

## Family Front and Centre

### Post Event Summary

August 17, 2009

Family Front and Centre was a day long community forum exploring the impact of HIV on children and youth and the roles family can play in responding to and preventing infection. Nearly 200 people from across Canada and the United States attended the event at the MaRS Centre in downtown Toronto on August 6, 2009. Included in the audience were academics, researchers, service providers, policy makers, community members, and people with HIV. They heard presentations and attended interactive workshops addressing effective American interventions, innovative Canadian programs and future directions for research, policy and practice. A short synopsis of presentations follows.

#### **Morning Plenary Session**

Welcoming remarks were delivered by:

*Sean B. Rourke, PhD, OHTN, St. Michael's Hospital, University of Toronto*

*Ellen Stover, PhD, National Institute of Mental Health*

*James Bray, PhD, American Psychological Association*

*Karen Vance-Wallace, The Teresa Group*

*Andrew Matejcic, CIHR, Institute of Infection and Immunity, HIV/AIDS Research Initiative*

These remarks were followed by a short presentation in which the American Psychological Association presented Sean B. Rourke, PhD, with a presidential citation for outstanding contributions to the fields of psychology and HIV research. The morning presentations were chaired by:

*Willo Pequegnat, PhD, National Institute of Mental Health*

*Rick Kennedy, Ontario AIDS Network*

*Stanley Read, MD, PhD*, of the Hospital for Sick Children and the University of Toronto, began the forum with an overview of Canadian families living with HIV. He surveyed the epidemiology of affected families, characteristics of families seeking services and common challenges that families face. He discussed prenatal transmission, issues of disclosure and developmental stages in relation to HIV.

*Wangari Tharao*, of Women's Health in Women's Hands, shared with delegates insight into the intersections of migration and HIV vulnerability. She identified extensive gaps in research data particular to migrant and refugee communities and the challenges of adherence and service provision to families in transit. Her talk explored systems-based issues, program and service related issues, the challenges of using evidence to inform policy and practice, and ended with a description of Ontario's attempts to use innovative services to meet the needs of migrant and refugee communities.

*Mary Jane Rotheram-Borus, PhD*, of UCLA, spoke broadly of the interventions that have been used, as primary or secondary approaches, with families with HIV. Using her experience working in the United States and Africa, she investigated the core elements of Evidence Based Practices relevant to families with HIV and spoke of ways to work within these established frameworks while incorporating innovations particular to the local community.

*Carl C. Bell, PhD*, of the University of Illinois at Chicago, discussed an adaptation of the successful CHAMP program to a South African school-based intervention. Over ten sessions, an undergraduate student and a Zulu woman educated hundreds of South African pre-adolescents about family dynamics, communication, puberty and HIV, among other topics. Results indicate that families that received the intervention were better informed about HIV/AIDS, had less stigmatizing attitudes, and demonstrated greater ease in discussing sensitive topics.

*Angela Paulino*, of the Bronx Collaborative Community Board and the Mount Sinai School of Medicine, shared her role and perspective in adapting the CHAMP model to a Bronx neighborhood. As a community member and a member of the board, she described a successful adaptation process and provided insight into the considerations for bringing an intervention to a new community.

*Clemon George, PhD*, of the University of Ontario Institute of Technology, was scheduled to provide an academic Canadian perspective to contextualize the discussions. He was, however, not able to attend the event.

*Karen Vance-Wallace*, of The Teresa Group, offered a Canadian service-provider perspective on GTA families infected or affected by HIV. Exploring the roles of social support and therapeutic interventions with HIV families, she discussed the challenges Torontonians face, the complexities of a diverse client base, and the efforts made to advocate for stronger and better services.

## **Afternoon Sessions – Interactive Workshops**

The afternoon consisted of six concurrent workshops occurring over two sessions. Each workshop was facilitated by a combination of Canadian and American experts and had an emphasis on skill development. Successful interventions were assessed for their applicability in a Canadian context. Through activities and role-plays participants had the opportunity to practice the skills they learned. Workshops included:

- Adapting the Eban HIV/STD Prevention Program Serodiscordant African-American Couples
- Adapting PATH (Parent/Preadolescent Training for HIV Prevention): A Program to Teach Parents to be AIDS Educators
- Adapting Strategies for HIV Disclosure and Adherence to HAART in Families
- Adapting CHAMP to Strengthen Families and Communities.
- Adapting the Mother-Son Health Promotion Project: Working with Families and Churches to Reduce Adolescent Risk for HIV
- Prevention Issues and Strategies for Sexually Diverse Youth

In total, thirty-three experts from Canada and the United States shared their insights with conference attendees. Recommendations made for future efforts follow.

## **Future Directions**

The workshops offered an opportunity to better understand the necessary next steps for the Canadian HIV field. Note takers in each of the workshops documented gaps in research and service delivery that must be addressed to further support families with HIV. Important themes and topics from the six conversations are summarized below.

### *Recurring Themes*

To adapt interventions to local communities it is vital that research and service efforts be linked with other key stakeholders, that proper needs assessments occur and that local champions are identified. It is also tantamount that the community be involved in every level of program formulation. There is value in reframing the target of an intervention to be a couple, a household, or a family, rather than always focusing on individual change. A holistic approach to health and well-being was advocated in many of the discussions.

There is opportunity in the current age to make use of technology within interventions and engaging broader communities through virtual spaces. This is particularly true of work with youth communities, work that has not always been guided by the voices of youth. Through developmentally appropriate work, youth-specific programming can be developed in collaboration with youth communities.

As the communities affected by the epidemic are so diverse, many conversations centered around adaptations to different cultural needs and addressing the different ways that internalized stigma manifests. In several sessions, language was a key component and discussions centered on the effective use of language and the necessity of avoiding stigmatizing or alienating language. This tenet can also be seen in the need to allow for disparate conceptions of ‘family’.

### *Practice Gaps*

Identified gaps vary greatly across the six workshops. As noted previously, a movement to reframe the 'client' or 'patient' is advocated by many in the community and in the field. Targeting interventions at the couple or the family will lead to greater, more systemic change than individual behavior-change interventions can.

Cultural competency repeatedly arose as a necessary component in creating safe space for families with HIV. In addition to having knowledge of the communities one serves, it is necessary to understand how HIV is viewed within that culture or community. This can lead to greater insight into the internalized stigma a family may be struggling with. In one workshop it was suggested that having members of a different group act out the role plays may make the information easier to digest than seeing members of one's own community engaged in the activity. Others felt that local actors can have a greater impact.

In discussions of adherence to medical regimens, more information at all levels was advocated. It would be beneficial to see more information available to caregivers, information created by youth for youth about HIV and medical adherence, and pictorial descriptions for younger children to understand. Additionally, access to care was discussed in times of transition and solutions brainstormed that could lead to more consistent access to medical care.

Repeatedly, structural issues were raised and efforts to reduce poverty, stigma, and discrimination encouraged. These efforts, it was noted, would increase access to and effectiveness of service provision. It would also lead to a different model of service provision in which individuals did not have to fit into an identity category to access care as many feel they must do now. In the current atmosphere of ethno-specific services and services by income level or housing status, some feel it restricts both what services can be accessed and what identities are acknowledged.

### *Research Gaps*

In addition to the need for better understanding advocated across all the discussions, and included in the summaries above, the following topics were identified for future investigation.

Structural and identity issues were noted, particularly in the context of communities such as the Black, African, Caribbean community. A richer understanding of what different identities within these communities can mean is desired. Exploring social location and its impact on HIV progression and prevention would offer service providers a stronger base from which to offer services.

One group discussed the need for more research on HIV and its impacts at different developmental stages in children and youth. This would also be broadened by understanding these realities in the context of different ethnoracial, gender and sexual orientation identities.

Another group wondered about the feelings of guilt that parents may have if they are HIV+ and have HIV+ children. Specifically, what impact could these feelings have on HAART adherence and self care?

As the pandemic continues to change and spread, it is noted that additional research is necessary to understand the impact of HIV on emerging populations such as the First Nation community in Canada. This was also noted in a discussion about sexually diverse youth. As these youth are no longer among the fastest rising groups for HIV infection, what has this meant for stigma among LGBT youth, including internalized stigma?

### *Training Needs*

Note takers were asked to track the training needs that arose throughout the dialogues. Primarily, these became an issue of capacity building and enhancing skill sets. The community would like insight into how best to involve constituents in their work. This was raised in relation to youth and adolescents, but also in the context of families. How can families be engaged at every level of program and policy development? Participants would like to see a focus on engaging and training service providers from diverse backgrounds in order to enhance the cultural competence of service systems.

Additionally, providers would like to enhance their skills at transitioning clients from youth-oriented services to 'adult' mainstream services upon aging out. Topics could include ways of smoothing the transition and ensuring gaps do not arise during the process.

Participants noted a need for stronger collaboration between agencies to avoid duplication of services and to create a stronger network of services. Training that addresses working across agency boundaries and across issues and sectors is desired. This could be enhanced by 'messaging' training in which service providers learn how to 'market' their services and reach the hard-to-reach individuals in a community.

### **Evaluation**

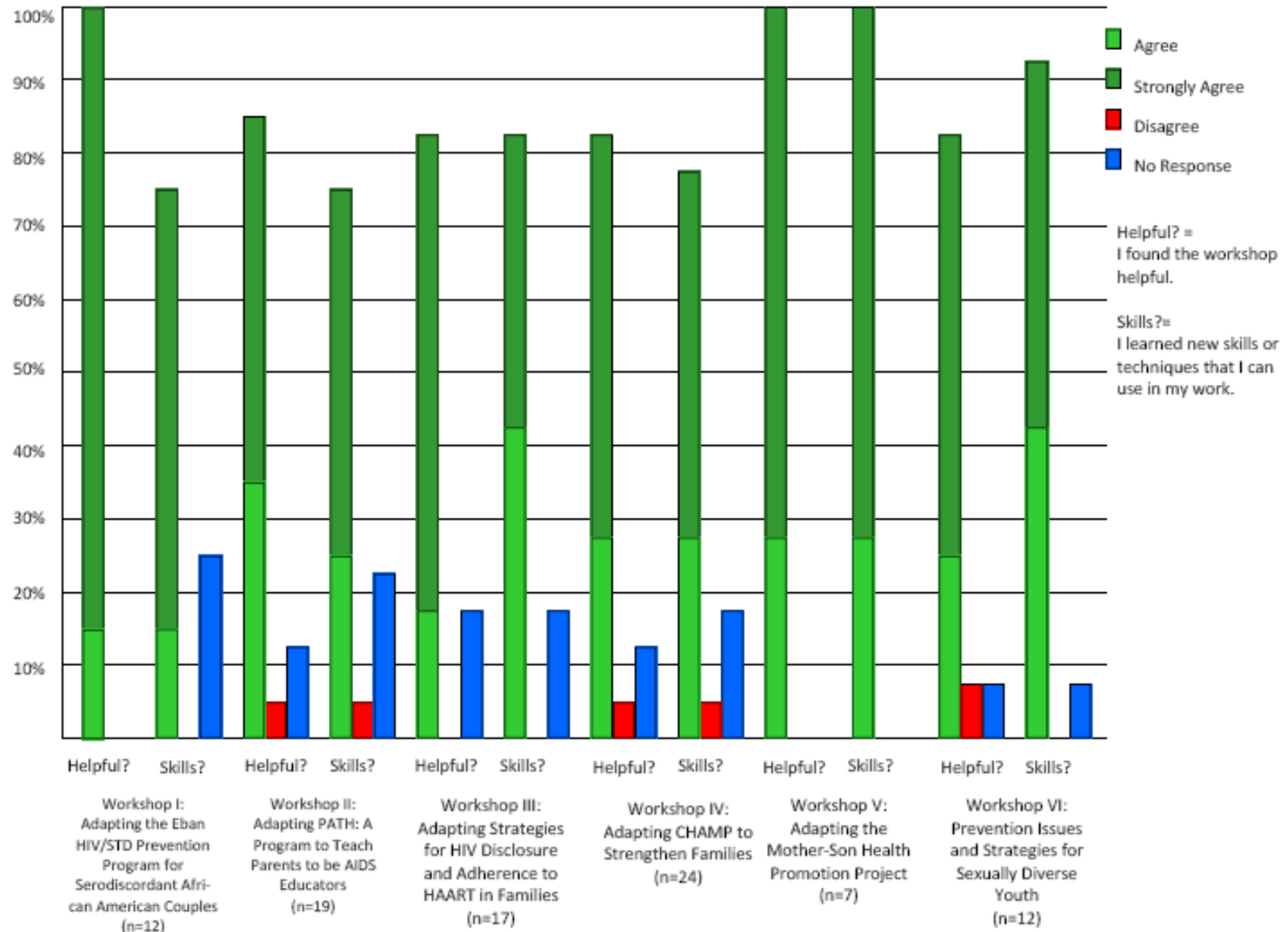
Evaluation feedback from participants was overwhelmingly positive. Of the 52 evaluations collected, 94% of respondents agreed or strongly agreed with the statements:

- "The morning presentations were helpful in setting the context for HIV/AIDS work with families in the US and Canada," and
- "The morning speakers enhanced my understanding of the role of families in preventing or adapting to HIV."

Sixty-nine percent of respondents 'Strongly Agreed' that "Family Front and Centre was a meaningful and enriching look at children, families and HIV," and 30% 'Agreed.' Full evaluation results are included in Appendix A.

Feedback regarding the workshop was also extremely positive. Not only did participants find the sessions helpful, they also consistently reported gaining new skills. Across all workshops an average of 88% of respondents agreed or strongly agreed that the workshops were helpful; 83% of respondents agreed or strongly agreed that they had learned new skills. Appendix A contains evaluation results for each workshop session and they are summarized the graph that follows.

### Family Front and Centre Workshop Evaluations



Qualitative feedback was diverse but primarily positive. Participants liked the space and the programming, the presenters and the focus. Consistent themes were difficult to identify among the constructive feedback received, but one respondent reported a desire for more people with HIV among the presenters, two requested a stronger youth presence and one commented on the lack of Aboriginal-focused programming. Three respondents felt that there were too many speakers in the morning plenary and would have liked presenters to have more time. Another respondent asked that sessions continue on for several more days. A full list of qualitative comments is listed in Appendix B.

Appendix A - Family Front and Centre Post Event Summary  
Participant Evaluation Summary

Total Attendees: 186

Evaluations completed or partially completed: 52

The morning presentations were helpful in setting the context for HIV/AIDS work with families in the US and Canada:

	Responses	Percentage
Strongly Agree	31	60%
Agree	18	35%
Don't Know	0	
Disagree	2	4%
Strongly Disagree	0	
No Response	1	2%

The morning speakers enhanced my understanding of the role of families in preventing or adapting to HIV:

	Responses	Percentage
Strongly Agree	30	58%
Agree	19	37%
Don't Know	0	
Disagree	1	2%
Strongly Disagree	1	2%
No Response	1	2%

The morning presentations will have an impact on my work:

	Responses	Percentage
Strongly Agree	30	58%
Agree	18	35%
Don't Know	1	2%
Disagree	2	4%
Strongly Disagree	0	
No Response	1	2%

Overall, Family Front and Centre was a meaningful and enriching look at children, families and HIV

	Responses	Percentage
Strongly Agree	36	69%
Agree	15	30%
Don't Know	0	
Disagree	0	
Strongly Disagree	0	
No Response	1	2%

**Workshop I: Adapting the Eban HIV/STD Prevention Program (12 responses)**

I found the workshop helpful:

Strongly Agree	10	83%
Agree	2	17%

I learned new skills or techniques that I can use in my work:

Strongly Agree	7	58%
Agree	2	17%
Don't Know	1	8%
No Response	2	17%

**Workshop II: Adapting PATH (19 responses)**

I found the workshop helpful:

Strongly Agree	9	47%
Agree	7	37%
Disagree	1	5%
No Response	2	11%

I learned new skills or techniques that I can use in my work

Strongly Agree	9	47%
Agree	5	26%
Don't Know	2	11%
Disagree	1	5%
No Response	2	11%

**Workshop III: Adapting Strategies for Disclosure and Adherence in Families (17 responses)**

I found the workshop helpful

Strongly Agree	11	65%
Agree	3	18%
No Response	3	17%

I learned new skills or techniques that I can use in my work

Strongly Agree	7	41%
Agree	7	41%
Don't Know	1	6%
No Response	2	12%

**Workshop IV: Adapting CHAMP to Strengthen Families and Communities (24 responses)**

I found the workshop helpful

Strongly Agree	13	54%
Agree	7	29%
Disagree	1	4%
No Response	3	13%

I learned new skills or techniques that I can use in my work

Strongly Agree	12	50%
Agree	7	29%
Don't Know	1	4%
Disagree	1	4%
No Response	3	13%

**Workshop V: Adapting the Mother-Son Health Promotion Project (7 responses)**

I found the workshop helpful

Strongly Agree	5	71%
----------------	---	-----

Agree	2	29%
-------	---	-----

I learned new skills or techniques that I can use in my work

Strongly Agree	5	71%
----------------	---	-----

Agree	2	29%
-------	---	-----

**Workshop VI: Prevention Issues and Strategies for Sexually Diverse Youth (12 responses)**

I found the workshop helpful

Strongly Agree	7	58%
----------------	---	-----

Agree	3	25%
-------	---	-----

Don't Know	1	8%
------------	---	----

Disagree	1	8%
----------	---	----

I learned new skills or techniques that I can use in my work

Strongly Agree	6	50%
----------------	---	-----

Agree	5	42%
-------	---	-----

Don't Know	1	8%
------------	---	----

Appendix B - Family Front and Centre Post Event Summary  
Comments from Participant Evaluations

*Note: Comments were transcribed from the evaluations with only minor edits for spelling and punctuation.*

General Positive Comments

- Just by organizing this event and giving voice to families affected by HIV/AIDS you have done so much. In Canada and elsewhere we are so caught up in risk categories (IDUs, MSM, CSW) that we forget about the entire networks of people who surround those infected with HIV. Families bear an immense burden and this event provided us with real tools we can use in assisting families. All the speakers were wonderful; all the workshops that I attended were very practical. Logistically, it was a very well organized event (Kudos Nico!) and was well facilitated by the moderators. Great Job! P.S. I hope we find a way to keep connected about people's projects and initiatives.
- Fantastic!
- I would like to say that today's sessions is one of the most inspiring workshops I've ever attended. I've learnt a lot! One of the amazing part also was that the collaboration from both sides of the border, academic and community. Heartfelt Thank you!
- I really enjoyed the morning plenary and first afternoon workshop on Eban. The second workshop allowed us to dialogue but I expected more information and new learning from the presenters.
- Excellent conference, very informative. Excellent speakers. Lots of great research being done.
- Very informative!
- Thank you!
- Thank you for providing a conference that focused on families!
- MaRS building is v. good, good location. Tables are too squeaky.
- I enjoyed the several perspectives when it comes to families. Children are very affected from HIV and I learned ways to address some of these issues. How to address kids when asking questions about sex can be very tricky. Nonetheless, through conversations, trust and re-assurance I know how to talk to them.
- The quality of speakers was excellent.
- I thought today's sessions, particularly the group discussions, were fantastic. To hear from various organizations, individuals HIV+ or HIV-, internationally diverse groups help to broaden my view of how to be a champion and advocate in the community. I particularly enjoyed learning about CHAMP and the collaborative partnership model.
- The forum was very well thought out. Gave us a picture of the States/Canada and the academic/community based perspectives. Presenters were well chosen, passionate about their work and knowledgeable. Good networking opportunities. Good academic spin to community work.
- Thank you for all the people that made this day possible. Good Work.
- Thank you to all the presenters and thank you for the opportunity to ask questions. The presenters provided a complex and different approach to HIV and families. Thanks.
- Very enriching and many more research ideas expected

- Very informative...enjoyed the presentations. The topic is timely and extremely important...this kind of focus can help us help others to stay healthy, well and live long vital lives. Hope this (or some similar forum) will continue.
- I found the presentations quite relevant to my area of study. The presentations were very inspiring and informative. I liked the topic on the Overview of Interventions in HIV Affected Families. I had never thought about it that way, yet I found it meaningful and a necessary approach to HIV intervention. Thanks for the work you put into all these. It takes commitment and good will to do all that. Bravo to the Teresa Group and to OHTN.
- Overall everything was very educative and very helpful to attend.

#### Specific Positive Comments

- Mary Jane Rotheram – Amazing speaker – concept of ‘paraprofessionals’ was an eye opener. Carl Bell – community based learning (cultural context) an open, shared collaboration – this concept will impact my approach to working with PHA communities and all at risk within my province. Good practical applications offered as to how to do prevention program.
- “Adapting strategies for HIV disclosure and adherence to HAART in families” Parent group: keeping track of the kids” Those two topics are really relevant and helpful.
- The Teresa Group staff were able to bring in the actual messages of children and teens. More of this could be highly awareness raising for the conference attendees.
- I enjoyed the afternoon session about discordant couples and sex therapies
- I personally I have a great time today. I learned a lot of skills and strategies. Especially workshop V was amazing. “Adapting the mother-son health promotion project” was presented very well and I got opportunity to learn about the strategies and how to approach the children to talk about sex. It is rewarding to be part of this team. Please have more workshops so that we could get access to educate ourselves and others. Thank you.
- I appreciated the CHAMP Family Program on prevention. Although it was very broad to grasp in a day, the examples and the involvement of participants in how the program is conducted was very helpful. I learned so much and I am grateful.

#### Comments Regarding Scheduling

- Good Food. Good Discussions. More time needed for morning sessions and less time in afternoon – I would have liked to have heard more from the experts. I was disappointed so many of the Black immigrant refugee committee skipped the sexual diverse workshop – it’s their issue too!
- Morning presentations too rushed. Why so many speakers!?!
- Limit time in asking questions.
- Sessions should continue for a few more days.
- Please give more time with presenters or get them to stick within their time limits. Many rushed and the material was not received properly. i.e. Wangari + migrants. Also questions periods should be facilitated and time-limited.
- Everything was well done as planned, but sometimes you need to attend another session and find that the schedule is conflicting. Means: happened in the same time.

### Comments regarding intersectionality and structural considerations

- The sessions highlighted important developments in the pediatric HIV/AIDS community. However, it also highlighted the strong feelings of constituents about differences pertaining to culture, gender, equity, etc. Recognition of the impact of cultural/gender/equity experiences is crucial – however it also has the potential to divide – at times it felt like we were in danger of moving into the realm of arguing about difference rather than to a point of understanding and joining forces to enhance support for children/youth with HIV/AIDS and their families.
- The underlying anger and aggression is not a productive addition to a capacity building event. It is more counterproductive. How can we make discussions of systemic problems and intersectionality productive? Also, this was supposed to be about children and families but it kept being removed from the focus!

### Comments regarding representation

- I understand that approx. 70 people who registered for the conference never showed up. Perhaps if you charged a nominal fee they would be more apt to attend. Where was the HIV+ youth panel? “The Mask” rap was excellent. Great for schools to play/act/creative dance out for AIDS Awareness Week. Thanks Teresa Group!
- I am very disappointed that a Canadian PHA perspective was not included in the plenary sessions. The OHTN is well known as a champion of CBR and PHA involvement and did not fulfill my expectations of involving PHAs. It is important to remember that community does not always equate to PHA! Please consider GIPA when planning the next conference or collaboration. Youth/Children missing at this conference
- Teresa Group does amazing work. I would have liked to hear more about their work. There was more emphasis on US programs than Canadian and more discussions (mostly from delegates vs. presenters) about racial politics than an emphasis on aboriginal families. Next conference I would like to see more emphasis on Canadian programs and Aboriginal families!
- 1. As one who is really kin with the youth, also as one who believe the youth as the foundation of a good family, and above of all the youth gets a message and transmits well, I would suggest their involvement in HIV/AIDS prevention. 2. I didn't see a [??] youth representative in this meeting.

### Miscellaneous Comments

- I need to have the second presentation edition.
- Maybe include more research and discussion on causes (it's hard to speak about solutions if the problematic is not fully understood)
- It would have been nice to know about tomorrow's presentations before coming to Toronto, so I could arrange to stay and attend.
- Also presenter (facilitator) for workshop #2 PATH was using inappropriate language – she was ineffective as a communicator – (There were only two facilitators and it was NOT Monique Fong, she was excellent) I do not recommend using her again – there was no clarity.