

BEYOND INCLUSION: DIVERSITY IN WOMEN'S HEALTH RESEARCH **presented by Wanda Thomas Bernard**

Thanks to the Maritime Centre of Excellence for Women's Health for this invitation to be your keynote speaker for this year's policy forum. I am pleased to see the number of people here; this is in itself a statement of commitment to women's health research. The awards ceremonies have also been a wonderful celebration of the work that has been done in women's health research in the Atlantic region.

The focus of this forum is devoted to the notion of inclusion in women's health research and implications for policy and practice. I suggest that an understanding of, and critical analysis of exclusion and power is essential to our ability to understand diversity, and to move beyond inclusion in women's health research. Furthermore, an understanding of the material reality of exclusion, that is the reality of oppression, and implications for health research are needed to ground this discussion of inclusion.

I want to begin with a discussion of social exclusion and a definition of diversity. Colman's (2000) statistical profile of women's health in Atlantic Canada will be used to help contextualize my remarks. I will go on to examine the everyday reality of diversity and the interlocking nature of oppression and the impact on women's health. Finally, I will conclude with some strategies that could help us to move beyond inclusion in women's health research.

Social and Economic Exclusion

One cannot begin to discuss social inclusion without first examining the impact of social exclusion on women, children, families and communities who are most affected by exclusion. The notion of social and economic exclusion stems from a critical perspective on definitions of poverty and the move from an individual to structural analysis. The Maritime Centre of Excellence for Women's Health and its Social and Economic Inclusion Project has played a crucial role in changing the discourse and advancing the agenda from poverty to exclusion, and the goal of inclusion. In their report, *Social and Economic Inclusion: Will Our Strategies Take Us There?*, they quote Monica DasGupta who states that "the real analytical utility of the concept of social exclusion is that it draws attention to the processes whereby people become deprived, and the multidimensionality of the deprivation they face. The concept of social and economic exclusion moves us beyond the class biased model of poverty, to the structural realities that underpin the real exclusion that marginalized people face.

"Women's Health in Atlantic Canada"

Colman's (2000) study *"Women's Health in Atlantic Canada,"* that was commissioned for last year's forum, reinforces the reality of the ways in which the various determinants of health affect women's health. Whilst he acknowledges that this is not a comprehensive overview of women's health in the region, it does point out a number of alarming facts that could form future research agendas. I will comment on a few of the key findings of Colman's report, in relation to this discussion on diversity and inclusion.

Education

There are four times as many women graduates from university in Atlantic Canada as there were in 1971, and there are fewer female high school graduates than male. Health status and healthy lifestyles are both associated with educational attainment. However, we also know that the region's marginalized groups are under-represented amongst university, and high school graduates. What are the figures for Aboriginal women for example? What are the figures for Acadian women? For new Canadian women?

At the recent convocation at a local university, I noted little diversity in the graduating class. There were also few women graduating in the non traditional areas such as engineering and computer science. These are things that we ought to be concerned about. Current research that I am conducting on race relations in the education sector suggests that there has been little change in terms of the challenges that First Nation and African Nova Scotian students face in the education system. They are still less likely to graduate from high school and hence would have fewer opportunities to go on to higher education.

Income Distribution and Lifestyle

Colman (2000) says that women in Atlantic Canada earn only 81% of the hourly wage of their male counterparts. Additionally, those with identical education and training still earn about 10% less than men. One in five women in Atlantic Canada live in poverty, and income inequality and poverty are two very significant and reliable predictors of poor health. Seventy per cent of single mothers live below the poverty line, and the majority of the region's poor children live in single parent families.

Aboriginal and African Canadian women, and Persons with Disabilities in Atlantic Canada are disproportionately listed amongst the poor and single headed households. Given these statistics, we know that most women are adversely affected by income distribution and this has an impact on lifestyle. Dr. Lynn McIntyre's recent study on hunger found that 57,000 families (1.2% of Canadian households) with children did not have enough food at some point in 1994. A hungry child is eight times more likely to be living with a single mother. McIntyre says the social trends have gone the wrong way for these folks. The more deprived women are, the more likely they and their children are to have poor health.

Colman 2000:22 says that low-income earners have higher rates of hospitalization and health service usage, and that low-income families pass on poverty and lower functional health to their children. Clearly there is an urgent need to implement policies that will reduce poverty which will have long term benefits in terms of health care spending.

Mental Health

Women in Atlantic Canada report higher stress levels, and 20% more women than men report low levels of psychological well-being. Within the region, Newfoundlanders have the highest levels of mental health, and Nova Scotia has the lowest. We need to understand those factors that contribute to this high level of mental health in Newfoundland, as we can learn much from this type of analysis. Conversely, we also need to develop a critical analysis, through research and practice, of what is contributing

to mental health issues amongst Nova Scotian women. As an African Nova Scotian woman, I know that I find this particular statistic alarming, especially as I come from a community where mental health services are under utilized, and there are few culturally relevant services in the mental health field for African Nova Scotians. In addition, I wonder when we will recognize that racism is a health issue, as it affects both physical and mental health. I suggest that this is an area for research.

Social Supports

Research done in America by the Association of Black Cardiologists states that persons with strong, positive social supports tend to recover from health problems faster than those without supports. Recent research that I conducted with Black men, which examined the strategies that helped them to survive in societies where they were expected to fail, rated positive relationships and interaction with family and friends as their number one strategy. Colman reports that the health effect of established supports may be as important as established risk factors. The message here is clear: social supports can serve as both a prevention and intervention strategy in health care. Atlantic Canadians do this well! We have the highest rate of volunteering in the country, and much of the social caring work that is done in our communities is not visible or counted here. And we do know that much of this work is done by women.

More and more, families are expected to care for their sick, dying, disabled and elderly members at home. Deinstitutionalization has many positive aspects to family health and well being, however, the responsibilities are being downloaded to families without the necessary support mechanisms. At the same time, people are working longer hours, for less real money. This is wrong folks! Families cannot be expected to continue doing more with less.

Diversity

Now that the context for women's health research has been set, I want to turn your attention to the issue of diversity. However, just before we begin to look at diversity, I want to ask you a question: when you hear the term woman, what image comes to your mind? Now I want you to look around the room and notice who is here, but more importantly, I want you to notice who is not here.

The term diversity has almost become cliché, as people use it in different contexts. For purposes of discussion in this paper, I use the term diversity to refer to cultural, racial and social differences that serve as a demarcation of oppression or marginalization, for example poor people, Aboriginal people, people of color, persons with disabilities, gay, lesbian, bisexual and transgendered people, and women [the list could go on]. The term also refers to diversity within these groups. Understanding diversity means moving beyond recognition that this dynamic exists, and toward appropriate action (Hardy and Mawhiney 2000:24-25).

Those who live with some demarcation of oppression have little power as compared to their counterparts, who have more power and privilege. Hence, I want us to be mindful of the experience of power when we discuss exclusion and inclusion in health research. We

cannot talk about diversity in the context of change, without first talking about power and privilege. I invite you to also think about the role of power and privilege in health care and health research!

Power and Privilege

Evans (1992: p.141) says that power is the capacity to influence the forces which affect one's life space for one's own benefit. Power is the capacity to produce a change. Power is dominance and control. Power is embedded in social structures and institutions. Power is relative, as people may hold power in one social grouping, and be powerless in another (i.e., white women have race power over people of color, but have little power in terms of gender). Power may be exercised at a personal level and/or at a structural level. Western societies are characterized by unequal power relations. Knowledge plays an important role in empowering oppressed people: Knowledge is power. Power is the central component of oppression. The ability to oppress lies in the degree of power that one has to enforce the oppression, the exercise of power over others.

A legitimate use of power is empowering. The illegitimate use of power is grounds for malpractice.

It is important to also name powerlessness in the context of our discussion of power. Solomon (1976) says that the sources of powerlessness are: negative images oppressed people have themselves; negative experiences oppressed people encounter in the world; systems that systematically deny powerless groups opportunities to take action.

Pinderhuges (1997) suggests that marginalized groups that lack power actually serve a positive function for those with power, as they provide stability for those in the dominant groups. Those in positions of power and authority are reluctant to give it up because of these benefits, and the system of exclusion is therefore reinforced. Those with power and privilege are taught not to see it and not to name it.

Privilege is unearned power and advantage conferred systematically (MacIntosh 1990). Privilege allows doors to open for some groups, whilst closing doors for others. Privilege advantages some, while disadvantaging others. Using *systemic racism* as an example, I have stated elsewhere (Bernard 2000:8) that "the social privilege is rooted in the notion of white superiority, which says to white people, "no matter what your economic lot in life, you are better than those who are not white". Systemic racism is perpetuated through this conference of unearned, and unnamed social privilege on people of European descent. The effect of this social privilege is emotional or psychological reward. This emotional reward reinforces the feeling of white superiority. The positive feelings associated with this can only be maintained if systemic racism is maintained, as this inferiority of race reinforces the notion of superiority. In summary, economic privilege, social privilege, and emotional or psychological reward are the underlying, unnamed rewards of systemic racism. Systemic racism is the manifestation of a complex social process revealed in acts of individual racism, that are rooted in incidents and consequences of stereotyping, prejudice, and notions of inferiority. For one to have power, is to have the ability to oppress others. In a recent conversation with Yvonne

Atwell, she reminded me that one of the biggest challenges is that those with power are often unable to use it effectively because they are held back by fear, guilt and a lack of personal will to challenge the status quo.

Oppression

One visible abuse of power is that it is used to oppress others. As noted above, there are many groups in our society that are oppressed. By oppression I mean the inhuman or degrading treatment of individuals or groups; hardship and injustice brought about by the dominance of one group over another; the negative and demeaning exercise of power. Oppression often involves disregarding the rights of an individual or group and is thus a denial of citizenship (Thompson 1993). The term oppression is used to emphasize the pervasiveness of social inequality in social institutions, as well as embedded in our individual consciousness. Oppression denotes cultural and material constraints that significantly shape a person's life chances and sense of hope.

Oppression is the systemic dehumanization of an identifiable target population. To systemically dehumanize a population is to treat explicitly or implicitly the members of that population as lacking some human abilities, needs and wants that are seen as defining what it is to be a complete human being at that time in that culture. Oppressive structures are social structures that serve as mechanisms for oppression. These might be laws, policies, social stereotypes, jokes, hiring practices or distributions of resources, to name only a few. Individuals are oppressed to the extent that they are affected members of such target populations. (Obviously, some individuals have the resources to migrate or change the impact of oppressive structures; others may bear the brunt as they are affected by multiple oppressive structures.) Both oppression and exploitation can separately affect different groups, e.g. white women who own business may be oppressed as female, but are not exploited, as they are owners! (Clatenburg, 1986 pp. 17-18)

The Interlocking Nature of Oppression and the Material Reality in Women's Health

An understanding of the interlocking nature of oppression requires an analysis of the glue that keeps oppression in operation - what bell hooks calls the 'politic of domination'. The Ideological Roots: A belief in domination (power and control); A belief in the notions of superior and inferior.

Bishop (1994:61) states that separation, hierarchy and competition are kept intact through the maintenance of oppression across individual groups, cultural and structural levels. Social divisions contribute to the power and oppression in society. According to Thompson (1995), these divisions form the basis of social structures, and the network of social relationships which informs the distribution of power, status and opportunities. Individuals and groups are located by these social divisions. It is the "location" which informs differential treatment - a process that I call "othering". Through this process of "othering", people and groups are denied equitable access to what organizations and institutions offer. People's location is also informed by their location in terms of the intersection of oppressions, such as race, class, ability, sexual orientation, gender, age, etc. Collins (1990) has helped us to understand the interlocking nature of oppression, and

how each system needs the other to operate. Whilst each form of oppression operates in different ways, they are all a part of an overarching structure of domination.

Each form of oppression is perpetuated by a socialization which teaches all of us to accept the dominant views about cultural and social differences. We are taught to be prejudiced against people on the basis of race, class, gender, age, ability, sexual orientation, or anyone who is *different than the norm*. Children are born without prejudice, and systematically socialized in a world that teaches us to accept oppression, and oppressive systems. Socialization takes place in the home, school, and community; children learn prejudice from loved ones, educators and care providers. The socialization is reinforced by the media, the education system, and other social institutions. To change how the system of domination and oppression operates, we have to take individual action, which begins with an unlearning process, as well as collective action for social change.

Oppression may be present in a number of forms, however, the common denominator is that each form of oppression has an oppressor, agent (those with power), group, and an oppressed, target (those without power) group. Agent groups have greater access to social power, in the particular context under study. Target groups are denied, or have limited access to social power.

Members of both groups are capable of prejudice, as indicated above, most of us are socialized to be prejudiced. The significant difference, however, is that target groups do not have the institutional, social, or cultural power to back up, and support their prejudices against the target groups. Oppression is based on negative stereotypes of targeted groups, and is embedded in our social structures where there is institutional power to back up the negative, prejudice attitudes.

Oppression is manifested on multiple levels simultaneously: individual, institutional, and cultural. By individual manifestation, we mean attitudes and actions that are rooted in negative stereotypes, and reflect prejudice. Institutional manifestations are the rules, policies, norms, customs, laws, and practices of social institutions and organizations, that advantage some social groups, and disadvantage others. Cultural manifestations are the rituals, norms, roles, language, art, music, drama, that reflect and reinforce notions of superiority of one group over another or others.

Many people have a number of social identities some of which are visible, and others may be invisible. The intersection of oppression is like a web, where each line represents one social identity. These can not be separated, they are interconnected, woven into our lives and shaped by the fabric of our society. A student once asked me, "What affected me most, being Black, or being a woman?" I responded, "It depends on which part of myself I leave home on any given day, as some days I am Black, some days I am a woman, but most of the time, I am a Black woman, and therefore, constantly deal with issues of racism and sexism, as they intersect, not as separate entities." Please complete the web as a representation of the intersection of your social identities.

The Impact of Oppression

Think about society's attitudes towards poor people as an example. What are some of the stereotypical thoughts that are commonly expressed about poor people? For many members of oppressed groups, the oppression can also be internalized.

Now think about the institutional sites where such attitudes and opinions are likely to surface.

Next I would like you to think about the psychological effects on those individuals and the collective.

Finally, think about the coping strategies that poor people use. And then think about the impact of these on their health.

I recently was able to explore the notion of intersectionality in research that was funded by the MCEWH. The project, "*Winning over Addictions: Empowering Black Mothers with Addictions to Overcome Triple Jeopardy*" was a participatory action research project with Black women who were struggling with addictions, were mothers, and had some involvement with child welfare. These women experienced multiple oppression, and the oppressions interlocked on many levels.

The goal of the project was to engage Black mothers, who have addictions, and are or have been involved with a child welfare agency in an exploration of the issues that impact on them, and the barriers to successful intervention.

Findings

The findings suggest that there is a lack of culturally relevant services; there are no residential treatment services where women can bring their children; the involvement of child welfare serves as a threat and creates a barrier to intervention that really helps, plunging them further into despair; most lacked family supports, as their families were either unavailable or unable to provide supports. There are a number of policy issues here that affect health and social welfare.

The general consensus was that there is a severe lack of available resources for Black women struggling with addictions. Some of the contributing factors to African Nova Scotian women developing addictions are race, class, gender and geography. The majority of the services are not culturally relevant for the participants; services lack insight into social realities resulting in further oppression; and programs lack follow up services and available supports to sustain women after the completion of treatment. There is an urgent need for more preventative programs.

Recommendations

- More African Nova Scotian service providers and support persons are needed. Services are not reflective of racial differences, clients cannot identify with

practitioners. African Canadian women need a support network, including a worker who is African-Canadian, someone they can identify with.

- Further consideration must be given to class and culture in terms of availability to services. Poor African Canadian women simply do not have the money to access the benefits of private clinicians or extended health care systems.
- Additional residential services are required. Residential transition houses and services are geared toward men only. There are no residential programs for women and their children.
- Addiction follow up support services are needed in order to prevent re-occurrence of the addiction. Our social service delivery system is narrow minded, focussed on short term results. There is a need to sustain the momentum started with such programs, rather than losing connections after a given period of time.
- More education and awareness training around culture and ethnicity. African-Canadian issues get thrown into a multicultural pot, important that we recognize specific cultural needs and special circumstances.
- Community Capacity Building- government must be made aware of the limited resources. Alliance with the government is necessary because the community simply cannot afford to maintain the services themselves.

Empowerment

According to Thompson (1993) empowerment is the process of giving greater power to clients in whatever ways possible, such as resources, education, political and self-awareness. Empowerment practice encourages and facilitates self-sufficiency, independence, and challenges traditional power hierarchies.

Empowerment refers to both one's perceived and actual ability to determine the course of one's life (Evans 1992). Empowerment is having the ability to self-define. Swigonski (1996) states that regaining the use of one's own terms to understand and defines one's life affirms personal power. Empowerment is gaining mastery over one's self and community.

Strategies for Change: No hope, no dreams, no dreams, no future!

To move beyond inclusion in women's health research, women from diverse communities need to be an integral part of decision making, at the level of policy development and in the provision of services. We cannot be an afterthought, we must be a central component of the work that is being done. As I previously noted, understanding diversity means moving beyond recognition to action. The following are suggested actions that I have been developing over the past year or more, and these have been shared in part with the IWK/Grace Health Centre conference on violence in the lives of young women held in February 2000.

Both Carol Amaratunga and Yvonne Atwell have talked about a just society. People who live with the reality of oppression have no sense of entitlement, so for them a just society is but an illusion.

Working Towards Accessibility: Eliminating Barriers for Women From Diverse Groups

The following are areas to consider within government departments and your organization to help reduce barriers to women from diverse groups.

Agency Environment

Capital budget funds be dedicated to providing physical equipment, specialized communication and other accessories required for women from diverse groups. Consultation is carried out with women who require specialized communication services, physical equipment and other accessories to determine specific requirements within an agency. Agencies display posters, paintings and other symbols which reflect the realities of women from diverse groups. Information of available services, specific to and inclusive of women from diverse groups. Materials displayed in areas open to children reflect the values of women from diverse groups. Volunteers, staff and board members, through ongoing sensitivity-awareness training be made aware of the significance of an environment which reflects and values diversities.

Volunteers, staff and board members be encouraged to create a physical environment which confirms the agency's commitment for the celebration of diversities. Volunteers, staff and board members should reflect the diversity the organization is serving.

Agency Programs and Services

Whereas the programs and services offered by an agency should reflect the diversities of the users of the service, it is recommended that: agencies provide ongoing and compulsory training to staff, volunteers and board members in order that they possess a distinct understanding of the significance of inclusive programs and services; all pamphlets, forms and handouts used within an agency be reviewed and amended to be inclusive of women from diverse groups; agencies coordinate efforts to gathering and sharing resources which would enable each to provide accessible, culturally relevant and appropriate programs and services.

Agency Policy and Procedures

Whereas the policy and procedures adopted by government departments and agencies serve as a guideline to protect the rights of staff, volunteers and clients, it is recommended that: the principles and values of government and agencies be reviewed and amended to contain statements specific to the inclusion of women from diverse groups; that government departments and agencies adopt a work plan for servicing women from diverse groups as part of their strategic planning; a process of review and accountability be established to ensure that agencies remain committed to constant action as identified in their work plans.

In Research

There needs to be targeted research with and on diverse groups; more funding is needed for such research.

In addition, research that is done on women's health issues must not view women as a homogeneous group, and diverse views, opinions and experiences should be seen as central to women's research. So what I am saying is that both diverse specific research, and an integration of diversity in women's health research are needed to move us beyond the inclusion agenda.

A similar approach is needed in policy planning. A work place audit can be helpful in moving us beyond inclusion. Some tough questions need to be asked.

Workplace Audit

- Who does your organization serve?
- What communities does it serve?
- Do agency programs, services, policies and procedures reflect this diversity?
- Who is employed by your organization?
- What positions do they hold?
- Are the employees reflective of the persons and communities being served?
- Does the agency environment welcome diversity?
- Where are the gaps?
- What are the positives?
- What power do you have to effect change?
- What responsibility do you have to effect change?

Remember that research is the production of knowledge, and the persons who produce such knowledge increase their power to effect change in the condition or issue under study (Bernard 1996). To talk about inclusion in women's health research means that we have not achieved inclusion. To move beyond inclusion requires a major paradigm shift; that is a shift in our thinking, in our world view, our values and most importantly, in our actions!

As advocates for women's health research, policy and practice, you need to dare ask the following questions:

- Who's at the table?
- Who's not at the table?
- Why are they not there?
- What needs to change?
- What am I doing about it?
- What will I do about it?

The call to action in women's health research includes a call to make diversity and inclusion the cornerstone of women's health research, policy development and practice.

Thank you for this opportunity and the privilege to share my views with you!

Bibliography

Bannerji, H., Carty, L., Dehli, K., Heald, S., and Mckenna, K., (1991) *Unsettling Relations: the university as a site of feminist struggles*. Toronto: Women's Press.

Bernard, Candace; Bernard, Wanda Thomas; Ekpo, Chioma; Enang, Josephine; Joseph, Bertlyn and Wane, Njok (2000). She Who Learns Teaches: Othermothering in the Academy: A Dialogue Among African Canadian and African Caribbean Students and Faculty. *Journal of the Association for Research on Mothering*, 2(2), 66-84.

Bernard, W.T., (1996) *Survival and Success: As defined By Black Men in Sheffield, England and Halifax, Canada*. Unpublished Doctoral thesis, University of Sheffield, England, Sheffield.

Bernard, W.T., Lucas-White, L., and Moore, D., (1993), Triple Jeopardy: Assessing Life Experiences of Black Nova Scotia Women From A Social Work Perspective, *Canadian Social Work Review*, 10 (2), 256-276.

Bishop, A. (1994) *Becoming An Ally*, Fernwood, Halifax

Colman, Ron (2000) Women's Health in Atlantic Canada: A Statistical Portrait, in *A Portrait of Women's Health Volume One*, edited by The Maritime Center of Excellence For Women's Health, Halifax.

Collins, Patricia Hill. (1990) *Black Feminist Thought*. Routledge, New York and London.

Evans, Estella N. (1992) 'Liberation Theology, Empowerment Theory and Social Work Practice With The Oppressed', *International Social Work*, 35, 135-147.

Hardy, Sheila and Mawhiney, Anne-Marie (2000) Diversity in Social work Practice. In Sullivan, Steinhouse and Gelfand (Eds) *Challenges for Social Work Students*, Canadian Scholars Press, Toronto.

[h]ooks, bell (1994) *Teaching To Transgress*, Routledge, New York.

McIntosh, P. (1990) White Privilege: Unpacking the Invisible Knapsack, *Independent School, Winter*, 31-36.

Pinderhuges, E.B. (1983) Empowerment for our clients and for ourselves. *Social Casework*, 64(June), 331-346.

Thompson, N. (1993), *Anti-Discriminatory Practice*, MacMillan, London.