

***'On the Margins' - from Research to Action
Conference proceedings***

**April 27-29, 2006,
Yarmouth, Nova Scotia
And
October 27-28, 2006
Halifax, Nova Scotia**

ON THE MARGINS CONFERENCE – FROM RESEARCH TO ACTION

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Acknowledgements

The OTM project would like to thank the following for their involvement with the Black Women OTM: From Research to Action Conference:

Audio-Visual Support

Audio-Visual Support

Bunmi Oyinsan.

Soji Oyinsan.

Olesegun Odusanya

Key note Speaker:

We would like to thank Mrs. Sharon Davis-Murdoch for lending her time and talents to the OTM Conferences in Yarmouth and Halifax. Her speech wasn't just a speech... it was an eloquent, self-reflected piece that spoke to the shared experiences of Black womanhood. Her self-reflection was masterfully executed and conveyed through her tone and body language.

The OTM project would also like to thank the following for their support of the Conferences:

Sponsors:

Atlantic Centre of Excellence for Women's Health (ACEWH)

Canadian Institutes of Health Research (CIHR), (IGH)

Dalhousie University

Dalhousie University- School of Nursing

Dalhousie University- School of Social Work

Nova Scotia Community College (NSCC):

Akerley Campus

Nova Scotia Health Research Foundation (NSHRF)

Nova Scotia Tourism, Culture and Heritage (NSTCH)

Office of African Nova Scotian Affairs

(ANSA)

Population Health

Community Contributors:

Community members and community-based organizations have played an active and integral role in the OTM project. We would like to thank the 237 women who willingly shared their experiences and time in the individual interviews, and all who participated in the community consultations and focus groups. We also wish to thank the following partnerships, businesses, professions, health and social policy- makers/ analysts:

Annapolis Community Health Board
Association of Black Social Workers (ABSW)

Atlantic Centre of Excellence for Women's Health (ACEWH)

Black Employment Resource Centre

Digby & Area Community Health Board

Health Association of African Canadians (HAAC)

Holiday Inn Harbourview: Dartmouth

Municipality of Annapolis

Municipality of Clare

Municipality of the District of Yarmouth

Nova Scotia Community College (NSCC)

Rodd's Grand Hotel, Yarmouth

Shelburne County Community Health Board

South West Health

Western Area Women's Coalition

Weymouth & Area Community Development

Society

Yarmouth Health Board

Door Prize Contributor(s)

Association of Black Social Workers
Black Fatherhood Project

Canadian Health Network: Women's Affiliate
Dalhousie University School of Social Work

1.0 INTRODUCTION

1.1 The Conference

The Conference 'Black Women On The Margins (OTM) –From Research To Action' took place in Yarmouth, South West Nova Scotia from the 27th – 29th April, 2006. It was the culmination of a three year OTM research project into the health status, health care delivery and health services utilization among marginalized Black women residing in rural and remote regions of Nova Scotia, specifically in the towns and villages along the south and west shores of the province – from Liverpool to Annapolis Royal. It was organized to discuss the research findings and inform the communities, health care educators and professionals as well as policymakers of health. It was also to generate recommendations for action from the various participants.

The Conference opened on April 27th at the Conference Hall of the Rodd Hotels and Resorts Yarmouth, which also lodged the participants. A good part of subsequent proceedings took place at the Yarmouth Community College. The two and a half day period witnessed series of presentations on the OTM research, small group workshops on related events and Talking circles on the OTM data which were aimed at envisioning solutions. There was a keynote address and warm interchange of ideas at some question and answer sessions.

1.2 The Opening

By Dr Wanda Thomas-Bernard

The Conference was declared open by Dr Wanda Thomas Bernard, Associate Professor and Director of School of Social Work at Dalhousie School of Social Work who is also the project's Principal Investigator. Dr. Wanda Thomas Bernard welcomed all participants on behalf of the OTM team. She paid special tribute to the 237 women in the target communities who gave up their time to be interviewed during the research aspect of the project.

'These are all phenomenal women,' she said, 'and the Conference is actually an opportunity to hear their voices and the information they shared with the OTM team.'

She paid homage *'to our ancestors on whose shoulders we stand everyday to do this work'* Rendition of the Black National Anthem and other uplifting songs by the young boys and girls from the 'Black Educator's Tutoring Program.' set the tone for the Conference.

Dr Thomas Bernard concluded by describing the OTM project and Conference as a *'fight for Black Women's health and community health to ensure that the future will be a better place especially for our children.'*

Her two co-investigators Dr. Barbara Clow and Dr. Josephine Etowa followed immediately with the presentation of the overview of the OTM research project.

2.0 OVERVIEW

THE OTM RESEARCH PROJECT – AN OVERVIEW by Dr. Barbara Clow

2.1 Project background

Dr Barbara Clow informed the conference that the project began in the year 2000. The project itself was conceived by Dr. Barbara Keddy, a Professor at the Dalhousie School of Nursing who put together an initial team of three to join in actualizing the dream. The process of securing

funding was tedious because it involved trying to convince people who are normally far removed from the rural setting that the project was important and necessary. Finally, funding was secured for a 3- year project whose purpose was 'to investigate the health of African Nova Scotian women and their communities in the south west portion of the province'.

The team changed in the course of the project. First, the initiator Dr. Barbra Kelly retired and Dr. Josephine Etowa took charge for a six-month transitional period.

Finally, Dr. Wanda Thomas- Bernard came on board fully to assume leadership as Principal Investigator. Meanwhile, the project recruited three community facilitators who assumed direct liaison with the communities while the core research team based in Halifax continued to be responsible to the funders. A project coordinator also came on board.

Dr Barbra Clow paid tribute to the facilitators and the coordinator as those whose brilliance and commitment made the research successful.

2.2 Reasons for the Research

Dr Clow gave an insight into why the OTM team was particularly keen on embarking on a project such as this:

- Black people represent the largest proportion of the visible minority in the province of Nova Scotia.
- A lot of initiatives have in the past been focused on newcomers. While this is not undesirable, African Nova Scotians who have been around for generations have been left out. As such, not much is known about their health and well-being.
- The related information available comes from outside Canada especially the United States where there have been a lot of efforts to understand the experience of African Americans. While African Americans and African Canadians may share a lot in common, this, she said, does not justify the total absence of data for Canada.

2.3 Goals and Objectives

Dr. Clow itemized the basic goals and objectives of the project as follows:

- To investigate the status of health care and health services utilization of African Canadians living in rural and remote regions of Nova Scotia.
- To evaluate the impact of social, economic, cultural and political barriers to health and health care.

She emphasized that the OTM concept of health in this regard is holistic. It is inclusive of whether a community has the necessary support such as 'infrastructure, job creation program and recognition.'

2.4 The choice of South West Nova Scotia

On why South West Nova Scotia was chosen, Dr Clow explained:

- It has a large and established population of African Nova Scotians.
- It is a region that has typically not received much attention like for instance communities such as the Prestons.
- It is geographically large, very rural and remote and quite far removed from the main provincial health facilities in Halifax.

2.5 The Research approach

The research approach, according to Dr Clow, was 'Participatory Action Research'. This means that the goal is not a research *on* people but a research *with* people, a genuine partnership with the people who have the information and a sharing of knowledge between equal partners with a desire to change situations.

2.6 Preliminary findings

Altogether 237 Black women over the age of 18 were interviewed for the purpose of the study. Some sessions took 2 to 3 hours at one stretch with each woman.

The interviews were conducted by three community facilitators and Dr. Clow described as phenomenal the amount of information gathered according to research standards.

When the large amount of information was coded and analyzed, the OTM team was able to come up with some broad themes which included:

- ❖ Understanding the context of the Black woman's health
- ❖ The strategies they are already implementing to improve their health
- ❖ Interactions which they have with the health care system and other kinds of social services support
- ❖ The barriers they face in getting excellent, appropriate and culturally competent care.

Dr Clow challenged the conference participants to envision solutions and come up with concrete strategies in the course of the conference.

RESEARCH OUTCOME

By Dr. Josephine Etowa

2.7 Information sharing

In the presentation that followed Dr. Josephine Etowa a co-investigator and an Assistant Professor at the Dalhousie School of Nursing focused on the outcome of the research especially those elements which are traditionally missed out in research reports.

She opined that the coming together of people of different backgrounds and different expertise turned out to be a mutually enriching experience and made the project a huge success. The OTM research, she said, brought together:

- ❖ people of academic and clinical background
- ❖ social workers
- ❖ people of nursing background and
- ❖ people with community development background

The coming together thus:

- ❖ Facilitated the establishment of credibility and created the opportunity for mutual learning and spontaneous sharing of ideas and
- ❖ Created personal growth in terms of new knowledge about the intimate things that happen in the community.

2.8 The Challenges

Dr. Etowa identified the challenges that the research team had to confront and the steps taken to address these challenges:

First the core research team for the most part was all located in Halifax. The geographic and social isolation of the targeted Black communities therefore became a challenge. To address this, the team had to fall back on colleagues in the Yarmouth School of Nursing who assisted in supervising the three facilitators for the first two years of the project

There was also the fact that research work of this nature was new to the facilitators. More challenging was the personal, complex and social issues which the stories they heard created for them. Therefore to build the capacity necessary for the job and deal with the personal issues, the facilitators went through specially designed certificate courses in

- computer literacy and media presentation
- public speaking
- ethics and professionalism
- data collection and information coding
- conflict resolution and
- Stress management

The lack of information on Black people's health in Canada was a major limitation and the research team had to fall back on the work already done on Black men's health which they shared with the facilitators.

The following results show evidence of the success of these efforts:

- A health information manual for African Canadians has now been developed
- Community mobilization programs are now being organized in the communities.

Also these excerpts from the feedback from the facilitators show the success of OTM strategy:

'I now have a better understanding of women in our communities...'

'I have learnt how to do a good interview and code data...'

'Giving women a chance to tell their story is a good way to get information....'

Dr. Etowa concluded that all these show that the project has been a mutually enriching experience.

3.0 THE CONTEXT OF BLACK WOMEN'S HEALTH

Opening the presentation on the **Context of Black Women's Health**, Dr Clow explained that the OTM research involved the overall health of African Nova Scotians and not just the physical aspect.

This was why the research came up with five key factors that impact on the health of Black women living in rural and remote areas of Nova Scotia. The factors are intertwined and interconnected and cut across economic, social, political and cultural aspects of life. They are:

- Poverty
- Employment
- Racism
- Black women's care giving roles
- Black women as community members

At every point, the voices were relayed on how these factors impact their health.

3.1 Poverty:

Of the 237 women interviewed

- 62% reported average **personal** income of less than \$15000.00 per annum
- 28% had an average **household** income of less than \$15000.00 per annum
- 75% reported having constant financial difficulties.

Poverty thus impacts their lives through:

- ❖ Stress: worries about not being able to pay bills or make ends meet

As the conference heard from the voice of one of the women:

'Stressed out everyday... Everyday of my life... Yes I am. Worrying about paying this and worrying about paying that, Can't sleep hardly at night.....'

- ❖ High blood pressure and heart disease.

These health conditions are closely linked to stress and are very predominant among Black communities.

- ❖ Poor eating habits: though knowledgeable about healthy eating, poverty did not allow them to incorporate this in their daily lives.

'My biggest concern,' one of them said 'is not being able to eat healthy....not being able to afford to eat healthy...I mean last payday when I paid my rent and paid \$50 on my phone bill, I had \$20 left...So I don't eat healthy..... I don't even have a social life'

- ❖ Inability to afford the cost of necessary medication and proper treatment.

3.2 Employment/Unemployment

Of the 237 women interviewed

- 46% were employed outside their home environment
- 22% were over the age of 65 and retired
- They were engaged in a wide range of jobs – health care, seasonal jobs in fish ponds, domestic work and housekeeping

Thus many talked about work-related stress such as

- working on two jobs to make ends meet
- being a single mother
- difficult management and difficult co-workers
- financial concerns

Many were unemployed which was also stressful. Access to job places was equally a source of stress. One of the women talked of commuting one and a half hours to her place work everyday.

3.3 Racism

All the women spoke of racism as a source of distress especially where they felt they were not being treated properly by co-workers. Some also talked of systemic racism and discrimination when looking for jobs. Others talked about being victims of racial comments and attitudes either

when in school or as adults; and because they believe they will be improperly treated many do not bother to seek professional medical attention or advice

" Why go to hospital," a woman asked, "If I'm just going to be discriminated against? There's really no sense... If you are stressed out because you have something, why go to the hospital and be more stressed because people are going to be judging you?....."

3.4 Black women as care givers

Black women play central care giving roles in their families looking after children, parents, husbands, relatives and non-relatives. For them this provides a sense of feeling good. However, it creates a constraint of time, heavy demands and sometimes conflict with care recipients. These, coupled with lack of support services, result in emotional stress. The majority put their own health on hold to be able to take care of other people. One of the women encapsulates this:

"I am taking care of my mother.....She was living in town and she wasn't well. I'll go...get her up in the morning, get her fed and dressed, go to work, go back in the evening, get her supper and then walk home. Some nights, I didn't think I'd make it!"

3.5 Black women as community members

Community is central to the lives of Black women. It means togetherness, a large family. Some of the women in this study were involved in volunteering on school boards, in nursing homes, and church related activities that require helping others. This puts a constraint on their time and adds on to their physical stress.

Poverty, employment or lack of it, racism, care giving and community membership therefore give a broader sense of the economic, cultural and emotional factors that affect the health of Black women and their families.

4.0 HOW BLACK WOMEN DEFINE HEALTH

Dr Clow underscored the importance of knowing how Black women define and understand their own health in order to be able to explore the issues relating to health and health care delivery. Participants were also presented with the women's voices on their definitions of health.

The statistics that emerged from the OTM research show that of the 237 women interviewed:

- 48% were struggling with high blood pressure
- 35% had high cholesterol
- 28% are diabetic

4.1 Definitions

- Many women therefore saw health as a state of **physical** well-being
- Many defined health as **spiritual** and emotional well-being
- Some saw health as the capacity to do what they wanted to do like looking after the family and others

"Health," one of the women typically said, "means to me to be on my feet and to be able to be there for my husband and look out for him because he's not that well, and take care of my house."

- Still some defined health as the capacity to participate in healthy activities which their circumstances do not permit them to do, like eating right, eating the proper food, etc

"Health..... I think being able to afford the proper foods. I find some of them are very expensive. You know they are always saying eat right, eat right. But when you're on a limited budget, you can't always eat right....."

4.2 Shifting perception

Dr. Clow noted that the importance placed on health shifted with the changing circumstances in the women's lives namely:

- becoming a parent
- losing a loved one
- being diagnosed with a serious ailment
- becoming a single parent

"I didn't really think about being healthy. And when I lost my mother two years ago with heart disease... So that's when... the light bulb just came on. I'm obese, which is not good for your heart."

The importance placed on health shifted with each and any of these circumstances. While for some the shift was negative for others it was positive. The health implication was that the health perception was incorporated in their lives in form of

- changed behavior like quitting smoking
- changed diet
- getting more worried or
- redefining health in a broader sense

Dr Josephine Etowa summarized these by pointing out that the health of Black women is very much tied to the context of their lives. As such, it will be futile to look at the health conditions of these Black women without looking at the stimulants

- the multiple factors of poverty, employment, racism care giving and community are issues that impact on the women's health and
- The definition of health among them which changes with the conditions in which they find themselves.

5.0 MANAGING HEALTH and ENVISIONING CHANGE IN RURAL AND REMOTE COMMUNITIES

By– Dr. Wanda Thomas Bernard and Gail Jarvis

In this final presentation on the OTM data, Dr Thomas Bernard identified two key themes

1. Strategies for managing health - that is, how women attempt to attend to their physical, emotional and spiritual well-being
2. Solutions – the factors envisioned by the women themselves as ways of effecting change

5.1 Strategies

The women talked about the following strategies which they adopt for managing their health

- Mainstream remedies. They were open about the medication they take even though the elderly ones were worried about the dangers of overmedication
- taking things one day at a time as a way of managing the stress of life
- spirituality- that is, an individual personal connection with a higher power helps them to manage their health
- Support system: support from the family also assists in managing their health.

5.2 Solutions

In envisioning solutions, the women focused on three key areas: They proffered that:

1. It is important to improve health care services not only for women but holistically, that is for all members of the community
2. medication should be made more affordable in the absence of a health plan for members of the communities
3. Health services should be decentralized and made more accessible. Concentrating all in Halifax creates a great barrier.
4. Avenues should be created for information sharing among those diagnosed with similar conditions. Preferably this should be among people of the same gender and the same race.
5. It is important to create recreational facilities for young people within the community so that they can divert their attention and energies from undesirable habits which idleness encourages.
6. They especially emphasized the need for more culturally competent health care and health care providers. This is considered a very crucial issue. There is need for professionals who understand the context of Black women's health.

Finally Dr. Thomas-Bernard noted that the women recognize that working for change must be a combined effort of the women, the families, communities, politicians, policy makers and health care providers. Finally she challenged young Black students to move from the urban areas to the rural communities on qualifying in order to stem the resource drain from the Black communities,

After the presentations the conference participants broke into groups to participate in various workshops. These workshops focused on reports of already completed research projects which have some bearings on the OTM Conference theme.

6.0 CONFERENCE WORKSHOPS

6.1 Finding the Way – A Community Research Project

Speaker- Yvonne Atwell; Recorder – Louise Delisle

Yvonne Atwell who piloted this explained that **Finding the Way** is a community research project commissioned by Health Canada, Population and Public Health to establish dialogue with Rural African Canadian communities in the Prestons. The project began in October 2000 and over 200

people in the community were interviewed. Church leaders and members of the congregation were also interviewed and the research team heard from young people who spoke about the importance of support programs and recreation facilities.

The research established that the lack of information on the health status of rural African Canadian communities was because:

- People never talked openly about their health and so did not get proper information from doctors. Many people went for long periods of time before they went to the doctor – often times waiting too long. People only identified themselves at focus groups as being ill.
- People, especially the younger ones had no confidence in the doctors available because of what they perceived as disdainful treatment borne out of racism. One woman shared a story about how her mother went to the doctor on account of food poisoning and the doctor said she was drunk, because she was Black. Older people tended to trust doctors a bit more.
- In a few cases people experienced inaccurate diagnosis because doctors were not familiar with typical Black people's ailments such as sickle cell and did not inform themselves about family histories which play a part in the illness of people.

The research also identified a total lack of access to facilities like breast screening and emphasized the need for further studies.

As a result of the research some projects have been generated within the community. For instance a Youth Health Educators program in the Prestons has now been developed in Shelburne and in the Weymouth Falls area. Cancer Care has also partnered with young groups.

6.2 Attending to the Health Needs of African Nova Scotians

Speaker- Dr. Victor Maddalena; Recorder – Barb Hamilton-Hinch

Research motivation

Dr. Maddalena stated that the motivation for this research came from his personal observation that people were not being equitably served and that the workers in health care are mostly white males like him. He also explained that equitable care involves being able to obtain palliative care at home.

The research also looked at how the Boards and senior management view issues around minorities. He noted that since little research information is available in Canada (Nova Scotia) he sought direction from HAAC.

He observed that:

- District Health Boards (DHB) and the Capital Health Boards (CHB) i.e. (governing boards) are predominantly white middle class.
- There is more diversity at the Capital Health Board but as you move to the District Health Management, most are white and the gradual change observable in some areas is nothing significant yet.

The research found that:

- The Board was overwhelmed with the information they were receiving and are finding it difficult to dissect all of the information.
- The existence of so many 'Special Needs' groups looking for support makes financial support difficult.
- Culturally competent care is lacking and this is very important because it explains why many Black women do not use mammograms as often as they should.
- There is a need to pay attention to other vulnerable populations such as the deaf community who do not always access the health care system.
- There are still not enough health professionals who are Black and there is need for more partnerships with the Black community
- Developing research agendas with the community is key for positive results

Capital Health Board and District Health Board

The study also found that the relationship between these two bodies is seen as a source of frustration. The District Health Board has not bought into the idea of community health and does not completely understand population health despite the pressure from Capital Health Board. Authorities still see 'high tech' as where most money should be invested rather than recognize that it is more productive and beneficial to educate the community and give employment that will generate a difference.

Capital Health Board on the other hand is having difficulty keeping its membership because members feel they are not being listened to. A participant observed though that the CHB has resources and that it seems each Board has partnerships with school boards and works with youths. They also partner with HRM.

Accountability

The workshop noted that the District Health Board is not accountable to the public but to the Minister. This implies that the community cannot hold its representatives accountable to it. The Board is accountable to the Minister and the Minister to the community.

Consequently the public has limited opportunity to hold the Board accountable except through the media and at public meetings. In spite of this the DHB has all the decision making capacity. Even in Ontario, the first province which seems to have established some formal accountability policy, there's no transparency. Meetings are not open to the public. There's nothing in the legislation that says it must be accountable. Thus people who are elected or nominated by the community do not become accountable to the community but to the Minister.

To influence change

It was suggested that to influence change, particularly for African Nova Scotians, Black folks who often do not access health facilities because of the fear of racism and therefore resort to home remedy have to be involved at the policy level. This will help to reach a better understanding about how to make the palliative care for the community more welcoming.

To drive this point home, a participant shared the story of her mother who was diagnosed with a brain tumor and the severe emotional stress and great difficulty the family underwent trying to get support.

Cultural Competencies and the Boards

The CHB and the DHB as presently composed undermine the issue of diversity and cultural competence as illustrated in this experience shared by one of the participants:

'My grandfather's death could have been avoided. He was in the hospital for a broken limb but he was also a dialysis patient. He had a shunt in his arm and it was itching. Granddad was over 90 years and his skin was very dry and wrinkled. Before entering the hospital he was living at home with my mother. Well, while in the hospital his arm was itchy so he kept scratching and scratching and perhaps in his sleep. He scratched until he scratched the skin out of his arm. The result was he bled to death! Wow. I know for me it has really pushed me into seeing more and more about the importance of cultural competency!'

She suggested that it would be great to recruit more in the Black communities and have some Black people sit on the Health Boards.

6.3 Black Men's Health Issues:

Speakers: Steve Benton, George Bernard, Dion Thomas Hodges

Steve Benton: The Black Men's Health Network group was formed in 2000. It approached Health Canada and submitted a proposal which Health Canada accepted.

The group's objectives were to:

- identify major health issues in the Black community,
- disseminate information back to the community

Some of the findings of the group were:

- Blood work usually does not represent an accurate indication of prostate cancer; physical examination needs to be done.
- Black males distrust the health care system and consequently make no regular visits to doctors.
- There is grossly inadequate education and awareness especially among Black males about mental health issues.
- Substance abuse is a major health issue and those who are addicted fail to see the consequences as they continue to use the substances.

To stop the substance abuse cycle the study recommended:

- Early education as a preventive measure.
- The institution of culturally sensitive programs because cultural issues play a big part in addictions.
- Rehabilitation and treatment options for inmates of prisons.
- The strengthening of the family structure, because lack of family structure contributes to addiction and must be addressed.

George Bernard one of the workshop presenters shared his own personal experience. He had been faced with a life threatening disease – colon cancer. While he was employed with Canadian

Armed Forces (CNR) he always did preventative health care. However, later fear kept him from going to the doctor. Encouraged and propped by his wife, in May 2003 he went for an annual check-up only to be diagnosed with colon cancer. Within a month he underwent surgery. Now in 2006 he is cancer free. It is instructive that he feels his health care team gave him excellent treatment because his surgeon was a Black man.

The lessons:

- Had he kept up to date with health check ups, the cancer would probably have been noticed earlier but because he felt no symptoms, he never went to the doctor, and the cancer would have progressed.
- Black men need to be educated on the importance of maintaining health. Far too many Black males are dying because of neglect of their health, and fear.

The workshop noted certain questions that remain to be studied:

- How can men be made to engage in conversation about their health?
- What are the effective ways to disseminate information?
- Why are men so afraid to go to a doctor?

Dion Thomas Hodges:

Dion shared information on the reasons for drug use, some definitions of addiction, as well as some examples of signs and symptoms that may affect an addict and others affected physically, psychologically, emotionally, spiritually, socially, and behaviourally.

I also briefly touched on available resources and where to find services to access
REASONS FOR USE OF A DRUG

- To have a good time with friends 65%
- To experiment, see what it's like 54%
- To feel good or get high 49%
- To relax or relieve tensions 41%
- Because it taste good 41%
- Because of boredom, nothing else to do 23%
- To get away from my problems or troubles 22%
- To fit in with a group I like 13%
- To get though the day 8%
- To seek insights and understanding 7%
- To relieve physical pain 4%
- Because I'm hooked 2%

DEFINITIONS

- **DRUGS** – any chemical substance taken to cure or prevent diseases, enhance mental or physical performance or to escape or cope with reality
- **PSYCHOACTIVE DRUGS** – chemical substances that alter behavior or change consciousness

DEFINITIONS

- **PHYSICAL TOLERANCE** – is the adaptation in the brain resulting in the needing more a drug to get the same effect.

a. Physical dependence is the adaptive mechanism at the biochemical level that effects the rate of the drugs metabolism, elimination and sensitivity of the receptors.

b. Behavioral tolerance is learned tolerance; example, drinker learns strategies for functioning normally and appearing sober.

Acute tolerance occurs when the user physically adapts to a drug during a single episode of use. The second dose has a diminishing effect.

d. Cross tolerance after developing a tolerance for a drug in a family having a tolerance for drugs in same family.

e. Reverse tolerance after prolonged use a reverse in tolerance is experienced.

f. One of the first signs that you were an addict

- **PHYSICAL DEPENDENCE** is the altered state when a person can not stop taking a certain drug without suffering withdrawal. The cells have changed and now need the substance.
- **WITHDRAWAL** symptoms are physical symptoms resulting from the stopping use of a drug. Symptoms vary on the drug, amount and length of time using.

Use

- Use – appropriate use for set and setting
 - A glass of wine with dinner
 - A beer after work watching TV

Abuse

- When an individual's drinking interferes with one's normal functioning
 - Drinking the night before and calling in sick the next day

Dependency (Addiction)

- Is a chronic, progressive, primary incurable, but treatable disease characterized by loss of control over alcohol and other drugs of the same family that impact on the physical, psychological, emotional, behavioral, social and spiritual.
- Disease of compulsion/obsession
- Does not consider the consequences
- Loss of control
- inability to stop when others do
- Unable to maintain periods of abstinence
- Can be fatal
- If the drugs don't kill the lifestyle will

Where to Get More Information,

- Contact the Addictions Services Office in your area

6.4 Increasing Cancer Information

Speaker- Donna Smith; Recorder – Wanda Doucette

This workshop deliberated on findings from a previous research project. The goals were:

Conference proceedings for 'On the Margins' –From Research to Action

- To reduce the incidence of cancer mortality in Nova Scotia
- To have standardized high quality cancer care across the province.

This research was especially relevant because in 2006 alone in Nova Scotia

- 5200 people will be diagnosed with cancer and
- Prevalence of cancer in Canada will increase by 70% by the year 2015.

The 'Patient Navigation Community Liaison' research method was employed to identify unique community needs and improve education and access to communities that have traditionally found it difficult to access cancer care.

The report found that all the 20 African Nova Scotian communities visited

- Needed education
- Wanted to know where cancer had come from
- Wanted information on PAP testing, screening for cancer, CCNS
- Were anxious to see that young people are taught about cancer.

The community needs were identified as

- Breast health
- Cervical health and
- Tobacco reduction.

Four community members, three women and one male under the age of 25, in East Preston were mentored in a two- day training period during which all these needs were addressed. Partners involved in training were:

- Cancer Society volunteers
- Cancer Care Nova Scotia (CCNS)
- Health Association of African Canadians
- Dalhousie University

The training involved 5 education sessions. It was noted during the sessions that sexually active young people do not realize the need to have PAP testing

Recommendations

The workshop made the following recommendations and observations:

- Women should continually speak with their doctors and keep asking questions.
- Women should avoid multiple partners because the more partners, the more is the risk of cancer.
- Women should be educated that Mammograms are very important and testing in Canada is free.
- People need to be educated about why the Health District keeps data collected on them when they go and get tested for cancer.
- There is need to get more Home Care Workers in the African Nova Scotian homes
- More and more education is needed in order to help people live with cancer.

6.5 Surviving on the Margin of a Profession: Black Nurses

Speaker- Dr. Josephine Etowa; Recorder – Juliana Wiens

Opening the workshop, Dr. Josephine Etowa emphasized that it is important for peoples of African descent to come together if they must move away from the margins especially of the nursing profession. She noted that Black workers in other fields (e.g. social work) face similar experiences of racism and marginalization and therefore:

- African Nova Scotians, Caribbeans and all other immigrants need to work together as a group and find strength in order to be able to draw from each others' talents and meet each others' needs
- Black people need a united front to work through the issues. Peoples of African descent are needed who can teach everyone else and make allies
- Black women in the work force have to let the powers that be know that they are just as educated and just as smart as anyone else
- The unions and professional associations must acknowledge lack of diversity within the nursing profession and collect data that demonstrates this especially in the form of data that identify race
- Applications to professional training programs must be set up in a way that asks potential students to identify their race (an affirmative action).

6.6 Food & Health in African Nova Scotian Families

Speaker- Carolyn Gill; Recorder – Pauline Byard

It was noted that in the area of food and health in African Nova Scotian families, there is good research work in progress. This study was on the inter-relatedness of food and health of African Nova Scotian families.

The study noted that even though people talked about costs and food being expensive but due spirituality and beliefs such as "God provides," they still ate well. Families typically eat together though sometimes kids eat in another room.

Like in Eastern countries where people live in small communities and like some African communities, some African Nova Scotians make their own gardens and grow their own herbs.

In rural areas, families said they cooked extra in case someone dropped by.

Plates were always overflowing. Some commented that the Black population is made up of heavy eaters and so they need a lot of food. Even when teenagers do not want that much food, parents- the women- always wanted to give more to the children, perhaps because mothers felt that young people play hard and burn much energy.

No one actually felt the need to watch weight.

When the question was asked 'if you wanted some information on healthy eating where would you go?' Some said the internet; others said PDR (children) in school, or the community health. In general, people do know how to access information.

And when it came to people's readiness to alter or change recipes the response was negative.

As for preparing the meals, for the most part the women felt it was easier if they did it.

There are typical Black ways and food choices which constitute an African Nova Scotian culture. This is a cultural comparison that will be published.

6.8 “THE STRONG BLACK WOMAN”-A myth or reality?

By Dr. Felicia Eghan

Dr Felicia Eghan presented a study on ‘The Strong Black Woman’ -Myth or Reality? This was a research project funded by the Nova Scotian Health research Foundation. She explained that the study was based on the traditional construct which sees Midlife Black Women often painted as “Strong Black Women” within their own communities. It is a construct rooted in slavery and post slavery experience, in the legacy of Black women’s ancestors who survived slavery.

Even though the 50 women involved in the study are divided in their attitude to this image, most agreed that the concept embodies both myth and reality.

It is only fictional to the extent that ‘.....*Black women have weaknesses just like anyone else even though they may look strong on the outside.*’

The purpose of the study was to explore the impact of this construct on these women’s health and well being. Broadly the objectives of the study are:

- to investigate the experiences of health and well being among African Nova Scotian women, with particular attention to how they are affected by this dominant ideological construct, ‘the Strong Black Woman.’
- to place those experiences within a determinant of health framework where intersecting inequities – including racism, poverty, and sexism – are recognized as having a significant impact on their abilities to access and receive equitable and informed health care services.
- to examine how time, resources, and sense of entitlement affect their participation in activities that promote health and well being as well as develop community-supported and culturally appropriate health education and promotion materials.

The study found that the reality aspect of the strong Black woman is contained in:

- the expectations of the Black woman to be strong enough to able to take care of others such as children, grandchildren, parents, grandparents, spouses, extended family, community members, colleagues and their race’ Even those who reject the notion acknowledge that their everyday activities require them to be strong to survive.
- the attitude that makes her see herself as a positive role model positioned to carry on the legacy of her forebears who ‘endured slavery, fought uphill battles and overcame all,’ “*If they did it, I can too...*”
- Family expectations that positions her as the back bone and social expectations that sees her as “*the pillar of the community*”

Health Implications

The image eventually takes its toll on the Black Woman physically, emotionally and spiritually. The women acknowledge they are paying the price of being strong because they “*don’t know when to stop.*” The sense of never being able to rest becomes a default drive that is stressful and “dangerous” to women’s health.

The image also ‘leaves no room for the women to express themselves as individuals, to acknowledge weaknesses or to talk with others about their emotions.’

This expresses itself in a number of physical conditions such as:

- Physical and mental drain
- High stress.
- Depression.
- Heart conditions
- Loneliness and Self care.

New Visions

Several women were beginning to take stock of their own needs and to address these. They are coming to recognize their physical limitations and were learning the need to pace themselves according to their altered abilities and share their load with someone else

There is also a growing realization of the need to find a balance between caring for themselves and caring for others as well as the need to hand over some these responsibilities to the younger generation of Black women in order to be able to live healthier lives.

CONCLUSION

The study concludes that

“Although the image of the Strong Black Woman contains elements of truth, it is a source of stress and it is destructive because it creates unrealistic expectations and creates a barrier to women’s abilities to take care of themselves.”

6.9 Racism, Violence and Health Project (RVH)

Dr. Wanda Thomas Bernard

Recorder – Juliana Wiens

Dr. Wanda Thomas Bernard presented the project on Racism, Violence and Health, a study she jointly conducted with Dr. Carl James and Dr. Akua Benjamin (Toronto), Dr. David Este (Calgary) and Dr. Bethan Lloyd (Research Coordinator)

The RVH project was sponsored by the Canadian Institute for Health Research (CIHR) to examine physical and mental health racism-related stress among Canadians of African descent in Halifax, Toronto, and Calgary.

Qualitative Interviews were spread among individuals from various sectors namely: Health, Social Services, Education (teachers/students), Faith Communities, Business, Arts / Entertainment, Sports, and Others

The 2001 census figures show that of the total population of people of 18 and above, Blacks in Halifax represented the largest visible minority group; in Toronto they make up the third and in Calgary the fifth largest minority group.

Findings:

➤ Racism related stress

The study shows a significant relationship between the level of **MENTAL** health of participants and both racism-related experiences and racism-related stress. The experiences that cause the most racism-related stress included being:

- underestimated/undervalued,
- criminalized,
- subjected to blatant acts of racism.

- accused or treated suspiciously because of race
- insulted, called a name, or harassed because of race
- told an offensive joke or overhearing one

The more everyday acts of racism are:

- Being left out of a conversation or activities
- Being mistaken for someone who serves others
- Being stared at

Halifax respondents report the highest degree of racism-related stress followed by Calgary and then Toronto. The same pattern is true for racism-related experiences.

➤ **Racial profiling**

Participants also spoke of Racism related stress by profiling. These are:

Racial Profiling by Police:

Violence by the police . . . I have experienced it so many times, it's not even funny. The police say they are looking for a Black male so any Black male is a victim, any Black male. They say maybe we all look alike to them, that is how I see it, but that is not a way every Black person is a criminal – that's a way of saying every Black person is a criminal. -Toronto Male

Racial Profiling outside of Police context:

. . . in the grocery store and better yet the department stores. I mean you are at their whim, right when they come along behind you. "Can I help you?" and the White lady can walk in and shoplift in front of them and they never ask, "Can I help you?" She is helping herself – right . . . Black Female (Halifax)

Impact

Impact of Racism on the Health and Well-Being of African Canadians is thus visible in

- Low self-esteem
- Stress caused by underemployment (unemployment)
- General stress and Family stress
- Psychological damage to children
- Depression/hopelessness
- Feelings of marginalization
- Lack of confidence
- Physical health – ulcers, stomach problems, hypertension

Recommendations

- It was noted that men do not participate in mental health issues perhaps because they don't know how to articulate issues and experiences around racism. To address this and other issues, it made the following recommendations:
- More education is required to promote awareness around these issues and how to talk about them
- Initiatives must be provided to encourage men to get together and talk about these issues
- Interactive communication must be encouraged amongst men themselves and with their partners.
- The younger ones must be deliberately educated to instill self-worth and high self-esteem
- More education must be given on what mental health entails and this must be tailored to remove the stigma
- Province-wide campaign project should be organized among communities to raise awareness around mental health as well as solicit support
- Conferences and awareness workshops must be organized on an annual basis for Men.

7.0 TALKING CIRCLES from Yarmouth Conference

CONFERENCE RECOMMENDATIONS

Reflecting on the OTM team report and the research findings at various talking circles, the Conference unanimously made the following comprehensive recommendations, namely that:

7.1 Mental Health

Steps must be taken to remove the stigma associated with mental health. One such step will be to have African doctors and Black nurses or other culturally competent professionals in the system who will know enough about Black people's health issues.

7.2 Health Authorities

Initiatives from The Department of Health must be "forced" down to local Health Authorities

7.3 Health Care Delivery- Wellness centers

Clinics must be established in rural and remote places that presently have none.

Awareness should be created among the Black community about the various resources available within the communities and where and how these can be accessed.

Members of the Black community should be involved in Community Health Board initiatives and deliberations.

7.4 Education

Black issues and health issues must form part of the regular presentations to students.

Institutions should put programs in place to promote diversity and protect the workers when they have to face racism.

More funding should be provided to sponsor and offer scholarships to African Nova Scotian children. The church or the community may have to take the initiative even with a small initial investment and subsequently seek to the support of government and other organizations to match this.

More awareness should be created within the Black community about the importance of education for women, men and youth on all health issues including education on healthier ways of preparing food

Some program should be developed to make students aware of the scholarships that are already available for African Nova Scotian students as well as for seniors,

Teachers must be employed who are committed and who would overhaul a system that has seen students graduate from school without being able to read or write. Parents and grandparents have show more concern about the education of their children.

Members of the community must be encouraged to take advantage of the existing Tutoring programs especially since they are being funded.

Formal education of the youth must start early and they must be encouraged to get beyond high school. To stem the rend of young people dropping out of school and getting involved with drugs...it is important provide them with incentives that would see them from through elementary school to high school and Community college Parents and grandparents need to go into schools, talk to the counsellors to ascertain what these need are

Also creative and relaxation outlets for Black youths must in place for necessary energy outlet and purposeful diversion.

7.5 Men's Health

The cycle of non-communications between men is broken to help them talk openly to each other about their health issues. In this regard subsequent conferences must engage men's health issues and have men talk about their health with women.

Men and women must be motivated to have regular comprehensive medical check ups and the fear among Black people about going to see a Doctor must be confronted.

7.6 Racism

The problem of racism must be addressed urgently especially in the school system. Racism is particularly identified as so active in the school system that children are busy confronting it to the detriment of their education. Presently few supports are available to Black children for addressing racism in the school system.

Racism should be seen as a form of violence and parents should be able to write letters and ask for a meeting to address the issue. There is a need for re-education within the school and the communities.

Institutions should put programs in place to promote diversity and protect workers when they face racism

Parents, community, and the Law enforcement officials should unite to expose corruption and fight racism

7.7 Employment and Cultural Competence

More culturally competent teachers must be brought into the school system whom the children can identify with and who have a stake in their future.

African doctors and nurses must be injected into the healthcare system, people who would know about Black people's health issues.

The Federal government must ensure employment equity and recognize the importance of diversity in practical terms.

7.8 Information sharing and dissemination

More workshops and information sharing on the findings of *ON THE MARGINS (OTM)* should be organized. Workshops have to be an ongoing activity

Steps must be taken to ensure the dissemination of collected data to policy makers

Research should be carried out on the high prevalence rate of cancer among seniors in the Black community especially in Lucasville.

7.9 Support system

The Conference advocated the necessity for establishment of the following support groups within the Black communities:

- A Black women's support group for Black girls
- A support group for young boys of single mothers
- A support group for all victims of mental disorders
- A support group for rural professionals

These support groups should work with related organizations via email, backed up with occasional meetings to:

- Build strategies, raise awareness, openly acknowledge racism, and draw strength from one another.

The Conference also called on the entire Black community – indigenous Blacks, immigrants, Africans, Caribbean – to forge a common ground to bring about change since they all face the same kind of challenges.

The Yarmouth conference concluded with a call to action regarding the various recommendations that were made. Participants also urged OTM to present the conference in Halifax and to share the information with a wider audience.

8.0 THE HALIFAX CONFERENCE

A second conference was held in Halifax Nova Scotia on the 27th- and 28th of October, 2006. The two day Halifax conference began with an encore presentation of the play *"Who will care for Aunt Ethel?"*

Although some of the cast members were different from its original showing in Yarmouth, the messages delivered through the play were just as powerful. Indeed, some who were watching it for the second time commented that it was even better!

A short reception followed during which the OTM quilt was unveiled. Conference delegates from Halifax who had not previously seen the quilt were impressed by how well it spoke the research findings. The reception was the final session for the first day.

The second day of the Halifax Conference began with registration followed soon after by a presentation of the Research Project and Findings by the OTM project team. As in Yarmouth, the OTM findings were:

- Contexts of Black Women's Health
- Definitions & Perceptions of Health
- Managing Health and
- Envisioning Change in Rural and Remote Black Communities

After a short break, proceedings from a recent Think Tank in Montreal involving representatives from Toronto, Montreal and Halifax as presented. The presentation titled: 'Developing a New Mental Health Service Model for African Canadians' included:

- ❖ Background & Context
- ❖ Summary Of The Focus Groups & Interviews
- ❖ Summation Of The Think Tank

The speakers presented new and interesting material which was well received by conference delegates.

After lunch, Sharon Davis-Murdoch again presented her powerful speech titled: **"Resilience- The Life and Hope of Nova Scotia's Rural, Black Women."**

The speech was followed up with a response panel titled **"Making Action, Taking Action"**. The panellists were:

- Dr. Barbara Clow -Director, Atlantic Center for Excellence in Women's Health
- Dr. Swarna Weerasinghe - Health and Wellbeing lead, Atlantic Metropolis Domain
- Hon. Maureen MacDonald - MLA Halifax Needham; NDP Caucus
- Paula English - Director Primary Health Care, Nova Scotia Department of Health
- Susan Sanford - Program consultant, Public Health Agency of Canada, Atlantic Regional Office

The Halifax conference wrapped up with a submission of written evaluations and the distribution of posters of the quilt titled 'Breaking the Silence'.

CONFERENCE RECOMMENDATIONS

Five talking circles took place following another short break. Suggestions for action based on the findings presented at the conference were made and recorded for inclusion in the conference report.

8.1 Talking Circle – A

What actions would you recommend to government?

- Government should take black women's issues and health needs within the policy network. Should have a black member on these boards.
- There has to be recognition – allocating money in their budget (hard \$) to work on these programs.
- There is a budget to initiate these programs for cultural programs. These programs will be broadened eventually. We need to understand how to connect to leverage more money. There is funding for “small” ideas – project proposals for specific needs; connecting people to ask “right” to propose for more money for:
 - 1) Delivering cultural competence training
 - 2) Employment equity, affirmative action
 - 3) Data collection – evidence that you have a high need for cultural persons in the healthcare system – identifying your race on MSI or health card (to show a need for programs)
 - 4) Collecting race-specific evidence (self identifying helps to make others more confident with healthcare system for cultural diversity)
- Putting our collective minds together to put forth our issues – having a comfort level.
- Social Security – diversity – Budget and money is there.
- Personal experience – noted how much power in using opportunity – we do not need to think small – what opportunity.
- Oprah coming to Shelburne – use the opportunity – bring up health issues; community issues, connecting the dots – no more isolation – use a holistic approach.
- Books – suggest having the authors coming to speak to communities.

What Other Actions are supported?

- Community based organizations – promoting public services in the community to work with people.
- Education – 10 years promotion guidelines – Actions louder than articles which no one reads; they have to speak a different language – not scientific.
- How to make research visible– The play is an example of how you would take data and present to the public.
- A lot of information on health literacy; means people need to be able to understand what is being said – some don't know how to read; or jargon of professional sectors.

How do you solve this problem?

- South West leading by taking data and turning it into a play – a relevant option; a solution to health literacy – connecting the dots – how to get the data out in the public – churches, plays, community centres; involves everyone. Opportunities are there.
- Like to see participatory action research – encourage research community to move forward. Budget times the amount of money to move the community forward.
- Take a look at mental health outcomes in rural communities – resources for the rural community. Access for outlying communities – a community possibly come together to make things happen.
- Some children going to school – tutoring – some people would like to have children on meds. There is funding for testing for children to see if they have a learning disability or a drug program – if you take time, there are ways to be successful.
- Concerned that there hasn't been any mention of fighting for black children to have testing done. Offered to whites; not pushed for blacks.
- Education to make the community aware of resources to help the families and their children. Children are being expelled from institutions.
- There has to be an awareness of what is available to parents to access these resources.
- Misdiagnosis – given medication has caused more problems – instead of trying new techniques to help children learn, has to be stopped. Teachers need to accommodate these needs.
- As a society – we need to ask tough questions. Are behaviours medicalized?
- Children need strong families – community members can outreach to families in crisis.
- As a group there is a responsibility of the black community to work on these issues in a proactive way.
- In terms of government – not just the community or government is involved. A layered effect is needed.
- We need to be creative with teaching the children who have behaviour issues – no need for meds.
- More resources are needed for Cultural Enrichment Programs and tutoring. Creative black role models needed in the classroom.

8.2 Talking Circle B

Examples of the current situation

- Being the only black person present... Why aren't they coming? Don't see themselves reflected in meetings or events "I don't set myself up for isolation". Don't think it's for us because we've always been told that.
- How to get people mobilized? Busy lives. People who are concerned about feeding their family takes precedence.
- People wanted to talk and had something to say. Still a lot of work to do to help people lead more productive lives.
- A Caucasian who lived in rural Africa and knows what it felt like to live as a minority said she: Experienced racism. Couldn't experience the same as a white person in North America. Stayed for a time but not whole life. Needed energy daily to survive racism. Reminds you of your 'separateness'.
- In-grown natural fear of Black men when it's not necessary. Built-in fear, adamant on educating and protecting our Black males. If negative – affects Black male youth. Need to continually build each other up. Our importance includes ourselves in all aspects of society.

- Impact of racism, have internal fear from being Catholic, living in part. Never had a Black teacher, no such thing as a Black doctor or a black teacher. Internalized, psychological damage of racism.
- Fit into society with the denial of the problem. The Black person is at fault. Until it comes out, don't know how to handle it. How will we deal with it as a Black person? It's your problem; we need to learn to look after ourselves.
- Racism is killing us. Almost genocide. Has impact on our health; stresses of racism like diabetes, cancer, stroke. Through education we can make a difference; share with others.
- Illiterate, raised son alone. Back to school for upgrading.

What actions recommend to government?

- How people are recruited needs to change.
- Black communities need support; people in government should go away, debrief, come back to the table.
- Usually only one Black person on Board. This needs to end- no more tokenism

What other Actions?

- Change how people become able to join Community Health Boards and other groups. Recommend the necessity of first voice and modification of requirements.
- Get members of Black community to be a link to the greater community. Lack of knowledge of a board to begin with.

How do you resolve this situation?

- How to be supported? Not clear on that. Debriefing. Knowing there's people to call on. Support was offered.
- More inclusive, reflective of community. Need to have more than the token Black in this day and time. Diversity weak word.
- Start a national program as a point of contact, a resource, support.
- Needs to be something important to get people out to take action. What can you do? Rather, we should be assigning tasks. Need to implement training.
- Connective threads of Black people's journey of health, i.e. remedies.
- A Black Women's Health Centre is needed in every Black community.
- Need to show the importance of our roles. We need to be continuously striving to express the importance of our roles in our communities, N.S. Canada, the world. Like MADD. If it's important we need to make it important.
- Need to go to Black community for something positive and not only negative as we do currently.
- Simply acknowledge racism. Atlanta GA, 85% Black. Overwhelmed with fear in stone mountain. Stayed with other friend with more diversity and felt more comfortable. Had fears I couldn't understand. Only Black person in high school and university. Believed the stereotypes scared of Black people. Need to be able to see the truth. Need opportunity to know you're okay; fear is disabling. Product of environment where I grew up. Bill Clinton started Americans talking about racism.
- Atlanta and Mecca – empowering. Need to empower people locally.

Next Steps/Action

- Newsletter, quarterly publication to target Black women on health issues.
- Share info with all Black communities.
- Contact government to take action and recognize the need.
- Disseminate to: churches, schools, doctors, hospitals, newspaper, electronically.

8.3 Talking Circle – C

Speaking from personal experience, what actions do you recommend to the OTM team?

- Continue with what they are doing now, possibly get more people involved in the communities, younger people – we also need. Community Health Board is another area we need to see what we can do.
- Dartmouth and Halifax have youth groups; would be nice to see the youth to see the play and hopefully show them what the ladies have put together on our culture and health care. Good to get groups involved in our community to see this happen.
- First conference I've been to and it is an eye opener. Play needs to go anywhere it can be taken. In the schools, our youth – we need to continue to educate the youth and our old. We need to get to all the communities. I praise you for the way you are going about this work.
- Community Health Centres in general – find with a lot of projects, you don't get the support to run the facilities. Through the years seniors would like to see a Black Seniors home. A lot of our Black Seniors - it's a big thing because they do not want to leave their homes as they are leaving their own Black community with Black infrastructure.
- Push for Health/Wellness Centre while it's fresh in the government's mind, research is there and we've done it in the Prestons. Can model the existing ones. Continue with the work you were doing. There were things in the play – not touched on, i.e. young woman- not married. All of the issues need to be brought out more. Another play.
- Community wise – a community doing for itself. We as Black people need to depend on ourselves, not the Caucasian race because they take over. Important for parents to take a part in the school system.
- Older women in Inglewood are marvellous with the youth. Out of this small community we have 9 Black Teachers, 3 Black Nurses, 1 Black Surveyor, A Chemist. It's because they, the community, were so close. Got a paved road. We can do a great deal and on our own, all we have to do is put our heart and soul in it and stick together.
- Good experience previously mentioned with Inglewood. Action – like Women's Resource Centre, perhaps not women but Resource Centre. For us it's education – math help for my child, how can I get a job? I can't write a resume, good step in bringing the community back to a community. It's not a burden – it's our responsibility.

What do you recommend – the play and what was brought out today, what can they do for us as Black women?

- More money for education. Government needs to figure out a way to keep our black youth in school. Have a facility where young women can go and get assistance for health, school, etc. We need more Blacks out there.
- Not all medications work the same for our culture. Not very responsive in the health care system. Until government does something, Doctors still have to use the same medication.

Health Board medication doesn't work. How do we get over this – get the medication we need?

- We need to educate the teachers to stop hating. Our youth often feel they are not worth anything. We need to notice our downfalls as Black people because no one else is going to.
- Doctors do not understand our genetic background. Black unit to have health professionals or Social Workers, i.e. our own Health Centre; for health, mental, psychologically, etc. You need Black people doing this.
- In talking about Health Centres you have to have all blacks running it, not whites. A holistic approach.
- In order to have people in place in the meantime you could have peers to relate to. This is something they do within the mental health system. Talk to present Doctors to have someone from your culture sit in as an example of someone.
- Change the system – the government needs to find a different way and based on the findings, this research – build further.
- Government needs to change the whole system – the set up.
- Perhaps parents can direct their children to knowing themselves as well.
- More Black teachers, more Black workers in the school system. Black teachers should not be afraid – they have a union that can support them. We need to be on top of our children because if not we are going to lose them. Parents need to go to the parent/teacher meetings.
- Give us the services we need with the money we have right now. If there's a teachers' union – you're Black first. You become ostracized. In addition to asking government to take action – go back to young – instil cultural pride.
- We need to change entire perception that it's not kosher to do race-specific research...Black career development officer advises me not to put that I am interested in Black research on my resume.

What do you recommend more recruitment from communities/areas from our communities?

- Youth need to know what's out there for them.
- Take one month of the school year and put them with them instead of them hearing "oh you can't do that". Let them know how education will impact their life. Experiencing it may get more Black youth involved.
- Has to start at home. Teach your child stand tall, walk tall because you're from kings and queens. They need to hear stories from our black seniors. They need to see the play.
- Lack of communication – no social interaction, more verbal – story telling. Youth have gotten away from the social and communication side of it.
- Educate – bring speakers in community. Have career days in schools – year round and start young.
- Money for university is not always out there. Make it known to all.
- Guidance counsellors on how to get access to tuition.

8.4 Talking Circle – D

General Actions

- Start within places like ABSW, BEA, etc.
- What we need is to come together
- Let each other know what the other is doing
- We need a link
- We need to come together especially at times when policy is being developed
- We sometimes fight for the pit when we could be coming together.

Individual Community Actions

- Get together to incorporate all of the resources available by adopting a family/a family with issues: kids not doing well in school, etc., helping them with all the resources we have and can find
- We have a lot of youth in conflict with teachers, even parents aren't able to reach them
- Maybe we could step in; it helps to encourage them
- Once reports are done they need to be taken to groups for follow up
- We need to be patient (the play helped with this) and let ourselves be known in the community. If we are outside of the Black community we need to be patient and watch the community and wait to be invited instead of jumping in
- Education is a key. Members work needs to get to various levels where health professionals are being trained. Should be a part of the curriculum
- So many people go into Black communities and know nothing about the community where they are going to work
- Personal education, social work needs more cultural competency. It's good to have different backgrounds. Could be community and professional people. I.E. at my work we go into homes where there are immigrant families and they may not have the language and cultural competency to deal with difference and some didn't even realize they would even have to know this. Didn't think of it as an issue. Didn't think they would have to work with diversity. So the training in the beginning is beneficial
- Need sensitivity for new immigrants as well
- Organizing groups to take action... don't always try to create new ones. Look for what already exists (groups and organizations)
- Social determinants of health need to be revised to include income
- Work with white parents raising Black children. Making information available to them so they can be better prepared/equipped to teach them about their culture. They need to be taught about hair care, food preparation, etc.
- Need help for Black parents to communicate with their Black children to teach them about racism and why things are the way they are. So we need something to help our kids so they don't feel inferior. BEA can/has helped but still need more
- Community groups need to be created so that if families/youth/parents, etc. need help they can get it from within their own community
- Need to get back to old values, then the whole adopt a family idea

Government Ideas

- More diversity in DCS. Staff needs to look different
- Hire well trained staff who are diverse beyond women replacing men. That way they will already understand the importance of respecting diversity
- Need to get information out about grants that are available (ex. For housing). Also losing child care seats which is a health determinant in some areas because some don't know they exist
- Re teen pregnancy: seems to be an ongoing cycle (this is a mind set). This needs to change
- Foster system needs to change. Some parents are losing their kids only to have someone who isn't any better taking over

Suggested Actions for Non-governmental organizations and Educational Institutions

- Need our history in the school system; Afrocentric philosophy needs to be included at all levels (i.e. the very lowest level even). So if kids knew their history and when we were enslaved and also the richness that comes from our heritage. This also has to be trained to parents as well so they can advocate for it in schools
- More financial support at all levels and all degree programs for African Nova Scotian students not just for certain degrees
- Social Assistance allowing recipients to go into post secondary education but not limiting the programs because this says you can only be : x, y, z
- Need more trained and qualified counsellors and advisors at schools at all levels elementary/secondary and post secondary, to help those students to stay; so many students are leaving because of diversity issues
- Africentricity and philosophy of this culture needs to be included in all professional degree programs. Train teachers, professors too
- Stop judging students based on their own experiences (educational/academic) i.e. if someone is a Caucasian educator they must realize that a student of a different ethnic background has a different writing type and way of expressing themselves and they should not be penalized for that
- More cultural field trips for students in the community and beyond
- We should all take the time to visit rural communities and understand how each other lives
- We need to lobby, change policies at organizational level and in organizations
- Having diversity training in all government departments from top up and down
- Re 600 page mental health (nothing about Blacks) reinforces that we still aren't considered as humans
- So we advocate for ourselves to be acknowledged and better serviced we still aren't seen
- Effective cultural competency trained facilitators need to be diverse. Should have those stories (their stories and experiences) to share sometimes being an academic having a PhD isn't what is needed to be an effective facilitator or cultural sensitivity/competency
- Encourage government to give time to white service providers to build up a rapport to their clients to build trust, in culturally effective ways i.e. if I work in addictions that doesn't mean that I jump into a community to help in addictions. I need to gain their trust first.

Participant Conference Evaluations

I Yarmouth Conference April, 2006

The women who participated in the OTM study were invited to attend a two and a half day conference in Yarmouth on the 27th-29th of April. Conference participant had a lot to say in their evaluations which were submitted on the last day of conference.

Conference participants came from: Annapolis, Birchville, Cherrybrook, Dartmouth, Digby, East Preston, Falmouth, Halifax, Lockeport, North Preston, Shelburne, Weymouth, Yarmouth and other parts of the province. They ranged in age from 18 to 65+. Their opinions of conference events are summarized below:

What we liked best:

Many conference attendees appreciated the opportunity to dialogue on issues and suggest action to address health concerns in our communities. Some said they appreciated listening to the stories people told, seeing the positive energy of everyone, the passion and determination of presenters as well as the willingness to participate in discussions throughout the event. Most found the keynote speaker's motivational message very uplifting.

The OTM team and conference organizers were commended on the health information booklets, the multiple avenues of presentation of research findings (i.e. the play, the quilt and the workshops) and the inclusion of first voice narratives of Black women living on the margins. The use of first voice was seen as a powerful and effective way conveying the experiences of the women who participated in the OTM study. Those who attended the conference were also pleased to learn that Capital District Health Authority is prepared to change the way in which it delivers service after being made aware of issues that affect Black communities. Overall, the conference was seen as an empowering process, for all who attended as one woman says:

"The play gave me a new sense of pride in who I am and what I can become; I will leave this conference with hope and faith that we have members of our heritage working not only towards the elimination of racism in healthcare but also the preservation of pride in our African descent"

What could be improved?

Conference participants suggested that more time was needed for discussion and that better and wider promotion of the event would have been good as it was a very informative and beneficial conference. One woman also suggested that technology should be provided for those with visual and hearing impairment. Some felt that while the discussion about District Health Authorities and Community Health Boards was useful and informative it did not flow from the OTM research and was thus perhaps better suited to a different venue.

Some of the material discussed in the sessions left conference attendees quite emotional and some participants suggested the provision of Kleenex, especially during talking circles. One woman also commented that she "felt I was missing too much" due to concurrent workshops on a variety of interesting and relevant topics.

While the meals were appreciated, it was felt by some that full meals were preferable to finger foods and breaks on the second day which was the longest day of the conference. Better use of microphones and handing out material for presentations was also suggested as the information could then be accessed

long after the conference. Finally, many women requested that information be provided on what happens next.

Suggestions for follow-up:

Some conference attendees requested the provision of a list of action items that could be addressed by government and local officials to improve rural health. It was suggested that the women in South West Nova Scotia join the Health Association of African Canadians (HAAC) which would keep them informed on health issues and needs as well as current research. Regional meetings with community leaders and District Health Authorities were also suggested as useful avenues to identify and address community-specific needs.

There was a general consensus that the play: 'Who Will Care For Aunt Ethel?' should be widely presented in various arenas across the province. The messages in the play were important for all to hear. It was also suggested that the conference report should be made widely available. It was suggested that incentives were necessary to attract Black health (and other) professionals to rural communities. Support from government and provision of accessible services and resources was seen as the government's responsibility. Some felt that it was important to develop a booklet for women to take along to the doctor's office to assist health care providers in knowing what to test for and assisting women in requesting information on specific health conditions. Finally, it was suggested that the project be expanded in scope to look at the health needs of Black women across the province.

II Halifax Conference October, 2006

As a result of the feedback from the first conference held in Yarmouth, a one and a half day OTM conference was held six months later in Halifax. Some of the women who attended the first conference from South West Nova Scotia were again invited to participate.

Women attended this conference from: Beechville, Dartmouth, Digby, East Preston, Falmouth, Halifax, Inglewood, Kentville, Shelburne, Weymouth, Windsor, Yarmouth and other parts of the province. Once again, conference participants had a lot to say in their evaluations which were submitted on the last day of conference. Their opinions of conference events are summarized below:

What we liked best:

Once again, as in Yarmouth the play was well received by all who saw it. Most said it was: "fantastic, fantastic, fantastic!" Many found the information shared by the speakers to be useful and relevant-things were "explained really well". A number of attendees commented on the 'respect, passion and openness' among all who were present. Some found that the research findings emphasized the connection between all Black women in the need to address health issues.

As well, Sharon Davis-Murdoch's keynote address was seen as "empowering". Quite a number appreciated the larger group discussion and the ability to share comments, concerns and strategies over the course of the event. Many also applauded the use of talking circles to find out the key action areas that can be used to inform policy out of what was heard at the conference. The OTM team was also commended for efficient organization, structure, inclusion, PAR and passion.

What could be improved?

Some felt that more should have been done to reach Black men in various communities and include them in the conference. A wider audience including more politicians was also suggested as one woman asked: "where were the elected representatives?" Many enjoyed the panel discussion; however some felt that while the content was great, and the information was important from a strategy perspective, it would be better to include more Black panellists – "the people on the panel did not look like me".

Some suggested that perhaps having talking circles around the issues raised in the play would have been a better format to present the research findings. Similarly there was a preference for discussion over individual presentations or a panel. Finally, although many enjoyed the conference, several felt that the timing and transportation could have been improved; older people travelled long distances to attend the conference; perhaps having contact numbers and transportation for those who had to travel long distance would have minimised physical exertion.

Suggestions for follow-up:

There was a call for continued advocacy, empowerment, capacity building and commitment within the Black community to continue to 'make ourselves (and our needs) heard". It was also suggested that Black women should join Community Health boards. More plays covering issues around: Black youth, care giving, single parenthood and so on were requested. Some suggested that future research and follow-up action should include the Black Diaspora. Additional alternative formats for material presented in the conference were suggested so that those who were unable to attend the conference can still receive it.

Some also felt that a newsletter specifically designed to deliver health information and education to Black Nova Scotians should be made available, perhaps by District Health Authorities or Department of Health. Finally, it was suggested that the end of project report should be launched with a press conference which should include concrete discussion on recommendations for future research and action including a commitment by government to reflect Black women's health needs in government policies.

