Final Report

IDRC Doctoral Research Award

Project Title: *"Strong Voices, Hopeful Futures: Enhancing Leadership Capacities for Determining and Sustaining Health Initiatives with Young People in Uganda."*

Awardee: **Susan Walker, M.A.**
McMaster University
Hamilton, Ontario

File number: **100821-036**

Date submitted: **March 2004**

Supervisor: **Dennis G. Willms, Ph.D., McMaster University, Hamilton, Ontario**

Country Advisor: **Dr. Nelson Sewankambo, Makerere University, Kampala, Uganda**

Contents

Executive Summary

The executive summary of this report has three parts, each representing a component of the research activities: Part I is the major component relating to young people, Part II concerns the student research team, and Part III involves the community Internet access component. While the report is meant as a 'Final Report', it is still very much a work in progress which will continue to evolve as my analysis continues and the community participates in the recommendation process. The report cover research undertaken during the last year (March 2003-2004), and represents an exciting period of successful participatory, collaborative work and social science research in the community.

PART 1: The Young People's Component

Background: Today, young people in Uganda face unprecedented political and economic uncertainty and social change, as the HIV/AIDS epidemic destroys families and communities, and undermines the health, education, business, and agricultural infrastructure of their country. Young people, many of whom are orphans, are the most vulnerable to HIV infection, growing up with gender inequality, exploitation, neglect and poverty. However, with their ideas and newly developing sexuality, they also offer the unique potential to generate beneficial change. Unfortunately, young people are rarely involved in the decision-making and program development that affects their wellbeing.

Problem: Thus, the research asks, 'How might the experience, creativity, energy and leadership of young people be mobilized, and their complex understandings of risk and vulnerability be translated into personally compelling strategies for health?' This is not just a practical problem: it is a fundamental intervention research question about how best to transform research evidence into action for personal and social change. It involves understanding the life complexities that influence behaviour, communicating these in ways that promote reflection and understanding about vulnerability, and stimulating participant-generated solutions.

Objectives: As a primary objective, the research aimed to uncover, critically analyze, and come to a more complete understanding of the life experience of young people in a small trading centre town in south-western Uganda, ten years after the peak of the epidemic. It sought to examine the factors that contribute to risk of HIV transmission, especially social and economic inequalities, gender, identity and relationship issues, and how these concerns affect particularly disadvantaged young people, such as girls and out-of-school youth. It also aimed to explore a forum for young people to communicate with each other, tell their stories, generate shared understandings, and problem-solve around issues that affect their health and futures. Because young people do not live in isolation from their communities and need support for their strategies, the research also sought to develop inter-generational dialogue and understanding among adult community members, such as parents, teachers, health

workers, traditional healers, leaders of local community-based and non-government organizations, religious and political leaders, and government officials.

Methods: To achieve these objectives the research drew on an anthropological orientation and participatory action research philosophy and framework. The community was meaningfully involved in many ways: identifying the research problem; advising on methodology, organization and logistics; participating in research activities as researchers, facilitators, mobilizers, and discussants; and analyzing data and recommending solutions. The research also involved multiple partnerships from a variety of funding organizations, Universities in Canada and Uganda, community researchers, and local non-government organizations and community-based organizations. To facilitate the gathering of experiential, grounded data, the research used qualitative, ethnographic methods, such as participant observation, informal and in-depth interviews, active involvement of the researcher in community activities, and document analysis.

As well, the research tested an innovative visual methodology, called a *video-enhanced conceptual event*, to elicit people's stories and develop the participatory processes of dialogue, reflection and problem-solving which are fundamental to promoting personal and social change. The methodology was designed to overcome traditional barriers to communication between girls/women and boys/men, as well as between adults and young people. Such events differ from classic focus groups in a number of ways: they are open, intensive, extended, facilitated discussions; participants determine the scope of the discussion while the facilitator guides their reflection, learning and problem-solving – participant groups (e.g. boys and girls) meet several times, first separately to discuss their gender-specific understandings and experiences while their stories are video taped; then they meet again separately to view and discuss each other's video clips; and finally, they meet together to discuss what they have learned and to generate solutions.

In practice, the conceptual events were key in eliciting young people's experience, knowledge, reasoning and logics, and very successful at bringing out gender- and age-specific understandings of the issues. The process stimulated open and reflective dialogue between boys and girls, promoted new understandings, learning and participant-generated action. The video also proved to be a powerful tool for communicating the research data (personal experiences and opinions) back to other community members. It does this in a vivid, compelling way that readily elicits responses and is accessible, relevant and useful.

Results: More than a year of fieldwork generated a rich and wide-ranging body of ethnographic data which paints a vivid picture of young people's lives, what they are up against, what makes them vulnerable, and what gives them hope. The adults too contributed perspectives about the young people's situation, providing an intriguing triangulation of data on the complex issues which affect young people's health and well-being. Further, the research situates this knowledge in the context of their relationships, their community and the political/economic structures in which they live as citizens, locally, nationally and globally.

Young people's stories revealed that in spite of falling HIV prevalence rates in Uganda, young people are still highly vulnerable to HIV infection. They lack knowledge about their bodies, and counseling and guidance about sexual health, sexuality and sexual relationships. Some young people try to abstain, but many have unprotected sex and are involved in complex multiple partner sexual networks, for both emotional and material reasons. These relationships can be pragmatic, coercive and/or exploitative on the part of both boys and girls – men and boys lure girls into relationships with 'gifts' of money or goods, then feel entitled to 'demand' sex or take what is 'owed' them, if a girl refuses. As well, many girls actively seek out relationships with young and older (and often infected) men who can give them material assistance. This means that girls now often have sex for 'stuff', not just for survival. However, there is no escaping the great gaps in gender equality which put girls at risk: girls say they are sexually harassed and exploited by men at every turn (boyfriends, teachers, employers, health workers, policemen, politicians, and relatives). Because of cultural norms around gender, girls struggle to stay in school and see few options for employment, other than having sex for money.

Both boys and girls spoke about the many negative influences they experience in their home, school and social environments that increase their vulnerability. In the latter, for example, they are both attracted to and confused by Western culture and values that they are exposed to through the media, entertainment and ways of dressing. In their day-to-day lives, young people are also marginalized and discriminated against; their basic rights as children are denied and their social environment provides little opportunity and few positive role models. Many young people feel neglected and unsupported by their families, other adults in their lives, and their government; they are truly alone and see little hope for the future – they are growing up certain only of uncertainty.

Importantly, however, the young people who participated in the discussions said the experience gave them reasons to hope and a good foundation for the future – it gave them tools for building 'strong hearts', which they say are protective. The participants were keen to share their experience with friends by holding similar discussions. Some boys even wrote and performed plays at their schools. The participants also asked that the video tapes be copied so these could become resources for generating dialogue with other young people and adults, both in the community and more widely in other parts of the country and Africa.

The adults who participated in the video feedback events were troubled by what young people had to say. They were quickly mobilized, motivated and committed to action aimed at improving the health and well-being of young people. Teachers pledged to 'check themselves and their peers' over sexual abuse and set out to monitor their colleagues. Parents learned that they are 'falling down on their jobs' and they committed to sensitizing other parents. Health workers and counselors realized that 'young people are all alone with their problems and are asking for help', prompting a renewed determination and motivation in the delivery of services to young people. Youth leaders learned that their peers, more than ever, need their leaders' advocacy and commitment, so they are writing proposals for leadership and skills development programs. Political leaders learned that young people are

really struggling with negative influences in their social environment, and further meetings are planned to discuss a way forward. Religious leaders, who had never met before, have set up a committee through which they will work together to address young people's problems. Representatives from local NGOs and CBOs are advocating for *long-term* programming and funding to facilitate and sustain social change, and they are writing a report to the local member of parliament. Thus, the feedback events promoted meaningful inter-generational understanding and dialogue around young people's concerns – young people's voices were heard and the adults in their lives responded.

Conclusion: This project was both an intervention and research which modeled the principles of ethical, right-based social science advocacy research. It has demonstrated the potential to affect change in young people's lives and involve them meaningfully in this change. The research generated awareness about the issues young people face and a wide-spread desire and commitment in community members to respond to their needs. This momentum must be sustained and enabled to move forward through program and policy development; to do less would be unethical and generate further hopelessness.

Recommendations: To this end, my report includes three major recommendations (with multiple subsections) which reflect young people's articulated needs and ideas, those expressed by adults in the community and a synthesis of understandings from the data by participants and the researchers. The first recommendation articulates the need for comprehensive program development aimed at improving young people's access to health knowledge and life skills, guidance and counseling, health services, recreation and social activities, leadership development, education, employment, and support for children's rights. The second recommendation urges a coordinated effort at delivery of programs and services through the newly built community development centre. The third recommendation pleads for an increased and coordinated effort aimed at orphan care and support.

PART II: The Student Research Team

Background and research question: HIV/AIDS is a complicated health and development problem which requires complex analysis and solutions. Today, researchers from various disciplines work together to find solutions, and the goals of many funders are now aimed at developing and supporting such strategic collaborations, partnerships and research initiatives. Thus, this research also set out to determine, how might graduate students from a number of different disciplines work together to support and facilitate research on such a priority problem? What is the role of students in this process?

Results: To investigate a model for transdisciplinary university student research collaboration, the idea was first introduced to and well received by university faculty and graduate students. Exploratory work on mounting the student research team shows that such model is worthwhile because it provides a much needed opportunity for graduate students to carry out research, disseminate their results and receive academic support which might not

otherwise be available. Community collaboration in selecting and mentoring students was particularly valuable to the process. However, there were structural, process and communication challenges and lessons learned in putting together a team of students, and these are outlined in the report.

Recommendation: It is recommended that the idea of a transdisciplinary graduate student team be pursued and expanded with the establishment of a mentorship/internship award which will enable graduate students from LICs to gain experience in Canada.

PART III: Community Internet Access

Background: One of the community's development objectives was the establishment of Internet access, through which they hoped to access health information, communicate with others who have similar health and development challenges, and if possible, generate income as a community Internet provider. Funding from the IDRC grant was to support equipment purchase, training and Internet provider costs for the first year of operation, as a feasibility project.

Results: An Internet access facility was established for the community and members of KATUWA, the community-based organisation (CBO) initiating the project, were able to learn about information technology, researched suppliers and equipment, made decisions on the business plan and are now running the facility. The process was a good capacity building activity which will be valuable as they continue to operate the facility. However, the communication connection will primarily be used only to send and receive email because of technological and financial limitations and the town's remote location, which make surfing the Internet very expensive. KATUWA members decided it was still worthwhile to develop the facility as a service to the community and it will be able to cover its costs for email use. It will not be the big income generator people hoped for until technology and provider charges become cheaper and more accessible. It is a start, and the community members are learning more about computers and using communication technology. They are still enthusiastic about having a web presence and the web page should be in place by the end of 2004. In addition, the email link is currently being used to facilitate communication between researchers in Canada and the community in Uganda at the Community Development Centre (CDC).

Concluding remarks and additional recommendations relating to development practice:

My time in the field, living and working with 'recipients' of development in a lower income country, was a privilege and an immensely worthwhile experience. It allowed me to see and understand in a grounded way some of their perceptions and feelings about development

research and practice. This experience has broadened my perspective and generated some questions about what we do and the way it is done. I discuss these insights in the report and offer two recommendations related to development practice: one, that funding be made available for advocacy and policy work, should a project's results merit such activity; and two, that it is critical that research projects be linked to project funding.

The research just completed reveals the depth of the social and structural barriers to young people's active citizenship. I understand now that the notion of 'enhancing leadership' and 'hopeful futures', as identified in the project title, are quite privileged – let me say Northern – ideals, given young people's reality in Uganda. In this place, young people are essentially powerless because of structural and social norms; in practical terms they have no real voice and virtually no rights. Hopeful futures are far from the imagination of many, and the ones who dare to hope, who want to make a difference, have little opportunity. If we are to enhance leadership, young people here need much more enabling, in the form of encouragement, respect and support. They need to feel valued and to have opportunities for meaningful participation and personal development.   They need to feel that change is possible and that there is a place for them future.

I am very grateful for the support of IDRC, SSHRC, community members, the field research team, NGO and university partners (particularly Salama SHIELD Foundation, and McMaster and Makerere Universities) and my family. Together, we all worked on a common human project of understanding and making better lives. The challenge now is to find ways for the work to continue and make sustained change.

Glossary

CBO	Community Based Organization
CDC	Community Development Centre
KADSA	Kabula and District Students' Association (a community youth organization)
KATUWA	Kabula Tusitukire Wamu (a community based organization)
IDRC	International Development and Research Centre
IMAU	Islamic Muslim Medical Association of Uganda
LIC	Lower Income Country
LWF	Lutheran World Federation
NGO	Non-government Organization
OCOBO	A non-governmental organization which aids orphans
OHTN	Ontario HIV Treatment Network
PAR	Participation Action Research
QSR NVivo®	Qualitative data analysis software.
SRT	Student Research Team
SSF	Salama SHIELD Foundation
SSHRC	Social Sciences and Humanities Research Council
UWESO	Uganda Women's Effort to Save Orphans (a non-government organization)

1. The research problem

Today, young people in Uganda face unprecedented political and economic uncertainty and social change as the HIV/AIDS epidemic destroys families and communities, and undermines the health, education, business, and agricultural infrastructure of their country. Young people, many of whom are orphans, are the most vulnerable to HIV infection, growing up with gender inequality, exploitation, neglect and poverty. They suffer the crushing effects of the epidemic as they assume huge responsibilities and emotional burdens with little support. However, many people feel that it is the young people who, with their developing ideas and sexuality, offer unmatched potential for beneficial change.

There is one community, a small trading centre situated in south-west Uganda's Rakai district, which is rebuilding its capacity after being devastated by the epidemic[1]. Community members here have decided it is a priority to help its young people and prevent the devastation of the last decade from happening again with the next generations. They want to develop youth-oriented programs that will be available at the town's newly constructed Community Development Centre (CDC).

But, how are young people being involved in this process? Young people are rarely consulted or involved in the decisions which relate to their future and well-being. Yet, for such endeavours to be relevant and sustainable, it is critical to understand young people's experience and logics and involve them in generating their own solutions. Thus, this research sets out to answer the following questions:

> *What is the life experience of young people in this place today, ten years after the peak of the epidemic? How can they protect themselves from the effects of the epidemic and move forward with hope for the future? How, with the support of their communities, can we mobilize the experience, creativity, energy and leadership of young people in the generation, implementation and evaluation of their own health strategies?*

Underlying this question is the problem for intervention research involving how best to translate knowledge into action for personal and social change[2]. The essential issues of understanding lived experience and the complexities that influence behaviour, of

---

[1] IDRC funded ethnographic and participatory action research (PAR) in this town from 1992-1997, (Phases 1 and 2), which were led by Drs. Nelson Sewankambo and Dennis Willms. Salama SHIELD Foundation (SSF) has continued to support the work to the present day (Phase 3). Drs. Willms and Sewankambo, the SSF field staff, and IDRC were instrumental in facilitating the research project reported on here (Phase 4), highlighting the importance of long-term commitment and partnerships in health and development research. All phases of the research in this community complement and build on each other to respond to community needs and development.

[2] Please refer to the original research proposal for a more in-depth discussion of the intervention problem.

communicating these in ways that promote reflection and understanding about vulnerability, and of stimulating participant generated solutions are all central to this problem. Further, since HIV/AIDS is such a complicated health and development problem requiring complex analysis and solutions, researchers today must come together to find solutions. The goals of many funders are now aimed at developing and supporting such strategic collaborations, partnerships and research initiatives. Thus, the research also asks:

How might graduate students from a number of different disciplines work together to support and facilitate research on such a priority problem? What is the role of students in this process?

2. Objectives

2.1 List of objectives

The research encompasses a number of complex and interrelated objectives focused on the health and well-being of young people, sustainable and equitable development, governance, the strengthening of research capabilities, the production and use of knowledge systems, and the application of information technology to the research for development process. As stated in the proposal, its objectives were:

Objective 1:
> To uncover, critically analyze, and come to a more complete understanding of the life complexities that contribute to risk of HIV transmission among young people in Uganda today, especially those relating to social and economic inequalities, gender, identity and relationship issues, and how these concerns affect particularly disadvantaged young people, such as girls and out-of-school youth.

Objective 2:
> To mobilize young people's experience and creativity, and translate their complex understandings of risk and vulnerability into personally compelling, participant-generated strategies for health and well-being.
> 2.1 To explore a forum for young people to communicate with each other, tell their stories, generate shared understandings, and problem-solve around issues which affect their health and futures.
> 2.2 To examine the factors which enhance young people's involvement in their communities and nourish leadership capacity, and those which present barriers.
> 2.3 To develop communication networks aimed at promoting inter-generational dialogue and understanding among parents, teachers, health workers, traditional healers, local community organizational, religious, and political leaders, and government officials, which will support the young people's strategies, meaningfully involve them in future community activities and work for social change.

Objective 3:

To investigate an innovative visually-enhanced participatory research approach designed to achieve objectives 1 and 2.

Objective 4:

To strengthen research capability in young people and community members, that will encourage sustainability of their programs.

4.1   To develop and strengthen program planning, implementation, monitoring and evaluation skills.

4.2   To explore the ways that access to information technology can enhance this process.

Objective 5:

To investigate a model for transdisciplinary[3] university student research collaboration.

5.1   To examine the factors that need to be considered, and processes involved, in student transdisciplinary research collaboration.

5.2   To examine the ways that access to information technology can enhance the research process.

Objective 6:

To enable community access to information technology for income generating and research purposes, and study the effects this has on the community.

6.1   To train the field research team, community leaders, and a number of young people in the use of information technology.

6.2   To develop a community web site.

2.2 Did the project meet its objectives?

Given the complex and ambitious nature of this research project, I feel it was very successful at meeting its overall objectives, particularly its primary objectives (*Objectives 1, 2, and 3*). Over a year of fieldwork generated a large and varied body of data that paints a vivid picture of adolescent life in this Ugandan trading centre community, from the perspective of young people and the adults in their lives. Through this work, both young people and adult community members were mobilized and motivated to develop strategies for the health and well-being of young people and their community. The visual methodology was highly successful – a key factor, in promoting understanding and action around issues of importance in young people's lives. Other sections of this report will provide a more detailed discussion about the outcomes of the project.

---

[3] Please refer to the original proposal for an elaboration on the concept of transdisciplinarity.

Objective 4 was met with reasonable success, in that a number of young people and community members were able to develop and strengthen certain skills through their participation in the work (speaking in public, facilitating discussions, interviewing, planning, implementing and evaluating the work, and analyzing data). Through formal training sessions and on-on-one mentoring with the researchers, they also developed an understanding of translational research[4] and skills in proposal writing, program planning, and research design and methodology. Ideally, a measure of success for this objective would include whether these skills were translated into *new* program generation, implementation, monitoring and evaluation. Unfortunately, this requires a longer-term assessment of outcomes than time allowed. It also requires overcoming a number of political, structural and financial barriers to such activity, which necessitates a further commitment of resources and time.

Objective 5 was partially met, in that the idea of a transdisciplinary student research team was introduced and enthusiastically received at Makerere University by both faculty and students. Exploratory work on how to put such a team together took place, uncovering some of the structural, process and communication issues involved in mounting such collaboration (see further detail in the results section). These were challenges that prevented having a full student team in place in the time frame available, but one student from the Department of Gender and Women's Studies joined the field team and email communication with and support of her work is on-going.

Objective 6 was also partially met, in that an Internet access facility was established for the community and members of KATUWA, the community-based organisation (CBO) initiating the project, were able to learn about information technology, did some of the research on suppliers and equipment, made decisions on the business plan and are now running the facility. The process was a good capacity building activity which will be valuable as they continue to operate the facility. However, the communication connection will primarily be used only to send and receive email because of technological and financial limitations and the town's remote location, which make surfing the Internet very expensive. KATUWA members decided it was still worthwhile to develop the facility as a service to the community and it will be able to cover its costs for email use. It will not be the big income generator people hoped for until technology and provider charges become cheaper and more accessible. It is a start, and the community members are learning more about computers and using communication technology. They are still enthusiastic about having a web presence and the web page should be in place by the end of 2004. In addition, the email link is currently being used to facilitate communication between researchers in Canada and the community in Uganda at the Community Development Centre (CDC).

---

[4] Please refer to the original proposal for an elaboration on the concept of translational research.

3. Project Design and Implementation

3.1 Introduction

Because of the project's complexity and my family commitments, there were two periods of fieldwork, each of which focussed on specific objectives. The first period was primarily an orientation and ethnographic phase which took place in Uganda from January to June 2002. Data analysis, problem-solving and academic activities followed in Canada until January 2003. Details of the research activities and results from this period were submitted to IDRC in a Progress Report dated December 15, 2002.

Activities of the second field visit continued the ethnographic research begun in the first phase, but aimed to deepen understanding about young people's lives, build on the participatory aspects of the work, and develop the visual methodology component. Objectives for this visit also included constituting the transdisciplinary student research team and facilitating community Internet access.

A return to the field was scheduled for mid-January 2003 but was delayed by six weeks because field assistants were completing other work. Field research took place in Uganda from March to November 2003, followed by data analysis, report writing and academic activities in Canada to the present time.

3.2 Calendar of activities

The calendar of activities reports on the second research period, **March 2003 to February 2004.**

- *March 2003 (Kampala, Uganda)*
    - Attended to logistical/administrative matters (registered with Canadian Consulate, reported to Ugandan National Council for Science and Technology, extended student visa with Immigration, purchased supplies, met with Dr. Nelson Sewankambo, Ugandan advisor.)
    - Met with Makerere University contacts (Dean of Social Sciences, Department Heads and Coordinators of Gender and Women's Studies, Sociology, Anthropology, Social Sector Planning, Development Studies, Public Health, and Information/Communication Technology) to discuss aims of Student Research Team (SRT) component of the project and begin recruitment of students.
    - Met with Information/Communication Technology (ICT) resources at Makerere University about the Internet component of the research.

- *April 2003 (Lyantonde, Uganda)*
  - Attended to logistical/administrative matters: organized accommodation, re-acquainted with local officials and influentials.
  - Orientation with field research team – reported on preliminary analysis of first field visit; planned new research activities; organized responsibilities and reimbursement; discussed professional development/capacity building activities.
  - Met with local community-based organization (KATUWA) for information, planning and problem-solving about the Internet component of the project.
  - Participated in community activities and had informal data gathering interviews.
  - Prepared recruitment/information materials for teachers, students/youth and parents/guardians about the in-school and out-of-school youth *conceptual events* (described later in the methods section).
  - Visited schools to discuss the research program with head teachers and held selection interviews with participants.
  - Planned how to select students for Student Research Team and reviewed students' research topics with field team.

- *May 2003 (Kampala, Mbarara and Lyantonde, Uganda)*
  - Held orientation and interviews with student groups at Makerere University interested in participating in the Student Research Team.
  - Met with faculty at Mbarara University Department of Development Studies regarding the Student Research Team project.
  - Gathered information on providers and equipment for the Internet project.
  - Made mobilization and logistical arrangements for in-school and out-of-school youth *conceptual events*[5].
  - Recruited facilitators for conceptual events and held orientation and strategy meetings.
  - Held first conceptual event with in-school young people (10 days): discussions, video analysis, editing, and clip preparation.
  - Illness – malaria.
  - Held group discussion with local Youth Leaders.
  - Held half-day capacity-building workshop on proposal writing for Youth Leaders.
  - Held discussions with local Youth Association.
  - Continued participation in community activities and informal data-gathering interviews with young people and other community members.
  - Held regular meetings with field team to plan and discuss on-going research activities.
  - Met with Dr. Nelson Sewankambo, Ugandan advisor.
  - Held information session for out-of-school youth participating in discussions.

- *June 2003 (Lyantonde, Uganda)*
  - Interviews with students at Mbarara University.

---

[5] Conceptual events are intensive video-enhanced facilitated discussions and are elaborated further in Section 3.

- o Reviewed statements of interest from students applying to participate in the Student Research Team project and selected a short list.
- o Mobilized and made logistical arrangements for out-of-school youth conceptual event.
- o Held second conceptual event with out-of-school youth (10 days): discussions, video analysis, editing, clip preparation.
- o Held second half-day capacity-building workshop on proposal writing for youth leaders and community members.
- o Prepared information materials and mobilized health workers, counselors, youth leaders, teachers and parents for discussion and feedback sessions.
- o Planned video feedback strategy for counselor and health worker discussions.
- o Prepared video clips for these events.
- o Held third and fourth conceptual events, for health workers and counselors respectively (1 day each).
- o Held discussion and career guidance session with local Youth Association (KADSA) executive members.
- o Continued participation in community activities and informal interviews with young people and community members.

- *July 2003 (Lyantonde and Kampala, Uganda)*
  - o Finalized selection of students for Student Research Team.
  - o Compiled information on Internet project and held discussion with KATUWA (local community-based organization).
  - o Translated and transcribed audio and video data from young people's conceptual events.
  - o Copied videotapes recorded at conceptual events to VHS tape for use as a community resource.
  - o Field visit by supervisor, Dr. Dennis Willms (5 days): Salama SHIELD Foundation retreat, meetings with field team, progress report, community meetings on vaccine preparedness.
  - o Illness – second episode of malaria.
  - o Continued participation in community activities and informal data gathering interviews with community members.

- *August 2003 (Lyantonde, Uganda)*
  - o Continued with translation and transcription of audio and video data.
  - o Continued copying video recordings to VHS tapes.
  - o Made final selection of students for Student Research Team; on-going communication and meetings with students.
  - o Planned video feedback strategy for Youth Leader conceptual event.
  - o Prepared video clips for Youth Leaders' event.
  - o On-going participation in community events and informal data gathering interviews with community members and workshop participants.

- *September 2003 (Lyantonde, Uganda)*
  o Continued with translation and transcription of audio and video data.
  o Continued copying video recordings to VHS tapes.
  o Made logistical arrangements and mobilized for Youth Leader workshop.
  o Held fifth conceptual event for Youth Leaders (2 days).
  o Planned video feedback strategy for Parents' and Teachers' conceptual events.
  o Prepared video clips for these events.
  o Made logistical arrangements and mobilized for Parents' and Teachers' conceptual event.
  o Prepared and discussed business plan for Internet project with KATUWA.
  o Continued participation in community events and informal data gathering interviews with community members and workshop participants.

- *October 2003 (Lyantonde and Kampala, Uganda)*
  o Held sixth conceptual event with Parents and Teachers (5 days).
  o Finished transcription and translation of audio and video data.
  o Finished copying video recordings to VHS tapes.
  o Planned video feedback strategy for Political Leaders.
  o Prepared video clips for Political Leaders' event.
  o Made logistical arrangements and mobilized for Political Leaders' workshop.
  o Held seventh conceptual event with Political Leaders (1 day).
  o Planned video feedback strategy for events with Religious Leaders and representatives from non-governmental organizations (NGOs)/community-based organizations (CBOs).
  o Prepared video clips for these events, which were later conducted by field team.
  o Met with researchers at the Rakai Project.
  o Interviewed District and local political, administrative, law enforcement officials and cultural leaders.
  o Continued participation in community events and informal data gathering interviews with community members and workshop participants.
  o Met with students chosen for Student Research Team.
  o Met with Ugandan advisor, Dr. Nelson Sewankambo.
  o Return to Canada.

- *November 2003 (Canada)*
  o Re-united with family and friends.
  o Organized discussion materials for Religious Leaders' and NGO/CBO conceptual events; on-going communication with field team.
  o Met with supervisor.
  o Data analysis.

- *December 2003 (Canada)*
  o Prepared report for Ontario HIV Treatment Network (OHTN), which funded purchase of the video camera.

o Prepared report for, and met with, thesis committee on fieldwork.
o On-going communication with field team regarding conceptual events.
o Field team held eighth and ninth conceptual events with Religious leaders and NGO/CBOs.
o Data analysis and reading.

- *January 2004 (Canada)*
  o Met with supervisor.
  o Health problems.
  o On-going communication with field team regarding Student Research Team, final community conceptual event, field report.
  o On-going communication with students regarding Student Research Team; organizational matters relating to this activity.
  o Submitted abstract on research to 2004 International Conference on HIV/AIDS.
  o Lectured to McMaster University undergraduate students on this research.
  o Data analysis and report writing.

- *February - March 2004 (Canada)*
  o On-going communication with Ugandan student and field research team.
  o Report for IDRC and Ugandan Council for Science and Technology.
  o Data analysis and preliminary outline of thesis.

3.3 Description and discussion of research methods and activities

The research methods and activities will be discussed separately for each part of the project: the young people's component, the student research team component and the Internet component of the project.

3.3.1 Methods and activities relating to the young people's component

This was an action-oriented, participatory, community-based health and development project. Such applied research is both a philosophy and a way of working which requires particular methodologies, partnerships and a community-centred approach.

In the case of this project, a number of different partners were involved, including the field team of community researchers/health workers[6], university researchers in Canada (McMaster University) and Uganda (Makerere and Mbarara Universities), and Canadian and local government/non-government/community-based organizations such as the International Development Research Centre (IDRC), Social Sciences and Humanities Research Council

---

[6] Members of the field research team were Rose Kawere, Benjamin Kamalumba, Hanifa Namuli, George Williams, Stevens Bechange, and Hajati Sarah Matovu. Their advice, hard work, wisdom and skills were critical to the success of this project and are gratefully acknowledged.

(SSHRC), Salama SHIELD Foundation (SSF), Kabula Tusitukire Wamu Organization (KATUWA), and Lutheran World Federation (LWF). Partners contributed and shared knowledge, expertise, facilities, networks, and human and financial resources.

As well, members of the community, both young people and adults, were meaningfully involved in identifying the goals of the research, its planning, activities, and evaluation, as well as translating and analyzing data. The project came about because of a perceived community need – the community's desire to help young people who live in a place badly affected by HIV/AIDS. Since young people are rarely involved in program development, the project was designed to learn about the life experience of young people from a variety of perspectives, including the young people themselves and adults with whom they interact. The young people were then actively involved in generating solutions.

An anthropological disciplinary orientation is most useful and suited for this kind of project because it provides a framework for understanding people's experience from *their* perspective and the meanings they attribute to this experience. It also considers the complex social, cultural, spiritual, political, economic and environmental issues that influence people's lives and decision-making.

The use of qualitative ethnographic methodology, which is central to the discipline, enables the gathering of such experiential, grounded data (evidence). Therefore, the research used methods such as participant observation, active researcher engagement in community activities, informal and in-depth interviews, focus group discussions, document analysis, and an innovative methodology which involves participants in intensive, video-enhanced facilitated discussions called *conceptual events* [7].

I will elaborate on this latter methodology because it was designed specifically to overcome barriers to communication, understanding and action. It aims to elicit people's stories (knowledge, understandings, rationalities and experiences) and enhance participatory development processes – that is, stimulate dialogue, reflection and problem solving aimed at personal and social change.

At the young people's conceptual events, small groups of eight boys and eight girls came together in a supportive environment to raise the issues they considered important in their lives. The agenda was set by them and they spoke the language with which they were most comfortable. First, groups of boys and girls met separately for several days to discuss their gender-specific experiences and concerns. Normally, girls/women do not feel comfortable talking openly in the presence of men/boys, so this process provided them with a safe way to do so. All the discussions were videotaped, with participants' permission. The video was then edited into 'clips' which communicated the key issues and themes. The girls and boys again met separately to view each other's video clips, then to talk about and reflect on what

---

[7] The methodology builds on and visually enhances the original concept of the '*conceptual event*' developed by Dr. Dennis Willms, which is described in more detail in the original project proposal. The rationale for visually enhancing the discussions can also be found in the original proposal.

they had learned from each other. Finally, the boys and girls came together to discuss the issues and to generate solutions. *See Figure 1.*

Figure 1.   *Young People's Discussions*
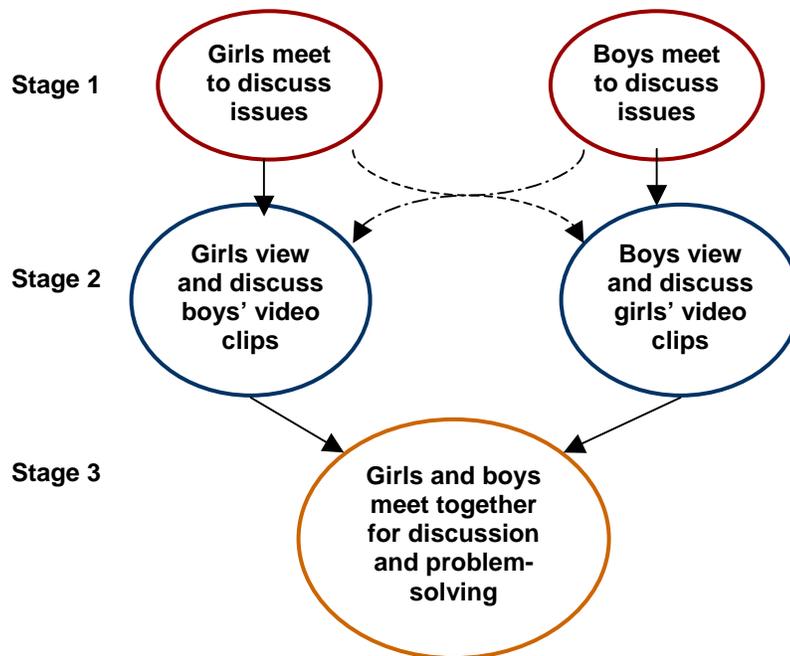
There were two 10-day events – one for school-going youth and one for out-of-school youth. Participants were between the ages of 17 and 22. Those who came from local schools were chosen either by their peers or by the head teacher. Non-school-going youth were approached and asked to participate by community volunteers. All participants were interviewed, given written information about the events for themselves and their parents/guardians (in Luganda and English), and had the opportunity to make suggestions or ask questions before the final selection. They knew they would be attending the discussions not only to voice their own experiences and concerns but also to represent those of their friends and peers; they were researchers too[8].

The format and discussions were extremely well received by the young people. They learned a great deal from each other, generated many ideas and solutions, and said it was a life-changing experience (see more details in the results section). Participants asked for copies of the videotapes so they could hold similar discussions with their friends. The experience

---

[8] Much of the success of this project is due to the contributions, courage and commitment of the young people and adults who participated in the discussions. Their interactions were honest, thoughtful, moving and inspiring.

motivated two other participants to write and perform plays about some of the issues raised, as another way of bringing the discussion to their peers. They wanted others to share their knowledge and experience; they were proud of what they had accomplished and understood its importance for their futures.

The young people also had messages for the adults in their lives so the video clips were shown in feedback conceptual events held with parents, teachers, counselors, health workers, political, administrative, religious and cultural leaders, and local NGOs and CBOs. *See Figure 2.*

Figure 2. *Community Feedback Events*
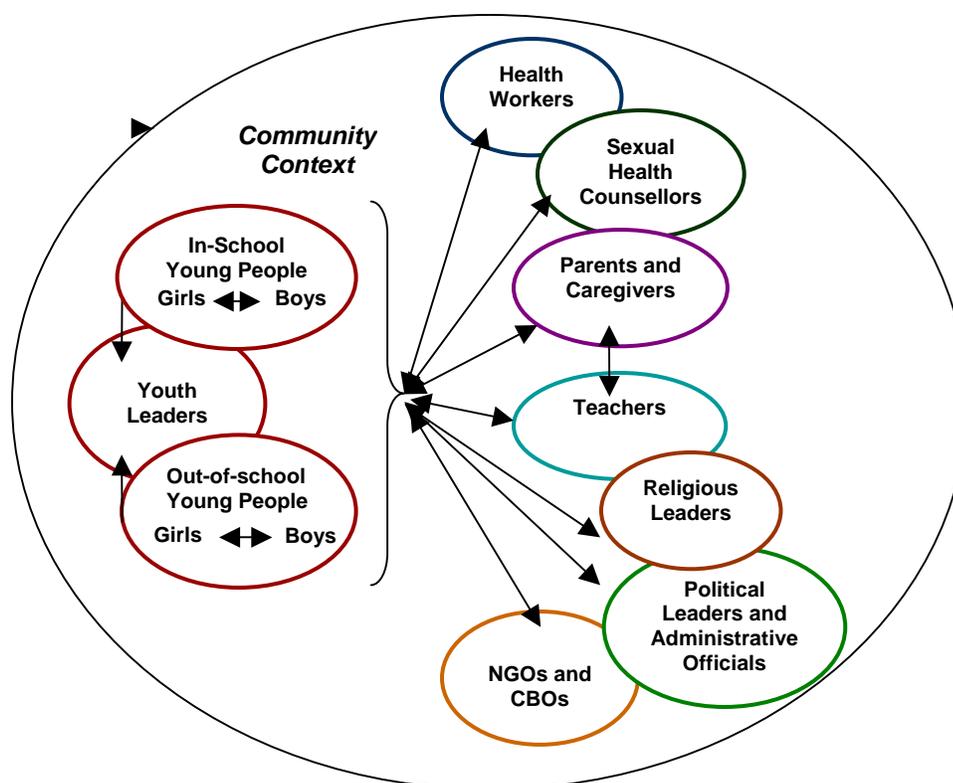
The purpose of these events was to provide a forum for young people to communicate with adults, open dialogue, stimulate awareness, and generate understanding and support. In addition, the methodology provided a way to feed back the research data to the community and encourage action.

People participating in the feedback events were invited because of their influence and position in the community, as well as their interest and availability. The length of each event varied from five days for teachers and parents, to two days for youth leaders and religious leaders, and one day each for the other four groups. At each event, the adults first gave their

perspectives on what issues they thought were affecting young people and discussed solutions. They then viewed the video clips from the young people's events and focused their discussion on problem solving and action plans. The process generated lively discussion, reflection and motivation for addressing the problems of young people. Young people's voices and perspectives were heard.

3.3.2 Activities relating to the Student Research Team (SRT) component

The student research team component of the project began in March 2003 with visits to the Deans of Medicine (Dr. Nelson Sewankambo) and Social Sciences (Dr. Edward Kirumira) at Makerere University to discuss the concept. They were most welcoming and interested in the idea of a transdisciplinary student research team and facilitated contact with the heads of Public Health and the Faculty of Social Sciences (Anthropology, Sociology, Gender and Women's Studies, Social Planning). I also met with faculty in Development Studies at Makerere and Mbarara University, where the graduate program is based[9]. Contact was limited to these departments only for practical reasons and time constraints.

At meetings with each department head or coordinator, I introduced the concept of the SRT project, answered questions, left an information package and a copy of my research proposal for faculty to distribute to their graduate students. The faculty were very interested in the project, offered suggestions about how to proceed and agreed to inform their second semester students of the SRT opportunity. To facilitate logistical planning, we discussed the students' time frames for exams, holidays, proposal submission and approval deadlines and the students' tentative research interests.

A month later, I returned to talk with interested students about the SRT project and provide them with more details about the community context. They were still deciding on their research topics, but once these were finalized, the department head sent a list of projects for the field research team and I to review. We identified a short list of two or three projects from each discipline, selecting those which were most relevant to young people's needs and community issues. The students on the list were contacted, interviewed by myself and members of the field research team and asked to submit a letter of intent. The letter included a brief description of their research, why they wanted to participate, how they thought they would benefit from being on a team, what they might be able to contribute to it, and what problems they anticipated along with proposed solutions. From the eight students who responded, we selected four – one each from Gender and Women's Studies, Development Studies, Sociology, and Social Planning. Since everyone was at a different stage of proposal writing and approval and had not yet been assigned supervisors, we maintained contact by phone and personal visits until all could be ready to enter the field (see more detail in results section). Communication has continued by phone and email since my return to Canada.

---

[9] I am grateful for the warm welcome and interest from Makerere and Mbarara University administrators and faculty.

3.3.3 Activities relating to the Internet access component

On my arrival in the community, the community-based organization which initiated the idea of the Internet access (KATUWA) was most keen to begin installation of the Internet facility. They had done some research on the providers and technology available prior to my return to the field and decided they wanted satellite rather than land line access. But, because of the very much higher costs for this technology, we held a meeting to review and revise their objectives, do a business plan, assess the challenges they would face and draw up a work plan. Community members were actively involved in decision-making, contacting suppliers for further pricing and organizing installation.

3.4 Data and analytical techniques

The ethnographic research activities and video-enhanced conceptual events generated a wide-ranging and rich body of data about young people's lives from a variety of perspectives. The data are in the form of written notes of interviews and group discussions, verbatim transcripts from the conceptual events (translated from the video and audio tapes), video recordings of the conceptual events, the researcher's written reflections, newspaper articles, NGO reports, CBO minutes, government documents and literature. Data from participants speaking Luganda (one of the local languages) have been translated into English.

Data management and analysis is supported by QSR NVivo® qualitative data analysis software. And, in keeping with the project's participatory principles, research users were also involved in preliminary data analysis in the field. For example, young people identified key messages they wanted to communicate to their peers and various adult groups, underscoring themes that were important to them. As well, community research assistants watched all the videotapes with the researcher to select the main themes they thought were important for feedback to various participant groups. This was an important component of the research that enriched the quality and relevance of the data analysis; the data were analyzed in the context of what was significant to the participants and research users, as well as the researcher. Sometimes opinions differed, generating lively discussion; everyone learned from the process.

3.5 Successes and problems in data collection activities

The successes and problems of each component of the research (relating to young people, SRT, and Internet access) will be discussed separately.

3.5.1 Successes and problems related to the young people's component

This component of the research generated a number of successes, some of which have been identified in the previous discussion, but are listed here, with others, for completeness.

- The research was a collaborative, participatory project which was both research and an intervention – research put to practical purposes to stimulate personal and social change.

- The project was able to build on a welcomed, trusted, and respected research presence in the community[10]. The project developed good working relationships with political leaders and community influentials, such as teachers, parents, traditional and biomedical health workers, religious leaders, cultural leaders, local NGOs (Salama SHIELD Foundation, Lutheran World Federation) and CBOs (KATUWA, OCOBO and UWESO orphan support groups, Tusubira Post-Test Club and Kitovu Mobile HIV care/support groups, Theatre Amazon, The Ssenga/Kojja Program, Kabula and District Students' Association (KADSA), Islamic Medical Association of Uganda (IMAU)).

- The research involved research users in a number of essential ways. They identified the project's focus and assisted with its activities, implementation and evaluation. Young people and other community members participated freely, giving their stories, learning from each other, and contributing ideas for improving their lives. Research users and community researchers also reviewed the data and assisted with data analysis. They will be applying the results in their daily lives and in future program development.

- Research generated a rich and wide-ranging body of ethnographic data. Because of its anthropological orientation, the research was able to generate a powerful, grounded picture of young people's lives, what they are up against, what makes them vulnerable, and what gives them hope. Further, the research situates this knowledge in the context of their relationships, their community and the political/economic structures in which they live as citizens, nationally and globally.

- The visual methodology was highly successful at enhancing dialogue among young people, and among young people and adult community members. It promoted understanding and reflection, and motivated people to look for solutions. It also served to communicate data to research users in a way that was accessible, relevant and useful.

- The research was rights-based – it directly addressed gender issues, and young people's marginalization and discrimination.

- The research enabled young people's voices to be heard and the adults in their lives to respond. Youth leaders, teachers, parents, sexual health counselors, health workers,

---

[10] Research has been on-going in the community, first funded by IDRC from 1992-97, and continuing with the support of Salama SHIELD Foundation. The research team members have lived in the community for years, and are well respected for their Participatory Action Research (PAR) work and contributions to the community.

religious leaders, CBO/NGO representatives and political/ administrative leaders all identified actions that they would take, including writing letters to members of parliament, sensitizing parents and teachers, setting up committees to continue the dialogue, writing proposals for leadership development workshops and sexual health counselor training.

- The visual products from the research (the copied videotapes of the discussions) will be used as resources in the community for sensitizing adults and young people, generating discussion, and stimulating future action. Young people suggested this and the adults readily agreed. Some young people have already used the tapes and written plays to bring the discussion to their friends. People really responded to the format of hearing and seeing people they can relate to talking about issues they have in common.

   Community health workers, researchers and leaders told us how difficult it is to get people to come to sensitization sessions or discussions. We are hoping the visual resources will stimulate people's curiosity and encourage their participation. Community members think they will.

- The research benefited from a number of partnerships that were useful in achieving project objectives. Partners included university researchers in Canada and Uganda, community researchers, and government and non-government organizations. Partners shared human and financial resources, facilitated networking and capacity development, and provided advice, encouragement and leadership to each other.

- Capacity building was a priority with this research and it occurred at every opportunity. For example:
  o Members of KATUWA, (the local CBO), learned about program and business planning, problem-solving, and communication technology. They now have several resource books on the internet, email access, a computer and printer and are gaining computer skills.
  o Some community members worked as research assistants, learning interview skills, practicing facilitation skills, and developing skills in translation and preliminary data analysis. Some learned video recording skills and simple video editing. They now have a set of resource books on ethnographic fieldwork to use as reference material for their on-going learning. Their experience may help them gain employment with other projects in the future.
  o Others learned how to write proposals through formal training and mentoring, and several proposals are in the process of being written to obtain local funding for activities.
  o Members of the research team and youth leaders learned administrative and organizational skills which will strengthen their work. They also now have the use of a VCR and audio recorder for future research activities.

o Many young people who attended the events said they learned to be comfortable speaking in public, particularly the girls, and for the first time felt free to offer their opinions. Girls and out-of-school youth, who are particularly marginalized, felt that for once, their voices counted. Young people commented that they learned skills that will give them a good foundation for the future.

o The researcher developed ethnographic field skills (participant observation, interviewing, data analysis and interpretation), video recording and editing skills, and program management and budgeting skills. She also made numerous contacts which enriched her experience and the people she worked with helped her develop the understanding, patience and acceptance needed to do this work.

As well as the above successes, the research encountered a number of problems and challenges over its two year course.

As noted in my interim report, some problems were the result of the project being nested within a large, complex, already existing project funded and run by other organizations; others involved the negative effects of personal and political agendas[11]. During the second field visit, we applied the lessons learned from our initial experience, improved communication, clarified roles, expectations and arrangements for financial reimbursement, and renewed our commitment to the success of the project.

I will focus my discussion primarily on issues encountered and lessons learned in the second field visit. Some challenges were of a technical, logistical nature, while others relate to some ethical issues.

The visual methodology presented a number of technical and logistical challenges:

- Video recording needs relatively good sound and lighting conditions, which were almost impossible to find. Meeting facilities were in busy, noisy locations and it was difficult to record participants' voices at times. As well, the strong African light created exposure problems while recording dark faces. In spite of these technical challenges, we did manage to get relatively good quality recordings. This was primarily due to having a professional level camera with extra-capacity batteries, using both external and internal microphones for recording voices, carefully assessing facilities for aesthetics, lighting and sound problems, explaining to participants and people in the recording vicinity the technical issues relating to sound, and carefully planning location, camera and participant positions before recording.

- Editing of videotapes for feedback is very time consuming and challenging. We needed to add extra time in the schedule to accommodate this.

- Supplies are difficult to find, are very expensive and may be of poor quality. We needed extra videotapes to record additional feedback sessions and had to obtain the tapes from Canada. I also had to purchase and ship another external hard drive to store the edited video. This incurred costs and extra time to sort out customs

---

[11] Please refer to the Interim Report for the detailed discussion.

clearance problems. The VHS tapes and connector cables I purchased locally were faulty, which added aggravation and considerable time to copying the video recordings to VHS tapes. Suppliers refused to take responsibility and replace their faulty products. These had to re-purchased, so the lesson is 'buyer beware'.

- A major challenge was the almost daily electricity failures, typically lasting 8-10 hours throughout August, September and October, which slowed the video editing, translation and transcription of data from the video and audio tapes. Power failures also disrupted the showing of video clips at two of the feedback events, so renting a generator should be built into the budgets of such activities.

Holding discussions also brings logistical challenges:

- Participants are routinely late, which can constrain the success of events. Workshops scheduled to begin at 8:30 am (with breakfast) started around 11 a.m., after sufficient numbers of people arrived, at least with the adults (young people kept time). Differing ideas of time need to be considered when planning a day's schedule of activities so that it is realistic and achievable.
- Participants expect a per diem and meals when they attend discussions. Many people give up a day's work to attend discussions and need to be compensated or they will not attend. Expectations are particularly high if people know an activity is funded by an NGO or project. This creates problems for researchers who follow with small budgets because expectations, assumptions and perceptions of relative wealth cannot be dispelled. If compensation is considered too small, it can create bad feelings toward the researcher and lack of participation.

There are also some ethical issues to consider [12]:

- While people participated willingly in the research, it was clear that they had real expectations that something should come from the work. Part of the problem is that we (as researchers with projects) raise expectations simply by being there. Another aspect is that this community is badly off, has participated in a great deal of research and is ready to see real change as a result. People give their time, tell their stories and want to see something in return, especially when they have so many problems. Why talk about your problems and get your hopes up if nothing is going to change? In this case, community members knew the results of the research were meant to inform program development for the Community Development Centre (CDC) and they were actively involved in discussing what was needed. There is an ethical imperative to ensure that something happens and programs are developed and offered soon. I discuss this issue more fully in the Recommendation section.
- Because this community has been so badly affected by the epidemic and been the object of so much research, it has developed a notorious reputation in the country as a place of death, sickness and immorality. Community members avoid telling other people where they come from. They say, 'AIDS is our disease'. Research has played a role in shaping these feelings of identity and how others see the community. This,

---

[12] Please see also my Interim Report for discussion on reimbursement of participants.

and the previous issue must make us reflect seriously about the ethical tenet of 'doing no harm'.

- A third ethical issue is one of confidentiality relating to the use of video tapes. Everyone who participated was informed as they were recruited that a camera would be used if they gave permission. They were also asked again for permission at the beginning of each event and told they could signal for the camera to be turned off at any time. (This happened twice during the many days of filming.) Participants were also asked several times during the events if they were comfortable to continue with the camera. They were aware that their video would be shown to other people. They were also asked at the end of their events how they felt about being filmed and their video shown to others. No one had objections and all said they felt the video greatly assisted their discussion and understanding. They asked for their video to be shown to others, as I described earlier, and said they were not worried about being seen by people who might know them. I think there is need for caution, however, and have asked people who use the tapes to monitor the activity for possible ill-effects. As a strategy to protect those who are viewed on tape, we emphasize to the viewers that the participants are talking on behalf of others, not about themselves.

3.5.2 Successes and problems related to the Student Research Team (SRT)

Faculty, administrators and students were interested in the idea of a transdisciplinary student research team. They thought the concept made sense and would add value to all students' work. They particularly welcomed the potential of academic and financial support for their students. Often students take years to do their degrees because they need to work due to lack of funding. Some never finish because the extra time incurs additional tuition fees, which they cannot afford. Students also lack academic support and consistent access to supervisors, who have large student loads and are often out of the country. Thus, faculty members were pleased that students would have access to additional academic resources (the researcher and field team). Faculty also welcomed the opportunity for students to disseminate their research findings; there are many students doing valuable research but their work goes largely unnoticed.

As the recruitment of students proceeded and the community research team and I began to review the proposed research topics in the community context, we could see that a team of students working together in the community would be exciting, stimulating and a wonderful learning experience which would benefit everyone, including the community.

However, after a promising start, assembling a student research team proved to have its problems and challenges. First, the faculty did not actively distribute the information to their students. Only a few students were vaguely aware of the project, so extra time was needed for recruitment. Second, students' schedules for handing in research proposals and getting approval varied from department to department, making it difficult to have everyone ready to enter the field at the same time. As well, exam dates were shifted so the July date to begin team fieldwork had to be moved to mid-August. Third, students had lengthy delays in

getting proposals written and approved because they had not settled on their research topics and/or their supervisors were unavailable. Fourth, the process of selecting a student team was prolonged by unreliable telephone and email communication which caused gaps in contact with students. Sometimes these gaps were due to students needing to go off to work, falling ill, having phones stolen, or just being inactive. Faculty warned at the very beginning about the 'poor quality of our students', but there were some who were very keen. In the end, one student dropped out because he couldn't get a supervisor, one just disappeared, a third lost interest because the others took too long to get approval, and the fourth joined the field team in January.

The lessons learned from this experience are: 1) that faculty need to be aware of such opportunities at least one year in advance so they can be thinking of potential candidates and facilitating/coordinating departmental schedules as much as possible; 2) recruitment needs to be done by the organizer through in-class presentations rather than relying on faculty to distribute information; 3) a good communications network is essential; 4) the coordinator should optimally be based in Kampala to keep a close eye on the recruitment process, assist students and faculty and nudge them along; and 5) the idea of a student research team is still very worthwhile pursuing.

3.5.3 Successes and problems related to the Internet access component

As indicated earlier in the report, the community now has access to email and the Internet. Members of KATUWA participated actively in decision making, problem solving and obtaining information from Internet service providers during the process. They have learned about the Internet, have some text-based resources for on-going reference and are pleased to have a computer and printer, which community members will use to learn and practice computer skills.

However, there are several problems. First, the original quotes obtained for installation and Internet access by land line were not accurate and were outdated by the time the project actually went ahead. In the meantime, new technology (satellite dish) became available and was preferred by the community because it would provide better Internet access. However, prices soared for equipment, installation and provider fees with both kinds of technology and we had to revert back to the original plan of land line access.

Currently, the connection is used for email primarily because the cost per minute for the telephone makes 'surfing' too expensive for most people. Charges are relatively high because of the town's remote location. While community members see that email is useful, they are disappointed that Internet access is so costly. They hope that charges will come down as time passes and the Internet will become more accessible. As well, with the current set up, it may turn out that confidentiality is a concern, since all email is sent and received through one mailbox. We will continue to monitor and evaluate the site's use and future successes and problems.

3.6 Project outputs and dissemination

Project outputs and dissemination have been in the form of information, knowledge creation and training. These include:

- Interim and final reports to IDRC and the Ugandan National Council for Science and Technology, a report on the visual methodology to the Ontario HIV Treatment Network (OHTN), reports to my thesis committee and an abstract submitted to this year's International HIV/AIDS Conference in Bangkok. Future publications will include a report for the community, a doctoral dissertation, and several peer review papers.
- A guest lecture to undergraduate students on "Doing Fieldwork in 'Dangerous' Places". Future presentations may be given at the 2004 International HIV/AIDS conference, the 2004 Canadian Conference on International Health, and graduate seminars.
- Web access to research highlights, scheduled for December 2004.
- New knowledge embodied in video resources produced for the community, as a way for them to access the research data, generate more knowledge through dialogue and reflection, and stimulate action.
- New knowledge in the form of an innovative ethnographic methodology which enhances participatory development processes (as discussed previously).
- Training in the form of proposal writing workshops; mentoring to students on research methods and proposal writing; community capacity development (as described previously).

3.7 Project management

Project management by IDRC was excellent. Communication with the Centre was clear and straightforward. The awards officer, Jean-Claude Dumais showed interest in the work and was encouraging and flexible in his consideration of my needs. He was professional but approachable, appreciative of the nature of fieldwork and responded to requests for guidance promptly and with understanding.

3.8 Changes in orientation occurring since the project was designed

The original title of this project was 'Strong Voices, Hopeful Futures: Enhancing Leadership Capacities for Determining and Sustaining Health Initiatives with Young People…". I could feel my 'orientation' shifting as the work progressed and I came to appreciate the depth of the social and structural barriers to young people's active citizenship. I realized that the notion of 'enhancing leadership' and 'hopeful futures' are quite privileged – let me say Northern – ideals, given young people's reality in Uganda. In this place, young people are essentially powerless because of structural and social norms; in practical terms they have no

real voice and virtually no rights. Hopeful futures are far from the imagination of many, and the ones who dare to hope, who want to make a difference, have little opportunity. If we are to enhance leadership, young people here need much more enabling, in the form of encouragement, respect and support. They need to feel valued and to have opportunities for meaningful participation and personal development.   They need to feel that change is possible and that there is a place for them future.

While it is not a specific 'shift' in orientation, I would like to have had a quantitative component to the research to get base-line information of a different kind about issues young people face. I had hoped to do this originally, but was advised to keep the research entirely qualitative. While in Uganda, I tried to obtain quantitative data about young people from health clinics and other sources but it is difficult to interpret such data because data gathering is often inconsistent and record keeping is unreliable. Obtaining quantitative data may be required in the future, if programs are developed.

4. Results

4.1 Introduction

The results discussed in this section are preliminary since I have been back from the field a short time and have not fully completed analysis of the data. I am still developing ideas and these early results will become more advanced as the dissertation is written. IDRC will receive a copy of the thesis upon its completion, for attachment to this report.

My Interim report to IDRC discussed some of the preliminary findings from the first ethnographic fieldwork period with young people and adults in the community. Data from the second field visit confirmed and deepened these understandings of young people's life experience, as girls and boys discussed with each other how they are affected by influences in their home, school and social environment. Together, young people painted a vivid picture of how they understand their reality and the way they reason and make decisions. The adults too contributed perspectives about young people's lives, providing an intriguing triangulation of data on the complex issues affecting young people's health and well-being.

In this section of the report, I will first discuss what young people are up against – their experience and how it influences their lives and choices. It is impossible to do justice to the quantity and quality of the data in a report like this, but I will note the main issues and some of the advice they give themselves. I will also discuss what contributes to and inhibits their leadership development. Next, I will focus on development practice. The field experience was helpful in broadening my perspective on development itself, as I saw it through the eyes of participants and as I experienced the development process myself. I will discuss these observations and lessons drawn from this experience. Last, I will outline what contribution the research has made to knowledge and policy development.

Recommendations have been made relating to some of the issues noted below, and where this is the case, further discussion of the issue can be found in the Recommendation section.

4.2 What young people are up against

Young people are not a homogenous group, but in this town, what they have in common are lives that are deeply affected by insecurity, loss, threats to survival and little opportunity. None has emerged unscathed from the tumultuous, heartbreaking situation of the last decade caused by HIV/AIDS, which has shredded the social fabric of their families and community. Many have experienced terrible hardship, as they care for sick parents and watch family members die. They have endured hunger, disease, grief, and often, harassment and exploitation. They scrounge for school fees, clinging to the thread of hope that school represents, lost without it. They live their short, hard lives certain only of uncertainty.

Uncertainty is the term young people actually used when talking about the problems of adolescence. They spoke openly of being uncertain about changes they are experiencing in their bodies – what to do about sexual urges, about the meaning of sex, about what it means when someone says 'I love you'. Relationships, and questions about them, are a primary concern for young people. Their relationships involve complicated understandings about money, expectations, reciprocity, security, acceptance, power, friendship, fertility and male entitlement. They feel alone with their questions because parents are absent or too uncomfortable or busy to talk. Guidance is no longer available from other relatives, who have moved away or died. Schools do not fill the gap, especially for those who have dropped out. Young people, in reality, lack knowledge and guidance about their bodies, sexual health and sexuality. They have many misunderstandings about sexually transmitted infections, HIV/AIDS, condom use, and family planning. In the end, this results in hurried, unprotected or forced sex, high STI rates, pregnancy, abortion, girls who leave school and boys who run away to avoid the ten year term of imprisonment for defilement.

The implications of leaving school are tragic for young people, particularly young pregnant girls. They seek dangerous, illicit abortions that frequently end in death. If they choose to have the child, they are usually chased away from home by angry parents or caregivers, abandoned by the father, and left on their own with no means of support. The answer for many girls is to find a man, or several men, to support her. Multiple relationships are the norm for both girls and boys, and not just for those out of school. Girls spoke about having one man to love, and others to 'solve your problems'. Boys also expect to have multiple partners, and money or material items are used to attract girls. There is an implicit expectation of exchange which both boys and girls acknowledge – boys 'help' girls; girls owe boys sex. If a girl 'eats' what the boy has given her and then says no to sex, the boy feels entitled to take what is 'owed' to him.

Materialism, or sex for 'stuff', is a driving force behind girls seeking partners. There are those who do it for survival, but many girls talk about sex as a way to pay for stylish clothes,

fancy bags or entertainment. Older men with money (and often with HIV) know this and seek out young school girls who want nice things. School-going-boys angrily blame the girls for going with older men and bringing HIV back to their age-mates. In the community, widows (often with HIV) will entice boys, who will have other partners in- and out-of-school. Thus, a cycle of risk exists with young people through mixing older/younger and in-school/out-of-school relationships. When a lack of knowledge about sexual health is added to the mix, it means young people are highly vulnerable to HIV transmission.

Sadly, many have resigned themselves to the inevitability of getting HIV. Even those who have decided to abstain and concentrate on school fear their partner will 'kill' them when they eventually marry. Many young people have given up, living only for the present. Some said they fear pregnancy more than HIV. They see others dying from AIDS, malaria, accidents and other illnesses and have little hope for the future. It is interesting that life expectancy statistics, which are taught in school, factor into young people's attitudes about the future. They see that they will have a short life (42 years), but have not been taught how to interpret the numbers. They reason that if they are going to die at the age of forty-two or before, they should live life now and have children early: 'Even a snail leaves a trail', one girl noted.

Their short term view of life and lack of planning is not only due to fatalism, but is also affected by limited opportunities and possibilities. Without education, or without good education, opportunities for young people are very restricted, often to working a day at a time to pay for food and rent. Those who finish school may have the chance to go to university or get a government job, but increasingly, even those with post-secondary education are unlikely to find work. Part of the problem is that there are not many jobs, but young people also do not want to work at 'petty' or 'dirty' jobs and so they remain idle.

There are also many influences in their social environment that young people say negatively affect their well-being and make them vulnerable. These range from the lure of socially undesirable entertainment to negative Western influences on values and ways of dressing, sexual harassment and discrimination, poor adult role models, widespread prostitution, pervasive corruption, political officials who seem not to care, few jobs, poverty and the destructive effects of HIV/AIDS. There is also the dark side of social relations involving jealousy and malice that cause people to mistrust and to fear relationships and success. The problems are complex and intertwined.

Young people all agreed on the harmful effects of entertainment, such as disco dances and video halls. Discos are notorious places of drinking, drug taking and sexual activity, as are video halls, which show pornographic movies. Young people who frequent such places know the risks but unfortunately there is little else for young people to do for recreation in town.

The problem of entertainment is closely tied to another issue raised by young people – Western influences. As well as explicit videos, magazines and music, both boys and girls think ways of dressing (short skirts, tight blouses and jeans, and bare midriffs) are a problem

– boys feel girls are asking for sex; girls want to look 'smart' but don't want boys to bother them. Unfortunately, gender relationships are such that boys will 'take' if they think a girl is asking, even when it is not offered. There is widespread adoption of Western sexual values and behaviours, but the young people in our discussions were troubled by these outside influences. Many blame the West for its cultural colonialism and negative effect on Ugandan life. The participants came to realize through their discussions that they should start thinking more critically about the consequences of these influences on their lives, adopting what is good and discarding what is not.

Sexual harassment, abuse and discrimination are serious and pervasive problems for young people, and they feel powerless to stop them. Girls frequently experience sexual harassment, not just from their peers, but also from teachers, police, political and religious leaders, employers, medical staff, and relatives. Boys too talk about physical abuse and sexual harassment from teachers and others. International Children's Rights are promoted but not well understood or upheld. Young people feel exploited, unprotected and vulnerable.

Young people also raised many issues relating to their home environment. Problems in this domain of experience include harsh or absent parents/guardians, poor communication with parents, parents who do not value or support their education, too many chores which interfere with schoolwork, step-mothers who harass and physically and mentally abuse them, and gender discrimination against girls relating to housework and property ownership. Young people want parents to do their jobs, be better role models, guide and counsel them, and support them when they have problems.

When the parents heard what young people had to say, they acknowledged that 'we're falling down in our roles' and vowed to sensitize other parents about young people's needs, the necessity of improving parenting skills and working with teachers.

In the school environment, young people raised the serious issues of pervasive sexual harassment and physical abuse by teachers, the poor quality of their education, a lack of access to textbooks and other educational resources, the crippling problem of school fees and the politically corrupt distribution of bursaries to those who do not need them. Poor students who must go schools with lower fees are more likely to do poorly in the national school leaving examinations. Wealthier students who go to better schools will do better and will likely get the few government university scholarships that go to top students. Thus, young people in poverty will likely remain there while their better-off peers benefit.
Teachers who heard the young people's comments agreed that these problems exist and committed themselves to monitoring and sanctioning their fellow teachers for poor behaviour. They also planned to begin sensitizing other teachers about the problems, improving quality of teaching and working more closely with parents.

Other adults, such as health workers, counselors, political and administrative leaders, religious leaders, and NGO and CBO representatives were troubled by what young people had to say. Political and administrative leaders asked for more discussions; religious leaders

(who were meeting for the first time) organized an ongoing committee to attend to young people's needs; NGO and CBO representatives decided to write letters to the member of parliament; and sexual health counselors renewed their commitment to support young people 'who are all alone with their problems'. However, their work is severely restricted by lack of funds and trained workers.

4.3 Advice they give each other

Throughout the discussions, young people themselves worked out solutions and learned from each other. They discovered that this experience gave them hope and tools for the future. They developed many messages for other young people; here is a sample of their words to live by, which come alive when said by real people on the video clips:

- 'Young people should change their behaviours. Concentrate on your studies and do not be tempted by men with money. Work hard at school and you will be able to avoid activities and situations that cause you problems. You will not waste your parents' money and will avoid their tears.'
- 'Avoid entertainment or you will be spoiled.'
- 'With Western influences, let's change what is good and leave others.'
- 'Think about courtship because it encourages virginity. With courtship you are free of worry.'
- 'Girls should say 'no' like they mean it; boys should listen and respect a girl's 'no'.'
- 'Don't participate in risky behaviours. Participate in healthy activities like discussions and games.'
- 'Don't despise work. Be patient and take petty jobs because these are better than nothing and will help you get to the next step.'
- 'Respect your leisure. Parents do not want their young people to go out, so if they allow you to go, treat your leisure time with respect and do not let your parents down.'
- 'Join groups because one day they may be able to help you. You will get ideas and be exposed to the outside world.'
- 'Attend discussion groups to find out how to take care of your life.'
- 'When you join a group, make sure you have good behaviours and abstain. Some go with other intentions and give the group a bad name.'
- 'Take your life as important. Girls are not sex objects. Value your life and take responsibility for it. It is up to us.'
- 'Develop a strong heart.'

4.4 Preliminary analysis

This last bit of advice – 'develop a strong heart' – resonates with a preliminary analysis discussed in my Interim report[13]. Briefly, at that time I noted that people use metaphors of the heart to describe each others' personal qualities. For example, they would say that those who are kind and giving have 'good hearts'; those who are self-interested, mean or exploit others have 'bad hearts'. In my analysis, I extended the metaphor to represent qualities I observed in young people that seemed to help them survive suffering and uncertainty, saying they have 'strong and courageous hearts'. At the time, this was an 'outsider' perspective on an 'insider' concept. It was a surprise therefore, to hear the young people themselves use this metaphor in the conceptual events, as they urged each other to develop a 'strong heart' in order to protect themselves and have a good future. Their use of the metaphor encompasses notions of self-control, self-knowledge, strong will and determination, which echoes some of the qualities I observed earlier.

The notion of a 'strong heart' is of value from both an analytic perspective and as it applies to practice. First, I think it helps diminish the problems and hopelessness associated with a risk analysis. People here see their lives consumed by risk – poverty, lack of education, sickness – all kinds of problems of which AIDS is only one. Health and development messages constantly tell people about the risks they face and become part of their identity. The notion of survival, and strong hearts, shifts the emphasis from inevitability and hopelessness to 'we're going to get through this, so we have to take steps to protect ourselves'. The ability to survive because of a 'strong heart' leads us to thinking about survival as a more active, positive, and protective force. Maybe, in the HIV/AIDS era, this is what distinguishes this generation of young people, and it can be built upon to grow 'stronger voices, more hopeful futures'.

In a practical sense, I believe this metaphor might have some application for prevention practice. One evening, I was asking a young man about what it means to have a strong heart and he said, "Oh, you mean the *ssenga o'watima*", which translates into 'the aunt or *ssenga*[14] of the heart'. The expression refers to a person's inner *ssenga* or counselor – the voice that advises a person about the consequences of his or her actions. The meaning is close to what we might think of as a conscience. The *ssenga o'watima* is the symbolic embodiment of emotion and reason. The brain is involved to the extent that it carries out the decided action. The *ssenga* 'knows' what to do and speaks, but a person might not listen or even hear, especially if s/he is not on good terms with his or her *ssenga*.

---

[13] Please refer to the Interim report for the full discussion.

[14] *Ssengas* are the paternal aunts whose culturally sanctioned role is to counsel and guide young people about sexuality and good behaviour. The traditional *Ssenga* role has been all but lost in recent years, but the notion has seen a number of contemporary adaptations. For example, the community now nominates trusted women and trains them to act as sexual health counselors called *Ssengas*. There is also a newspaper column entitled 'Ask the *Ssenga*', which responds to written questions of a personal nature from young people.

Now, in terms of prevention, this is interesting. In prevention messages, young people are asked to make reasoned action, which assumes planning, anticipating and understanding consequences. The decision to act, or not, is a personal one, governed by many influences both inside and outside the individual.

In the case of the young people who participated in this research, I was struck by how 'externalized' their lives were. That is, things happen *to* them; they have little control over so many aspects of their lives. They are used to thinking of themselves as insignificant and powerless – submitting to authoritarian parents, teachers, subjected to rote learning, marginalized and exploited. I observed a kind of passivity and acquiescence in their decision-making, as if action and consequences were inevitable and the 'internal voice' had no role. For example, boys talked about being 'forced' to have sex when they saw a girl wearing a short skirt. They used the word 'forced' in referring to many behaviours.

If prevention involves helping young people understand the concept and role of inner reasoning and their individual responsibility for making healthy decisions and behaviours, the *ssenga o'watima* may be a useful, culturally compelling metaphor to which young people can more easily relate. Because of their past experiences and stage of development, young people may not fully understand that reasoning about consequences and decision-making *can* take place within the individual, that they have this potential, and that they can have a significant part to play in what happens to them. If this is the case, developing the inner voice that guides and counsels – listening to one's inner *ssenga o'watima*, who advises one about consequences and helps make decisions – could be an important prevention message to bring to young people in this place. Adolescents are going through an intense time of identity construction, and if they recognize and embrace the knowledge that a 'strong heart' can be a way of being and living, a conscious part of who they are, which they can draw on and be proud of, it may be something that can help keep them safe. It may be a strategy which responds to the young people's recommendation and be a small but useful piece of a complex prevention and survival tool kit.

This discussion is preliminary and needs a cautious approach to avoid the issue of blame, which comes with focusing primarily on individual responsibility to the exclusion of other influences on behaviour and decision making. This is especially so in a place where people have so little control over many aspects of their lives and structural inequalities are fundamentally linked to continuing poor health and futures. I hope to expand this part of the analysis in my dissertation because global and national structural issues clearly have a critical role to play in local young people's continuing vulnerability, and this has implications for how we think about prevention.

The above analysis is only partial; there are many other analytic threads to follow, including those relating to gender, ethics, and health and development research itself. There are also the lessons Ugandan youth have to teach us about being human, how we can live. Most young people I see at home will never have to test themselves with the kind of suffering young

people here endure and survive; there are lessons here to explore. These will advance as the data is revisited and the dissertation is written.

4.5 *What contributes to and inhibits leadership development*

Youth leaders were among the young people that participated actively in the research and many are very committed to improving life for their fellow youth. Unfortunately, they have three main barriers to carrying out their mission. First, young people who have a vision and want to lead get little encouragement from adults. Adults do not take them seriously, think they are incapable and treat them with suspicion and disrespect. Young people are used by adult leaders only to get elected, then are ignored. The result is that young leaders get little facilitation to help them do their work or mentoring to develop their leadership skills. It is no small irony that government policy sets out to develop youth, give them a voice and uphold their rights, but in practice young people remain unheard, unprotected and without opportunities.

Second, it is difficult for young people with leadership potential to motivate and encourage participation in their peers. Young people often do not want to involve themselves in activities unless they know there is something material in it for them, e.g. food, sodas. The attitude of self-interest is pervasive and may be contributing to the demise of the volunteer spirit seen lately in the community. In general, young people are skeptical about the motives of their leaders, thinking they are only in it for themselves. It reflects a more common problem – young people have given up on the system and have no faith or trust in their leaders, both young and old. They see money intended for them 'eaten' and wasted, or withheld until they are willing to give half of it to the official in charge. They feel that no one cares about youth and that any apparent official focus on them is lip service.

Finally, young people who want to succeed and become leaders risk making others jealous and having their plans sabotaged. It makes anyone with ambition or willingness to lead cautious of incurring potential malice.

However, as youth leaders became involved in the research, I was struck at how they responded so positively to opportunities for active participation and to people who encouraged them. They felt their opinions mattered and they were so hungry to learn. They were strengthened by opportunities which supported and facilitated their work. Such opportunities renewed their motivation and energy and helped diminish feelings of hopelessness. It is a lesson for future action.

4.6 *Thoughts about development practice*

Development practice, as it is described in text books and NGO literature has a different face from that which is experienced and received on the ground. My time in the field, living and

working with 'recipients' of development in a low income country, allowed me to see and understand some of their perceptions and feelings about what we do. I saw aspects of our work in a more grounded and real way. This experience has broadened my perspective and generated some questions about the way development is practiced. I will discuss some of my observations and lessons drawn from this experience, particularly as they relate to a) the ethical question of people's expectations, the imperative of researchers giving back, and the need to connect projects to program funding; b) the economic and social disconnect created by the actions and conduct of development workers/researchers, the grounded implications of this and the need for long term monitoring and supervision; c) long term funding for programs; and d) capacity building. This discussion is partial and preliminary; it is something I hope to discuss with others, reflect and write on more in the future.

4.6.1 The ethical problem of expectations

By our very presence, we set up expectations in participants and research users that something will happen because of our work. It is a tremendous challenge to negotiate realistic expectations for several reasons which are interrelated. First, when there is so much need, whatever one does is never perceived as enough. Second, when people have had extensive and varied experience with development organizations and programs, they expect research projects to deliver the same tangible products they obtained from other service delivery projects. People's expectations are also affected by what they observe about the behaviour of development organizations, and I will elaborate further on this below. Third, research projects, by their very nature take from subjects, and reciprocity in a practical sense is expected. Reciprocity in people's preferred terms may not be in the mandate of the research and thus, it is practically impossible to fulfill people's expectations. However, I feel after my experience in the field, that it is unethical for research projects not to give back in some way. This might be in the form of knowledge, mentoring, advocacy work or program development. The latter seems to be more valued and to meet more closely people's expectations, so I strongly suggest that every effort be made to link research projects to program funding. At the very least, I feel that researchers must make the effort and take the time to find ways of giving back. The consequences of not doing so are several, and include: poor relationships and cooperation in research projects, which can affect the quality of data and outcomes, poor relationships and cooperation with researchers who come later, and feelings of exploitation in those with whom we work. I will pursue this theme in the next section.

4.6.2 Development culture and its implications

People in lower income countries like Uganda are exposed to development organizations, researchers and aid workers frequently and have their own perceptions about development practice. More than half the country's income comes from outside donors and there are over 700 NGOs working there; their presence is impossible to miss. We are perceived as wealthy, privileged and superior; what we do and how we act reinforces this, as workers drive around in expensive cars, hold workshops in upscale, westernized locations, spend money on

expensive food and lodging, and pay excessive per diems and reimbursement for services by local standards.

Even when projects are run by nationals, people observe what they consider rampant spending and conduct aimed at personal gain. Project managers who try to run projects with the ethic of spending project money frugally to maximize its benefits to the project are ostracized by co-workers and friends who see prospects for personal gain. People perceive NGOs and outsiders as opportunities not only for learning but also for social and financial benefit. For example, there is a dual pricing structure – one for locals and one for NGO funded projects. People know NGOs have deep pockets and charge accordingly.

Over time, people have come to see NGOs and outside researchers as a bottomless source of funds and this has created a culture of manipulation, expectation, resentment, entitlement, dishonesty, and suspicion among local people. Those who work for NGOs are beset by many of these negative social forces. Our presence, with all its baggage, reinforces existing, deeply felt class distinctions and a pervasive mindset in the workforce of 'take while you can'. There is some indication that the expectation of financial gain has actually contributed to a loss of 'volunteerism' in community members, which is a serious impediment to building and maintaining sustainable, community-based programs. A loss of volunteerism also makes rebuilding strong communities, badly weakened by the HIV/AIDS epidemic, that much more difficult.

What can be done about these unfortunate perceptions and implications? The lessons for development practice are:
- We need to market to research participants the ways in which they benefit from our work and match these as closely as possible to clearly negotiated expectations.
- We also need to visibly model to nationals the ethical principles and expectations that drive the research – walk our talk, and avoid doing and living in ways that generate jealousy, resentment and unrealistic expectations.
- We need to model transparency and accountability to clearly demonstrate these principles. As well, we need to follow up with *long term* monitoring and guidance to get the most out of development funding.

4.6.3 Program funding

As noted above, my research experience helped me see that it is important for research projects to be linked in some way to program funding. I would add that that facilitation of program development and support must also have a *long term* mandate. Why? Because many countries have barely emerged from extensive periods of instability, which have constrained infrastructure and economic development and weakened governance. In Uganda, for example, the historical context shows that a relatively positive climate for development has existed for only a short time, that is, in the last twenty years. Real change will take decades more, especially when fundamental structural problems exist, such as corruption, civil unrest, tax evasion, lack of awareness about and enforcement of human rights, as well as

a weakly developed infrastructure. Development processes here are further challenged by new global influences and the catastrophic effects of the HIV epidemic. Our program development timelines should consider these issues. Many donors' programs are limited to periods of one to five years, but real change cannot be expected or properly measured in such short time periods. Change will quite naturally take many years, and short term funding and programs only set people up for disappointment, failure and hopelessness. It is another form of social violence.

4.6.4 Capacity building

My research aimed to build capacity in small ways with young people and other community members (for example, to develop research, technical and leadership skills). This grounded experience and my observation of previous small-scale capacity building activities in the community generated a few insights.

While people were eager to learn from capacity building activities during the research and did gain some experience, I could see that there were few opportunities for people to practice and further develop their skills and knowledge. I attribute this lack of opportunity, in large part, to structural problems such as lack of financial support and encouragement for youth leaders, lack of access to education and employment, poverty and a pervasive distrust of 'the system', which breeds apathy and hopelessness – the enemies of action. Short term capacity building initiatives will not go far in solving long term structural problems, and in fact may be relatively useless when people are prevented from practicing, or further developing their newly built capacity *because of* structural problems. Capacity building is an ideal concept, full of good intentions, but hollow when it is short term and there are few opportunities for people to apply skills and knowledge. We must self-consciously ask, 'capacity for what ends?'

Capacity building can also be harmful if erroneous assumptions are made in the beginning about what people know and their learning is incomplete, because when things go wrong, they are blamed. Since capacity building often involves shifts in deeply ingrained behaviours and ways of thinking, it should also include on-going support, mentoring, problem-solving and opportunities for further learning. As capacity builders, we should also be mindful that the undertaking is a mutual learning process and be prepared to question our biases; we should be open to the possibilities presented by other 'ways of knowing and doing'.

4.7 Contribution to knowledge/policy

This research makes a number of contributions to knowledge, and I hope ultimately to policy and program development. Its contributions are noted below, and more may emerge as analysis continues.

- The research produced a rich picture of young people's experience in a small Ugandan town, the issues they face and how they reason about their lives. It showed

that some things have not changed over the last decade, and these continue to affect the health and well being of young people in spite of government policy aimed at change. Young people are still deeply affected by ingrained gender issues and discrimination. They also have a serious lack of knowledge about sexual health, and pervasive fatalistic thinking. They continue to be highly vulnerable to HIV transmission, despite reports of falling HIV infection rates in Uganda.

The research also showed that some things may be changing: too many children are growing up with uncertainty and a lack of adult guidance and attachment; there is increasing materialism and sex for 'stuff'; sex is losing its meaning and is more openly about girl power; young people are losing interest in the institution of marriage; they are losing faith in their leaders and political system; and global and Western influences are changing the cultural landscape of Uganda.

Fundamentally, the research points to a need for intensified and sustained programming aimed at young people's health, in its widest sense. Programs specific to their needs and experience is critical.

- The research tested and demonstrated the potential of a compelling new methodology (the visually-enhanced conceptual event), which is both a research method and a *mediating experience* aimed at personal and social change.
- The research also demonstrates the principles of a model for activist social science research which is community-based, participatory, involves multiple partners, and is aimed at building capacity and polity change.
- The research established a strong foundation for program development and motivation for change in the community. It demonstrated the need for a coordinated commitment of resources to achieve the community's goal of helping young people and influencing policy change.
- The research illuminates the need for a fundamental shift in donor philosophy, from short-term program funding to one that considers longer-term strategies, in order to give change a chance. The *"Strong Voices"* research provides a grounded example which illustrates that capacity building and social change occur very slowly, especially in newly evolving governance structures. Their needs are incompatible with the short- term strategies and programs of most donors.
- The research revealed that the potential for active youth leadership exists; however, the support and encouragement of young people's participation, which is critical for their leadership development and future political involvement and action, is lacking. Policy purported to involve and benefit youth must be supported with program funding and political will.
- The research proposes that development research projects incorporate time and resources to enable policy work and activism.

5. Impact

The impact of the project will be discussed in two ways: 1) as it relates to reach, (the reception and use of knowledge), and 2) impact, (the implications for policy and development).

5.1 Reach

The knowledge produced as a result of this work reached many people in the community and has the potential to reach numerous others. Young people, both in- and out-of-school, produced, learned from and creatively responded to knowledge they produced. They were eager to become ambassadors and share their experience with their friends. Some young people started showing the videotapes and holding discussions in their schools. Others wrote and performed plays based on what they had learned, spreading the reach of the knowledge they and their friends produced.

Their knowledge also reached adults in the community such as teachers, parents, health workers, sexual education counselors, political, administrative and religious leaders, and representatives of NGOs and CBOs. They listened to and thoughtfully interacted with the knowledge, producing their own knowledge and action plans. Parents now want to hold discussions with other parents, and teachers want to monitor the behaviour of their peers and hold discussions in their schools and with parents. Sexual education counselors want to recruit and train more workers to respond to young people's needs. Town politicians and administrators see that changes are needed in the social environment and with school bursaries/funding and want to continue the discussions with a wider representation of officials. Religious leaders from different faiths, who have never met together before, have organized a committee to discuss how faith communities might respond to young people's needs. Representatives from area NGOs and CBOs are contacting members of parliament, and members of the local research team are eager to carry information to policy makers.

The young people and adults who participated keenly want these activities to become a permanent program offered through the local Community Development Centre, using the videotapes as a resource. They feel it is important to continue discussions on harassment and discrimination, gender and relationship issues, behavioural issues, sexual health education and influences in the social environment, so that other young people can learn and reflect on their own vulnerability. Every adult feedback group, also wants such discussions to continue in order to sensitize and involve the wider community in action to improve young people's well-being.

There is great potential here to extend the reach of this work and mobilize and capitalize on the leadership of young people. Young people need the opportunity to practice and develop their skills with others, but the funding is not there to support such activity. By way of example, one of the young men who wanted to show the tapes and hold discussions in his school met a variety of obstacles. He had to convince the head teacher to make time, then

find and rent a VCR with money out of his own pocket. It cost him the equivalent of C$ 5.00, which is significant for a boy who is an orphan and does not have enough money to pay his $70.00 school fees. He felt so strongly about bringing the discussion to his peers, he carried his uncle's TV across town to the school and borrowed the $5 for the VCR. Twice the people with the VCR let him down but he persevered and managed to hold one session. This demonstrates his commitment and leadership but clearly such activity needs on-going support. The costs would be little, and the potential benefits could be great, not only for young people's health but also for their personal development. Support of such activities would give young people the opportunity, experience and the social profile to become leaders and extend the reach of the research.

People who participated (both young and old) said they also want people in other parts of the country and Africa to have access to the videotapes. We only had time to show a sample of the work to the Rakai Project youth program director, and he immediately asked for copies. Another local NGO also asked to use the tapes in its programs. This potential for wider use of the knowledge resources is exciting, but before it happens, the tapes need more technical work, such as added subtitles, voice-overs in other languages and further editing. As well, I would like to prepare a manual for facilitators to accompany the tapes, with an index of topics and corresponding tape times where topics can be found on each tape, since there are over 70 hours of tape. To produce such a resource properly is another project which requires its own time and resources.

5.2 Impact on decisions/development

At the local level, this work has the potential to affect decision-making concerning the well-being of young people. Uganda has decentralized government and decision-making is at the local level, so opportunities to make local change should be maximized. All sectors of the community and many of the town's influentials were involved in this work so they are now fully aware of how young people are disadvantaged and marginalized, and how they are affected by issues in the social environment, the school and the home.

There are people now who have new motivation and the will to take action around such issues as human/children's rights, law enforcement/safety, school bursaries, teachers' standards of behaviour, responsible child care and the needs of orphans. The challenge we face now is to find ways to nurture and facilitate this momentum so that influence for change can be exerted in the right places.

The project showed that there is a place for young people in this kind of change for development.   I was struck by how powerfully they responded to an experience that encouraged them and showed them possibilities. They were very hungry to learn. They agreed on ways they could work together to be taken seriously and help their fellow youth. Another election will take place in 2006 and some young people who see the need and potential for change may be a strong influence on its outcome. They may eventually become

political leaders themselves, but they know that change will be slow. They need nurturing, facilitating and more opportunities to develop their leadership so they can mobilize other young people and be ready when their time comes.

6. Overall assessment

My overall assessment of this research project, considering the investment of time, effort and funding involved is that it was highly successful. For graduate research, this was a 'dream big' project in its scope and complexity (so I have been told). I am very grateful for the support of IDRC, SSHRC, the community, the field research team, NGO and university partners (particularly Salama SHIELD Foundation, and McMaster and Makerere Universities) and my family. The research was costly in relative terms, but spending was managed carefully and frugally. Sometimes this was a source of friction in the research team, but we made every shilling count. Given its impact on the young people and other community members, and its potential to generate future change, I consider that it was money well spent.

It was also a big investment of time and effort on many people's parts and we were often very tired. But the way people responded to the opportunities the project provided was extremely motivating and rewarding. It was clear from their feedback that community members valued the research highly and felt it was important. They were very aware of the time and effort spent on the work and the commitment it involved. They realized that this was not 'hit and run' research, which in my opinion and I think theirs, objectifies, disrespects and primarily *takes* from research 'subjects'. Community members in this case saw that the research was concerned with building relationships, valuing their knowledge, and giving back to the community. Because of this, they saw not only the research but also themselves differently.

From my own perspective, doing this research was a privilege and an immensely worthwhile experience. Its value to my learning and career has been huge. I am pleased that the research met its primary objectives and that it fulfilled my own personal objectives – that it made a difference to people's lives; that it generated data that will be useful to program and policy development; that produce practical and academic knowledge in the area of health and development; and that was 'ethical'. What I mean by this is that it considers the questions "research for whom, by whom, and for what purpose?" If my aim for the project had simply been to get (take) data for a dissertation, the project would have been simpler, less costly, and shorter. But I would not have considered this ethical, and neither would the community members who want (and deserve) to be respected and to benefit too. Thus, the research was driven primarily by community needs and the participants; the results have been communicated and are accessible, relevant and useful to the research users; and we all worked together on a common human project of understanding and making better lives.

The ethical challenge and question now is how to maintain the momentum, keep the dialogue going and facilitate the development of longer-term program activity. This is especially important in light of the fact that there has been a research presence in the community for over a decade, and now people are hoping to see real, sustained action and change.
They feel it is time for a commitment to programs that will help the most vulnerable in the community, and that these will be run through the new Community Development Centre[15]. It will be tangible evidence to community members that change is possible.

7. Recommendations

To this end, I would like to make recommendations in a number of different areas. Some relate to young people and their program and funding needs; others relate to development practice; and the last, to the funding of student research and capacity building. These recommendations address only a small proportion of the issues raised in the course of data gathering which need attention, for example, HIV treatment and care. As data analysis and work in the community continues, other recommendations may be put forward.

7.1 Recommendations relating to young people and the community

A primary goal of this research was to identify issues in young people's lives which make them vulnerable to HIV transmission, and involve them in generating solutions. The recommendations here reflect young people's articulated needs and ideas, those expressed by adults in the community and a synthesis of understandings from the data by participants and the researchers.

Recommendation 1: Comprehensive program development for young people

We recommend that funding (Government and NGO/CBO) for program development and delivery in this community should comprehensively target the young people's needs listed below. Each represents a gap in existing programs and services that adversely affects the health, well-being and development of young people in this place today. Each is critical to the future of young people, the social fabric of the community and subsequent generations of Ugandan citizens.

A. It is recommended that programs which offer young people *knowledge about sexual health, guidance in developing life skills, and comfortable opportunities to discuss* issues that make them vulnerable to HIV transmission be developed and implemented.

---

[15] The CDC is being built by Salama SHIELD Foundation with funding from Rotary Canada, CIDA, and other Canadian donors. The CDC will be run in partnership with a community-based organization (KATUWA) in the short term, with full community ownership as a long term goal.

Further, it is recommended that such programs:
- **Start before young people are sexually active, i.e. mid-primary school.**
- **Be continuously available.**
- **Be accessible to both in-school and out-of-school youth.**

The research found that knowledge, guidance and opportunities for discussion are badly lacking for young people and are urgently needed. Increased emphasis on funding research and programs related to treatment and care is eclipsing the continuing need for strong prevention programs. Message fatigue may exist for those who have heard them, but new generations of young people get little information, misinformation, or information that does not relate to their own particular young lives.

The research also found that the majority of young people (particularly girls) are sexually active by the time they reach their teens, so they need access to good information, opportunities to ask questions and a forum for developing life skills while in middle primary school. This programming should continue all the way through secondary school, so as young people develop and are exposed to new situations, they can be continually sensitized, can access the information and counseling they need, ask new questions, and develop age- and experience-related skills. Since many young people drop out of school and would therefore lose access to such programs, special effort is needed to reach these marginalized and disadvantaged young people, who have particular situational needs.

B. It is recommended that programs which provide young people with access to *'youth friendly' guidance and counseling* be expanded, strengthened and supported. An existing community program – the *Ssenga and Kojja* program [16] (see earlier footnote) – could respond to this need.

The research found that young people have few places to turn and feel truly alone in the world. There are many reasons for this. Too often young people can not talk to their parents because they have died, are away working, are too busy, too harsh, or unwilling to communicate with their children. Relatives too have died, moved away or have become bad role models for, and abusers of, these children. Young people also do not trust many other adults in their lives (e.g. religious leaders, teachers, health workers etc.), who also harass or abuse them. As well, more and more young people are living away from home, often on their own, either because of problems at home or to access better schools and improve their chances of getting into university.

---

[16] Details about this community-based prevention program, which came out of the IDRC funded PAR research and is now supported by Salama SHIELD Foundation, can be found in the original project proposal. The *Ssengas* and *Kojjas* are to be congratulated for their important volunteer work and commitment to building a caring community. They participated actively in the research discussions and a number of other research activities.

A *Ssenga* or *Kojja*, who would be a neighbour and trained sexual health counselor, is well positioned to provide confidential, accessible information and support to young people, couples, and parents/guardians. The *Ssengas* and *Kojjas* also help deliver sexual health information and counselling in schools, but currently there are only a handful of volunteers trying to fill a huge need. The program should be expanded and well supported since it has the potential to respond to young people's need for guidance and counseling.

> C. **It is recommended by the community that confidential, *youth-oriented health services*, treatment for sexually transmitted infections (STIs), family planning and relationship counselling be established at a clinic located at the CDC.**

The research found that young people feel stigmatized and embarrassed accessing such services at local clinics because they might be seen by someone they know, and the clinic staff often treat them badly. As well, at the government health centre drugs to treat STIs are usually not available, and drugs in private pharmacies are too expensive. As a result, many young people suffer from infections, become pregnant, seek abortion and risk other threats to their health. Many lack basic knowledge about anatomy, family planning, condom use and sexually transmitted infections.

If the clinic is established at the CDC, young people would be able to drop in for health services, counseling, drugs or condoms when they are there for recreational activities. It would be a youth-friendly environment which responds to young people's health needs.

> D. **It is recommended that a *comprehensive social and recreation program of activities* be developed for young people, and that these are offered through the CDC. A community commitment is needed to make such activities sustainable.**

Both young people and adults commented during the research that young people here have nothing to do, and when they are idle, they get involved in risky activities. 'An idle mind is the devil's workshop'. In town, many young people are bored since there is little employment or healthy recreation, especially during school breaks and the long holiday for school leavers, which is 10 months. Young people know that the entertainment found in video halls, discos, bars and 'hang out' places where drugs are consumed puts them at risk. They say they need a place to meet their friends and access healthy recreational activities and interests, like sports and board games, music and discussion groups, drama clubs, and reading and study materials. The new CDC hopes to organize such activities and provide young people with a badly needed social alternative to risky places; it would be 'their place', where they can come together and participate in leisure, health and leadership activities, (see next). Community leaders especially need to be committed to sustaining the programs with funding, and young people to promoting and supporting them.

F. It is recommended that an *internship program aimed at leadership and personal development* for young leaders be establishment and run through the CDC.

The research found there are few opportunities for young people to develop personal and leadership skills. An internship program would involve young people with leadership potential in developing and running programs (discussions, sports, entertainment, youth leaders' conferences) for the CDC, while developing their own personal skills with mentors and gaining experience, perhaps in exchange for educational scholarships.

G. It is recommended that a comprehensive effort to *improve young people's access to education* be constituted. It should include:
- **Upgrading and coordinating bursary programs, and ensuring transparent distribution of funds.**
- **Strengthening local schools through improved standards and access to educational resources such as textbooks.**
- **Programs to sensitize adults about the value of education,**
- **Programs to support parent/teacher relationships and cooperation.**
- **Programs to provide adult literacy and help school drop outs return to school.**
- **Advocacy by youth leaders, teachers, NGOs and field staff aimed at the central government to fulfill its promises of universal secondary school access and alternative skills training institutions in each sub-county.**

Young people must be able to go to school. The research demonstrated that dropping out of school presents many risks for young people and increases their vulnerability to HIV. Lack of school fees are a real problem for many young people, causing them to drop out of school permanently or for extended periods. Difficulty finding fees interferes with students' ability to achieve, because of the worry and time spent away from school looking for money. Many students also cannot afford to buy books, supplies or uniforms. Some government and NGO bursary programs exist, but parents and students are concerned about the lack of transparency of the bursary distribution process and want proper monitoring. Funding for bursaries should be a higher priority for the local government, coordinated with the work of other agencies doing the same work, and should ensure bursaries are distributed to the truly disadvantaged.

Young people's access to education is also affected by the poor quality of local schools; local schools need strengthening. Students are educationally disadvantaged in poorer schools, which tend to have poorer teachers, poorer facilities and very few textbooks. This negatively affects students' educational achievement and subsequent access to post-secondary education through government sponsorship – a classic case of the poor staying poor while funding and advantages go to those who are better off. Even the simple purchase of textbooks for the library at the CDC would give students access to resources for learning they can't get in school.

Another influence in lack of access to education is that it is not valued in this town by many parents/caregivers and other adults. Both teachers and young people say that this results in parents not paying fees, making children work, and marrying girls off. Sensitization programs are needed and could be run through the CDC, perhaps by teachers, parents and the *Ssengas* and *Kojjas*.

Many parents themselves are not well educated and are not involved in their children's education. Teachers, parents and young people who participated in the research all said a stronger relationship between parents and teachers would improve the quality of young people's educational experience and their success.

Many young people we talked to who had to drop out of school would like the opportunity to return and finish. This should become a policy item for discussion with teachers and local politicians. Adults too asked for literacy programs and opportunities to finish secondary school.

> **H. It is recommended that several strategies be instituted aimed at** *protecting children's legal rights and decreasing the amount of harassment and sexual and physical abuse* **they experience. These include:**
> - **Sensitization programs and local commitment to uphold Universal Children's Rights and fight discrimination.**
> - **Training of child advocates and sensitization for young people about where they can go for help.**
> - **Local access for young people and parents to legal advice.**

The research showed that young people are frequently sexually and physically abused and their legal rights are ignored. They need protection and advocacy. There is an urgent need to plan and implement an active, high-profile, community-wide sensitization program about Children's Rights and gender and age discrimination, targeted at all sectors of society (e.g. young people, businesses/employers, health, law enforcement, schools, religious and political leaders, parents/guardians, NGOs).

People need to discuss and understand what constitutes abuse and discrimination, how this relates to their learned cultural values, and the consequences and sanctions there are against those who abuse and discriminate. There then needs to be a commitment by local leaders and law enforcement officials to impose sanctions and reinforce messages about rights and discrimination.

At the same time, young people, who learn about Children's Rights at school need to know where they can go for help with problems of discrimination and abuse. We recommend the identification and training of child advocates who have the support of local leaders and law enforcement officers to investigate and sanction those who discriminate or abuse. As part of their learning about Children's Rights, young people need to be sensitized about the responsibilities that come with their rights.

Young people need local access to legal advice for serious problems, such as land and property inheritance disputes. A visiting lawyer program should be instituted whereby young people can seek free legal counsel in the local community for their problems. Not infrequently, relatives of orphans steal land, property, and/or income left to them by parents. Often, orphans are not aware of their rights, but if they are and want to fight for their inheritance, there are many barriers. They do not know how to access lawyers or have the income to pay them. Young people also do not have the income to repeatedly travel long distances to the capital, Kampala, to search for someone to help them. If they are going to school or working to stay alive, they cannot spend the considerable time required going through layers of time-consuming bureaucracy, nor can they fight the corruption and power that works on the side of the relatives. In the end, orphans give up and suffer.

Parents planning for their soon-to-be orphaned children could also benefit from the recommended legal counseling program in order to protect their children's rights and property from scheming relatives.

> **I. It is recommended that a comprehensive program to enhance access to employment be developed and instituted. This would include:**
> - **Sensitization and education about saving money and life planning.**
> - **Career guidance (assessment of academic strengths, advice on career and studies choices)**
> - **Entrepreneurship training and development.**
> - **Access to apprenticeship opportunities.**
> - **Youth accessible start-up financing and business training.**

Poverty underlies many of the problems experienced by young people and with few jobs, they see little way out. Young people need to work. Opportunities to plan and prepare themselves for the future are critical if young people are to have any hope of extricating themselves from repeated cycles of poverty. Those in school are desperate to have guidance on choosing the academic subjects which will optimize their chances of future work and further education. They also need advice about short term work planning, saving and money management as they struggle to pay school fees or support siblings. Young people who have dropped out of school try to find daily work to survive and few think of the future. They need opportunities to learn about longer-term planning, saving small amounts of money, apprenticing to develop technical skills (e.g. trades), start-up funds for buying tools, machines etc. Currently, they are unable to start their own businesses even if they have found training because existing loan systems require security deposits. Without access to the comprehensive program recommended above, young people will remain in poverty.

> <u>Recommendation 2:</u> **Coordinated program delivery and development for change.**
>
> **It is recommended that funding be sought and committed for staff to a) consolidate the work begun by this research; b) to develop, implement, monitor and evaluate the above programs; and that their delivery be**

coordinated under the umbrella of the town's newly built Community Development Centre (CDC).

Further, it is recommended that funding be sought to support regular networking and communication among community leaders and all those delivering programs in the community, with the overall goal of developing policy changing strategies, improving access to resources, identifying program gaps and setting community priorities.

The work and momentum generated by this research need consolidation through a community meeting to determine next steps. A coordinated and holistic approach would be better able to influence policy from within and ensure that scarce resources are targeted at the most pressing problems. Such an approach is now required by some donors. For example, a recent district funding initiative required communities to perform an analysis of overall needs and set priorities in order to be eligible for funding.

It is also recommended that the CDC administrators/coordinators assume leadership for these networking, coordination and communication functions among program providers and users in the community.

Such organization and coordination does not currently exist in this community. Poor communication among community program providers, leaders and interested citizens is a common barrier which prevents people knowing about and attending meetings, accessing educational and funding opportunities, and sharing scarce resources and information. Since a number of different programs will be based at the CDC and it is a physical and symbolic space of common-unity, such a role seems appropriate. Leadership of this kind would facilitate a more effective and efficient distribution of information about meetings, programs, learning and funding opportunities.

Finally, it is recommended that the CDC administrators/coordinators compile an inventory of program providers, the service each delivers, client eligibility requirements/restrictions and contact names and numbers.

With this information at hand, community members can access information and be guided to the right places for assistance in a timely manner. The CDC could not only work for the benefit of program providers but also program users by functioning as a kind of 'clearing house' or 'bulletin board' for program information.

<u>Recommendation 3:</u> **Orphan care and support**

It is recommended that appropriate funding be obtained for orphan care and support, and that this problem get urgent attention involving problem solving with all sectors of the community.

Care and support of orphans is a heartbreaking problem of immense proportion in this community and the surrounding villages. A few local NGOs and CBOs help as many orphans as they can, but there are far too many for the resources that exist. Orphans in the villages live without the bare necessities of food and shelter, and they have huge responsibilities and emotional burdens. Many end up coming to town to look for work as housemaids/boys or bargirls, entering new cycles of risk; others hang about, exposed to the risks of street life, and end up in trouble with the law for stealing. The physical, social and emotional needs of these young people are not being met and the consequences are frightening. They are the most disadvantaged, vulnerable and marginalized young people of all. Some local residents in town try to help orphans by taking them in, but such families have so few resources that they can barely survive. Such social suffering needs an urgent, coordinated effort to meet the burden.

7.2 Recommendations relating to development work

Recommendation 4: Funding for advocacy and policy work

It is recommended that funding be available for carrying out advocacy and policy work if a research project's results merit such activity.

More and more, research has implications for policy development but it takes considerable time and incurs costs to raise awareness and influence the thinking of policy makers. Without this critical activity, it is difficult to see how our research can effect policy/structural change. If such funding is not possible, perhaps policy work should be another component, like evaluation and monitoring, that we need to allow time for and build into project budgets.

Recommendation 5: Linking projects to long-term program funding

It is recommended that research projects be linked to program funding, and that this funding be long-term rather than short-term, quick fix support.

When we do our research, we set up expectations in research users that something will happen as a result. For our work to be truly ethical, we need to be able to take the next step and ensure that program activity is possible – otherwise, we are just doing the research for ourselves. In addition, the time between research project and program should be as short as possible, especially when we are dealing with problems like HIV, where two or three years can change a child's life; they cannot wait.

This report has argued elsewhere for funding be *long-term*, and that it consider the historical development context of a situation when development decisions are made. See also the related discussion on the need for context-specific, long-term capacity building.

7.3 Recommendation relating to student research

Recommendation 6: Mentorship award program for graduate students in LICs

It is recommended that a mentorship award program be developed for graduate students in lower income countries (LICs) that would support their research, permit them to disseminate their work, and give them the opportunity of an internship (mentorship) for research/study or employment experience in Canada.

Further, it is recommended that the idea of graduate student research teams, as pilot tested by this research, be pursued and incorporated in the mentorship award.

There is very real value in enabling graduate student research with award programs. As I discussed earlier in section 6, the research support I received from IDRC has enabled me to access opportunities and experience that would otherwise have been unavailable. Because of the interactions I had with graduate students in Uganda during the course of my research, I think they would benefit greatly from a research/study mentorship award.

Many students I met hope to leave their home country and gain outside experience, which they feel is important for their personal growth and development. A mentorship award would broaden their perspectives, expose them to other possibilities and enable them to develop a rich network of new contacts. Students who gain opportunities overseas are usually more employable when they return home and better able to contribute to the development of their country – a fact noted by a Ugandan member of parliament who advocates out-of-country experience for students. Certainly while in Canada, awardees could contribute greatly to *our* learning if the mentorship program would provide opportunities for this.

Because of the Student Research Team project, I learned that relatively small amounts of money (approximately C\$ 2,000) would enable graduate students in Uganda to carry out their research projects. However, students also need access to academic resources, mentoring and mechanisms for making their research findings accessible to others, both within and outside their country. Faculty at the university noted that there is a large body of valuable information being produced by students that never sees the light of day. The recommended award would respond to all these needs and build Southern capacity in a way that does not happen when the North goes South. Further, it would not just teach students skills but would provide students with opportunities to practice and further develop what they have learned – often a missing link in capacity building when it occurs in LICs. If young people are to become future leaders, they need as many opportunities to broaden their experience and develop skills as possible.

Literature Consulted and/or Cited

Abu Lughod, Lila
    1991   "Writing Against Culture." In *Recapturing Anthropology: Working in the Present.*
           Richard Fox (ed.) Santa Fe, N.M.: School of American Research Press. Pp 137-162.

Bohmer, Lisa and Edward Kirumira
    1997   "Access to Reproductive Health Services: Participatory Research with Adolescents for
           Control of STDs." Report, December 1997. Pacific Institute for Women's Health.
           http:\\ www.piwh.org/publications.html

Comaroff, John L. and Jean Comaroff (eds.)
    1999   *Civil Society and the Political Imagination in Africa: Critical Perspectives.* Chicago, Ill.:
           The University of Chicago Press.

Csordas, Thomas
    1993   *The Sacred Self: A Cultural Phenomenology of Charismatic Healing.* Berkeley:
           University of California Press.

    1994   *Embodiment and Experience: The Existential Ground of Culture and Self.* (Editor)
           Cambridge: Cambridge University Press.

Evans, J. et al
    1990   *Health Research: Essential Link to Equity in Development.* Commission on Health
           Research for Development. Toronto: Oxford University Press.

Farmer, Paul
    1992   *AIDS and Accusation: Haiti and the Geography of Blame.* Berkeley, California:
           University of California Press.

    1999   *Infections and Inequalities.* Berkeley: University of California Press.

Farrah, Francois and Rose Nalwadda
    nd   "Uganda Programme for Enhancing Adolescent Life (PEARL)." Government document.

Freire, Paulo
    1970   *Pedagogy of the Oppressed.* New York: Seabury Press.

    1973   *Education for Critical Consciousness.* New York: Seabury Press.

Hall, B.
    1981   "Participatory Research, Popular Knowledge, and Power: A Personal Reflection."
           Convergence 14(3): 6-19.

Johnson, N., N. Higgenbotham, and R. Briceno-Leon
    2001   "Best Practice and Future Innovations in Applying Social Science to Advancing the Health of Populations." In *Social Sciences and Human Health: Case Studies from the Developing World.* London: ZED Publications. (In press)

Korten, D.
    1984   "People Centred Development: Towards a Framework." In D. Korten and R. Klauss (eds.) *People Centred Development.* West Hartford, CT: Kumarian Press. Pp. 299-309.

MacDougall, David
    1998   *Transcultural Cinema.* Princeton, Mass.: Princeton University Press.

Merleau-Ponty, Maurice
    1964   "The Eye and Mind." In *The Primacy of Perception.* J.M. Edie (ed.) Evanston, Illinois: Northwestern University Press.

    1992   *The Phenomenology of Perception.* London: Routledge and Kegan Paul.

Mitchell, C. and A. Smith
    2001   "Sick of AIDS: Towards Reconceptualizing the Meanings and Significance to Life of Literacy for South African Youth." Paper presented to the International Conference on "National and Cultural Identity in Children's Literature and Media." University of Reading, April 5-8, 2001.

Msimang, Sisonke (UNIFEM)
    2001   Member Comments re: Youth Involvement in UN General Assembly Special Session on AIDS (UNGASS). Break-the-Silence discussion list, June 20, 2001.

Mukwaya, Janat
    1999   "The AIDS Emergency." *Progress of the Nations 1999.* UNICEF

Naamara, W., and F. Plummer
    1988   "Cross-Sectional Study of HIV Infection in SW Uganda." II International Conference on HIV/AIDS in Africa. Naples, October 1988.

Scheper-Hughes, Nancy and Margaret Lock
    1987   "The Mindful Body: A Proglomenon to Future Work in Medical Anthropology." *Medical Anthropology Quarterly* 1: 6-41.

Schoepf, Brooke
    2001   "International AIDS Research in Anthropology: Taking a Critical Perspective on the Crisis." *Annual Review in Anthropology* 30:335-61.

Spittal, Patricia
    1997   "It is Finished, We are Dying." In *Nurtured by Knowledge: Learning to Do Participatory Action Research.* New York: Apex Press.

Tilley-Gyado, Abiola, Noah Lukoda, Iyeme Efem
    2001   "A Strategy to Attain the Global Goals for Orphans/Vulnerable Children." Paper presentation at the 8th Canadian Conference on International Health, Nov. 21, 2001, Ottawa, Canada.

Topouzis, Daphne
    1994   "Uganda: The Socio-economic Impact of HIV with an Emphasis on Youth." Report for the FAO. http://www.foa.org/docrep/t2942e/t2942e02.htm Accessed January 4, 2000.

Ugandan AIDS Commission, Government of Uganda, Joint United Nations Programme on AIDS
    2000   "The National Strategic Framework for HIV/AIDS Activities in Uganda: 2000/1 - 2005/6"

UNICEF
    2001a   "Adolescents and HIV." http://www.unicef.org/programme/hiv/youth/youth.html Accessed April 28, 2001.

    2001b   "Young People and HIV Counselling and Testing." UNICEF Gender, Partnerships and Participation Programme. http://www.unicef.org/programme/youth/hiv/vccov.html Accessed March 28, 2001.

UNGASS   United Nations General Assembly Special Session on AIDS, June 2001.
  2001

Walker, Susan
    1999   *Many Voices in Dialogue: Translating Research Evidence into Community-based HIV Interventions.* Hamilton, Ontario: M.A. Thesis, Department of Anthropology, McMaster University.

    2000   "Action Through the Aesthetic: Possibilities for the Visual in Anthropology." Unpublished manuscript.

    2001   "How, and to What Extent, Can Visual Methods Enhance Participatory Processes?" Unpublished manuscript.

Walker, Susan and Dennis G. Willms
    1998   "Ethno-cultural Community-Based HIV/AIDS Interventions: Translating Research Evidence into Action." Presentation to the 5th Canadian Conference on International Health. November 17, 1998. Ottawa, Ontario

Wallman, Sandra
    1997   "Appropriate Anthropology and the Risky Inspiration of 'Capability Brown': Representation of What, by Whom, and to What End?" In *After Writing Culture: Epistemology and Praxis in Contemporary Anthropology.* Alison James, Jenny Hockey, and Andrew Dawson (Eds.) London: Routledge. Pp. 244-263.

Wang, C. and M. A. Burris
    1994   "Empowerment Through Photo Novella: Portraits of Participation." *Health Education Quarterly* 21(2): 171-86.

Warry, Wayne
    1992   "The Eleventh Thesis: Applied Anthropology as Praxis." *Human Organization* 51: 155-163.

Wawer, M.J., D. Serwadda, S. Musgrave
    1991   "The Dynamics of Spread of HIV Infection in a Rural District of Uganda." *British Medical Journal* 303: 1303-1307.

Wikan, Unni
    1991   "Toward and Experience-Near Anthropology." *Cultural Anthropology* 6: 285-305.

    1992   "Beyond the Words: The Power of Resonance." *American Ethnologist* 19: 460-482.

Willms, Dennis
    1998   "An Argument for Supporting Translational Research and an Intervention Science." Paper presented at AFRICLEN workshop on the "Translation of Evidence into Action." Harare, Zimbabwe, October 21-23, 1998.

    2000   "Advancing *Translational Research* and and *HIV Intervention Science*: Designing, Disseminating, and Evaluating 'Enabling Resources' for Behaviour Change." Career Scientist Project Description, submitted to the Ontario HIV Treatment Network.

Willms, Dennis and Nelson Sewankambo
    1995   "The Risk Reality Model: An Ethnographically-Derived Model for Eliciting and Explaining Socio-Cultural Deteminants of Risk for HIV/AIDS." Oral presentation to the 9th International Conference on AIDS and STDs in Africa. Kampala, Uganda. December 10-14, 1995.

Willms, Dennis, Alfred Chingono, Maureen Wellington
    1996   *AIDS Prevention in the Matare and the Community: A Training Strategy for Traditional Healers in Zimbabwe.* Hamilton, Ont.: Department of Anthropology, McMaster University.

Willms, Dennis, Susan Walker, Gertrude Khumalo-Sakutukwa, Alfred Chingono
    2001   "*Dialogues for Life*: Generating HIV Prevention Strategies with and for Women and Men in Zimbabwe." Unpublished documents.