

Conference Report*

Barriers to Health and Well-being:
A Conference on Race, Class, and Gender in Northeastern Nova
Scotia

May 12 and 13, 2005

Held at
The Keating Millennium Centre
St. Francis Xavier University
Antigonish, Nova Scotia, Canada



Hosted by:
The Race, Class and Gender Health Research Group
St. Francis Xavier University

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The StFX Centre for Regional Studies

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This Conference Report is dedicated to the people of Northeastern Nova Scotia. We give special thanks to our speakers Kerry Prosper, Sister Rita MacEachern, Josephine Etowa, Jean Knockwood, Christine Johnson, and Evelyn Lindsey.

BACKGROUND

The Barriers to Health and Well-being Conference was initiated by a group of researchers and community activists from St. Francis Xavier University and the surrounding area. This group came into being as a result of the Poverty and Social Inclusion Symposium which was held in November 2004. This was one in a series of symposiums sponsored by the Guysborough Antigonish Strait Health Authority, St. Francis Xavier School of Nursing and St. Francis Xavier University.

The symposium highlighted the need for research regarding the multitude of barriers faced by visible minorities, women, rural people and people of lower social economic status. Hence the *Gender, Race, and Class Health Research Group* was formed to further examine barriers to health and well-being.

Members of the Gender, Race, and Class Health Research Group are:

Agnes Calliste, StFX Dept of Sociology
Colleen Cameron, StFX School of Nursing/Coady International Institute
Donna MacDonald, StFX Dept of Sociology
Elizabeth McGibbon, StFX School of Nursing
Elsa Arbuthnot, St. Francis Xavier University (StFX) School of Nursing
Hope Graham, StFX School of Nursing
Jean Knockwood, First Nations, Shubenacadie, NS.
Joy Hanley, StFX School of Business and Manager, Co-op Programs
Katherine Reed, Antigonish Women's Resource Centre
Lars Hallstrom, StFX Dept of Political Science
Raewyn Basset, Dalhousie University

The mission of the Gender, Race, and Class Health Research Group is to:

- Initiate and foster dialogue about barriers to health and well-being specifically related to race, social class and gender;
- Facilitate collaboration and networking among communities, policy makers, and academic researchers;
- Initiate participatory research concerning barriers to health and well-being in order to bring about positive change

Since the beginning of 2005 the Research Group has been meeting to develop a broad research agenda, and to find and submit research proposals which address some of these barriers. In addition, the Group organized this conference to bring together researchers, service providers and community people from Northeastern Nova Scotia to discuss barriers to health and well-being. It is hoped that this conference will help to develop networks of people who are interested in identifying research issues and questions, and participating in the investigation of those questions. The conference was sponsored by the Centre for Regional Studies at St. Francis Xavier University.

OVERVIEW OF THE CONFERENCE

The overall goal of the conference was to bring community-based individuals and groups, researchers from various disciplines, and policy makers together to identify and develop research priorities. The conference was well attended by a balanced mix of community members and researchers from Northeastern Nova Scotia. There were a total of 74 registered participants, including members of the Gender Race and Class Health Research Group. Results of written conference evaluations indicated that participants of the conference were, overall, very pleased with the conference and thought that the goal of the conference was met. A number of research themes were identified, and an initial discussion of research questions was initiated. Specific research questions were not identified due to lack of time. This will require further follow up, and is considered a major goal of the Group following the conference.

ACTIVITIES AND OUTCOMES OF THE CONFERENCE

The following is a summary of activities and outcomes of the conference.

Thursday Evening Sessions

The Health Information Tree

In the first few hours of the conference, participants were given an opportunity to post their sources of information about health on the “Health Information Tree” which was mounted on the wall. The purpose of this activity was to stimulate discussion among participants regarding where people get information about health. The results were included in the ‘Geoethnography of Barriers to Health and Well-being’ research proposal which was submitted to the Nova Scotia

Health Research Foundation in the spring of 2005. This proposal seeks to determine some of the barriers to health and well-being faced by people in Northeastern Nova Scotia.

The following is a list of participants' responses about where they get health information. Some responses were cited many times and some were cited by one or a few participants. The participants' responses were colour-coded to allow conference organizers to separate the responses of health practitioners from researchers and from those of community development workers, advocates, and individuals facing barriers to health and well-being. The combined sources included:

oral tradition	textbooks	posters	television
help lines	pharmacists	grocery stores	advertisements
the gym	history	the land, sea and air	life experience
the elders	diabetic clinics	patients	recreation
advocacy groups	guidance offices/schools	internet	youth groups
conferences	workshops	co-workers	the library
women's centers	magazines	health care workers	friends and family

Conference Opening: Spirituality and Health

The opening of the conference was led by Kerry Prosper from the Patqtnkek First Nation, Antigonish, Co. Kerry provided an opening blessing in Mi'kmaq. He then spoke of how First Nations people see the connection between spirituality and health, and attend to the health of the earth.

Sr. Rita MacEachern, Congregation of St. Martha's, spoke about her experiences as a sister and pastoral care worker in hospital settings. She talked about spirituality and health from the perspectives of people from different religious backgrounds who connect to a greater spiritual power for healing. Sr. Rita said that a belief in a spiritual power and healing is what unites us all as humans.

Following the opening, participants were asked to discuss at their tables how they experienced spirituality and health in their own lives.

Josephine Etowa on African Nova Scotian Women's Health

Josephine Etowa, Assistant Professor in the Dalhousie School of Nursing spoke about the barriers to health and well-being which people of color, especially African Nova Scotian women, face. Josephine discussed the diversity of people in Canada, how the health care system does not reflect this diversity, and the reasons why diversity must be considered in our health care system. Using the Determinants of Health Framework, Josephine highlighted some of the statistics for African Canadians. One of her main points was the fact that most health statistics and related data about North Americans of African descent comes from the United States. There is much less data available in Nova Scotia or Canada. Josephine also discussed race and racism in the health care system and in society as a whole. Racism is a major determinant of health, even though Health Canada does not specifically identify racism separately from culture. Josephine concluded her talk with the following points:

- Poverty, unemployment, educational disadvantages, poor health, and inadequate access to appropriate health care are barriers that are all too common among marginalized groups.
- Although marginalized groups may be sicker and may have greater health care needs, they have less access to appropriate health services.
- Increasing access to health care services by itself will not improve the health status of marginalized people.
- Effective strategies need to address the larger systemic public health issues related to the various determinants of health, including racism and poverty.

Friday Morning Sessions

On Friday morning participants were divided into small discussion groups. Participants were asked to discuss the following questions:

Question One: What do we know about barriers to health and well-being and why do they exist?

Question Two: What needs to change?

Question Three: What do we need to know in order to bring about changes?

Question One: ‘What do we know about barriers to health and why do they exist?’

After individual group discussion, all groups reported back to the larger group. This stimulated much discussion and participants added further ideas about barriers to health and well-being. The following is a list of participants’ answers:

- Income, especially low income; poverty and distribution of resources
- Literacy or lack of literacy; level and quality of education
- Shortage of health staff especially in rural areas
- Lack of access, especially transportation or access within walking distance, wheelchair access
- Multiple barriers related to oppression
- Cost of prescriptions
- The short term nature of government plans
- Lack of diversity in health care professionals, lack of cultural and language competence among professionals; treating everyone the same despite difference in culture, gender, race
- Technology as a barrier to customer service: the drawbacks of “go to the website” kinds of advice
- Lack of government funding
- Advertising/commercials; influence of mass media; perception of media about health problems
- Unhealthy lifestyles, sugary foods
- Complexity of the health care system; lack of one stop (collaborative) services providing services such as exercise rooms; health care around childbearing; community services; legal concerns, etc.

- Lack of integrated approach to mental health and addictions; knowing what questions to ask, what services are available?
- Freedom of information act and privacy (legal barriers to collaboration)
- Responsibility of health falls mainly on women: gender roles
- Lack of balance between research funding and prevention funding: unequal distribution of resources
- Stigmatization
- Medicalization of health, focus exclusively on physical health, naming everyday processes as a medical disease.
- Environmental degradation; larming practice – unsustainable practices affect food, environment, our health; chemicals lawn sprays, etc.
- Social isolation
- Lack of research funding
- Greed (affects research funding and preventative health programs)
- Lack of employment; lack of access to training and education leading to employment
- Food security and nutrition
- Globalization has lowered the barriers to infectious diseases
- Personal and institutional attitudes, values and beliefs
- Lack of power (constant need to ask for funds)
- Stereotypes
- Lack of affordable and safe housing; homelessness
- Lack of regulation and policing of violence; lack of community safety from violence for children and women
- Lack of subsidy – children do not have money to participate in many community based activities (exclusion)
- Lack of access to new and existing health data
- Chemicals (scents) that disable others
- Information needs to get to basics
- Lack of awareness (system and personal health)
- Disability
- Isolation of specific needs, eliminating participation, for example, children with ADD
- Lack of child care services

Questions Two and Three: What needs to change, and what do we need to know in order to bring about changes?

The results reported from these discussions led to a wealth of responses and ideas. Over the lunch period the conference steering committee organized the responses into draft research themes. These themes were then presented to the larger group after lunch to see if the steering group captured all the ideas under these themes. A few other themes were added to the list. Below is the list of overall themes from the group discussions:

- Policy, values, attitudes, beliefs

- Housing
- Access to services ('one stop shopping' with access to several services and information under the same roof)
- Education (in all kinds of ways: case studies, etc)
- The need for cultural sensitivity, cultural competence
- The need for holistic health; the health consequences of medicalization
- More data is needed on specific groups
- The need for a health impact assessment, including impact of actual and potential government policies
- Media: the need for media literacy and information about media manipulation and utilization
- Disabilities
- Capacity building
- Technology: how are individuals affected (positively, negatively)
- Better models of effective public participation
- Miscellaneous: Bridging divisions between sectors and segments
- Income
- Gender
- Homecare
- Isolation
- Social support networks

Friday Afternoon Sessions

Introduction of the Members of the Gender, Race, and Class Health Research Group

Friday afternoon session began with Colleen Cameron introducing the Gender, Race, and Class Health Research Group and informing the participants of the various research proposals that the group has submitted. Research proposals submitted for funding are:

A Geoethnography of the Barriers to Health and Well-being experienced by Northeastern Nova Scotians submitted to the Nova Scotia Health Research Foundation, May, 2005

Inequities in access to health services for rural Aboriginal and African Canadians: A scoping review submitted to the Canadian Institute for Health Research, June, 2005

Additional projects under development are:

StFX/UNB/UPEI – Atlantic Tri-Provincial Community Health Research Network

Applied Health Informatics and Public Policy Application to AIF

Jean Knockwood on Ethical Issues in Research with Aboriginal People

Jean Knockwood, an aboriginal researcher and advocate presented some "lessons learned" about ethical issues arising in conducting research among Aboriginal peoples. Jean related some of the

negative experiences which Aboriginal people and their communities have had through their participation in research projects. These experiences left them with a feeling of being “researched to death.” She detailed the core principles underpinning ethical research with marginalized communities.

The acronym “OCAP” can help researchers remember these core principles. OCAP refers to ownership, control, access, and possession. Most researchers involved in projects conducted in Aboriginal communities have denied the opportunity for ownership of the research process by Aboriginal people and their governance agencies. This exclusion was evident in the lack of involving Aboriginal people in the planning research or even in deciding research question(s). The communities were not able to control the research process or the ways that findings were subsequently used. In some cases findings were used in ways that were destructive for the communities.

The people and communities under study had no access to the results of the research, nor were they allowed to possess the physical materials gathered and produced as part of the process. In one instance, research data and results were taken out of the country and when the Aboriginal research participants requested copies of the materials, they were refused. Ms. Knockwood told conference participants that Aboriginal people have learned from these experiences and are now only willing to participate in research that embodies the OCAP principles: ownership, control, access, and possession.

Christine Johnson on Successful Collaborative Research

Christine Johnson, a registered dietitian, presented an example of successful collaborative research. The Participatory Food Security Projects, which have been ongoing since 2001, are a collaboration among a number of partners. Core partners include the Nova Scotia Nutrition Council, the Atlantic Health Promotion Research Centre at Dalhousie University, and Nova Scotia Family Resource Centres/Projects (funded by CAPC/CPNP). Other project partners have included a National Advisory Committee; Nova Scotia Public Health Services; Nova Scotia Departments of Health/Office of Health Promotion, Community Services, and Agriculture; St. Francis Xavier University, Acadia University, Dalhousie University, Mount Saint Vincent Universities; and the Atlantic Canadian Organic Regional Network (ACORN).

The focus of the research was building capacity to address the issue of food insecurity through policy intervention. The projects used two main strategies to explore the extent of food insecurity among families in Nova Scotia: (1) conducting a study of the cost and affordability of a nutritious diet; and (2) sharing stories of the lived experience of food insecurity. The projects then moved into action by supporting community leaders to facilitate dialogue within communities. Dialogue focused on food security and policy and eventually led to the development of a workbook entitled "Thought About Food?" In addition to local actions, advocates for social and economic justice have used the research findings to lobby for improvements in social policy, such as increased welfare allowances and the development of affordable housing.

Evelyn Lindsey on the Health Literacy Project

Evelyn Lindsey, Chair of the Antigonish Town and County Community Health Board made a presentation on the Health Literacy Project. This research was initiated by the Departments of Human Nutrition, Adult Education, and the School of Nursing, all of St. Francis Xavier University; and the Guysborough Antigonish Strait Health Authority. The research investigated the relationship between low literacy levels and negative health impacts, as well as the ways in which both literacy and health outcomes could be improved. The geographic scope of the research was Health District #7, which includes the Strait Area of Cape Breton, and Antigonish and Guysborough Counties. The research was funded by the Social Sciences and Humanities Research Council (SSHRC) and the National Literacy Secretariat.

The purpose of the study was to:

- learn how adults with limited literacy find and use health information, services, and support,
- identify what should be done to make it easier for people with limited literacy to have better health,
- increase awareness of health literacy as an important public issue; and
- provide a basis to improve policies and programs that enhance the health of adults limited in literacy living in rural northeastern Nova Scotia.

The project report, “Taking off the Blindfold” is available through the Antigonish Town and County Community Health Board. The research found that literacy affects health in direct and indirect ways. Some direct effects are difficulty understanding and using health information and accessing services to support health. Some indirect effects are food insecurity, poverty, poor quality housing environments and unsafe work environments.

Potential Research Areas – Reports from Workshop Groups (Friday afternoon)

Participants self selected into interest groups to discuss concrete ideas for research. Groups were labeled using the research themes identified in the morning. Since many of these themes overlapped, participants chose groups which most closely reflected their areas of interest. Not all themes were discussed, due in part to the large number of research themes and the order in which themes were chosen. There were five theme areas: Access to services; Capacity building; Housing; Disabilities; and Education. Below are the research themes that people selected for discussion and some of the ideas discussed. It should be noted that not all the groups recorded their discussions and therefore we are unable to provide this information.

1. Policy Group (attitudes, values & beliefs)

Discussion:

Focus on policies related to youth.

1. Parenting struggles:
 - Best childrearing practices (Who defines 'best?')

- some loss of First Nations parenting knowledge due to the impact of residential schools
2. Mi'kmaq language and culture acquisition
 3. Perception of value in relation to health determinants
 4. Listening to young people
 5. Present physical fitness/health of community people

Potential Research Questions:

1. How does one make an impact on youth through the use of policy?
2. What are the current policies that affect youth? How were they established? How do existing policies affect youth?
3. Are youth involved in policy making? How do policy makers, community members, Band staff, community service providers and Band leadership hear what youth are saying? How does one get policy makers etc., to listen to youth?
4. What do youth have to offer our community? What does the community have to offer youth? Is there evidence that children and youth are valued as a resource in our community?
5. Is there evidence (e.g., policy evaluations, written community feedback/complaints, community focus group reports) that indicates policies do what they claim to do (say youth's views are important)?

A group contact list is available from Donna Mac Donald (on request).

2. Access to Services Group

Discussion:

Focus on how people access information and actions communities can take to make information more accessible.

Potential Research Questions:

1. How do we change the Nova Scotia government policy re: community services clientele being supported to go to university?
 - Design a web page form to send to members of government
 - Money to develop the web page
 - Place to promote the web page
 - Media access to numbers being sent
2. What would be the cost/benefit of supplying people with services such as access to a computer?
 - Randomly select 1000 families to study 5-10yrs
 - Give family a computer and dial up account
 - Establish a process to build participatory resources that people can contribute.

3. Capacity Building

Discussion:

How to focus on the varying motivations and styles of learning of people in thinking about access to health?

Information is not available on the following three groups. Please feel free to contact us if you have this information:

4. Housing

5. Disabilities

6. Education

NEXT STEPS

The Gender, Race, and Class Health Research Group is planning to continue to facilitate this process of developing research networks. In the fall we plan to have monthly lunch sessions and will invite people who expressed an interest in a particular research topic. The purpose of this meeting will be to bring these people together to further identify the research questions and potential funding sources. At this time we envision having perhaps one lunch per month with a different research topic each month. We will also be looking for, and encouraging, additional community members and researchers to become more involved in these research topics. Stay tuned for notice of these lunch meetings in the fall.

Appendix A.
Participant Affiliation

Participants at the conference included:

- 10 community advocates/workers
- 10 health, social service, and education administrators
- 16 community members
- 26 researchers/professors/instructors
- 2 health care service providers
- 10 members of the Gender, Race, Class Research team

Total: 74 registered participants

Appendix B.
Contact list for Race Gender and Class Research Group

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Appendix C.
List of participating organizations

Antigonish Women's Resource Centre
Paq'tn'kek First Nation
Congress of Black Women
Cape Breton Black Employment Office
Maggie's Place, Family Resource Centre
Antigonish Town and County Community Health Board
Human Services Worker Program
St. F. X. U. Master of Adult Education Program
NSCC, Strait Campus
Atlantic Health Promotion Research Centre
Research Grants Office - St. Francis Xavier University
Cape Breton University
Health Care Education and Research, University of New Brunswick
Pictou Landing First Nation
Race Relations and Cross Cultural Understanding and Human Rights
Dept. of Community Services
MDLogix Inc.

* This Report was authored by the Gender, Race and Class Health Research Group at St. Francis Xavier University.