Over the past five years, CLEAR investigators have witnessed a growing sophistication within Community-based AIDS Organizations (CBAOs) in posing research questions, offering suggestions about how to reach people (methodology) and what comparisons would answer the question (design). Most importantly, CBAOs have made large contributions to the interpretation of findings. This interpretive function leads to new questions with more rigorous designs because CBAOs have new ideas about reaching and serving persons living with HIV/AIDS (PHAs), maintaining them in studies, and what should be compared. Studies have grown from those only applicable to the setting in which they were conducted to studies more relevant to HIV/AIDS in the province as a whole. CLEAR will continue the projects already begun that have been driven by specific CBAO interests.

Research interests’ questions for CLEAR investigators have grown over the past five years that parallel the emphases outlined in the Proposed HIV/AIDS Strategy for Ontario to 2008 document and the role CBAOs should play in carrying out those new strategies.

At-risk populations are more clearly defined and four of CLEAR’s studies show that high users of CBAOs are those with low incomes, mental health, substance use, homeless problems and culturally diverse people frequenting or living in risk circumstances, bath houses, internet chat lines, and/or a prison setting.

The growing number and complexity of issues facing surviving PHAs coupled with finite CBAO and other community services has created a need to use a determinants of health approach and thus integrate other local human services with CBAO services to address this wide range of health and social needs. The AIDS Bureau has now formalized the importance of local community planning to address this issue. CLEAR investigators are studying local community service integration over time. At the same time, provincial HIV/AIDS service provider groups, research centres and advocacy groups have grown in number. Recently, the AIDS Bureau has begun to explore the possibility of synergistic efforts between these provincial groups and/or more carefully delineate our respective roles.

As the strategy document highlights, we need to develop, disseminate and apply the knowledge required to improve prevention, support and treatment programmes, foster an integrated approach to HIV prevention, support and treatment at local and provincial levels, improve PHA access to health and social services, and monitor resources used. Finally, CLEAR must continue to help CBAOs assess the comparative effects and expense of alternative and innovative ways of providing HIV programs and services that address the Ontario Strategy. The Asian Community AIDS Services (ACAS) test of the Sexpert in bath houses and the i-Rice in internet chat rooms are but examples of innovative targeted prevention strategies advocated by the Provincial Strategies Group and of interest to other CBAOs. CLEAR should be assisting CBAOs as individuals and as collectives in making their contribution to these strategic directions.

We look forward to our continued work.

Gina Browne
Director, CLEAR Unit
Recent Announcements

Comments from an Executive Director on Attendance at AIDS Conference in Thailand

“At the XV International AIDS Conference in Bangkok, Thailand, Asian Community AIDS Service (ACAS) had an opportunity to present 2 posters and meet many Asian AIDS Service Organizations. Since we did not have an exhibition booth at the conference, with courtesy of CATIE, we displayed ACAS and CLEAR Unit materials at CATIE’s booth. After the conference, I visited the Thai Red Cross Nursing College at Chulalongkorn Hospital in Bangkok. The College did extensive research studies on HIV/AIDS treatment, social aspects of PHAs lives and provided treatment services to PHAs through the HIV clinic. I was hosted by Dr. Duangkamol Watradul, a nursing professor at the College who is an HIV treatment counselor of Chulalongkorn Hospital. We exchanged views about research studies in the area of women and HIV and evaluation research. Presently, there doesn’t seem to be an academic evaluation unit that functions like the CLEAR Unit in Thailand. Dr. Watradul expressed her interest in exchanging information with the CLEAR Unit and ACAS in the future.

On behalf of ACAS, I wish to express my sincere thanks to the CLEAR Unit and McMaster University for their assistance in making this valuable trip happen. I learned a great deal about the global AIDS endemic and good practices. This makes me realize there have been many good works around the world to eradicate HIV/AIDS but there is still much work that needs to be done.”

Noulmook Sudhibhasilp, Executive Director, ACAS

Points of View

Excerpts From Telephone Interview Between Trevor Gray, Ex Co-Chair, and Charlene Catchpole, Toronto People With AIDS Foundation, February 13, 2004

TREVOR: Can you tell me about the process you went through to sit on the CLEAR Committee - were you interviewed for this position?

CHARLENE: The Ministry contacted my Executive Director (ED) at the Toronto PWA Foundation, who recommended me for a position on the Committee. I received an orientation package and some information about the history of CLEAR to get up to speed on the Committee’s activities. In addition, I had been involved in previous projects with the Committee, and had a colleague who was already invested in the Committee, which helped make joining the Committee a less daunting task. In the beginning, I was unclear about my role within the Committee. Was I being asked to sit in because of the organization I worked for, or was I selected more as an individual? There wasn’t any question about bringing my valuable experiences to the table, and I certainly feel that I am able to sit at the table and be heard. In the beginning though, a lot of time was spent observing. As part of my culture as an Aboriginal woman, we don’t speak unless there is something to say, otherwise we’re just wasting energy.

TREVOR: So, that’s really interesting. You received information from two sources that helped you make the decision to be on the Committee rather than just being overwhelmed without prior knowledge.

CHARLENE: The part that is intimidating is if you’re not well-versed in research, and not involved in research. It can be intimidating, but you don’t necessarily need to have that background to sit at the table. You have to have ideas, commitment, and passion about the work being done! I think that prior to somebody getting invited to the Committee, someone from the Unit, or one of the co-chairs could have a conversation about what it’s like to sit on the Committee, or to have a conversation about the kind of work that’s being done. I think that would be very beneficial.

TREVOR: Good stuff. This will help us evaluate how we bring people into the Committee. It’s not because you didn’t have anything to contribute but the gap between researchers and community that created a sense of ambivalence. Do you think that members of the committee could act as ambassadors to the Unit? What do you think about that?

CHARLENE: I think that asking committee members to act as ambassadors is a great idea. Not just for the committee, but for the Unit itself.

Read the entire interview on our website at www.fhs.mcmaster.ca/slru/clear/dialogue.htm

Community-Based HIV Education and Prevention Workers Respond to a Changing Environment

Dale Guenter, Basanti Majumdar, Dennis Willms, Robb Travers, Gina Browne, Greg Robinson

The purpose of this study was to understand the culture, values, skills and activities of staff involved in education and prevention activities in community-based AIDS Service Organizations (ASOs) in Ontario, Canada and to understand the role of evaluation research in their prevention programming. In this qualitative study, 33 staff members from 11 ASOs participated in semi-structured interviews that were analyzed using the grounded theory approach. ASO staff experience tension between a historical grassroots organizational culture characterized by responsiveness and relevance and a more recent culture of professionalism. Target populations have changed from being primarily gay men to an almost unlimited variety of communities. Program emphasis has shifted from education and knowledge dissemination to a broadly based mandate of health promotion, community development, and harm reduction. Integration of evidence of effectiveness, social-behavioral theory, or systematic evaluation is uncommon. Understanding these points of tension is important when engaged with ASOs in programming or evaluation research.

If you would like a copy of the entire article which is published in the Journal of the Association of Nurses in AIDS Care (JANAC), Vol. 16, No. 1, 29-36, January/February 2005, please send an e-mail to: Charlene DiCesare at dicesc@mcmaster.ca.
Questions To Help You

(The AUDIENCE) Who is reading the proposal? Is the goal to get funding? If so, is study relevant to the mission of the funder? Follow funding guidelines correctly. Communicate with funding agency through project officer.

(The IDEA) What “exactly” is your research question? Not just what you want to know BUT will the results have an impact and be worthwhile in contributing to the literature and society as a whole? The research question and study design are two important components. Will it produce something new, unique and important?

(The RELEVANCE) What answers do you expect to find to your question? Why is this important today? Who do I want to study it? How are you going to do this?

(The LITERATURE) Has my question already been cited in the literature? Check successful trials and can I duplicate in my setting or is my question unique?

(To STRENGTHEN) Involve appropriate key people (experts) and do I want to pilot project first?

The message...convince me that you have the ability to do what you propose!

2) Summary/Abstract Page

This is sometimes the ONLY page read by readers so therefore the most important. This is your “organizer” for the full proposal. This will also save you time if you want to submit an abstract and present at a conference later.

3) Full Proposal - The Research Plan

Purpose/Objectives: “The purpose of this study is to...”

Background and Significance: Why are you doing this...cite literature...what has already been done and your reason why this is important to you today - explain how you are going to approach this problem and how your study will help solve this problem - it’s relevance. Show that you have done your research and are knowledgeable in this field to make a significant contribution.

Research Design: What is the best research design to answer your question (compare designs and show why you choose this over another)? Do you want an intervention or simply observe, or do you need a control group to compare? Explain this process. What is the best design to answer your research question? Select design. Biases, threats - loss of subjects. Convince people. What statistical methods will you use? Explain thoroughly and ensure this is well thought out.

Select appropriate instruments or methods: Modify or create a new one, reliability and validity of existing tools is important to compare findings with others. List measurement tools to be used to answer your research question.

Think Like a Researcher

Preparing a study and research proposal is a process where researchers discuss a topic and a research question and weigh the pros and cons of various designs and methods to use to collect information; e.g., measurement tools. It can bring researchers back to re-consider decisions they’ve made and also take new directions. Writing a grant can take several weeks but the planning of the study takes longer (4-6 months is not unreasonable). No study is perfect. “Remember, good writing will not itself produce a good research grant proposal”. Nevertheless, a well-organized, well-written proposal can help you get funded, so it’s worth some effort. Inspire “excitement” about your project. Funders are most interested in funding the development of science, rather than discrete projects that will not lead to further new discoveries.

The Proposal Continued


Trial Flow Diagram: Create diagram - this will help you organize your thoughts and plan of research. How will you keep track of study?

Timelines: Create diagram to help you organize the study.

Limitations and/or Challenges of Study: Explain in your opinion what limitations and/or challenges you expect.

Ethics: Ethical approval by a research ethics committee is essential to protect subjects and their records by assessing risks/benefits, unbiased selection, confidentiality and incentives to participants. Include information sheet about the study and letter of consent in Appendices (lay language).

Key Personnel Involved in Study: A one-page biographical sketch of key players to highlight the credentials and to ensure people are capable of conducting the study scientifically and administratively.

Anticipated Results and Conclusion: Your expected results.

Budget and Justification: Submit budgets for each fiscal year detailing expenses (personnel, consultants, equipment, subject costs for participation, travel expenses related to project and also to present results at conferences). Appropriate justification.

Resources: Letters of support from experts. Include in Appendices.

References:
Tornquist, EM, Funk, SG. Journal of Nursing Scholarship, Vol. 22, Number 1, 44-51, Spring 1990.
QUESTION: How can communities who work with academics really own their own data and their project results?

ANSWER: A condition of being retained as an investigator with CLEAR is the investigator’s commitment to CLEAR’s Vision, Mission, Values, Goals and Objectives. These include CBAO ownership of the outcomes of research. Whenever data is shared or partially owned by one of CLEAR’s investigators, this is negotiated in the partnership agreement.

We would love to hear from you! If you have any feedback on our newsletter, please write to us, e-mail Charlene DiCesare at dicesc@mcmaster.ca, or fax us at 905-528-5099.