

DARE TO DREAM

Reflections on a National Workshop on Women and Primary Health Care

February 5 – 7, 2004 Clarion Hotel Winnipeg, Manitoba

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National Women and Primary Health Care Workshop Report February 5 – 7, 2004 Clarion Hotel, Winnipeg, Manitoba

INTRODUCTION

In Canada, since publicly funded access to physicians and hospitals was introduced some forty years ago, primary health care has been effectively defined as that which was delivered by physicians, largely in private practice, backed by the resources of the hospital system. While this system brought care to thousands who couldn't otherwise afford it, it tended to marginalize other facets of health care, particularly those focused on disease prevention and health promotion. It also produced a dominant discourse among health policy makers that focused on services rather than the broader, social determinants of health.

By the mid-1970s, governments began to articulate a wider set of factors as important contributors to health, including the physical environment and personal lifestyles, but this did not fundamentally alter the organization of health services. For the past decade, the focus on primary health care reform has been on new organizational forms and funding practices, without the benefit of a gender analysis to inform decisions about whether the primary health care system is appropriate for women. As national dialogue on primary health care reform intensifies, it is important to question whether and through what mechanisms any reforms support women in all our diversity.

In early February 2004, over 40 people participated in a national workshop in Winnipeg, sponsored by the National Coordinating Group on Health Care Reform and Women, a working group of the Women's Health Contribution Program supported by the Bureau of Women's Health and Gender Analysis of Health Canada, to discuss primary health care reform in Canada from the perspective of women (see Appendix B for agenda, Appendix C for participant list). The workshop was co-hosted by the Prairie Women's Health also supported by the Women's Health Contribution Program, Bureau of Women's Health and Gender Analysis.

Workshop Purpose

The purpose of the workshop was to bring together constituencies with different perspectives on primary health care reform in relation to women in order (1) to examine primary health care from the perspectives of women in various social and geographic locations, (2) to develop strategies to include women and a gender-based analysis in the planning, development and delivery of primary health care (including establishing continuing networks among workshop participants), (3) to use the discussions from this workshop to produce materials to contribute to primary health care reform in Canada, and (4) to identify research gaps for formulating a research agenda on women and primary health care.

Workshop participants included health care practitioners, researchers, social services and policy makers from the local, provincial and federal governments, each of whom occupies a unique position in relation to primary health care reform. We were concerned to ensure that discussions and analysis were related to the concrete, everyday practice of primary health care, that our discussions were informed by evidence and that the challenges of policy making were visible throughout the workshop.

We met for three days to examine innovations in primary health care, to debate women's primary health care needs, to articulate a possible research agenda and to understand the current context of health care reform. This report summarizes the proceedings of the workshop. Given its preliminary nature, the workshop raised more questions than could possibly be answered. However, we hope that we have contributed to a national dialogue on the issues and posed questions for women and women's health advocates to consider as we continue the processes of health care reform.

Workshop Format

Prior to the workshop, participants were sent a discussion paper commissioned by the National Coordinating Group. This paper, and a companion slide presentation by the authors, Lissa Donner and Ann Pederson, was intended to stimulate discussion on the nature of primary health care reform and its implications for women (see Appendices A and D).

During the evening preceding the workshop, a public presentation was held at the University of Winnipeg with three workshop participants offering comments on primary health care for women (see Appendix E).

Donna Cherniak, a physician working in a community health centre (CLSC) in Quebec, spoke about her experiences providing women-centred care in that organizational context and the changes in primary health care she has observed over the past two decades. She observed that many of the priorities and standards of practice in primary care are established by specialists. She argued that women consumers, nurses and physicians need to participate in setting the goals and evaluating the strategies used in primary care. Donna illustrated her discussion of primary care by using examples of medicalization— the process of defining normal life processes as illness or of applying a medical therapeutic model to risk factors—and continuity of care, arguing that while both are important issues for women and men, women are affected at younger ages, experience them more often, and experience them over a greater span of time. Moreover, women's economic status makes them more vulnerable to the consequences of both whether a condition is treated as a medical problem and of changes in the definition and practices surrounding continuity of care. Dr. Cherniak's reflections on "the science, the art and the organization of care" offered insight into the particular issues of physicians, many of

whom, like herself, value their work but find it challenging given their lack of control of administrative, budgetary and paramedical aspects of practicing primary health care.

Sharon Davis-Murdoch, from the Department of Health in Nova Scotia, offered a policy maker's perspective in her presentation. She outlined the approach being taken by the provincial government with respect to primary health care renewal. She described how primary health care renewal is being implemented with a social inclusion agenda specifically focused on issues of social exclusion arising from race, ethnicity, language and culture, noting the intersection of these issues with those of gender, poverty and lack of education. She outlined a three-year initiative that will result in the development of guidelines for culturally-competent care and culturally-inclusive primary health care policy in Nova Scotia. She illustrated the impact of social exclusion with several examples of significance in the province, including Aboriginal midwifery, immigrant persons' ideas about pregnancy, the lack of health status information on African Nova Scotians, as well as physical inactivity, addictions and stress. She spoke movingly about her family's experience of her mother's dying within a health care system that was not responsive to her dietary, spiritual or psycho-social needs. The initiative has two years remaining, during which nine community workshops will be held throughout Nova Scotia, and linkages will be made with key initiatives such as the provincial chronic disease management strategy in order to inform the development of culturally-competent guidelines and policies.

Anna Travers, Program Director of Primary Care Services for Lesbian, Gay, Bisexual, Transgender and Transsexual Communities at the Sherbourne Health Centre in Toronto, spoke about how heterosexism, homophobia, and transphobia "add layers of distance and difficulty" to women's relationships with primary care providers. Compounding sexism, racism, poverty, geographic isolation, and other barriers to health care, heterosexism, homophobia and transphobia (inside and outside the health care system) can lead to inadequate or inappropriate treatment, denial of treatment, or avoidance of health care visits. Primary health care providers must acknowledge that gender identity, sexual orientation, and the systemic and individual discrimination against lesbian, bisexual, transgender, transsexual and two-spirited women are key issues in the delivery of quality health care. She illustrated her presentation with examples of the impact of hiding or revealing one's full identity to health care providers and the limited understanding that most health care providers have regarding primary care services for lesbian, gay, bisexual, transgender and transsexual individuals.

The weekend workshop itself included plenary and small group discussions. The small group discussions were framed by morning plenary sessions. Members reported back each afternoon. Notes were taken throughout the workshop, in all small group sessions as well as during the plenaries.

Workshop Summary

These proceedings do not attempt to reproduce the entire workshop on paper but rather to highlight key discussions and to invite reflection on aspects of primary health care reform that are contentious, unexamined, about which we lack evidence, or for which evidence is not leading to appropriate action. Further, these proceedings do not reflect the views of individual participants nor draw conclusions on how to move ahead with respect to primary health care reform. Rather, they are intended to depict the nature of the discussions that occurred in Winnipeg and to offer others the opportunity to engage in reflecting on the issues raised during the workshop.

Overall, the workshop participants affirmed the need to ask whether current and planned primary health care services meet the needs of women in all their diversity. Participants provided examples of particular services that are working, such as some of the community health centres across the country, as well as of challenges facing women in accessing the services they need. Participants identified numerous barriers to access including geography, discrimination, funding arrangements, professional practices, language, culture, age, ability, sexual orientation, income and hours of service. They also described dedicated health care providers, decision-makers and researchers who are working to improve primary health care.

The issue of the definition and scope of primary health care, and the implications of the definition for care and priorities, was a central issue for some participants. This topic was raised in the background discussion paper as well as within the breakout and plenary discussions. The group hotly debated the value of broadening the definition of primary health care to reaffirm the principles of the *Declaration of Alma Ata* (see Appendix G) versus the practicalities of working with a framework that defines primary health care as the first point of contact with the health care system. The participants connected this debate to discussions of the relationship between primary health care and disease prevention/health promotion.

Workshop participants were invited deliberately to represent the perspectives of policy makers, researchers and health care providers. These differences in perspective informed all the discussions and challenged participants to understand the day-to-day realities of their respective roles within primary health care reform. The participants affirmed the need to continue to ensure that dialogue on primary health care reform needed to include all these perspectives but more importantly, that deliberate efforts were needed to ensure that women's perspectives were included—in governance and decision making, as health care providers (both formal and informal, paid and unpaid), and as researchers and program evaluators.

The workshop participants made progress on outlining what primary health care for women should look like by outlining principles that should inform the design, delivery and evaluation of primary health care. Foremost among the principles was the need for any initiative to be undertaken with the perspective provided by a gender-based diversity analysis. Such analyses increase the likelihood of identifying potentially significant gaps in service across the spectrum of services falling under the rubric of primary health care. Finally, as the rest of this document elaborates in more detail, the workshop participants identified the need to learn from successful innovations in primary health care to inform primary health care reform. Initiatives funded through various means, including the Primary Health Care Transition Fund, are helping to explore and document what models of care work. The participants cautioned decision-makers and communities from seeking simplistic, one-size-fits-all solutions to the complex issue of primary health care reform, arguing instead for sustaining initiatives that meet community desires and standards of relevance, accountability and quality.

FRIDAY, FEBRUARY 6, 2004

Welcome and Greetings

Welcoming remarks were made by the following individuals:

Anita Neville, MP Winnipeg South Centre, Chair Liberal Women's Caucus

Deanna St. Prix-Alexander, Executive Director, Bureau of Women's Health and Gender Analysis, Health Canada

Margaret Haworth-Brockman, Executive Director, Prairie Women's Health Centre of Excellence

Morning Plenary Session

Pat Armstrong, Chair of the National Coordinating Group on Health Care Reform and Women, introduced the plenary session on Friday morning, encouraging the participants to "dare to dream outside the categories." She tried to illustrate this by claiming, "We're realists—we seek the impossible; it just takes longer." She also reviewed the objectives of the workshop and guiding questions for the weekend's discussion.

Workshop Objectives

- To examine primary health care from the perspectives of women in various social and geographic locations.
- To develop strategies to include women and a gendered analysis in the planning, development and delivery of primary health care.
- To use the discussions from this workshop to produce materials that will contribute to primary health care reform.
- To identify the research gaps for the purpose of formulating a research agenda on women and primary health care.

Guiding Questions

• How are primary health care reforms being shaped by the current politicaleconomic contexts and what are the implications for women in all their diversity?

- What can we learn about primary health care reforms from those working for social justice, including the women's health movement?
- How do women's social and geographic locations influence their participation in, and need for, primary health care, paying particular attention to women as users, providers and decision-makers?
- What do women need in primary health care?
- What criteria should we use to identify successful models of primary health care?
- What do we know and what further research is needed to identify primary health care approaches that meet the needs of women from diverse backgrounds, communities and regions of Canada?
- How can women in Canada influence the direction of primary health care reforms?

Discussion

In a roundtable discussion that followed the outline of the guiding questions, participants were invited to contribute other questions or issues that spoke to their concerns about primary health care. These questions and concerns can be thematically organized as follows:

Contextualizing Primary Health Care Reform and Its Impact On Women

- Look at women's use of the system 'in both directions'—the way primary health care system interacts with women creates particular patterns of use; a lot of our use of primary health care comes out of the demands the primary health care system makes upon us (medicalization, role expectations—e.g., the good mother).
- Women are triaging themselves out of primary health care; part of this is related to the rhetoric around the burden of care on family physicians and there needs to be relief.
- What federal initiatives that are not specific to primary health care still have an impact on primary health care—e.g., legislative renewal, direct-to-consumer advertising?
- We need to ensure that the collection of health status information is facilitated and not hampered by other federal legislation not specifically related to health (e.g., privacy legislation).
- Examine how issues of health protection and primary care dovetail.
- The issue of medicalization is critical to seeing barriers to primary health care for women—focus on commercialization that is hampering women's access to quality primary health care.

Gendering the Analysis, Planning and Implementation of Primary Health Care Reform

- Women are invisible in the literature on the social determinants of health.
- It is important to incorporate a gender-based analysis, create a community consciousness around gender and health.
- How to infuse discourses of efficiency and cost with gendered aspects of primary care, including relational aspects of primary health care?
- Women's issues get lost in day-to-day implementation of the efficiency model.
- Can regionalization deliver the things that women need—where are the 'legs' of visions previously introduced?
- Women need to have a voice in these processes.
- Women must participate not simply as users but as citizens.
- Gender is absent in population health reporting—introducing gender into a universe that is premised upon/deals with the standardized individual.
- Most people in the policy universe do not see gender or see it as relevant.
- We must attend to the impact of health care reform on women who provide care.

Using a Diversity Lens in the Analysis, Planning and Implementation of Primary Health Care Reform

- It is important to pay attention to culture, including historical dimensions of cultural relations between Canadians and Aboriginal peoples.
- Psychological services are needed in northern Aboriginal communities.
- Think about the Métis identity and cultural connection as a determinant of health.
- Providing culturally appropriate services for Aboriginal people would encompass a holistic approach, inclusive of traditional healing practices; social and economic conditions (e.g., poverty, low education, over-incarceration, addiction) remain challenges; young population—if conditions do not shift now, there will be a crest of health concerns in the years ahead.
- Developing Aboriginal community health centres are understaffed and underresourced; need to establish an equalization strategy to correct this.
- Urban Aboriginal Strategy is a start, but not sufficient.
- We need to ensure access for Black and First Nations women.
- Consider the impact of historical marginalization.
- Confidentiality in small communities affects access.
- Rural women, low-income women, Aboriginal women in the Prairies—how health is affected by the social determinants of health (housing, income, interactions with service providers. . .); how to make primary health care more responsive to women currently not well-served (care must be appropriate to women's needs).
- Need comprehensive primary health care for lesbian, gay, bisexual, transgender, and transsexual people, and for homeless youth.
- Disabled women's access to primary health care—looking way outside the box.
- Must attend to regional inequities (intra-provincially).
- Deal with women's health concerns across the life course.

Knowledge Transfer/Dissemination/Brokering

- We need to share research results.
- We need linkages across sectors; how those who work within government can work better with researchers/activists.

Expanding the Notion of Primary Health Care Beyond Conventional Medical Care and Adopting a Structural Analysis

- Acute care issues tend to dominate the health care agenda.
- We must be clear about the distinction between primary care and primary health care (exclusion/lack of integration of social determinants of health).
- We need an integrated perspective on the lives of women.
- Include health promotion, disability and end-of-life issues in primary health care.
- We need to integrate from a women's perspective health promotion into primary health care reform, taking into account the social determinants of health; integration happens around chronic disease—this presents an opportunity and a risk (risk if chronic disease takes over the whole area of health promotion).
- We must speak to the social determinants of health as well as medical care.
- Linking child and family poverty with gender and health.
- We "need to become communities that are hotbeds of social unrest."
- Primary maternity care could be guided by principles of midwifery, e.g., continuity of care.
- We are concerned that primary health care gets boiled down to women's individual experiences/interactions with the primary health care system—how can women get what they need from their providers? How can providers be educated to provide this?
- Remember that primary health care is more than the services provided by Regional Health Authorities.

Policy Work and Action Strategies

- Community health is an organic, community-based process; concerned that Health Transition funding will be directed by physicians and professionals, and that community ownership is/will be overlooked.
- 'Healthy communities' is turning into 'healthy individuals.'
- We must propose strategic and do-able interventions; champion each others' initiatives.
- It is important to work outside our bubble; need a proactive strategic approach that can be implemented.
- Look to international contexts for 'best practices'/inspiring examples.
- We must take up one another's issues and concerns and initiatives, e.g., First Nations, consent re: access to medical records.

- Concepts such as integration, continuity, effectiveness, have been on the table for over 20 years; problem with adoption of a model that is very segmented—need to integrate initiatives across policy sectors.
- The Primary Health Care Transition Fund has been a great catalyst for getting primary health care reform underway; it's a long road to a primary health care system that is highly functional; challenged to provide research and evidence of efficiency and effectiveness—need to develop capacity for research and evidence production.
- How do we balance accommodating individual needs and circumstances and dealing with 'funding silos' that still leave out many groups of women (especially regarding Aboriginal women's health)?

Producing Knowledge and Evidence

- Exhausted staff, many middle-aged women who have devoted themselves to change—they still carry the attempt to make changes, it's important to meet them.
- Focus on evidence—what does it mean? How and what evidence influences primary health care reform?
- An environmental scan of women's health research and policy in Alberta found small pockets with little connection; very few self-identified women's health researchers.

Presentation

Lissa Donner and Ann Pederson made a slide presentation entitled "Beyond Vectors and Vessels: Women and Primary Health Care Reform," (see Appendix D) based on the discussion paper they wrote for the event (see Appendix A). In addition to arguing that primary health care in Canada would benefit from a reassessment of the *Declaration of Alma Ata* (see Appendix G), the authors outlined at least six ways that sex and gender matter in primary health care and illustrated these with examples. They note that sex and gender have an impact on primary health care through:

- (1) sex-specific conditions,
- (2) conditions more prevalent in women,
- (3) conditions which appear to be sex neutral but are not,
- (4) through the influence of gendered roles on health,
- (5) through gender stereotypes in health care, and
- (6) through over-medicalization of women's lives.

They described how issues of gender are absent from discussions of primary health care reform and noted similarities in the discourses of population health. They challenged participants to consider how to address the realities of sex and gender differences in ways that challenge stereotypes, rather than perpetuating them. They closed their presentation with three questions that might help move us toward answering this challenge:

• Do we look for opportunities where we think there is the most benefit to women?

- Do we look for threats and attempt to mitigate harm?
- Do we emphasize those areas where there is the most existing evidence, thinking this is our strongest case?

Small Breakout Group Work: Dimensions of Primary Health Care for Women— Building on Case Studies

The afternoon was devoted to small group discussions. Groups were established to encourage a mix of practitioners, policy makers and researchers in each. Workshop participants were assigned to four breakout groups, with two National Coordinating Group members (and Lissa Donner) facilitating and recording discussion in each group. Each group was assigned a different set of case studies: "Every Day/Every Night Health," "Diabetes," "Mental Health," and "Sexuality and Reproductive Health" (see Case Studies, Appendix F). Participants were asked to address women's needs in relation to 'inside' and 'outside' contexts, i.e., those specific to primary care in relation to particular issues and broader contexts and structures in which primary care is situated. The case studies provided both a concrete place for discussion to begin, and a means of elucidating concrete principles for identifying the dimensions of primary health care for women.

Guiding questions for the case study sessions included:

- 1. Thinking about the case studies, what do they tell us (and not tell us) about girls' and women's primary health care needs, how do they change over time, and how are they different for different girls and women? Consider:
 - Disease prevention
 - The trajectory of care needs over a lifespan
 - The context of care
 - The use of interdisciplinary care teams.
- 2. How should girls and women participate in the planning, development and delivery of primary health care and in relation to their own health issues? Consider:
 - Governance
 - Records and information
 - Entry points
 - Decision-making
 - Responsibility
 - Range of treatments (interventions)
 - Forces (e.g., demographic shifts, cutbacks, international trade agreements, etc.).
- 3. What elements are necessary in primary health care to address these needs and take into account these contextual issues for girls and women from diverse social and geographic locations?

Afternoon Plenary: Small Breakout Group Reporting

At the plenary session at the end of the day, each breakout group shared a summary of its discussion.

Every Day/Every Night Health

Based upon the wide-ranging discussion within this group, the members decided to begin the process of defining primary health care from the perspective of women. This workin-progress follows.

Defining Primary Health Care for Women

For women, primary health care is an approach¹ that understands and seeks to improve women's health in the context of their varied social, economic and geographic locations. Primary health care involves promoting health, preventing illness and injury, and providing assessment, treatment and care. It involves and responds to women as users and providers. It attends to women individually and collectively, in all of the environments in which they live, work and play. It recognizes and addresses the interactions of the determinants of health² as basic to women's health.

Women, individually and collectively, have a right to a full opportunity to participate in the planning, development, delivery, and evaluation of primary health care, taking into consideration women's diversity. Women have the right to participate in decision-making about their own health and health care. In order to promote women's full participation and leadership in a just and inclusive manner, capacity building at the individual and organizational community levels is essential.

¹We use the term "approach", as opposed to either a philosophy or a model, as has been done in the Declaration of Alma Ata (see Appendix G).

² The determinants of health are, according to Health Canada (http://www.hc-sc.gc.ca/english/women/womenstrat.htm#gender), gender, culture, income/socioeconomic status, biology/genetic endowment, education, employment, personal health practices/lifestyle, physical environment, social environment, family/friends/social support, healthy child development, and health services. Others might add race/race relations, nutrition/food, the quality of working life/the quality of life, and housing.

The terms primary health care and primary care are often used interchangeably. For women in particular, primary care is one of the key components of primary health care. Primary care involves a range of providers working collaboratively and across sectors in primary health care. Primary care includes, regardless of venue, promotive, preventive, curative, therapeutic, palliative, rehabilitative and supportive care that is women-centred and culturally responsive. It permits continuity of care across services and over time. Women have the right to equitable access to primary care, and to be treated respectfully.

To work for women, all components of primary health care must be adequately and continuously resourced, publicly financed and delivered by not-for-profit organizations.

Diabetes/Chronic Disease

Diabetes was used to stimulate discussion on the particular role of primary health care in chronic disease identification and management. Group participants noted that the case studies reminded them how often context is stripped away in the delivery of primary health care such that the complexities of individual patient's lives are not considered in the recommendations given by health care providers. Participants suggested that it would be valuable to talk about primary health care systems (plural) that are context-sensitive; however they recognized that there is a tension between meeting the practical demands of providing services and avoiding 'cookie-cutter' care. For example, one system cannot be applicable to all geographic locations, but we may be able to talk about linkages between systems that can address local needs. Moreover, we must recognize that primary health care is not simply the medical system—we must address other social determinants of health. We must build on innovative successes and build women into design, implementation and delivery of services.

Mental Health

This group started with the question: "Is primary health care reform a good idea?" and asserted that we must reframe what it means to make decisions (who's making decisions and how are the decisions being made?). An ongoing critical analysis is key. The group produced four principles to guide primary health care reform:

- 1. There must be multiple responses across multiple systems, rather than an attempt to create one universal solution for primary health care reform. Innovative programs in various parts of the country can be modified to meet needs in other regions. In order to produce these multi-sectoral responses, we need to have a much broader understanding of primary health care reform. We must also build *prevention* into primary health care and other sectoral responses to social justice problems.
- We must provide opportunities and resources to communities to come up with innovative solutions and must consult community members (users, providers of care). This capacity building includes GBA training at all levels in all sectors of policy and service delivery. It also includes policy education for communities.

- 3. Networking and relationship building is crucial for a revitalized primary health care system (this already happens among women's health organizations, e.g., Centres of Excellence). We need to expand that network of relationships to include users, policymakers, providers—and women in all their diversity. This will aid in the creation of a common vision of core principles of primary health care.
- 4. Women's participation in the planning and development of primary health care reforms is crucial. But we must be vigilant about the authenticity of participation processes—can participation genuinely influence the process or is it simply a show? We must support women in positions of influence to make gender an issue in primary health care reform, linking them with women's networks across sectors.

Sexuality and Reproductive Health

This group raised several concerns and identified eight principles to guide primary health care reform:

- 1. Value and respond to diversity: preserve population-specific needs; preserve and protect these, rather than a one-size fits all model; marginalized populations can provide expertise and enhance the whole system—they are a resource to the system, not a drain on the system.
- 2. Patient control of electronic records. What is in the medical record should be controlled by the client/patient (notion of partial consent exists).
- 3. Support accessibility and resist privatization. The smaller the gap between rich and poor, the healthier everyone is; must be very careful of the tendency to institute parallel systems where rich pay for services; when people shift to the private system, the public system loses people who are more healthy (the remainder are sicker) and loses the most articulate advocates for quality of care.
- 4. Incorporate the social determinants of health. The social determinants of health must be considered in policy development and built into accountability frameworks. Investments in the social determinants of health may not produce immediate effects so sufficient time must be factored into analyses. Health impact assessment must be applied to new policy proposals.
- 5. Conduct gender-based diversity analyses.
- 6. Provide resources for better community supports (which can take pressure off physicians' offices).
- 7. Develop cultural competence. We need cross-professional, cross-sectoral education re: diversity. There must be policy development re: cultural diversity (e.g., Nova

Scotia, Social Inclusion in Primary Health Care). There must be diversity policies in training schools and diversity training in core curriculum.

8. Support community involvement. Broaden the range of participants in decision making, e.g., feedback/evaluation in care settings: adopt a community health centre model where boards consist of people who use the services—this provides an opportunity for quality improvement.

SATURDAY, FEBRUARY 7, 2004

Morning Small Breakout Group Work: Defining and Designing Primary Health Care for Women

On Saturday morning, the participants reconvened in their small breakout groups from the day before. The group that had begun the process of defining primary health care continued their work, elaborating the definition and elucidating its foundation. The three other breakout groups took on the task of "daring to dream," imagining what good primary health care for women would look like.

In designing primary health care for women, the groups were encouraged to "think of the laundry!" This was in reference to a story told by Pat Armstrong about a recent trip to Cuba in which they observed that workers in one hospital laundry were permitted indeed encouraged—to use the hospital facilities to do their laundry from home. Such practices not only enable hospital workers to balance work and family obligations, they also use scarce resources such as machinery to the benefit of the entire community. In this example, laundry services are not considered ancillary to health care but rather as an important determinant of health.

Participants were guided by the following questions:

- Who: Who is served, who serves, who plans, who evaluates, who governs?
- What: What services, facilities, structures are needed, important? What kinds of care?
- **How:** How are these services delivered? What should be the processes and practices? What do 'integration' and 'continuity' mean in this model?

Other 'Whats': What's there? What's not there that should be there? What's there that should not be there?

These questions reveal tensions among different assessments of what needs to happen in primary health care reform. Two examples are illustrative. First, many people agreed that social determinants of health should be an integral component of primary health care, but some people were concerned that this can lead to the medicalization of social issues.

That is, health care providers may bring a biomedical (individualized) approach to social problems. Second, it seems reasonable to want (electronic) health records kept and shared between our health care providers to enhance continuity of care and to relieve individuals of the burden of having to repeat themselves at every visit. However, there may be some information we do NOT want kept or shared. There are also questions of access—who has control over the information added to the record or removed from it? Making the tensions among perspectives explicit can generate creative opportunities for envisioning primary health care reforms that are responsive to women.

Afternoon Plenary: Small Breakout Group Reporting

Orange Group

The group agreed that in its discussion, 'primary care' would refer to the contexts that promote health (social determinants of health, healthy public policy), while 'primary *health* care' is constituted by the service delivery and coordination of health care (this includes promotion, prevention, and primary medical care).

The major audiences for this discussion are women, funders, jurisdictions (provinces, territories, regions, non-governmental organizations, from which we might draw on funding to demonstrate different approaches), and Regional Health Authorities (where they exist).

Tensions and Contexts

Some of the tensions revealed in the discussion spoke to the contexts in which primary health care reform is occurring. The issue of 'turf' was characterized in a number of ways: the tension between the model that Health Canada has endorsed (population health) and the model endorsed by different jurisdictions (e.g., provinces); the tension between different sectors that use different terminology (e.g., what is meant by 'primary care'?); the tension between individual responsibility and social/collective responsibility (e.g., there is a perception that the state is reactive, responding only when an individual is sick, rather than providing important collective, preventive support); and the tension around who coordinates the care (e.g., physicians want to decide when other care providers come in).

There are also tensions around 'accountability,' which tends to be framed as surveillance. A lack of trust in service providers is one motivation for record keeping. The consequence of accountability surveillance is increased bureaucratization, which leads to a tension between standards and individualized care. Accountability can also be linked to cost-containment strategies, in which factory models are used in health care settings. Accountability is also linked to the pressure to produce more evidence—but what counts, and who's counting? Finally, there are tensions around job burden. For example, in the push for 24/7 care, we need to attend to several crucial questions: Who provides the care and under what conditions? Are there enough workers to share the load? Do we have the human resource capacity to increase routine access to care outside of 9 to 5 hours?

What's Not Working?

Three main issues were identified:

1) In the prevailing culture of (cost) efficiency, the only way to promote your agenda is to say you'll save money down the road. But tying (medical) care to financial pressures allows the discourse of the 'health care crisis' to take hold, and this threatens the public health care system. Moreover, women (as users and as service providers) are often blamed implicitly for the state of the system. Combined, the 'health care crisis' discourse and the intense workload on health care workers lead women to triage themselves out of the system.

2) De-contextualized responses to health concerns focus on individual behaviour at the expense of environmental (social and physical) contexts.

3) There is a severe lack of acute and obstetric health care facilities/services in rural and remote communities, with the result that very sick people travel to urban centres for care (far from their own supportive networks) and women move to tertiary care centres for basic obstetric care.

What IS Working?

The group identified the social determinants of health approach (which provides a language that legitimizes collective responsibility), health promotion programs, and other supportive community services as a positive element of primary health care. For example, in some jurisdictions there are youth health centres in junior and senior high schools; these provide a positive access point for young women when they are NOT ill. Other community services such as second-stage housing, well-women clinics, and community resource centres are designed for women to access without being labeled as sick. A public health care system is desired by and essential for women.

What Will Good Primary Health Care for Women Look Like?

This vision includes the following:

- Integration of a social determinants of health perspective (in policy and service delivery)—the more you take care of at the level of social determinants of health, the less must be addressed at the level of individual medical care.
- A healthy civil society—resources and opportunities for community-building and community governance.
- An integrated gender-based diversity analysis—measures and evaluations are missing women.
- Acknowledgement of women's competence and a focus on women's capacity; seeing women as a resource for their own health (within a supportive community).

- Involvement of women at the community level in governance of the system and in health-related research.
- Funded access to alternative/complementary care providers (e.g., physiotherapists, psychologists, nutritionists, midwives, massage therapists, food security workers, etc.).
- Community development and outreach—there must be more public points of contact where women can access information and supportive services (these services include: health education, care advocates, language services, etc.).
- Enhanced access to care via extended hours (evenings/weekends), physical access (geographic location, transportation, barrier-free), language.

How Would Primary Health Care Be Delivered?

Group members shared some excellent examples of primary health care that works for women (e.g., the Halifax North End Clinic). These approaches to primary health care affirmed the expertise of women at the community level, and enhanced their expertise through capacity building (e.g. training sessions on advocacy).

Green Group

This group prepared a draft definition of primary health care for women in Canada and presented it to the group electronically (see below).

They also presented some comments and questions to accompany their work-in-progress:

- How do we understand the interrelationship between primary health care and the social determinants of health (or how deeply embedded are the social determinants of health inside primary health care)?
- Tensions integral to the definition of primary health care:
 - Language and meaning.
 - Live, work and play (does adding 'play' weaken the message?).
 - Approach vs. philosophy and model.
 - Does 'social, economic, geographic' get at all the diversity of women's experiences (e.g., dis/ability)?
 - What does primary health care address/respond to? Do we need to define/repeat social determinants of health or do we need to add to/flesh out that list? Does a more general social determinants of health approach move us away from gender?
 - Who defines what is appropriate, scientifically-sound evidence? Do 'culturally-sensitive, women-centred' incorporate appropriate, scientifically-sound evidence?
- Key issues to consider:
 - Community organizing/development.
 - Public participation; barriers to influence.
 - Context questions would work well as a preamble for the definition.

- Appropriate staffing (numbers as well as range).
- Language flags: •
 - Civil society. _
 - Women-centred. _
 - Inclusive of 'alternative' health providers. _

Draft Definition (work in progress)





Gendering Alma-Ata

- Alma-Ata: "People have the right and duty to participate individually and collectively in the planning and implementation of their health , care.
- Gendering Alma-Ata: Women, individually and collectively, have a right to a full opportunity to participate in the planning, development, delivery, and evaluation of primary health care, taking into consideration women's different social and geographic locations. Women have the right to participate in decision-making about their own health care.

Alma-Ata: "Governments have a responsibilityPrimary health care is the key to attaining this target as part of development in the spirit of social justice." Gendering Alma-Ata:

Primary health care is more than health care services; it is more than the determinants of health; it creates the conditions to lead socially and economically productive lives.

PHC is both about the one-to-one relationship between a provider and a patient, and about a bigger picture. PHC is a key to attaining socially and economically productive lives, in the spirit of social justice. PHC is essential health care, and is accessible to women in their diverse communities. First level of contact.

Blue Group

In this group, the wide-ranging discussion on what it meant to design primary health care for women was recorded on multiple flipcharts. With respect to who the primary health care system serves, it was suggested that this be based on the principle of flexibility to accommodate diversity—one size need not fit all in terms of designing primary health care. As we said earlier, we should think about "systems" and be willing to learn from examples what works. Use interdisciplinary teams to maximize cost-savings and quality of care. Do not rely too much on the voluntary sector because this downloads responsibility onto women without compensation. "At risk" populations need to be particularly "targeted" in primary health care reform. In developing plans, encourage public participation, especially by those who experience inequities. We need to fill critical information gaps on specific groups, e.g., Black women in Nova Scotia, in order to ensure that their needs are met. The public should also be involved in evaluation, which needs to beyond patient satisfaction questionnaires, and in governance. Create avenues for the participation of women in governance. How can women participate in processes of influence, for example, in the media, with lobby groups, as advocates?

It was acknowledged that we need to rationalize the use of scarce resources. In order to facilitate access, identify system navigator—it was proposed that we build on the model of the "concierge," that is, someone who knows what services are available, when, where, etc... In a related vein, the system would benefit from "cultural health interpreters," that is, people who are culturally competent with respect to diverse communities, to facilitate people accessing the system and the system responding appropriately.

Innovative places such as the Sherbourne Health Centre provide resources for the whole system to learn from, not just the particular community it serves. While centres such as the Centres of Excellence, Aboriginal Community Health Centre and Women's Health Clinic are often seen as add-ons to the system, they should be regarded as resources and catalysts for the whole system.

Changing the entry point will change the system. We need to see a shift in the whole system regarding regulatory acts and structure to ensure access. Changes outside the

health care system itself may have a profound effect on the system: think of Scotland's experience with proportional representation. This resulted in an entirely different political climate, which in turn introduced a different political agenda, which in turn shaped policy. Hence change in the health care system can arise from other parts of society. We should influence those places as well as try to change the primary health care system itself.

Facilities need to be located and developed with consideration given to physical, attitudinal and bodily geography.

This group identified a number of tensions, including:

- The way our system frames doctors as gatekeepers of services; but structure doesn't allow them time or knowledge to provide that service.
- Lip-service is often paid to issues of equity.
- We need to be more explicit about discrimination in our work on policy and practice.
- Primary health care is sometimes seen as a resource only for needy people, which vilifies some groups. Instead, resources must be available and flexible. We must normalize access to services.

Yellow Group

This group emphasized the importance of identifying and understanding the contexts in which the current primary health care system has emerged and in which reforms are being planned and undertaken. They focused on identifying key messages to convey to policy makers regarding primary health care reform and women.

These messages are:

Gender-based analysis must be built into the planning and implementation of primary health care reform. Moreover, recognition of women's diversity must be integral to processes of planning and development—women are not a homogeneous group and their diverse needs must be met by diverse solutions.

There is been a persistent medicalization, commercialization, and corporatization of health care. Primary health care reforms must go beyond medical and pharmaceutical interventions, and take into account a much broader range of determinants of health. Our goal and priority is *public* health—this takes precedence over commercialized interests in health care. In the spirit of a social determinants of health approach, we affirm that health is more than health care. Accordingly, we acknowledge that health begins with health promotion and prevention. Issues such as labour relations, working conditions and poverty are determinants of health that can be addressed within the primary health care system. We also affirm the role of community organizations in providing primary health care services. There is an established hierarchy of expertise in the system that must be challenged in the restructuring of primary health care teams.

We must recognize the contributions to primary health care made by women's groups, women's movements, and community actions and initiatives. Women must be involved in the governance, planning and evaluation of primary health care. We must take steps to facilitate and ensure women's participation (via advisory groups, community-based participatory action research, etc.).

How should the primary health care system be evaluated? If its goal is to enhance the well-being of the population, it should be judged by its effectiveness in doing so. But a commitment to a gender-based, diversity analysis requires that evaluation methods and criteria be adapted to specific groups and areas being served. Accordingly, such evaluation should not rely solely on dominant hierarchies of evidence (e.g., randomized clinical trials). Contextualized, multi-method, participatory, community-based research can be a rich resource for primary health care evaluation and reform.

Finally, policy makers must be reminded of a shared commitment to stewardship of a compassionate, primary health care system that is universally available and accessible. Primary health care is a social trust—there is a duty to care, not simply a duty to 'fiscal responsibility.'

This group of participants reminded us that we need 'good news,' i.e., success stories of innovative, responsive services that can inspire and influence service providers, community activists, policy makers, and women in general. They invited participants to share examples of good quality primary health care for women.

"Five Minutes with the Minister"

For a closing exercise, and as a means of focusing on and prioritizing key concerns, participants were encouraged to consider what they would say if they had five minutes with a Minister of Health (federal, provincial, territorial) and were able to make an intervention on primary health care for women. Participants' remarks have been organized under several themes (some overlap occurs and while some comments are verbatim, others are paraphrases).

Focus on Women and Conduct Gender-Based Diversity Analysis (GBA)

- Women's issues are different than those of men; diversity among women must be recognized .
- All aspects of primary health care should be assessed as to whether a womanspecific version would be more effective.
- Think about what's important to my mother, sister, daughter—that's what's important to women.
- Start with where Minister is at; what concerns you about your, your daughter's, your sister's health; segue into areas where the Minister lacks knowledge.

- Women as consumers and workers in the health care system have the right to be treated with respect and to have their knowledge and needs validated and acted upon.
- Primary health care must take fully into account the diverse experiences and needs of women, and must treat women as full partners in the planning and delivery of primary health care.
- Enable all women to make informed choices about health care and what they need.
- If any report ends on your desk without a gender-based diversity analysis, return to sender with demands that it be included.
- We have an opportunity to make positive changes; we need to base changes on the evidence we already have on the impact of gender on health.
- Fifty percent or more of the population is not a special interest group. It is time to pay attention to women.

Address Diversity

- Come to our Aboriginal Community Health Centre; see our successes, listen to what we need for enhancements.
- Poverty must be addressed by all sectors for the well-being of all of us.
- Go beyond the rural/urban split and consider remote communities in policy, planning and implementation.
- Culturally inclusive policy and cultural competence in care delivery are essential to quality primary health care in a multicultural Canada.
- We live in a big country and it is essential to take into consideration the diverse needs of the women who inhabit it.
- Acknowledge and celebrate diversity, and value different approaches being used across the country.
- There is strength in diversity, it benefits everyone.

Focus On Communities

- We must include well-being not only of individuals, but communities—especially diverse and marginalized communities; we have studied and advocated for prevention and wellness and community support—when will it happen?
- Community supports and capacity building are central to women's health and must be integrated in primary health care reform.
- Empowerment is a concept that shouldn't be lost in primary health care reform; it is critical to improving health (it is one of the social determinants of health); it should be part of primary health care at the individual, group and community level.

Health Care Is Not A Business

- Protection of public health and safety must take precedence over corporate interests.
- The development of primary health care is not about the machinery of/doing the business of health care; it's about an attitude of care.
- Need to fully understand the principle that primary health care should be based on need, not greed.

Principles to Follow

- The more successful we are in working together to care for the health of each and every person, the less we will suffer the far-reaching negative consequences of illness.
- We must be guided by principles of openness and compassion.
- Health care is a national trust; you have a responsibility to preserve, protect, and maintain this trust; you can't do that unless you pay attention to how primary health care affects girls and women; you have tremendous opportunity.
- We must reinsert the broadest meaning of health into primary health care reform—if we don't, our reforms will fall short for the majority of Canadians, especially for women and our diverse communities; the health of Canadians is a national treasure.
- Remember Alma Ata!

Politics

- "I'm running for parliament; my platform is primary care for women."
- Vet this information with your wife, sister, daughter; ask cabinet colleagues how their work will support these initiatives.
- Make the personal political and the political personal.

Resources

- Women matter; we need money.
- What resources could be put in place to make these things happen?

ACTIONS

Following the two-day workshop, the National Coordinating Group on Health Care Reform and Women met to consider the actions proposed by workshop participants and next steps. Among the actions identified to be pursued were the following:

• Solicit success stories/innovative, successful examples/'best practices' from participants.

- Use the workshop discussion as a basis for developing paper for National Primary Health Care Conference in Winnipeg in May 2004.
- Use the discussion and intelligence of participants to inform the development of further materials to share with various policy, research, community, provider audiences.
- Put the next version of definition of primary health care on-line and invite people to comment.
- Create a listserv for participants and to build further networks.

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Appendix A – Dare to Dream

Women and Primary Health Care Reform: A Discussion Paper By Lissa Donner and Ann Pederson

1. What is Primary Health Care?

In the 1978 *Alma Ata Declaration*, the World Health Organization stated the following about primary health care:

The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.

Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures. A main social target of governments, international organizations and the whole world community in the coming decades should be the attainment by all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life. Primary health care is the key to attaining this target as part of development in the spirit of social justice.

Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process. (World Health Organization 1978, 1-2)

The *Declaration* goes on to define primary health care to include prevention, health promotion, curative and rehabilitation services.

The work of the women's health movement was important in setting this direction for health policy. It was the women's movement that pioneered the political approaches to health and health care, taking them from the domain of the personal to the domain of the political, understanding that "control over our own bodies" would be impossible without social and economic changes. As Barbara Ehrenreich and Deirdre English wrote in *Complaints and Disorders*, five years *before* the Alma Ata Declaration:

This, to us, is the most profoundly liberating feminist insight – the understanding that our oppression is socially, and not biologically, ordained. To act on this understanding is to ask for more than "control over our own bodies." It is to ask for, and struggle for, control over the social options available to us, and control over all the institutions of society that now define those options. (Ehrenreich and English 1973, 89)

In contrast to the Alma Ata Declaration, Health Canada has defined primary health care as "the first point of contact for Canadians with the health system, often through a family physician." (Health Canada 2001)

This definition, refreshing in its brevity and simplicity, leaves unanswered important questions, including what constitutes the essential components of primary health care.

Elsewhere, Health Canada has made a strong commitment to understanding the importance of the non-medical determinants of health, such as income and social status; employment; education; social environments; physical environments; healthy child development; personal health practices and coping skills; health services; social support networks; gender; and culture.³ This commitment dates back to the 1974 report by then Federal Minister of Health, Marc Lalonde, *A New Perspective on the Health of Canadians*. (Lalonde 1974) Health Canada also has an expressed commitment to both gender based analysis and women's health, as evidenced by Health Canada's *Women's Health Strategy*, its *Gender-based Analysis Policy* and *Exploring Concepts in Gender and Health*. Yet these do not appear to be reflected in its work to date on primary health care reform. The Canadian Health Services Research Foundation's recently published report, *Choices for Change: The Path for Restructuring Primary Healthcare Services in Canada* (Lamarche 2003) proposes a definition which is slightly broader than that offered by Health Canada:

The term "primary healthcare" has been interpreted in different ways. At its core, however, primary healthcare is defined as a set of universally accessible first-level services that promote health, prevent disease, and provide diagnostic, curative, rehabilitative, supportive, and palliative services. (Lamarche 2003, 2)

³ See Health Canada's *Women's Health Strategy* at <u>http://www.hc-c.gc.ca/english/women/womenstrat.htm</u>

The authors then list six broad effects which should be produced by primary health care: effectiveness, productivity, accessibility, continuity, quality and responsiveness. Equity – including gender equity but also equity more broadly conceptualized – is notably absent as a criterion. In fact, the authors made an explicit decision to exclude the equity indicator from their analysis due to the "ambiguity of its wording." (Lamarche 2003 Appendix 2, 50)

The definitions used by Health Canada and the CHSRF are both problematic. They are de-politicized definitions that exclude both any mention of the health determining systems outside of the health care system itself, as well as any statement about individual and collective rights to participate in the planning and implementation of health care. They lead to a focus on systems management rather than on attention to prevention. Like the approach of the Romanow Report, with its emphasis on individual behaviours and its silence on the structural determinants of health, this approach strips primary healthcare, and primary health care reform, of their radical roots.⁴

All of these definitions, including that used in Alma Ata Declaration, are written in language which ignores the differing primary health care needs of men and women.

Is primary health care thus defined healthy for Canadian women?

⁴ See Armstrong, P. et al. (2003).

2. Primary Health Care Reform in Canada

Primary health care reform in Canada is not a new idea. Nor is primary health care reform limited to Canada. Indeed, primary health care reform as we will discuss it reflects larger, global trends toward the commodification of health and health services.⁵

In Canada, primary health care reform has been underway for decades. Long before the Lalonde Report and Alma Ata, Saskatchewan pioneered community health centres with the formation of the Community Health Services (Saskatoon) Association in 1962 by promedicare doctors and citizens. The Sault Ste. Marie and District Group Health Association opened in 1963. Beginning shortly after the introduction of medicare in 1971, Québec introduced local community service centres (CLSCs). By 1972, Manitoba had joined this movement, issuing a *White Paper on Health Policy*, which called for the establishment of more community health centres and the introduction of district health boards.

In 1969, the Hon. John Munro, Federal Minister of National Health and Welfare stated:

The key is contact, the place is the community, the concept is preventative...group practice, community health centres, mobile outpatient clinics, increased case-findings through home visitation, greater availability of local alternate-care institutions, better home care, increased team work with community social agencies. (Government of Manitoba 1972, Appendix 1, page 16)

Later that same year, the Mr. Munro said the following about community health centres:

...I think that there are some advantages which are immediately foreseeable. The very fact that the consumer has a real role in the planning, development and operation of these centres on a community basis represents a substantial step forward. (Government of Manitoba 1972, Appendix 1, page 17)

All of the initiatives in primary health care reform from the 1960s and 1970s have several things in common. First, all are closer to the language and approach of the Alma Ata Declaration than current Canadian primary health care reform policy. Second, none led to major changes in the provision of primary health care, which is still for the most part delivered by physicians who are remunerated on a fee-for-service basis. And none of them acknowledge the importance of gender in primary health care, nor of the contribution of the women's health movement to primary health care reform.

⁵ See Armstrong, P. (2001).

Current initiatives for primary health care reform in Canada are being led by the Federal/Provincial/Territorial First Ministers and Ministers of Health. In 2003, in response to the Romanow Report, the First Ministers' *Accord on Health Care* identified primary health care reform as one of three areas which required additional investments. (The others were home care and catastrophic drug coverage.)

In this Accord, the First Ministers stated:

The key to efficient, timely, quality care is primary health care reform. First Ministers agree that the core building blocks of an effective primary health care system are improved continuity and coordination of care, early detection and action, better information on needs and outcomes, and new and stronger incentives to ensure that new approaches to care are swiftly adopted and here to stay. First Ministers agree that the ultimate goal of primary health care reform is to provide all Canadians, wherever they live, with access to an appropriate health care provider, 24 hours a day, 7 days a week. (Government of Canada 2003)

The First Ministers' statement of their "ultimate goal" as "access to an appropriate health care provider" is telling. Gone is any sense that primary health care reform is a tool to improve the health of the most vulnerable, or a means to a more just and equitable society. In this model, access is seen as an end in itself, rather than locating access to health services within the web of health determinants. Moreover, this approach to primary care is clinical, despite the aside to prevention, suggesting that prevention is a particular form of clinical intervention as well. Equity is not identified as a goal but efficiency is.

While the First Ministers' Accord did not include any statement of priorities, the federal, provincial and territorial governments have agreed on common objectives for the Primary Health Care Transition Fund (PHCTF), the purpose of which is:

to support the transitional costs of implementing sustainable, large-scale, primary health care renewal initiatives. As a result of such initiatives, it is expected that fundamental and sustainable change to the organization, funding and delivery of primary health care services will result in improved access, accountability and integration of services.

The objectives of the PHCTF are to:

- increase the proportion of the population having access to primary health care organizations accountable for the planned provision of a defined set of comprehensive services to a defined population;
- increase emphasis on health promotion, disease and injury prevention, and management of chronic diseases;
- expand 24/7 access to essential services;
- *establish interdisciplinary primary health care teams of providers, so that the most appropriate care is provided by the most appropriate provider; and,*

• *facilitate coordination and integration with other health services, i.e. in institutions and in communities.* (Health Canada 2002)

The problems of primary health care have therefore come to be represented in official policy documents as primarily lack of access to services and inadequate service integration. Framing the issues this way has clearly influenced the solutions proposed. Primary health care reform is now seen as a problem which can be solved through better management (to mandate co-ordination and integration) and the use of appropriate economic incentives and disincentives (to establish teams of service providers and expand the hours of service). Furthermore, accountability, in this rubric, seems to be primarily about financial accountability, rather than accountability for quality care and about accountability to the managers of the system rather than to communities and users of health services.

One can imagine how different the solutions and priorities would be if the problem had been framed as one of health inequalities (including for example, inequalities based on sex, socio-economic status, migration experience, Aboriginal status and disability), with an improved primary health system care as part of the solution.

This approach to primary health care is built, in part, on notions of population health. Population health, built upon epidemiological models, involves predictions about groups rather than individuals. This raises questions about how services are "planned" for individuals who do not fit the models, including standards for diagnostic procedures and treatment. This in turn has implications for rostering of users of the health services.

The spirit of social justice evident in the Alma Ata Declaration has disappeared from the dialogue about primary health care reform. This is not good for the health of women.

It is also important to remember that primary health care reform is taking place in the context of a broader health reform, which in Canada has been characterized by cost containment, reductions in services particularly through early discharge (and the assumption that families, particularly women, will take on increased unpaid caregiving roles), the introduction of corporate management systems and recently the incursion, in some provinces, of for-profit health services in areas that have been primarily in the public sector. These reforms are themselves occurring in the context of larger social and economic forces, notably trends to reduce trade barriers between countries, globalization, particularly international trade agreements, which may have the impact of limiting the ability of governments to mange social programs and may increase pressures on governments to privatize the delivery of health care services. The quality of care provided in for-profit hospitals has been shown to be associated with a higher risk of death to patients. (Devreaux 2002, 1399)

Pressures for privatization and the demands of international trade agreements are also linked, as noted in a report by the Canadian Centre for Policy Alternatives prepared for the Romanow Commission. (Canadian Centres for Policy Alternatives 2002) The authors state: If the underlying conflicts between Canadians' health care priorities and the commercial interests promoted in the most recent trade treaties are not addressed, the nation's health care system will come under increasing strain and the options for reform will be seriously diminished. Fortunately... there are many practical ways in which greater coherence between health and trade policy can be achieved. Governments should begin by acknowledging, rather than denying, that health care reform entails some risk of trade challenges. They should then fashion health reforms so as to derive maximum benefit from those limited safeguards that exist in trade treaties; this generally means minimizing the role of private financing and for-profit health care delivery. (CCPA, 59)

Who would benefit from such changes? As the health economist Robert Evans has noted, market mechanisms are popular because they operate to the advantage of influential groups (Armstrong 2001, 42). As Pat Armstrong has noted:

Most of those who benefit are men, albeit a small minority of men; most of those who bear the burden and express dissatisfaction with market solutions are women. (Armstrong 2001, 42)

3. Where are Women in Canadian Literature About Primary Health Care Reform?

Literature on the impact on women of the proposed changes in primary health care services is scarce.⁶

Most research in primary care ignores the existing evidence about the impact of gender on health care needs, preferences and utilization. Two recent synthesis reports, the Canadian Institute for Health Information's *Health Care in Canada 2003* (CIHI 2003) and the Canadian Health Services Research Foundation's *Choices for Change: The Path for Restructuring Primary Healthcare in Canada* (Lamarche et al. 2003) are examples of this.

The CIHI Report illustrates one of the problems created by ignoring the existing evidence on gender differences in health – not knowing that the information is even missing. CIHI's list of "What We Don't Know" about primary health care reform does not include missing evidence about gender as an "information gap." (CIHI 2003, 25)

Even newly published data designed to inform the primary health care reform process often publishes only data aggregated by sex, or only sex-adjusted data.⁷ For example, Statistics Canada's *Access to Health Care Services in Canada* (Statistics Canada 2001) which contains information about access and barriers to access to health services, including the reasons for self-reported unmet health needs, contains only sex-aggregated data. This is in sharp contrast to the stated commitment to gender-based analysis of Health Canada, one of the funders of *Access to Health Care*. The production and analysis of sex-disaggregated data is an important step, but not sufficient to understand these issues. Gender-based analysis, which wrestles with issues of women's social location, gender-related power and access to resources, is needed in addition to sex-disaggregated data to fully understand to women's lives.

Research supported by the Centres of Excellence for Women's Health has described the health issues of specific groups of women, for example, women with addictions (Poole and Isaacs 2002 and Tait 2000), immigrant women (MacKinnon and Howard 2000 and Weerasinghe 2000), lesbian women (Anderson et al. 2001), visible minority women (Sharif et al. 2000), Aboriginal women (Browne et al. 2000, Benoit et al. 2001, Dieter and Otway 2001) or rural women (Roberts and Falk 2001, Donner 2001). These reports approach the issues from the perspective of the women concerned, and draw conclusions about policy and services from their point of view.

Interesting work has also been done to develop women-centred models of care, notably the Winnipeg Women's Health Clinic *Model of Care* (Women's Health Clinic) and the Vancouver/ Richmond Health Authority *Framework for Women*-

⁶ See for example, Schellenberg, 2001 and Armstrong, P. and Armstrong, H. (2001).

⁷ In this process, the rate is adjusted to allow comparisons among different groups, by standardizing the sex distribution among the populations. While allowing inter-group comparisons it masks sex differences.

Centred Care.

While this literature, and other work by women's health scholars and activists, provides valuable information about particular programs and models of care for specific subgroups of women, it does not typically address the potentially different impacts of primary health care reform on women and men.

To summarize – women are largely absent from research about Canadian proposals for primary health care reform.

4. Why Focus on Women's Primary Health Care Needs?

Outside of the women's health movement, discussions to date about primary health care reform have excluded women's primary health care needs and how these might be different from the primary health care needs of men. This absence is based on the assumption that gender is not an issue in primary health care, that is, that the primary health care needs of women and men are the same. Are they?

At the most superficial level, if one examines the First Ministers' five objectives for the Primary Health Care Transition Fund, these changes will benefit women. After all, don't women need better access to services and better health promotion, prevention and disease management services? Won't women benefit from access to essential services "24/7"? Won't better co-ordination and interdisciplinary teams of service providers benefit women as well as men?

Of course they do and they will. But once one moves beyond these general statements, the differences between women and men (and boys and girls) become apparent.⁸

We suggest that these are manifested in six ways, all of which affect the organization and delivery of primary health care:

First, there are sex-specific conditions, including the full spectrum of reproductive care, which should be included in a reformed primary health care system. These include birth control for women, pregnancy, childbirth, menstruation, menopause and female infertility, all of which are part of women's primary health care. Other sex-specific conditions which are part of women's primary health care include screening for cervical cancer. Any reformed primary health care system must include the full range of reproductive health care services and their delivery must be organized in ways which recognize women's diversity and which promote women's autonomy, control and health.

Second, there are conditions more prevalent among women, such as breast cancer, eating disorders, depression and self-inflicted injuries.⁹ For example, screening programs for breast cancer are part of women's primary health care. And as more women live longer with breast cancer, more of their care will become the responsibility of the primary health care system. In the case of conditions such as eating disorders, depression and self-inflicted injuries, good primary health care for women must include prevention and treatment programs which recognize the gendered nature of these conditions, including women's distinct risk factors and the need for gender-specific interventions.

Third, there are conditions which appear to be sex-neutral, such as heart disease, but where the signs, symptoms and optimum treatment of the disease may be different in women and men (Grace 2003a). Good primary health care for women incorporates this

⁸ As our task with this paper is to discuss the impacts of primary health care reform on women, we have not addressed the sex- and gender-specific primary health care needs of men, nor the ways in which these may differ from women's needs.

⁹ For descriptions of some of the conditions that are more prevalent in women, see Donner (2003), Greaves et al. (1999) and Health Canada (2003).

knowledge into all processes of care, including health promotion, disease prevention and treatment.

Fourth, there are the ways in which women's gendered roles in our society influence their health. Examples of this have been documented extensively by women's health researchers and activists, including:

- women's caregiving responsibilities often cause them to give higher priority to the health of others than to their own health;
- the sex-segregation of the labour force, both in general and within health care in particular;
- the demands of women's caregiving responsibilities contribute to their own ill health;
- women have lower average incomes than men and lower incomes are associated with poorer health;
- women's paid work and their working conditions influence their health.

Good primary health care for women must both incorporate this knowledge and be a catalyst for change, helping to reduce the contribution of gender differences to health inequalities.

Fifth, there are the ways in which the gender stereotypes within the health care system negatively affect women's health. These include both stereotypes about women's use of care and stereotypes about women's caregiving roles.

Women are often assumed to use health care services more than men. But there is good evidence that this is related to sex-specific care and not to male stoicism or to women's predisposition to seek help. For example, in Manitoba in 1994-95, the per capita cost of providing females with health care services funded by the medicare system was approximately 30% higher than for men. However, after the costs of sex-specific conditions were removed,¹⁰ and considering costs for both physicians' services and acute hospital care, the costs of insured health care services for women were about the same as for men. That is, the female: male ratio went from 1.3 to 1.0. (Mustard et al. 1998)

There is also good evidence that negative stereotypes about women lead to women receiving negatively differential treatment in everything from the use of life-saving drugs during heart attacks (Grace 2003b) and the secondary prevention of ischemic heart disease (Hippisley-Cox 2001), to physicians being more likely to assume women's physical symptoms are psychological in origin (McKie 2000). The result of the application of these stereotypes includes increased costs for the system as well as individuals. If advocates of primary health care reform are truly interested in costs, they may want to eliminate sex- and gender-stereotyped practices.

¹⁰ These included for women, normal and abnormal reproduction, and for women and men, diseases of the genitourinary system and of the breast.

Despite all of this evidence, and in the era of "evidence-based medicine" and "evidencebased decision-making", those designing changes in primary health care persist in choosing to ignore the overwhelming evidence about sex and gender.

Sixth, there is the over-medicalization of normal aspects of women's lives including pregnancy, childbirth and menopause. This has been challenged by the women's health movement for over thirty years, with some successes (notably the reintroduction of midwifery into Canada and its organization as a licensed profession.)

But women are not ignored in the plans for primary health care reform. We have been assigned two important roles – as vessels (for future human beings) and as vectors for the transmission of things both good (e.g., breast milk, nurturing, health information, nutritious food, caregiving, a physically active life style) and bad (e.g., second hand smoke, alcohol during pregnancy, junk food, a sedentary life style) to our families. Every plan for primary health care reform includes women as the unnamed and unpaid delivery agents of health promotion without a critical examination of how this perpetuates unhealthy gender stereotypes.

Daykin and Naidoo (1995, 59) have argued, for example, that health promotion has neglected women's experiences of morbidity such that campaigns are based on "male-centred epidemiology." Further, they suggest health promotion strategies may put responsibility on women "despite their relative lack of power to effect change." They also suggest that the individualized, victim-blaming nature of much health promotion affects women in their caring roles by ignoring the social context that marginalizes that role. Finally, women are often the targets of health promotion campaigns not for their own sake, but for others', notably their children; the emphasis, for example, on preconception health, while well intended in its support for healthy child development, runs the risk of reducing women yet again to the state of being perpetually and always "prepregnant," thus emphasizing a woman's reproductive role over other aspects of her own health and well-being.¹¹

¹¹ For a discussion of the discourse around pre-conception health and mothering, see Greaves et al. (2002).

5. Considering Women's Health in Primary Health Care Reform

Even with the absence of literature about how various schemes for primary health care reform might differentially affect women and men, it is possible to use the lessons learned from other work in women's health and apply them to these proposals. These are discussed below using the five objectives of the Primary Health Care Transition Fund as a framework.

Objective #1- Increase the proportion of the population having access to primary health care organizations accountable for the planned provision of a defined set of comprehensive services to a defined population.

This objective includes many different types of organizations, from physician group practices, to managed primary health services based on rostering and capitation, to community health centres. It raises a number of issues of concern to women:

- Who defines the "set of comprehensive services"? In the physician-managed alternatives (such as Ontario's Family Health Networks), this is determined by negotiation between physicians and their representatives and government and/or regional health authorities. The sex- and gender-specific primary health needs of women are unlikely to be considered in these schemes. In community health centres, community based boards set their own service priorities, based on their perceptions of community needs (which may or may not be sensitive to women's health issues) and in negotiations with their funders (either the provincial government directly or a regional health authority). While some of the most innovative, gender sensitive primary health care programs have been developed by community health centres, others have focused on "family health", in which women are valued for their work as vectors to transmit health information, but in which women's distinct health needs receive little attention.
- What will be included in a "defined set of services"? These are crucial issues for women's health for a number of reasons. For example, will women's reproductive health care be included in ways which treat pregnancy, menstruation, childbirth and menopause as normal elements of women's lives? Will existing knowledge about sex and gender differences be used to design, implement and evaluate services? Will the service needs of all women be assumed to be the same, or will knowledge about differences among women (for reasons such as disability, migration, Aboriginal ancestry, ethnic and visible minority status and sexual orientation) be used? Will existing knowledge about the ways in which gender interacts with the other determinants of health (such as income, education and social and physical environments) be used? We have not yet seen evidence of the use of knowledge about sex, gender and diversity in the development of the defined set of services.
- Who will constitute the "defined population"? Unfortunately, women still encounter discriminatory treatment from physicians and other health care providers who are not sensitive to their needs. Examples of this include, lack of

detailed knowledge of sex-specific conditions (endometriosis for example) and biased attitudes (for example that women complain and seek help more readily). Therefore, systems such as rostering, which limit women's abilities to seek a second opinion without the consent of their designated family physician are not good for women's health.¹²

- How will the views of women who use the health care system be included in designing, implementing and evaluating these organizations? Given that no "consumers" were consulted, for example, in the recent Choices for Change project, the views of women as users of the health care system and as informal, unpaid care providers, are not reflected in their research, analysis or conclusions.¹³
- *How will these organizational models recognize the feminization of health care,* particularly family practice? According to Statistics Canada, in 1998/99 there were approximately 38,000 students enrolled in full-time and part-time undergraduate health professional programs, over three-quarters (76%) of whom were women. This mix has been changing over time: in medicine, for instance, women graduates have outnumbered male graduates since 1996. (CIHI 2001, ix) We know that part-time work is more common within the health care sector than other sectors of the labour market and physicians are among those working parttime. (CIHI 2001, 41) Women also practice differently than men; a recent selfreport survey indicated, for example, that women family physicians see a higher proportion of patients with chronic mental illness, provide a higher proportion of preventive services, particularly Pap smears, do more counselling and obstetrics, and are more likely to practice in an urban or suburban setting. (College of Family Physicians) Since most primary care reform models rest upon family or general practitioners (Armstrong and Armstrong 2001) and women account for an increasing proportion of family physicians, the organization of primary care needs to reflect not only this demographic change but also, as Woodward et al. (1996, 50-51) argue, the differences between female and male family practitioners "in the organization of physicians' practices, in the doctor-patient relationship, and in the profession's response to government health policy."¹⁴

Objective #2- Increase emphasis on health promotion, disease and injury prevention and management of chronic diseases.

The explicit inclusion of health promotion and prevention in primary health care is of course welcomed. One of the major criticisms of fee-for-service payment systems as we

¹² In Ontario, patients enrolled in Family Health Networks must be referred by their participating family doctor to a second family physician, should they wish a second opinion. This system may limit patient autonomy and privacy (see Family Health Network patient brochure, available from http://www.ontariofamilyhealthnetwork.gov.on.ca/english/index.html)

¹³ See the appendixes to Lamarche 2003 for a full description of the methods used to obtain expert opinions.

¹⁴ See also discussions on women in medicine in three papers from the 1996 Canada – U.S. Women's Health Forum by Phillips, S., Tudiver, S. and Zimmerman, M.

know them has been that they do not reward those family physicians who take the time to work with their patients on promotion and prevention. But the conceptualization of health promotion and injury and disease prevention will be critical to their success and to women's health. For example:

- Will health promotion focus on the behavioural determinants of health (such as diet, smoking and exercise) or will adequate resources be attached to challenging and changing the structural determinants of health (such as income, working conditions and education)? Given the current definitions of primary health care reform, this does not appear to be the case.
- Will gender as a determinant of health, and the ways in which gender interacts with other determinants, be considered in the design, implementation and evaluation of these programs? Given the absence of gender analysis from current plans for primary health care reform, this does not appear likely.
- Will health promotion and prevention programs promote gender stereotypes by uncritically treating women as vectors and vessels? For example, if women remain the target of health promotion campaigns because of their role as the "health guardian" (Heller 1986) of the family, to the extent that these campaigns individualize problems and blame women for their ill health and the health problems of family members, they compound women's sense of personal responsibility for health problems that are, in fact, largely beyond their control (Daykin and Naidoo 1995). There is little evidence to suggest that this practice will change.

Objective #3- Expand 24/7 access to essential services.

Expanded access to services is a good idea. However, "access" for women means more than an open door, or someone answering the telephone. For example:

- > What services will be provided over the phone?
- What does access to primary health care 24/7 really mean? The expectation is that additional services will be provided outside of "normal" office hours. Working women will benefit from the expansion of "normal" office hours so that they can seek primary health care for themselves in the evening, for example. However, what effect will establishing such hours have on the health of care providers, the majority of whom are women. How do we therefore balance the conflicting desires and needs of women from both of these perspectives?
- Will childcare services be available to women who need to seek care for themselves?
- What measures are needed to make services accessible to women with physical disabilities?

- How can services be culturally and linguistically accessible to women from minority communities?
- Will service providers recognize that women's work and family commitments limit their ability to seek care?

Objective #4- Establish interdisciplinary primary health care teams of providers, so that the most appropriate care is provided by the most appropriate provider.

While a comprehensive approach to health, including health promotion and disease prevention, is important for women's health and well-being, and the greater use of multidisciplinary and interdisciplinary teams has the potential to increase the quality of care available, there remain concerns for women.

- How will the appropriate mix of team members be established? CIHI acknowledges that even within the same profession, roles and skills may vary. Moreover, the mix of providers needed and available in a rural setting is not likely to be the same as in an urban setting. For example, rural physicians provide more emergency services than urban family practitioners; this difference has implications for the composition of the team needed to provide appropriate care to rural residents. (CIHI 2001) What will this mean for women, who are the vast majority of health care workers? Some proposals, for example, suggest that nurse practitioners will fill in during off-hours, an approach that implies that care will differ depending on the time of day.¹⁵
- How will adequate training for sex- and gender-sensitive health care be ensured? In British Columbia, gender-inclusive health training is being piloted with frontline workers, and in Manitoba training has been undertaken to teach genderinclusive health planning to health authorities. Such training is a first step toward a more gender-sensitive health care system but must be supported by entrenching this kind of training within formal health care training programs.
- How do we ensure that the patient/client is involved as an active member of this "team" and that continuity of care is maintained?

Objective #5- Facilitate coordination and integration with other health services, i.e., in institutions and communities.

Increased facilitation and coordination are also to be welcomed. However, this is frequently reduced to a discussion of an electronic medical record to address the desire of the system for a seamless flow of health information. This raises two concerns. First, it fails to recognize women's desires to protect the private nature of their discussions with

¹⁵ See Armstrong, P. and Armstrong, H. (2001), *Primary Health Care Reform: A Discussion Paper* prepared for the Canadian Health Coalition, available at <u>http://www.healthcoalition.ca/health-index.html</u>

their primary health care providers or with specialized service providers. Women may not discuss reproductive health issues, such as the decision to terminate a pregnancy or to give a child up for adoption if this information will be available to others. Similarly, women may not wish to discuss their experiences of violence by their partners if this information will be included in a chart which is available to other community agencies and institutions. These issues are especially acute for women in rural and remote communities. Second, an electronic medical record is the solution to a very narrow definition of "co-ordination and integration." The original promise of primary health care reform as an opportunity to improve continuity of care and flexibility of care appears to have been lost.

6. A Feminist Alternative: Gender-Sensitive Primary Health Care Reform

We have lots of questions, and some ideas. We don't have all the answers – yet. But, there are some things that "we know for sure":

- 1. The radical spirit of Alma Ata has been removed from current primary health care reform. If primary health care reform is limited to changing management, governance and payment schemes, the potential for primary health care reform to contribute to reducing health inequalities will be lost. Women's health will suffer as a result.
- 2. To truly promote women's health, a reformed primary health care system should incorporate how both sex and gender influence women's health.
- 3. To improve women's health, a reformed primary health care system should recognize the diversity of women's lives.
- 4. Rostering is intended to limit costs by limiting patient choices. Capitation proposals shift financial risks from provincial governments to individual practitioners and/or community boards. Both are potentially harmful to women's health.
- 5. A reformed primary health care system has the potential to reinforce gender stereotypes, by uncritically treating them as vessels and vectors. This is damaging to women's health.
- 6. If women in local communities are involved in the processes of designing and governing reformed primary health care organizations, then primary health care reform has the potential to improve women's health, by increasing women's social engagement and social control. If the design and governance of the system is left to "the experts," the system will lack this important information and this valuable opportunity will be lost.

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Appendix B & C – Dare to Dream

Appendix B: Workshop Agenda National Workshop On Women And Primary Health Care February 6 & 7, 2004 Clarion Hotel, Winnipeg, Manitoba

Friday, 8:00 a.m.	February 6 Breakfast		ay, February 7 Breakfast
9:00 a.m.	Welcome & Greetings Anita Neville MP Winnipeg South Centre	9:00 a.m.	Plenary Session <i>Reflections on Day One</i> National Coordinating Group on Health Care Reform and Women
	Deanna St. Prix-Alexander Women's Health Bureau, Health Canada	10:00 a.m.	
	Margaret Haworth-Brockman Prairie Women's Health Centre of Excellence	10:15 a.m.	Small Group Sessions
	Introduction to Plenary Session		Implications for Policy, Practice And Research
	Pat Armstrong National Coordinating Group on Health Care Reform and Women	12:00 p.m.	Lunch
	Presentation	1:00 p.m.	Plenary Discussion
L'an Da	Thinking About Primary Health Care for Women		Primary Health Care: Key Issues For Women and Strategies for Change
Lissa Donner and Ann Pederson			Chunge
10:30 a.m.	Break	5:00 p.m.	Adjourn
10:45 a.m.	Small Group Sessions		
	Case Studies on Women and Primary Health Care		
12:00 p.m.	Lunch		
1:00 p.m.	Small Group Sessions continued		
	Case Studies on Women and Primary Health Care	6 c	entres of excellence centres d'excellence
4:00 p.m.	Plenary Session	-	Jor WOMEN'S HEALTH pour LA SANTE DES FEMME support provided by Health Canada's
	Reports from Small Groups	Women's Health Contribution Program	
7:00 p.m.	Dinner		PRAIRIE WOMEN'S HEALTH

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Appendix D – Dare to Dream

Beyond Vectors & Vessels: Women & Primary Health Care Reform Text of a Slide Presentation National Workshop on Women and Primary Health Care February 6, 2004

Lissa Donner Ann Pederson

Background

- 2002 Literature review and synthesis for Women's Health Bureau, Health Canada
- Task was to synthesize English gender sensitive literature on primary health care reform in Canada
- Found little to synthesize
- Not able to locate research on the gender implications of primary health care reform

Background

- Knowing that, what we planned to write about for this Conference
- Gendered analysis of nine commonly included elements of primary health care reform, considering *women's* health:

Elements of primary health care reform:

- Changing methods of physician remuneration
- Increased use of allied health professionals in interdisciplinary teams
- Increased opportunities for preventative care, including health promotion and action on the non-medical determinants of health
- Decreased barriers to service
- Integrated service delivery mechanisms and improved co-ordination of services to patients (e.g. case management, linkages to the broader system and community services)
- Increased community based service delivery
- Changing systems of governance to increase community control of services and/or to increase community input into the decision making process
- Tele-health initiatives
- Increasing use of electronic health records

But how did primary health care reform come to be about these nine issues?

Alma Ata Declaration WHO 1978

- Health for All by 2000
- *"Primary health care is the key to attaining this target as part of development in the spirit of social justice."*

Early Primary Health Care Reform in Canada

- 1962 Saskatoon Community Clinic
- 1963 Sault Ste. Marie & District Group Health Assoc.
- 1971 CLSCs in Québec
- 1972 Manitoba "White Paper on Health Policy"
- 1974 "A New Perspective on the Health of Canadians"

Early Primary Health Care Reform in Canada

• Included the idea that in order to improve health, change was needed beyond the health care system

Women's Health Movement 1960s and 1970s

- Empowering women
- De-mystifying medical expertise
- Situating women's health in the context of their lives

Compatibility of Primary Health Care Reform and Women's Health Movement

- Community control
- Health promotion
- Contribution of other health professionals

Contemporary Primary Health Care Reform in Canada

- "the ultimate goal of primary health care reform is to provide all Canadians, wherever they live, with access to an appropriate health care provider, 24 hours a day, 7 days a week" First Ministers' Accord 2003
- The problems of primary health care have therefore come to be represented in official policy documents as primarily lack of access to services and inadequate service integration

Imagine...

- if the problem had been framed as one of health inequalities how different the solutions would look.
- The spirit of social justice evident in the *Alma Ata Declaration* has disappeared from the dialogue about primary health care reform.

Invisible Women?

• Primary health care reform has ignored the differing primary health care needs of women and men

• But women have been assigned two important roles – vessels and vectors

Six Ways Sex and Gender Matter in Primary Health Care

- Sex-specific conditions
- Conditions more prevalent in women
- Conditions which appear to be sex neutral
- Influence of gendered roles on health
- Gender stereotypes in health care
- Over-medicalization of women's lives

Choosing to Ignore Gender

• In the face of overwhelming evidence, how is this possible?

My, This Looks Familiar

- Women were also initially invisible in the population health model
- Women's health advocates have worked to challenge this, with some successes
- Centres of Excellence for Women's Health
- Recognition of gender as determinant of health
 - The challenge is similar with primary health care reform.

Overarching Challenge

• How do we address the realities of sex and gender differences in ways that challenge stereotypes, rather than perpetuating them?

Primary Health Care Reform Has Been Co-opted

- Primary health care reform has been changed into something the primary purpose of which is cost containment and human resource management.
- In this guise, no longer compatible with goals of women's health movement
- Consideration of other significant inequities has also been lost

Integrating Women's Health into Primary Health Care Reform

- There are three places to intervene:
- *Policy* F/P/T statements on primary health care and provincial primary health care policies
- *Practice* design of models of care, systems of remuneration etc.
- Research funding priorities for Primary Health Care Transition Fund; need for basic sex disaggregated data and gender-based analysis

Integrating Women's Health into Primary Health Care Reform

- Wherever we intervene, there are two messages:
- Successful primary health care recognizes women's diversity
- Women are more than vectors and vessels

Intervening in Primary Health Care Reform

- Three Questions for You
- Do we look for opportunities where we think there is the most benefit to women?
- Do we look for threats and attempt to mitigate harm?
- Do we emphasize those areas where there is the most existing evidence, thinking this is our strongest case?

Appendix E – Dare to Dream

Public Panel Presentation on Primary Health Care and Women Thursday, February 5, 2004 University of Winnipeg

Perspectives on Women and Primary Health Care: Identifying the Issues A Family Physician's Perspective Donna Cherniak, MD

Winnipeg, February 5th, 2004

I'd like to thank the organizers of this panel for giving me the opportunity to be a part of this important exchange on women and primary health care. As a family physician who often feels buried under the day to day demands of practice, I have few opportunities to come up for air and reflect with others who share a feminist perspective, on the consequences of the rapid changes in health care...the science, the art and the organization of care.

I'm particularly pleased to do so here in Winnipeg, a city that played an important role in my development as a feminist. As a teenager in the 60's while visiting a friend here, I stumbled upon the public hearings of the Commission on the Status of Women. I can still see in my mind the raised table where the commissioners listened attentively and the dignity with which Aboriginal women spoke of the discrimination they suffered in all aspects of their lives...social, economic and health. Since then, issues of feminism, diversity and social and economic equality have become part of my worldview and personal identity.

Let me tell you a bit about my work, as it is key to the issues I've chosen to address:

I am a general practitioner in a CLSC (the local community health clinics responsible for most public health services in Québec). From its beginnings, this CLSC has had a strong primary care programme; its physicians, who are salaried, are involved in all aspects of care, looking after patients in the clinic, at home and in hospital. Many of us have an area of expertise...mine is maternity care...but between us we offer a full range of services. We try to ensure some coherence in the way we treat patients and we help each other out when confronted with complex problems. Overall, we like and respect each other and enjoy working together, despite the demands and frustrations of the system. On the down side, we have little control over the administrative, budgetary and paramedical side of practice: the administrators have other priorities for which the health minister holds them accountable.

Our practice profile made us an ideal team to become one of the pilot Family Medicine Groups which the government chose to support. To be approved, we had to formalize in writing how we would care for our patients in terms of accessibility and continuity of care and how we would work with other frontline services such as home care nursing and social services. Rostering with a physician is implicit in the model but there are no restrictions on seeking services elsewhere.

Finally, we are clinical supervisors for physicians training in family medicine...the women and men who will take care of you and me as we age and who will be confronted with the issues we are here to discuss. We know that we are role models for them but that how they practice, how they deliver care, the choices they will have to make may well be different from what we have known.

I have chosen to discuss two issues that I feel are important for both women and men: medicalization and continuity of care. In both cases, women are affected at a younger age, more often and over a greater time span than men. Women's economic status makes them more vulnerable to their consequences.

Medicalization: Redefining Health And Illness

Most of us know when we feel ill. We may have a fever, less energy, pain and an inability to go about our daily activities. But acute illness...severe infections and injuries...are less frequent today than for our parents and grandparents, in large part due to public health measures...clean water, immunization programmes, seatbelts, etc. Why then, are health services so overcrowded?

We have a longer life expectancy, long enough to "expect" to suffer chronic illnesses such as arthritis and heart failure. We have a discourse on prevention, that it is better (i.e., that it reduces suffering and costs less) to either try to prevent or detect early any disease process so that early and effective intervention can be instituted.

Often, this is a valid approach. Promoting condom use and testing for STDs in healthy people are, for the moment, the only ways to control their spread. As an aside, it will be interesting to see if the government will support universal immunization programmes when the vaccines for herpes and venereal warts become available. Both illnesses have greater impact on women than men; will they be offered in schools? If not universal, will men bother to be vaccinated? Will women be able to afford them?

But early detection, either by universal screening or by case finding based on risk, is valid when we are certain that early intervention makes a difference in the evolution of a disease, that is, when we can reduce suffering and delay physical limitations and death. The treatment should have minimal side effects, that is, people who feel well should not be made to feel ill. Even more so, when such treatments are promoted for everyone.

Medicalization, the process of defining normal life processes as illness or of applying a medical therapeutic model to risk factors, opens the door to health care models which tend to be individual, pharmaceutical and expensive. Despite a growing recognition of the social determinants of health, social and economic strategies are rarely applied.

Let's look at a few examples: ...

Hormone replacement therapy is the most recent and blatant example directed at women of a misguided attempt to prevent chronic illness. Its supposed impact on reducing cardiovascular disease (a disease which strikes men earlier) was the impetus for recommendations that *all* menopausal women "be offered" HRT. Both physicians and the public were reminded, often in pseudo feminist terms, that heart disease is a major problem in women, often under diagnosed and under treated. The benefits touted for HRT were not based on "gold standards" and its risks were minimized. Physicians who publicly questioned this policy were treated as "granolas" and accused of depriving women of appropriate care. The Women's Health Initiative, a study that came about only because women's groups lobbied for it, has given us a more realistic view of the benefits and risks of HRT: the benefits are less and the risks are greater than expected! To my knowledge, no medical society has admitted to an error in judgment, to having jumped too quickly on a highly profitable bandwagon. So no lessons are learned and the search for magic pills continues.

Type II diabetes is a diagnosis often made by testing well people. Medical and public media are spreading the message about the increase in numbers of people with diabetes, particularly young people. Obesity and a sedentary lifestyle are blamed for the increase in diabetes which is expected to tax the health system's already challenged capacity.

Wouldn't it seem logical to address directly the twin issues of obesity and sedentarism? To look at the lack of investment in phys-ed programmes in schools? The influence of the fast food industry?

What we have instead are new recommendations for more severe criteria for diabetes with the intention to treat people earlier to avoid serious complications. However, we do not know if such very early intervention really gives results outside of experimental situations. Nonetheless, if accepted as routine practice, overnight we will have labelled as diabetic, large numbers of people, most of whom already know they are overweight or lacking exercise.

Labeling someone with an illness is not without consequences. Some people take up the challenge and make healthful improvements; many react with anxiety and see themselves as ill, missing days at work or limiting activities that they previously enjoyed. With diabetes, treatment moves rapidly from dietary interventions to drug treatment. And not only to control sugar levels. Because of the risk of heart disease associated with diabetes, concomitant high blood pressure and high cholesterol levels are treated aggressively in diabetics. And again, with medications with their associated costs and side effects.

Being labelled as a diabetic also makes it difficult and certainly more costly to get health and life insurance coverage.

Why is diabetic labelling a gender issue? Women are more likely to be tested than men because they use the health system for preventive care. Most are tested for diabetes of pregnancy, even though the benefits of such testing are questionable. Women are less likely to be adequately insured through their employment; they may be unable to pay for medications or to obtain insurance. Women with children and/or aging parents or in-laws often have less time and money to participate in exercise programmes and sports, considered so important for maintaining health in diabetics.

What about **mental health issues**? Yes, we have a much greater understanding of what happens in the brain when people have symptoms of anxiety and depression. We even have radiological images of healing or return to normal activity when depression is treated with medication or cognitive therapy. We are told that this healing is more likely when mood disorders are treated early.

So we are encouraged to diagnose and treat mood disorders early on and to continue medical therapy, sometimes for life. But we are often compensating for untenable personal and social conditions.

Let me tell you about two patients:

Marie-France, a 51 year old hospital nurse, had seen her family physician for a check up. When her physician questioned her about her overall health, she mentioned her sleep difficulties and fatigue. Her symptoms worsened, particularly before her periods. Her physician eventually suggested trying an anti-depressant, which she never took.

She chose to quit hospital work because of the increased workload and her difficulty coping with evening shifts. She found a day job with a private research lab and this, at first, helped her difficulty sleeping. But soon, the job was more stressful and less satisfying than she expected and she regretted her decision. When she did become depressed and was on sick leave, the insurance company accused her of lying on her application form, denying prior illness, basing their decision on her physician's record. They paid back her premiums and cancelled the insurance. She was left without income and without funds to cover her medication and therapy. She wasn't getting better and her blood pressure was increasing, a side effect of her medication.

Laila, an Iraqian immigrant whom I attended when she gave birth, came to see me for test results for abdominal pain that had been ordered by another physician. She told me that her husband had gone to Iraq in early December and that she had difficulty eating and had been crying since he left. I asked several questions and examined her. After she got dressed, she told me that when she was young, her family had moved to Lebanon from Iraq. Her father had returned to Iraq on a visit and was executed there.

Women are more likely than men to bring up or be asked about psychological issues during "routine" examinations. They often blame themselves for difficult life circumstances. Even though certain forms of therapy are recognized as having as great an effect as anti-depressants, they are either unavailable or beyond the budget of most women. Women are given anti-depressants for less severe emotional states, often an appropriate response to stressful life events. Women also receive anti-depressants for moderate mood changes before their periods; many of them should probably get a medal for being so patient the rest of the month!

Reproductive health or maternity care used to be about keeping pregnant women alive and reducing the negative consequences of childbearing on their lives. Having a healthy baby was a possible but not necessarily controllable outcome. With the great improvement in maternal health, due as much to better nutrition and family planning as to health services, all eyes are now on the foetus. If anything, women are considered obstacles to access to the foetus and are often blamed for its problems. This may get worse as the link between the intrauterine environment and health problems in adult life are understood.

On the positive side, women's rights to consent to testing and to confidentiality are still considered principles of care. In Canada, we are not supposed to do drug testing without consent nor are we expected to share such results with youth protection agencies or with the police.

But we are expected to apply the same principles of early detection leading to early intervention, assuming this will give a better outcome.

Sometimes, it does. When ultrasound reveals a malformation such as a diaphragmatic hernia, we can ensure that the woman gives birth in a hospital capable of caring for the baby. But other tests, particularly genetic screening, have become the norm, even when the tests are very imprecise. Women receive only limited counselling on the implications of the test; in many provinces, women must pay for them – a source of stress for poor women and of potential conflict if her partner does not support her decision. Results suggesting a greater risk create enormous anxiety and often lead to invasive testing (amniocentesis) which has a relatively high risk of miscarriage.

Funds seem to be available for newer and better ultrasound and laboratory equipment. But where are the funds for tests to be done in separate rooms rather than in curtained cubicles, where good or bad news is heard by everyone down the corridor? Or a private place to cry or call a loved one? Where is the money for trained counsellors or at least for better training of midwives and physicians who inform women about testing? And who set this agenda? Who decided that universal genetic screening is such a priority?

These examples of medicalization are all dealt with in primary care settings or, if done by specialists, are considered to be part of a basic standard of care. My point is that many of the priorities and standards of practice in primary care are established by specialists. Some specialist associations have started including primary care physicians and nurses on committees that formulate guidelines but their influence is limited. In day-to-day care, clinicians are too busy and too conscious of the medico-legal implications to stray far from official recommendations.

Women consumers, nurses and physicians need to participate in setting the goals and evaluating the strategies used in primary care. We also need to look outside the model for community and public health approaches to support resilience and enhance health.

Continuity of care: what do we mean by it and is it still possible?

Continuity of care, a fundamental principle of family medicine and other primary care disciplines, describes a one to one relationship over time, either within an acute episode or over the lifespan. This dynamic relationship between caregiver and patient grows and changes in response to individual, family and community events. It is based on trust built on multiple interactions during which the caregiver has intimate access to our bodies and our minds. Usually, this relationship provides satisfaction to both the caregiver and the person cared for.

When we talk about continuity of care, there is an implicit message that this relationship is useful and effective for caring and healing, enhancing more objective treatment modalities. It is a messy, old-fashioned...dare I say, female...concept in a world which values objective criteria and models of efficiency over human relationships.

Continuity of care as defined above is less and less a part of primary care for many reasons, good and bad. Walk-in clinics for episodic care have sprouted like mushrooms, answering a certain need for accessibility. They are a bit like the 7-11 or depanneur: open longer hours but at a greater cost and offering goods of questionable quality. Physicians are more protective of their own quality of life and limit their off-hour availability. The explosion of knowledge and expertise in health care makes it impossible for an individual or a profession to provide all primary care services needed. This has led to the growth of collaborative models of care and interdisciplinary teams. In addition, the complexity of care and the increased risk of error have stimulated the movement to computerize medical charts and permit access from different clinical settings.

For me, continuity of care takes on a new meaning when care is provided by several people, whether they be of the same or different professions. In these circumstances, caregivers need to share basic values and approaches to their work and to respect their differences.

Maternity care is one aspect where women have clearly expressed how important continuity of care is to them and how frustrating it is to be seen by a different professional, to have to recount your life history over and over and not to know whom you will encounter for an event as important as giving birth. Obstetricians and GPs often share their on-call schedules but very little else. The woman whose physician agrees to adapt to the birthing position of her choice may find herself with another doctor who only delivers with women in stirrups.

My colleagues who work in palliative care tell me that the same coherence is vital for their patients. To have agreed on and made arrangements for a patient to be able to die at home and then discover they have been unnecessarily readmitted to hospital over the weekend is a great source of stress and frustration to all concerned.

Patients who are treated by a group of professionals need to know that they will be treated similarly no matter which member of the team they encounter. Even more, they should be able to sense the cohesion within the caring team. This requires considerable transparency among professionals and with patients. If important differences exist, patients should at least be informed. This kind of cooperation in a clinical team doesn't happen magically; it requires leadership and commitment from the institution or organization and time for information sharing and for treatment plans.

There are risks to team care. It can easily turn into an assembly line approach to care, where people are triaged and undressed before seeing a professional. Or the talking part of care can get delegated to others; I have heard physicians suggest that the nurse be responsible for all psychosocial screening and for lifestyle enquiry and counselling, as though these were "softer" issues, separate from "real" health concerns.

Privacy and confidentiality may be lost in the enthusiasm for continuity of care. In some jurisdictions, physicians "report" all newly pregnant women to the public health programmes and both provide information to hospital personnel who in turn pass on information after the postpartum stay. Similar exchanges occur for patients receiving homecare.

Why is continuity of care a gender issue? Women have less episodic and more ongoing interaction with the health care system for themselves and their families. They will be the first to benefit from innovative approaches to team care and the first to suffer from bureaucratic, Orwellian organizations.

Women professionals such as nurses, physicians, physiotherapists and others, as well as medical technicians of all sorts will bear the responsibility of making multidisciplinary teams work, often without the conditions necessary for the success.

Sometimes it seems as though the system has forgotten the raison d'être of its existence: the individual, a real person in need of care and the community which is so much more than the sum of its members.

- The best way to ensure continuity of care is to see that the person is an active and informed participant in her own care. That her values and priorities determine the care she receives.
- That she feels part of a community which values and makes a place for all of its members, providing support and comfort for those more challenged by ill health, disability or simple bad luck.

What's exciting is that we have the tools to do this. Behavioural sciences have improved our abilities to help people better clarify their needs and make coherent choices. Information technology gives rapid access to up to date information. As a community, we have a traditional commitment to equality and to a social responsibility for each other. We need the courage and integrity to renew and redefine this commitment.

Presentation by Sharon Davis-Murdoch, Nova Scotia Department of Health

Diversity and Social Inclusion in Primary Health Care Initiative



Vision for Primary Health Care Recognizes need for primary health care services that value and respond to the cultural, racial and spiritual experiences of individuals, families and communities

Diversity and Social Inclusion in Primary Health Care

Social and economic inclusion "being accepted and being able to participate fully with families, communities and society"

Some "excluded" because of poverty, ill health, gender, race or lack of education and do not have the opportunity for full participation ... "An Inclusion Lens," Health Canada

Primary Health Care Section Inclusion Focus

To effectively address needs of culturally diverse populations:

- race

- ethnicity

- language and

- culture

Year 1 (2002-2003)

Develop DoH PHC Website information and links (regional, national, international)

March 27, 03 - Workshop on Diversity and Social Inclusion in Primary Health Care

Year 2 (2003-2004)

1. Partner with PHC stakeholders to facilitate 9 Community Workshops across Nova Scotia

2. Link with provincial programs and the Chronic Disease Management Strategy around diversity and social inclusion issues

3. Facilitate Continuing Professional Education opportunities to develop culturally competent care

Year 3 (2004 - 2005)

In consultation with primary health care stakeholders develop:

- guidelines for culturally competent care
- culturally inclusive primary health

care policy

Partners and Process

- The Atlantic Centre of Excellence in Women's Health
- Sharing expertise, networks and building capacity

Prenatal & Maternity Care

Lack of information on African Nova Scotians in comparison to other Canadians.

Midwifery in the Aboriginal community
#Immigrant ideas about pregnancy

Lifestyle Issues

%Inactivity and resulting obesity are risk
factors for various chronic diseases

- #Barriers to participation in physical activity
 #Dietary challenges
- #Addictions
- #Stress

End of Life Issues

#Cultural competence - providers

ℜPractical IssuesℜPsychological and Emotional IssuesℜReligious and Spiritual Care

Diversity and Social Inclusion in Primary Health Care Initiative

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Women and Primary Health Care Conference: Winnipeg, Feb 5th 2004

Good Evening, Thank you for inviting me – I come from Toronto where, for the last $2\frac{1}{2}$ years, I have been developing and running what I believe to be Canada's first comprehensive primary health care program specifically for lesbian, gay, bisexual, transgender and transsexual people.

When it comes to Primary Health Care, we need to recognise the potentially long-term and intimate nature of the relationship of care provider and patient or client. This relationship involves the body in its most private areas and most vulnerable moments. It may involve the disclosure of suffering, fear, shame, secrets and hopes. A primary care practitioner may come to know partners, children and other family members, may be a major support during periods of change and loss, birth and death.

Structurally, primary health care is not very well set up to nurture this type of relationship and it is a tribute to both care-givers and patients when it happens. Certainly, the demands of fee-for-service medical care often makes the office visit rushed and impersonal. The fact that few practices are open late or on weekends makes visits to walk-in clinics or emergency rooms and fragmentation of care hard to avoid. In addition to these factors, women are often too focused on caring for others to look after their own health needs.

For those of us who are lesbian or bisexual women, heterosexism and homophobia add still more layers of distance and difficulty to our relationships with primary health care providers, resulting in a lack of genuineness, poor service, or an avoidance of the health care system.

Some of us have friends that can recommend a competent provider, or live in cities where there may be choices. Some of us are able to use our knowledge of our rights, our friends or our anger to challenge negative attitudes, to demand proper care, to get what we need.

But for women in smaller communities, there may be no choices and providers may turn over often.

For the many women who also face barriers related to racism or poverty or disability, other battles for recognition and appropriate care may take precedence, or the decision that another stigmatized identity is better hidden than revealed.

Sadly, as lesbian and bisexual women become more sick or frail and more deeply involved with the health care system, they are also more likely to hide their identities or silently endure insensitive remarks or inappropriate care. In long-term care, where the whole issue of sexuality is still an uncomfortable one, many queer people go back into the closet. One elderly female couple in Quebec actually entered a nursing home as two sisters in order to be allowed to share a room. For young women coming out or questioning their sexual identity, there are few signs that such issues might be discussed safely, and even fewer signs that a lesbian or bisexual identity might be acceptable.

As adults, health care providers routinely make references to boyfriends and husbands, or assume that all women with children must be straight. For bisexual women, there is rarely any question if she is with a male partner and the disclosure of a bisexual identity is often regarded as a sign that a woman will feel ambivalent in any relationship. These situations make us feel invisible and inferior.

Women in same-sex relationships don't expect their relationships to be taken as seriously – there will likely be less sympathy and fewer supports offered if the partner who has just left us is another woman. If a partner assaults us, the issue may not be recognised for what it is and there is less likelihood that we will be referred to an appropriate community resource.

We're afraid to talk about our sex lives and how to stay safe from STD's and HIV. We can't ask how to get safe sperm or what the legal issues might be if we choose to coparent with a gay male friend. Women who seek alternative insemination services frequently end up in infertility clinics and often feel safer saying they are single than that their partner is a woman.

When we see our doctor or nurse, they rarely ask us if we are out to our families, or if our fathers are finally getting used to having a dyke for a daughter. They are uncomfortable dealing with the fact that our children have two mothers and may have one or more fathers as well.

They won't know how stressful and lonely it can be to keep our identities secret at work. They won't recognize that our high rates of depression, smoking and drinking may be ways of coping with shame or rejection. They'll wonder why we don't come in for our pelvic exams or to get our breasts checked. And when there is a difficult diagnosis to share, they may not know our partner's name or that the woman in the waiting room is the person we have lived with for half a lifetime.

Numerous studies have been carried out across Canada in the last few years (in Vancouver, Regina, Saskatoon, Toronto, and Ottawa) to find out how sexual and gender minorities experience health care. All reports raise concerns about negative attitudes, lack of knowledge on the part of providers, awkward and uncomfortable encounters and inappropriate health care advice.

There is currently no core curriculum for teaching health care or social service workers how to provide sensitive and competent primary health care to lesbian and bisexual women. Often, lesbian, gay, bisexual and trans issues are lumped together under sexual health education or reduced to one disease - HIV/AIDS. The negative outcomes for the health of lesbian and bisexual women are welldocumented: higher levels of stress, depression and suicide, greater incidence of cervical cancer, lung cancer and possibly breast cancer, later diagnosis of a range of health conditions; mental health concerns that are decontextualized and therefore improperly addressed; and violence related to homophobia or domestic assault that is too often undisclosed, unacknowledged and untreated.

In the health promotion area, there are still very few pamphlets or posters that contain references to lesbian or bi women or that contain graphics that show women as couples or as same-sex parents. A major exception is the fine booklet and postcards on lesbian health produced by the BC Centre of Excellence. Health care clinics and practitioners' offices rarely have any pictures, symbols, or magazines that could signal that this is welcoming environment and forms typically fail to allow patients to register a non-heterosexual identity.

Finally, we must talk about transgender, transsexual, and two-spirited people. Both maleto-female and female-to-male trans people may come for services within women's primary care services, either because they are biological females seeking help to align their bodies with their felt gender as men, or because they are biological males who identify as women and want to be served in a women's facility.

This group of people has enormous difficulty getting services within our health care system and there are many practitioners who refuse to have anything to do with trans people. The level of internal distress that trans people live with is considerable; the level of discrimination they face in society is extreme and, as a result, many face an extremely painful choice whether they decide to transition or not.

The health issues for people who identify as transgender, transsexual or two-spirited are often complex, but they are made far more complex by the fact that their access to relevant health services is typically contingent on a mental health diagnosis conducted at a gender identity clinic and, frequently, a long and arduous series of steps by which the person must prove that they really are transsexual. At the same time there are also trans people who do not want to cross gender lines in a linear fashion, or only want to change some aspects of gender identity but not others, or do not feel comfortable with the risks of certain procedures. In practices that enable trans people to self-identify and that allow patients to take more responsibility for their own body changes, the relationship with the provider is far more like that of other patients and there is much more variety in the choices they make.

At Sherbourne Health Centre where our Primary Care Program for Lesbian Gay Bisexual, Transgender and Transsexual People has been open for just over one year, we are seeing more than 100 clients from the trans community. This is a very large number even in a big city like Toronto.

The health needs of trans people in primary health care are best dealt with in a holistic framework where they an access regular day-to-day health care services, hormone

therapy, counselling, support, information, family therapy, groups etc. In Ontario, sex reassignment surgery was de-listed from the provincial health plan by the Conservative government and has consequently been available only to those who could obtain the required psychiatric approval and pay for surgery at private clinics.

The difficulty of getting appropriate medical services including surgery has left many trans people, especially trans women, unable to "pass" well enough to avoid exclusion from jobs, housing and social spaces and consequently they are vulnerable to poverty, homelessness and violence.

If we truly believe that gender is a social construct and that biology is not destiny, then we must be open to the possibility of gender transition and also to people who reject the binary notion of gender and are comfortable living in an ambiguous place on the gender continuum, defining as neither man nor woman or combining both in new and creative ways.

It seems that younger women, in particular, are rejecting rigid categories of sexual orientation and gender identity, choosing more fluid ways of expressing themselves sexually, coming up with their own descriptors, or rejecting labels altogether.

We have a long way to go in providing an equitable health care system for lesbian and bisexual women. We have even further to go in meeting the needs of trans people. As we discuss what is needed to make Primary Care Reform more significant and more responsive to the needs of women, I ask that we consider our the needs of our diverse and vibrant lesbian, bisexual and trans communities.

Appendix F – Dare to Dream

National Workshop on Women and Primary Health Care February 5-7, 2004

Case Studies: Every Day and Every Night Health

Case Study #1

Susan is 53 years old and a single mother of three daughters who are between the ages of 17 and 24. Susan was a stay-at-home mother during the time that her daughters were toddlers, and then she returned to the workforce in a sales position. When the company she worked for closed, she sought training through Employment Insurance. After her skills were upgraded, Susan was hired as a bookkeeper. When she was laid off last year, she began working out of her home, doing bookkeeping for friends and other contacts that she has made over the years.

Susan's health has been good for most of her life, although since she went through menopause, she has noticed some marked changes in how she feels. Her doctor attributes most of Susan's problems to the effects of a sedentary lifestyle. She has been told repeatedly to quit smoking, lose weight, improve her diet, and get more active. She finds all of this difficult to do, not because she isn't interested in getting healthier, but rather because other people's situations always seem to trump hers. One daughter is a single-parent with a small child, and they have recently returned to the family home; another daughter has just quit university, and can't find stable employment; the third daughter has just moved away to another city, and is making that adjustment (with frequent calls home to mom). Juggling work and family is tough. In addition to all of this, Susan's financial situation is always a bit precarious, so joining a fitness club or program is not an option for her right now.

Recently, Susan started to experience pain in her legs. The pain originally came and went, but now it is more regular. Even though Susan had made a conscious effort to go to a regular aqua-cize class, the pain in her legs is such that she hasn't been able to continue. Her doctor suspects that Susan may have peripheral arterial disease, a type of atherosclerosis.

Peripheral arterial disease: "The disease is caused by a gradual build-up of fatty material within the walls of the artery. This condition is called "atherosclerosis" and the fatty material is called "atheroma". In time, the artery may become so narrow that it cannot

deliver enough oxygen-containing blood to the legs and this is called "peripheral arterial disease". The presence of atheroma can also cause a blood clot (or thrombus) to form, blocking off the artery completely." (<u>http://www.bhf.org.uk/hearthealth)</u>

Case Study #2

Margaret is a middle-aged, single woman. She was enrolled in a doctoral program for a time, but when her personal life fell apart, it became harder for her to continue her studies. She now works in a call centre.

For many years, Margaret was involved with a man, Michael. Michael had a teen-aged daughter from a previous relationship. Together Margaret, Michael and Eva had set up a home in a large eastern city. Michael was fully supportive of Margaret's goal of getting a PhD, and he supported her in every respect - financially and otherwise.

Margaret and Michael's relationship went on the skids recently, and Michael decided it would be best to take a job opportunity in another city. After he and Eva moved away, Margaret could not stop crying, and she told her friend Liz that she hadn't slept in weeks. Liz suggested that she go to her physician to get some sleeping pills.

About three weeks later, Liz and Margaret got together for dinner at Margaret's house. When she arrived, Liz was stunned by what she saw B Margaret was "all together". She was back to her old perky self, and she had totally changed the apartment by re-arranging the furniture, and adding a few new pieces of decor. What a turn-around in only a few weeks!

As the evening progressed, Liz couldn't help but notice how much alcohol Margaret was consuming. In the time that Liz had had 2 glasses of wine, Margaret had had 4-5 stiff shots of rum and coke. At about 9:30 p.m., Margaret pulled out her stash of marijuana and began to roll a joint. She topped up her rum and coke, and then pulled out her new meds - anti-depressants and sleeping pills. She downed the pills with her rum and coke, and sat back inhaling from the joint that she was smoking. Liz tried not to react, but she could not hide her surprise. Margaret responded that this was her new routine, and "isn't it working out grand?"

A few weeks later, Liz received a call from Margaret in which she told her that she was not doing too well. She'd started to experience strange physical symptoms - tingling in her arm, she hadn't had a period in months, and her mood was more erratic than usual. When Liz gingerly raised the matter of her drug use, Margaret quickly dismissed this and said that that couldn't be the problem.

The Pradesh family came to Canada 20 years ago from India, bringing with them Pramela's mother to help care for their one year-old daughter. They settled in Mississauga, Pramela and Ganesh both found work in local factories and they bought a small house in a new development. Ganesh improved his English through governmentsponsored training programmes but Pramela and her mother were not eligible. They struggled with the language and could manage because their local grocer was also from near their home in India.

When Pramela became pregnant, they searched for a doctor who would speak their language and understand their culture. They finally found a family doctor who came from a region far from their own but who nevertheless understood some of their language and practices. When Pramela's pregnancy became difficult, she was rushed to the hospital where no one spoke her language and where the treatment of birth was totally different from her previous pregnancy back in India. It was a frightening experience, one which left Pramela totally convinced she would never have another child.

The family continued to visit the doctor they had found following Pramela's pregnancy and were quite satisfied with the way he responded to problems such as the children's sore throats and Ganesh's pneumonia. But as the girls got older, they began to resist going to this family doctor. The older daughter wanted birth control pills. She knew that their doctor would not only refuse but would also tell her mother. This would be a disaster. When she found herself pregnant, she left home rather than seek advice from the family physician or tell her parents. The younger daughter was also rebelling against family traditions, seeking an annual physical so she could participate in the school soccer games. The doctor supported her parents' disapproval.

Meanwhile, Pramela started to feel a tingling sensation her arm. Then the arm started to pain her at night and she had trouble as the day wore on at the sewing machine she operated at work. Finally, she told the doctor. He thought it might be linked to menopause. Pramela decided she would have to learn to live with the pain.

Amidst all this turmoil, Pramela's mother fell and broke her hip. She was hospitalized for five weeks. Because there were so few nurses on the ward and none of them spoke Punjabi, Pramela had to leave her job to help care for her mother. She thought she would be able to return once her mother recovered. However, her mother remained bedridden and Pramela became responsible for her total care. Neither her doctor nor the discharge nurse tried to arrange home care services. Weeks later, the woman who worked in the local grocery store noticed how tired and depressed Pramela was. On hearing Pramela's story, she urged her to apply for home care assistance. Ganesh resisted, and Pramela could not do it alone because she did not speak English. But her daughter agreed to interpret and Pramela made the application. She was turned down, however, because additional home care assistance was deemed unnecessary, given that Pramela was already doing the work.

Sharon had the marriage of her dreams. After secretarial college she had landed a job as a receptionist to a lawyer in a small northern town. Charles was smart and fun, handsome and made a good income. When he asked her to marry him, she could not believe her good fortune. They played golf with the doctor and his wife, took vacations in the south and shopped for Christmas in the city. The community seemed like a great place to raise children.

Their first child was a boy, born in the local hospital and delivered by their good friend. It was an easy birth and Sharon thought she would want many more. Sharon left her receptionist job and stayed home to care for her son. The baby was very good, sleeping through the night after only a couple of weeks. Two years later his sister arrived and she was not quite so "good". Although the birth was uncomplicated, she had colic and screamed most of the night. Charles became very frustrated and yelled a lot, especially when he had important meetings the morning after a night of colic. Eventually, things settled down and the family once again fell into a comfortable groove. Their third child also had colic. This time Charles could not stand the noise. He even hit Sharon once when she tried to calm him down.

The boys took to skating and then to hockey, joining the local team. Their daughter learned to play the piano and sang in the church choir. The family was constantly busy with community activities. Charles was involved in the town council and his business grew to include clients from the neighbouring towns. As the children and the law practice grew, Charles became more inpatient with Sharon. Sometimes he hit her, and several times he even kicked her. But he always did it in their room and the bruises never showed when she was dressed.

At first, she thought it would never happen again, but gradually she realized that it was simply getting worse. But whom could she tell? Everyone in town thought Charles was wonderful and they would never believe her. This was especially the case with their good friend the doctor. Leaving seemed out of the question, because the children were so attached to the community and because she had no employment options.

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Case Studies: Diabetes

Case Study #1

Jennifer is 16 years old and has recently been diagnosed with type I diabetes. She is in Grade 10 and lives with her parents and younger brother in a suburban community south of Vancouver. Last year, she was heavily involved in school athletics as a member of the cross-country running club and was planning to train for a marathon with her father this spring. Now she is depressed and worried about herself and has withdrawn from her running club. Although she was initially hospitalized due to her symptoms, since her diagnosis she has been under the care of her family physician. She is struggling to understand her illness and how she is supposed to care for herself. Her school cafeteria lunch program was cancelled this year when the chef's training program was shutdown. Eating at school and dealing with her insulin are major daily issues. Her parents are anxious about how to support Jennifer and monitor her closely, particularly her diet, blood glucose levels and activity.

Case Study #2

Nancy is a 30 year-old white woman who is expecting her first child. She is an elementary school teacher and has been married for 3 years. Her husband is a self-employed consultant who has not had a particularly successful year. At a recent prenatal visit, in her 20th week of gestation, her physician observed that she was quite large and suggested that they review her blood work. The results of those tests indicated that she has gestational diabetes. The medical advice she has been given includes eating six small meals a day and walking after every meal. Nancy does not believe the diagnosis and is frustrated that she is expected to give up so much time to walking every day; she is finding it impossible to meet the guideline given her busy work schedule. Nancy does not believe that she "really" has diabetes but rather that her large gestational size is due to the fact that "we have big babies in my family." Nancy herself was 10 lbs when she was born.

Case Study #3

Muriel is a 53 year-old Aboriginal woman from northern Vancouver Island with type II diabetes. She is a grandmother and is currently raising two grandchildren, aged 3 and 5, while her daughter lives away from the community working. Muriel lives on reserve, in a remote community that is accessible only by road in the summer. The rest of the year, the community depends on the regular run of the supply ship or seaplanes for travel and

supplies. There is no physician in the community but there is a community health nurse living in the village. Muriel's diabetes is no longer manageable through oral medication and she has recently had to begin using insulin. Muriel's sister and brother also have diabetes. Muriel's brother has had a lower leg amputation and this has frightened her about the risks of the disease. She doesn't know how she would manage caring for her grandchildren if she were less mobile than she is now.

Case Study #4

Louise is 73 and has been living with diabetes for many years. She has developed neuropathy in her feet and has to be very careful with foot care. She lives in a mediumsized city in a small apartment on her own. She is a pensioner who left her paid work as a volunteer coordinator in her early 50s because she was having trouble managing her glucose levels. She has been on long-term disability since. Louise is a large woman and has been increasingly short of breath in recent weeks. She has begun noticing that her chest is tight when she comes up from the basement laundry room. She lives on the third floor of a four-storey walk up. Louise checks her blood glucose levels morning and evening, before breakfast and supper. Despite her long years of using insulin and managing on her own, lately she's had more trouble maintaining her glucose levels appropriately. She has had laser treatment for retinal neuropathy and her physician mentioned that she is worried about Louise developing kidney problems. Louise is careful to use a cane when she walks outside and in the winter months; she is sometimes indoors for a week when the sidewalks are icy because she is afraid of falling. She is not sure how she would manage if she fell and broke a bone. Louise has a son but he lives in Toronto and comes to visit a few times a year but cannot be her steady source of care. She is a member of the senior's centre around the corner where she is part of a book club.

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Case Studies: Mental Health

Case Study #1

Jody is an 18-year-old Italian Canadian from a middle class family. She has been living with friends in a basement apartment since she left high school and moved to a nearby city. Although she had a family doctor while growing up, she has no regular health care provider in the city. After being sexually assaulted at a party by one of her "friends", she went to a clinic for emergency contraception. In the following weeks she became withdrawn and depressed. Eventually her older sister was afraid that she was suicidal and took her to the emergency room at the local hospital where she was admitted to the psychiatric ward. She has not told anyone about the sexual assault, and blames herself for letting it happen. Her father thinks "shrinks" are for "crazy people" – and tells her regularly that she should "snap out of it" and get her life together. Her doctors have determined that with medication she can leave the psych ward, but she needs a supportive place to live.

Case Study #2

Margaret is a 74-year-old Scottish Canadian farm woman married to a frail elderly man with Alzheimer's disease. They continue to live in the family farmhouse, but the surrounding quarter section is farmed by a neighbour, who lives two miles away. Margaret has two grown children who now live in Toronto and Calgary. Margaret is still able to drive into town for groceries and errands, but now schedules her trips for the one day each week that a home care aide comes to bathe her husband. The rest of the time Margaret feels that she has to stay at home to look after her husband. He has become increasingly confused, forgetful, and distrustful. She has been feeling exhausted, sad, unsure of what to do, and isolated from her friends and family. She doesn't sleep well and is worried a lot of the time.

Case Study #3

Anna is a 35-year-old Bosnian refugee who came to Canada two years ago with her husband and two young children. She is a physician by training and her husband is a professor of chemistry. They were able to flee persecution through the help of friends and the church, but not before Anna witnessed the slaughter of many of her relatives. Although the family is happy to be in Canada, Anna continues to have terrible nightmares – when she can fall asleep. She also cries easily and suffers frequent panic attacks. Anna stays home with the children while her husband drives a taxi because neither can find a job in their own field. In fact, Anna cannot get a license to practice in Canada unless she is admitted to a re-training program, and these are both costly and highly competitive. At home with her children, Anna also has few opportunities to learn French or English and so finds it almost impossible to communicate with neighbours, the parish priest, or the staff of a local community health clinic. Doctors at the clinic have prescribed sleeping pills, sedatives, and anti-depressants for Anna.

Case Study #4

Debbie is a 22-year-old Mi'Kmaq single mother with three small children. After the birth of her third child, she became very tired, cried often, and seemed unable to cope with many daily activities. When she visited the doctor for the baby's checkups, he never asked her how she was doing and Debbie didn't ask for help because she assumed that her lack of energy and enthusiasm was "normal" for someone raising a young family alone. One day a friend suggested she might feel better if she attended a post-partum support group. But it was difficult to get there by bus from her neighbourhood and when she arrived, Debbie was the only Aboriginal woman in the group. She didn't go back. Sometimes she isn't able to get her oldest daughter to school on winter mornings and she is afraid that someone will report her to Social Services and they'll try to take her kids away. She doesn't want to tell anyone what's going on for fear they will label her an "unfit mother".

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Case Studies: Sexuality and Reproductive Health

Case Study #4

Christine is a 32 year-old Cree woman who recently moved back to a northern Manitoba community with her male partner and two children. She is 7 months pregnant and has had a normal pregnancy. Her prenatal care is being handled by a combination of nurse practitioners and visiting physicians. There is no physician nearby to assist her in her labour and birth. Because of the small number of births in the community, the nearest hospital no longer does deliveries. At her most recent prenatal appointment, the visiting physician recommended that she travel to the closest hospital, which is 6 hours away by car, prior to going into labour.

She is unhappy about leaving behind her family and friends during this important time. She is aware that some women are having babies at home with the assistance of a registered midwife who has just moved into the area. She is considering this option, however the midwife may not be able to provide the service unless another midwife or other health care provider is available.

Case Study #2

Teresa is a 22 year-old white woman living in her parents' home in rural Ontario. She has worked as a clerk at the local hardware store since she graduated from high school four years ago, but she has been dreaming of going to university to become a teacher. Teresa's parents are not able to help much financially, but she's finally saved enough money to enrol next fall. Teresa's boyfriend (who is apprenticing as an electrician) supports her ambition. Having dated for two years, they have discussed getting married but plan to delay until Teresa has finished her degree. They have been having intercourse regularly for most of their relationship and use birth control "almost all the time." It's now 10 weeks since Teresa's last menstrual period. After talking over the options with her boyfriend (but not her parents) she decides to seek an abortion and makes an appointment with her family physician. In the waiting room, she meets one of her mother's close friends.

Anu is an 18 year-old South Asian woman in Vancouver. She is second-generation Canadian and lives with her parents. She and her parents have quite different views about "how a young woman should behave." Although her parents attempt to enforce strict rules around her social activities, Anu has creatively managed to 'bend' these. She has been sexually active with men for two years. The birth control methods she and her and her sexual partners have used consist of condoms and withdrawal, but Anu has been nervous about getting pregnant and wants to begin taking birth control pills. She has heard that physicians often make having a Pap test a condition of prescribing the pill. Anu has never had a Pap test before and doesn't know what to expect. She is also concerned about her parents finding out about her sexual activity.

Case Study #4

Anne is a 27 year-old lesbian woman with probable endometriosis and multiple fibroids. She has experienced painful, heavy periods since she began menstruating at the age of 15 and has been taking prescription nonsteroidal anti-inflammatory medication since the age of 16. Anne and her 32 year old partner Roewan have discussed the possibility of parenting together, and are currently weighing their options (e.g., adoption, alternative fertilization). Having recently moved to a new city, Anne was lucky enough to find a family physician who was accepting patients. Until now, Anne has had only one visit -- for a minor ear infection -- and did not disclose her sexuality to her doctor at that time. Presently, at Anne's annual physical exam, the following exchange occurs:

GP: When was your last Pap?

Anne: About 2 years ago.

GP: Are you sexually active?

Anne: Uh ... yes.

GP: Well you should really have a Pap every year. What do you do for birth control? Anne: Well, nothing.

GP: Are you trying to get pregnant?

Anne: Well, um, no, not right now.

GP: (gives a quizzical look)

Anne: Uh, I should probably clarify... my partner is a woman.

GP: Oh! Well, okay. Well then, uh, hop up on the table and let's have a look. I'll do a quick breast exam and then a Pap...

Upon completing an internal exam and reviewing Anne's menstrual history, the doctor refers Anne to a surgeon for a laparoscopy to determine whether endometriosis and/or fibroids are present, and to potentially provide relief from her symptoms. The doctor does not discuss Anne's fertility.

Ellen, a 72 year-old white woman, and her partner Rose (68) have been living together in Toronto for 15 years. Lately, Ellen has had difficulty remembering simple words, has had trouble keeping track of household bills, and frequently can't find her purse – one day she found it in the refrigerator. Both Ellen and Rose passed off these occurrences as 'forgetfulness' until Ellen called Rose in a panic from the local shopping centre, not sure how to get home. Rose insisted that Ellen see her doctor to find out what was going on and offered to accompany her. Ellen's physician gently suggested that she may be experiencing early symptoms of Alzheimer's. He recommended a series of tests to rule out other possibilities, but seems relatively certain of the outcome. Rose is worried. Her own health has been declining over the last few years -- her arthritis has become more severe and she and Ellen have required more help getting things done around the house. Although they have a good network of friends, neither she nor Ellen has any children. Rose's meagre retirement benefits package does not cover Ellen because she is not considered Rose's spouse. Rose thinks about selling the house and looking at assisted living residences for Ellen or for the two of them, but she and Ellen have always publicly described their relationship as 'housemates' and she isn't sure that they would be allowed conjugal visits, or be able to share a room if they wanted to live together. She worries about negative reactions from staff and other residents.

Appendix G – Dare to Dream

Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September, 1978

The International Conference on Primary Health Care, meeting in Alma-Ata this twelfth day of September in the year Nineteen hundred and seventy-eight, expressing the need for urgent action by all governments, all health and development workers, and the world community to protect and promote the health of all the people of the world, hereby makes the following

Declaration:

Ι

The Conference strongly reaffirms that health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector.

II

The existing gross inequality in the health status of the people particularly between developed and developing countries as well as within countries is politically, socially and economically unacceptable and is, therefore, of common concern to all countries.

III

Economic and social development, based on a New International Economic Order, is of basic importance to the fullest attainment of health for all and to the reduction of the gap between the health status of the developing and developed countries. The promotion and protection of the health of the people is essential to sustained economic and social development and contributes to a better quality of life and to world peace.

IV

The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.

V

Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures. A main social target of governments, international organizations and the whole world community in the coming decades should be the attainment by all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life. Primary health care is the key to attaining this target as part of development in the spirit of social justice.

VI

Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.

VII

Primary health care:

1. reflects and evolves from the economic conditions and sociocultural and political characteristics of the country and its communities and is based on the application of the relevant results of social, biomedical and health services research and public health experience;

2. addresses the main health problems in the community, providing promotive, preventive, curative and rehabilitative services accordingly;

3. includes at least: education concerning prevailing health problems and the methods of preventing and controlling them; promotion of food supply and proper nutrition; an adequate supply of safe water and basic sanitation; maternal and child health care, including family planning; immunization against the major infectious diseases; prevention and control of locally endemic diseases; appropriate treatment of common diseases and injuries; and provision of essential drugs;

4. involves, in addition to the health sector, all related sectors and aspects of national and community development, in particular agriculture, animal husbandry, food, industry, education, housing, public works, communications and other sectors; and demands the coordinated efforts of all those sectors;

 requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate;
 should be sustained by integrated, functional and mutually supportive referral systems, leading to the progressive improvement of comprehensive health care for all, and giving priority to those most in need;

7. relies, at local and referral levels, on health workers, including physicians, nurses, midwives, auxiliaries and community workers as applicable, as well as traditional practitioners as needed, suitably trained socially and technically to work as a health team and to respond to the expressed health needs of the community.

VIII

All governments should formulate national policies, strategies and plans of action to launch and sustain primary health care as part of a comprehensive national health system and in coordination with other sectors. To this end, it will be necessary to exercise

political will, to mobilize the country's resources and to use available external resources rationally.

IX

All countries should cooperate in a spirit of partnership and service to ensure primary health care for all people since the attainment of health by people in any one country directly concerns and benefits every other country. In this context the joint WHO/UNICEF report on primary health care constitutes a solid basis for the further development and operation of primary health care throughout the world.

Х

An acceptable level of health for all the people of the world by the year 2000 can be attained through a fuller and better use of the world's resources, a considerable part of which is now spent on armaments and military conflicts. A genuine policy of independence, peace, détente and disarmament could and should release additional resources that could well be devoted to peaceful aims and in particular to the acceleration of social and economic development of which primary health care, as an essential part, should be allotted its proper share.

The International Conference on Primary Health Care calls for urgent and effective national and international action to develop and implement primary health care throughout the world and particularly in developing countries in a spirit of technical cooperation and in keeping with a New International Economic Order. It urges governments, WHO and UNICEF, and other international organizations, as well as multilateral and bilateral agencies, nongovernmental organizations, funding agencies, all health workers and the whole world community to support national and international commitment to primary health care and to channel increased technical and financial support to it, particularly in developing countries. The Conference calls on all the aforementioned to collaborate in introducing, developing and maintaining primary health care in accordance with the spirit and content of this Declaration.

Source: World Health Organization http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf