctr - LA Wilks Clinic	C: Psychologist
Rev. Gale Jones	Unity Fellowship/ Street L.I.F.E. Ministries	C: Exec Director
Ezer Kang, PhD	HIV Center for Clinical & Behavioral Studies/NYSPI	R: Investigator
Steve Karpiake		
Susan Klein, MS	NY State AIDS Institute	G: CCC Member
Beatrice J. Krauss, PhD	Hunter Center AIDS/Drugs/ComHealth	R: CCC Member
Brett Larson	NYC Department of Health & Mental Hygiene	G
Rita Lawrence	CHAMP Program, Mt. Sinai Medical Center	C
Debra Lesane	Miracle Makers/Community Coalition Project	C: Project Dr
Joanna Loboza, PsyD	St. Lukes-Roosevelt Hospital	C
Elizabeth Londoñ	Aaron Diamond AIDS Research Center (ADARC)	C: Clinical Recruit

David Lounsbury, PhD	Memorial Sloan Kettering Cancer Center	R: Fellow, CCC Member
Oswaldo Luciano	HIV Center for Clinical & Behavioral Studies/NYSPI	R: Asst Research S
Frank McCorry, PhD	NYS Office of Alcohol, Substance Abuse Services	G
Mary McKay, PhD	Mt. Sinai, Psychiatry/Community Med.	R: CCC Member
Joanne Mantell	HIV Center for Clinical & Behavioral Studies/NYSPI	R: Investigator
Stephanie Marhefka	HIV Center for Clinical & Behavioral Studies/NYSPI	R
Marnee Meyer	AIDS Service Center NYC	C: Asst Dr Plan Eval
Mimi Minier	Harlem Directors' Group	C
Michele Montecalvo	Columbia Medical HIV Prev/Treatment Research	C: Recruit Coord
Jeanne Moseley	NYCDOHMH - HIV Epidemiology, Eval,Trng.	G: Project Dr,Eval
Christopher Murphy	Body Positive	C
José Nanín	CHEST/Hunter College	R: Dr Ed Training
Maija Neville	Settlement Health and Medical Services	C: Dr Health Ed
Sonia Noring	NYS Dept. of Health, AIDS Institute	G: Editor/Writer
Carline Numa	Minority Task Force on AIDS	C: Dr Soc Service
Daniel O'Connell, MLS	NY State AIDS Institute	G: CCC Member
Rogério Pinto	HIV Center for Clinical & Behavioral Studies/NYSPI	R: PostDoc Fellow
Joseph Punzalan	CHEST/Hunter College	R: Asst Project Dr
Bruce Rapkin, PhD	HIV Center for Clinical & Behavioral Studies/NYSPI	R: CCC Co-Director
Warren Reich	The Family Center	C: Res Eval Mgr
Bob Remien, PhD	HIV Center for Clinical & Behavioral Studies/NYSPI	R: CCC Director
Eric Rodriguez	Body Positive	C: Exec Director
Nina Rothschild	NYC Dept. of Health & Mental Hygiene	R: Res Scientist
Theo Sandfort	HIV Center for Clinical & Behavioral Studies/NYSPI	R: Investigator
Arbert Santana	Gay Men's Health Crisis	C: Asst Dr,Group
Ursa Scherer	CAMBA, Inc.	C: Program Sup
Ray Smith	Body Positive	C: Editor/Writer
Bill Stackhouse, PhD	NYC Department of Health & Mental Hygiene	G: CCC Member
Brenda Starks-Ross	AIDS Service Center of Lower Manhattan	C: Executive Director
Danielle Strauss	VIP Community Services	C
James Tesoriero	NYS Dept. of Health, AIDS Institute	G: Dr, Eval&Resrch
Kwardua Vanderpuye	Catalyst Consulting/CBO	C
Ana Ventuneac	HIV Center for Clinical & Behavioral Studies/NYSPI	R: Project Manager
Barbara Warren	LGBT Community Center, NYC	C
Ian Warwick	Thomas Coram Research, Institute of Ed., U London	R
Russell Westacott	Gay Men's Health Crisis	C: CCC Member
Melissa White	HIV Center for Clinical & Behavioral Studies/NYSPI	R
Heru Hameed Williams	HIV Center for Clinical & Behavioral Studies/NYSPI	R: Grad Res Asst

**Community  
Government  
Research**



**“BUILDING PARTNERSHIPS FOR HIV RESEARCH AND EVALUATION  
WITH THE COMMUNITY”**

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Friday, October 1, 2004

8:30 a.m.-4:30 p.m.

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**Clark Conference Center  
Milstein Building, Columbia Medical Center, Ft. Washington Ave.  
(between 166<sup>th</sup>/168<sup>th</sup> Sts)**

**Sponsored by the Community Collaboration Core (CCC)  
of the HIV Center for Clinical & Behavioral Studies at the  
New York State Psychiatric Institute and Columbia University**

## **Conference Schedule**

**8:30-8:45 a.m.: Coffee/tea/rolls; Registration**

**8:45-9:10 a.m.: Welcome and Conference Day Overview**

Robert Remien, PhD, Joyce Hunter, DSW, Bruce Rapkin, PhD,  
Co-Directors of the Community Collaboration Core

**9:10-10:30 a.m.: Session 1: Panel: Benefits of community-research partnership in HIV research**

Facilitator: Bea Krauss, PhD, Hunter Center on AIDS, Drugs, and Community Health  
Panel: 1. Mary McKay, PhD, and Rita Lawrence, CHAMP Program, Mt. Sinai Dept. of Psychiatry and Community Medicine;  
2. Frank McCorry, PhD, New York State OASAS

**10:30-11 a.m.: Break/Guided Networking**

**Facilitator:** Bill Stackhouse, PhD, NYCDOHMH

**11 a.m.-12:10 p.m.: Session 2: Panel: Funders interests in community-research partnership: Evaluation requirements and policy implications for government-related funding for CBOs and how CBOs can address their research interests.**

Facilitator: Robert Remien, PhD  
Panelists: Maria Favuzzi, NYCDOHMH, Charles Collins, PhD, CDC;  
Dan O'Connell, MLS, NYSDOH AIDS Institute

**12:10-1:10 p.m.: Lunch (networking, resource tables)**

**1:10-3:10 p.m.: Session 3: Forming Community-Research Partnerships:**

**Challenges and Rewards (Fishbowl Activity),**

1. Overview: Bruce Rapkin, PhD;
2. Fishbowl procedures: Joyce Hunter, DSW;
3. Fishbowl activity facilitator: David Lounsbury, PhD, Memorial Sloan Kettering:

**A. Community/CBO representatives:**

Brenda Starks-Ross, AIDS Service Center of Lower Manhattan;  
Soraya Elcock, Harlem United Community AIDS Center;  
Joanna Lobo, PsyD, Center for Comprehensive Care, St. Luke's-Roosevelt Hospital;  
Russell Westacott, BS, GMHC; Daniel Castellanos, MPhil, Queens Pride House;  
Carlos Allende-Ramos, MHSA, VIP Community Services, Bronx.

**B. Research participants:**

Alex Carballo, PhD, Theresa Exner, PhD, Joyce Hunter, DSW, Ezer Kang, PhD,  
Robert Remien, PhD, HIV Center for Clinical & Behavioral Studies/NYSPI and Columbia  
University;  
Maria Alvarez, MPA, Centers for Disease Control and Prevention (CDC);  
Laurie Bauman, PhD, Albert Einstein College of Medicine;  
Marya Gwadz, PhD, National Development and Research Institutes.

**C. General audience discussion of issues raised in the fishbowl activity,**

Facilitator: Joyce Hunter, DSW

**D. Feedback Discussant:**

Susan Klein, MS, NYSDOH AIDS Institute

**3:10-3:30 p.m.: Reflections and Future Directions**

Representatives from community, government, & research:

Carlos Allende, MHSA, Alma Candelas, MPH, Laurie Bauman, PhD

**3:30-4 p.m.: Evaluation of day**

Facilitator: Cindy Gordon, PhD, NYC Department of Health and Mental Health



**SUMMARY OF CONFERENCE SESSIONS**  
**“BUILDING PARTNERSHIPS FOR**  
**HIV RESEARCH AND EVALUATION WITH THE COMMUNITY”**  
**October 1, 2004**

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*Dr. Robert Remien, CCC Director, and Co-Directors Drs. Joyce Hunter and Bruce Rapkin welcomed more than 80 conference participants from community and governmental agencies and academic HIV research groups and outlined the topics and goals of the conference. The intent was to discuss issues, roles, procedures, benefits, barriers, agency capacity for research partnerships, and ways to find a research partner. Directors stressed that researchers and agencies learn from each other and that both partner with government. The goal is to establish partnerships sustainable over a long period based on shared experiences and values.*

**SESSION 1. Benefits of community-research partnership in HIV research**

*Dr. Mary McKay, Mt. Sinai Department of Psychiatry and Community Medicine, and Rita Lawrence, Morris Heights Health Center, discussed the CHAMP Program, a collaborative HIV Prevention and Adolescent Mental Health Project, and the importance of partnerships among families, providers, community agencies, and researchers.*

*CHAMP Program goals are to identify relevant and effective HIV prevention strategies that are acceptable to consumers and to learn to collaborate intensively and continuously on projects that will have direct community benefits. Guiding principles include the development of shared aims and shared decision-making power, the recognition and use of skills, and the creation of opportunities to build communication and trust. All research partners are involved in every step: aims, design, measurement, procedures, implementation, evaluation, and dissemination.*

***The CHAMP Board of 30 members (parents, teachers, community health people) make collaborative decisions. The Project works in low income communities in New York and Chicago. Partners must adapt to varied cultural environments. (They soon learn that “dialogue is different in Chicago, where people smile when they disagree, than in the Bronx, where they shout.”) CHAMP committees include those on school curricula (an HIV manual was written for 4<sup>th</sup>-5<sup>th</sup> grades, stressing abstinence, and one is in the works for 6<sup>th</sup>-7<sup>th</sup> grades), project implementation, research, finance, welcome (new staff, policies and procedures), grant writing, international prevention, leadership, and development. Through collaboration, the program has helped parents and kids talk about HIV and helped adolescents negotiate sexual situations. [See published papers.]***

***Additional lessons for researchers: Do careful homework about the community before starting (know where the bus stops and gathering places are, what people like to do, and why); ask, don't tell people what is important; involve individuals as well as community agencies; be on time and respectful of the intelligence and lives of community people.***

***Dr. Frank McCorry of New York State Office of Alcoholism and Substance Abuse Services (OASAS) discussed the “science to service” focus in substance abuse prevention and treatment, especially the provider-state OASAS Practice Improvement Collaborative.***

***The community agency is not a “site,” participants are not “subjects,” and the research does not provide “access.” Rather, true partnerships require paradigm shifts (see handout, page 4) to provider-partnered research, sustained community-based technology transfer, and bidirectional communication.***

#### ***DISCUSSION:***

***– In partnerships people often struggle for territory and authority (“I know more because I’ve studied;” “I know more because I live in the community and know the people.”) There is an obligation to respect different forms of knowledge brought by various collaborators, without compromising the interpretation of results, and to cross-train.***

- Partnerships and consensus take a lot of time and effort and are complicated; they require lead time, which is generally not built into either the grant proposal or the schedule, in order to hear all views and reach agreement. Parents, especially, generally do not have much time; it's helpful to give incentives to come to meetings.**
- It's important to establish the partnership and joint ownership at or before the grant writing stage (rather than presenting the project as “I have a grant; you can participate.”).**
- Researchers aren't trained in communication skills and building trust, nor are agencies funded to develop research capacity.**
- Funders are learning from experience – i.e., subsequent to federal research identifying successful methods to prevent STDs, not one collaborating site adopted the interventions. NIH is now considering how to involve providers in research, encouraging clinicians to come to research meetings, and calling attention to clinical issues in research design.**
- Partnerships are not static. They must be constantly renegotiated. Inheriting a partnership is particularly difficult and requires the rededication of all parties.**

**SESSION 2. Funders' interests in community-research partnership: Evaluation requirements and policy implications for government-related funding for CBOs and how CBOs can address their research interests.**

**Maria Favuzzi, Director of the HIV Prevention Program, Bureau of HIV/AIDS at the New York City Department of Health and Mental Hygiene, presented on “Government-Community Partnership for Evaluation Capacity Building.”**

**She stressed that consultants/researchers work with the agency over an extended time period, generally several years, using a model in which consideration has been given to how each person's contributions fit into the overall project and goals. Process includes capacity assessment, goal setting, and work plan with clear expectations.**

**Early results of the Evaluation Capacity Building Initiative indicate that it increased CBO understanding of behavioral science and measurement of objectives as well as CBO evaluation skills. One agency credited the partnership with contributing to its success in competing for CDC funding. Clients in the Department's Prevention Case Management Initiative decreased HIV risk behaviors.**

**Dr. Charles Collins of the CDC discussed the national "Diffusion of Effective Behavioral Interventions (DEBI)" program, which was developed in response to the lack of evidence that interventions developed by CDC funded research were being used by CDC funded CBOs. Overriding issues are 1) how to do diffusion within the CDC funding system that relates to the interests and needs of CBOs, 2) how to market DEBIs (satellite broadcasts, incentives, web sites, policy development, ties to funding, etc.), 3) how to evaluate and report interventions, processes, and outcomes, 4) how to meet the need for training curricula and technical assistance.**

**There is growing evidence that the impact of interventions in the community is greater than in research settings since there they are adapted to local needs. It is also evident that science is lagging behind community needs (for example, there are no interventions for transgender people or recent immigrants). CDC is interested in identifying the strongest interventions and diffusing them across the country, working with CBOs to develop training to replicate practices, and fast tracking new interventions to move them into practice sooner (for example, asking researchers to send drafts of papers to CDC so planning for implementation can begin before publication).**

**Twelve of the effective behavioral interventions listed are Voices (a film and discussion guide), SISTA (for African American women 18-25), Street Smart (for homeless and runaway youth), Mpowerment (for MSM), Popular Opinion Leader (for MSM), Real AIDS Prevention Project (RAPP, story telling by women), Many Men Many Voices (cognitive skill building), Safety Counts (street outreach), Partnership for Health (for MDs), Healthy Relationships (using movie clips), Teens Linked to Care, and Holistic Harm Reduction Plus.**

**Dan O'Connell, Director, Division of HIV Prevention, NYS Department of Health AIDS Institute, spoke about the "Evaluation of HIV**

***Prevention Activities at AIDS Institute Contractors.” He noted that for evaluation to take place it must be integrated into program design. While the AIDS Institute requires evaluation plans in grant applications, “rigor should not become rigor mortis,” that is, there should still be room for adaptation and innovation. (Many Men Many Voices, for example, was developed by a CBO in Rochester and is now a CDC-promoted national model.)***

***AIDS Institute capacity building includes free trainings throughout the year and efforts by the Institute’s Office of Program Evaluation and Research to help CBOs work with researchers to do effective evaluation. Research collaborations have included the five year CDC Criminal Justice Demonstration Projects (in conjunction with Emory University) and work with Beth Israel Medical Center and harm reduction contractors that has succeeded in breaking down some of the political resistance to harm reduction and needle exchange for substance users.***

#### ***DISCUSSION:***

- Concerning how consultants are hired and used (issues of race, class, gender), Mr. O’Connell noted that when agencies apply for state grants, they generally already have a relationship with a consultant; there is no stipulation about who they must use. Dr. Collins added that the CDC, which has \$21 million dedicated to its mandate to fund CBO capacity building, maintains a list of capacity building assistance providers (CBAPs). The Technical Assistance Clearinghouse also keeps a list (check online).***
- The CDC is prohibited by Congress from funding syringe exchange programs.***
- The state is trying to get funding to encourage agencies that do risk reduction counseling to promote female condom use.***
- Regarding effective interventions for transgendered people, Dr. Collins noted that a trial requires at least 200 people in each of the experimental and control groups, a number difficult to recruit for this population.***
- There has been a shift of funding from primary prevention to prevention for HIV-positives.***
- Effective partnerships require determination of the following:***
- Who are the partners?: their histories, identities, values, and goals;***

- ***What is the project?: setting out the assumptions, ownership issues, methodology, consequences, and research and other questions;***
- ***When will it take place?: needs, expectations, scheduling, potential delays;***
- ***Where will it take place?: location, logistics, shared space, community impact;***
- ***How will it proceed?: communication, problem solving, use of findings, evolution of relationships over time, recognition and use of new opportunities;***
- ***Why is it being undertaken?: the interests of science, the population, individual careers, the agency, larger organizations and agendas.***

**SESSION 3. Forming community-research partnerships: Challenges and rewards.**

***Dr. Bruce Rapkin gave an overview of the MOU agreement between researchers and agencies, and Dr. Joyce Hunter reviewed procedures for the “Fishbowl” discussion groups. Questions were posed to participants by moderator Dr. David Lounsbury of Memorial Sloan Kettering.***

***FISHBOWL 1: CBO representatives.***

**1. What are the benefits of research?**

***Research projects bring funding, resources, and an opportunity for critical self-examination. Although participating in research changes agency views of problems and issues, and research funds help build infrastructure, anticipated benefits far outweigh actual realized benefits for CBOs.***

**2: What do agencies want from a researcher?**

***CBOs want to be part of the discussion months before the grant application is submitted. The community should help shape the research agenda and remain involved through the dissemination of data and follow-up; it should be part of the process to determine where research money is spent and how. There is generally little or no money allocated for data analysis and evaluation and a great need for more. Researchers should develop a relationship with agency staff***

*through regular meetings, feedback, the development of research tools, and other methods. Researchers have some responsibility to increase agency capabilities for research and to understand agency culture. Agencies should turn down research projects if they do not have the staff, time, and structure to partner effectively and manage their participation.*

**3. What is a culturally competent researcher?**

*Researchers should understand the population and the CBO well before they arrive. Just because permission for a study has been granted, that does not necessarily mean staff leaders will allow it to run smoothly. Many research projects are not relevant to the community and do not produce change; agency staff want to feel that the project will improve the community and that the relationships with researchers are not just superficial and functional.*

**4. What is the worst that can happen from research participation (outside of something immoral or criminal)?**

*Bad outcomes include CBOs participating in a project that does not help build ongoing capacity for evaluation so there is no institutional memory or benefit, a lack of credit or thanks to the agency, and/or a lack of agency access to results and products of the project, especially effective interventions and critiques of ineffective ones.*

**5. What are the most important points to include in a research agreement?**

*Agreements should confirm that the community is an equal partner in the process from start to finish, that there is support for senior management, that there are sufficient resources, and that the project will actually take place and be completed.*

***FISHBOWL 2: Researcher representatives.***

**1. Why involve the community in research?**

*It is impossible to do effective research otherwise, and the interventions are more effective. Research has no meaning without consumers. Researchers also need relationships with communities and agencies to obtain grants. There are, however, a number of questions in defining a community: a hospital or clinic or agency is not a community or a population, and each has its own agenda. An*

*agency may have a diverse client base from many parts of the city or even a homogenous group of clients who are not one community. It's also difficult to determine who the legitimate community representatives and speakers are.*

**2. When do you involve the community?**

*In addition to the community and researchers, there is the third party in the relationship, the funding agency, which has its own culture and requirements. It's possible to involve the community at the very start and agree on what should be researched, but along the way in the funding process a lot of factors intervene to shape and change the project. Sometimes grant funding does not include money for evaluation and dissemination of findings, so additional applications are needed, and often publication and presentation at conferences must take place before results can be used, which adds to community frustration. There are also delays in receiving funds and roll out of the project, which is difficult both for researchers and agencies who need to do the work.*

**3. How do you address these frustrations?**

*They are easier to weather when partners have long-term, established relationships sustained through technology transfer.*

**4. Do CBOs think researchers have lots of money to share?**

*There are myths on both sides. It's difficult to put any money in the grant at all for the CBO. Grants also run out of money, and sometimes good projects can't be started or completed. Sometimes a research intervention does not work. Projects also have indirect costs that eat up funding. CBOs have a right to see research budgets and to know how money is being spent.*

**5. What is a culturally competent researcher?**

*A good researcher does his/her homework, because if the project cannot work in the culture of the agency, the research is doomed. It's helpful to give abstracts and drafts to agency partners to be sure the assumptions accurately reflect their experience and expectations.*

**6. If you see something that is a problem in an organization, whether it is or is not related to the research, should you and do you intervene?**

***Since research partnerships are about building and sustaining relationships, if you share trust you can comment in a respectful way.***

**7. What are some of the difficulties of building partnerships?**

***All participants have a lot to learn from and about each other. It is not just a matter of service and products; organizations also have an obligation to understand the research culture. It is especially difficult to sustain partnerships when personnel and circumstances change over time.***

**DISCUSSION:**

- Even through a research project, a CBO must stay true to the mission of its agency.***
- It would be helpful to ask that in funding from private foundations, indirect costs be no more than 10%. Researchers should lobby for a policy that provides a fixed amount of the grant, perhaps 25%, to go to the community.***
- Community research and collaboration are not particularly valued, or they would be part of the RFPs.***
- Broad steps are needed to educate agencies and researchers alike. (Notice of this conference was sent to as many agencies as possible, and most did not respond. Those most in need of information did not come.)***
- More should be done to build the internal research capacity of agencies themselves.***
- Some CDC model programs have not been replicated anywhere even once.***
- Science should not just come from academic institutions to communities; advances should be developed with and in communities. Public health research should evolve away from its “lab” and “medical” paradigms.***

**SUMMARY DISCUSSANTS:**

***Susan Klein, Deputy Director, New York State Department of Health AIDS Institute, noted that although the first response of community organizations regarding the value of research was that it brings***

***money and resources, researchers and organizations share an interest in the meaning of research, which is grounds for working together in fruitful collaborations. There are many voices involved in research partnerships. The timing of the project and the readiness of all partners (the agency, the clients, the researchers, the community, and the funders) are key.***

***All partners value communication, trust, clarity, shared engagement from project conception, and sharing of benefits. Cultural competence grows from interaction and respect. Research and intervention models for prevention are inadequate. There is no one size that fits all. The same is true for research relationships, the long term cultivation of which requires commitment, skill, negotiation, and constant re-evaluation.***

***Dr. Laurie Bauman stressed that there are strong reasons for CBOs, researchers, and government agencies to stay connected and work together. They share agendas and benefit from the development of research infrastructure. Although long term relationships are extremely beneficial, not all relationships must be long term. Each situation should be individually assessed.***

***Alma Candelas, Director of Special Populations, AIDS Institute, explained that in its many relationships with CBOs and other agencies, government has many different roles, as initiator, partner, advisor, and others, all in the interest of quality and common goals. Over time, HIV has changed many of these relationships and structures, which is good. In this environment of level or decreasing resources when government agencies and CBOs may change focus, all partners – researchers, CBOs, and funders – must establish principles and policies to maintain services and research. All have a responsibility to disseminate good models, engender trust, and build resources in communities. Government can act as a broker between CBOs and researchers.***

***Carlos Allende added that we can and must advocate for these partnerships.***

**SUMMARY: "BUILDING PARTNERSHIPS FOR HIV RESEARCH AND EVALUATION WITH THE COMMUNITY," Community Partnership Conference, October 1, 2004**

***The HIV Center's Community Collaboration Core held its first Annual Community Partnership Conference on October 1, 2004. This one-day conference, "Building Partnerships for HIV Research and Evaluation with the Community," was attended by 80 participants ranging from community/CBO representatives (34%), academic researchers and fellows (49%), and government representatives/policy makers (17%). The main objective of the conference was to provide a forum for communities, researchers, and government agencies who work in HIV prevention and care to enhance strategies for initiating and sustaining effective long-term partnerships and to foster research capacity within community settings.***

***The Annual Community Partnership Conference served an opportunity for a wider group of HIV/AIDS providers and policy makers to learn about the HIV Center's mission and resources. Second, it was an opportunity for networking among investigators and agency personnel who share common interests. Third, it provided a way for the CCC to present its work and get feedback on one of the major academic themes of the CCC – the formation of effective partnerships. Fourth, and perhaps most important, the conference served as an impetus for expansion of the dialogue among researchers, community/CBOs, and government in developing both the service and science activities of the Core. Feedback from the meeting was incorporated into future CCC planning. It also prompted a new discussion of alternative models for gauging the capacity of community settings to undertake a range of research and service collaborations. Conference participants also recommended that the HIV Center and the CCC articulate the scientific issues that effect standards for planning, implementing, and evaluating research projects done in partnership with communities.***

***Conference participants were asked to complete an evaluation at the end of the conference (Report, below).***

## **CONFERENCE EVALUATION REPORT**

**Of 80 conference participants, 60 completed evaluation questionnaires: 50% from community organizations, 33% from academic research institutions, and 17% from governmental agencies.**

**Respondents were very positive about the presentation of topics and the amount and type of information covered. They indicated that the conference was helpful in increasing their ability to make contacts and to find information and resources to initiate a research partnership.**

**However, all recognized that the conference was just a beginning. Participants came to appreciate both the benefits and the difficulties of effective partnerships. Questionnaire comments indicated that:**

- Community organizations learned about pressures on researchers; the time and work spent on grant writing, data analysis, and publication; and the lack of flexibility in funding allocations once a research grant is made.**

- Researchers learned about resentments at the community level when research is imposed on an organization, when preparation and resources are inadequate, when there is little or no follow-up, and when organizations that look for practical tools or other direct or immediate gain feel shortchanged.**
- Government agencies were challenged to help redesign the culture of research program funding/implementation to support true partnerships.**

**Trust, effective communication, shared goals, and equal power were cited as the primary factors in productive collaborations. A number of respondents indicated the importance of working to create durable relationships among organizations, researchers, and government agencies even when no research project is in progress and of creating policy and other structural mechanisms that facilitate partnerships.**

**Participants responded to questions concerning the usefulness of each conference presentation to their work. Figures below indicate**

**those who responded that a presentation was “very” or “extremely” useful:**

➤ **80% for Panel I, “Benefits of Community-Research Partnership in HIV Research,” (67% of CBO representatives, 100% of those from government, and 90% of researchers).**

➤ **79% for Panel II, “Funders’ Interests in Community-Research Partnerships.”**

➤ **65% for Panel III, “Forming Community-Research Partnerships: Challenges and Rewards (Fishbowls),” (48% of CBO-affiliated participants, 100% of government representatives, and 76% of researchers).**

➤ **72% for the “Guided Networking.”**

**During the “Guided Networking” session participants eagerly exchanged information and business cards (83% reported making one to four new contacts, and 70% indicated a high likelihood – four or five on a five-point scale – of their contacting one of these to explore a research partnership).**

**Much work remains to be done. Participants had many concrete suggestions for future conferences and for steps toward developing productive collaborations. Respondents indicated they would like to spend more time on the four main topics of this conference: community/research partnerships, tools for partnerships, government funding and policy issues, and networking.**

**Participant wish list:**

- outreach to smaller CBOs, clinically oriented CBOs, policy makers, organization administrators, and directors, and, in general, events that involve a wide range of participants with diverse perspectives;**
- more information from and discussion of pressures on funders and policy makers, including ways to work around political obstacles;**
- a consultation clinic with case studies of collaborative research for dissection and technical assistance;**
- specific examples of successful partnerships and development of “how to” tools;**
- more information, training, and funding for CBOs to conduct program evaluation;**
- dissemination of cutting edge research findings to CBOs;**

- discussion of ways to get agency “buy-in” and support for research;***
- discussion of how to ensure continuity in a research project when CBO staff changes;***
- a longer conference, with more space, better microphones, more discussion time;***
- more interactive events with breakout groups;***
- more concerted efforts to educate communities and CBOs about research and researchers about communities;***
- advocacy at all levels for more equality in research partnerships and for more time and funding built into grants for establishing and maintaining collaborative relationships;***
- appreciation for the complexity of practical issues and difficulty of meeting the needs of all collaboration partners.***