centres of excellence
for WOMEN'S HEALTH
RESEARCH BULLETIN

VOLUME 2 NUMBER 1 SUMMER 2001

NEW QUESTIONS NEW KNOWLEDGE

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POLICY FOR RURAL WOMEN

What's Policy Got to Do with It?

The Centres of Excellence for Women's Health (CEWH) were established in 1996 to improve women's health, in part by enhancing the Canadian health system's understanding of and responsiveness to women and women's health issues. The Centres were charged to employ networking as well as the generation of new knowledge and methodologies to facilitate research uptake and policy impact. In this issue of the *Research Bulletin* we ask what influence have the Centres had on policy to date.

The articles collected here tell us that policy making is about *both* content and process. The processes by which the research is done can change behaviour and attitudes. The processes by which new information is disseminated can invite new stakeholders into the policy dialogue, and widen the scope of policy development and impact. A common thread among the articles in this issue is therefore attention to the processes of both research and policy making in order to maximize their responsiveness to the people they serve.

Central to many projects within the program is a commitment to involving multiple stakeholders in research from inception through dissemination. "What would 250 women say …" describes, for example, what women in Saskatchewan and Manitoba told the Prairie Women's Health Centre of Excellence they wanted to see in a Health Action Plan. Similarly, the second paper from the Prairie Centre documents the experiences of farm women who, having been cut out of the policy-making process, need to have their voices heard again. Le Centre d'excellence pour la santé des femmes in Montreal hosted a symposium with caregivers' associations from the province of Quebec, and then took this information, along with five years of research experience on women caregivers and a coalition of interested groups, into public consultations to change policy at the local community health level.

Research sponsored by the Centres often includes a commitment to seeing the traditional "subjects" of research functioning as active partners in the research enterprise as study participants, advisors or investigators. Further, the research process is understood as an ongoing mechanism for capacity building among

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ISSN 1496-3612 Centres of Excellence for Women's Health Research Bulletin
Canadian Publications Agreement No. 40036219

CENTRES OF EXCELLENCE FOR WOMEN'S HEALTH

Launched in 1996, the Centres of Excellence for Women's Health (CEWH) are funded by Health Canada and administered by the Women's Health Bureau. Their work is a major component of the Women's Health Strategy. Four centres, each a dynamic partnership of academics, researchers, health care providers and community-based women's and women's health organizations are located in Halifax, Toronto, Winnipeg and Vancouver. The Canadian Women's Health Network (CWHN) is also funded under CEWH to support national networking and communications.

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UNION BUG

(WPG SUN: PLS PLACE LOGOS)

cont'd

both community and academic researchers, one that ensures that everyone grows through the experience of collaboration. Finally, the research process does not end with the writing-up of the findings. Rather, strategic dissemination is necessary to maximize the likelihood of research uptake. In "The Mice that Roared," Nancy Poole outlines her approach to research on women and addictions, an approach that is inclusive, action-oriented and women-centred. Poole believes that this approach, combined with a solid foundation of information about how women have responded to existing addiction policies and services, has been key to her success in moving the agenda forward.

We learn about some of the mechanisms used across the CEWH program to ensure that research findings become part of policy debates. The article about the Maritime Centre, for example, describes in detail some of the processes they used —including policy road shows, a dedicated research chair, and women's health awards—but all the articles include a description of how the researchers took their message to decision makers and other researchers. We see everything from media events to research symposia to websites to policy papers used as strategies to "get the word out."

Above all, good decisions require timely, relevant, useful information — including information that challenges taken-for-granted assumptions about the world. In "Policy from the Ground Up," Deborah Sarauer and Diane Martz describe the immediate uptake of observations made by their research subjects, farm women living in abusive relationships. The women's criticisms led the local counselling service to "change its world view,"and its protocols. Researchers need to be willing to tackle the seldom-asked questions so that more is known about how things in both women's health and policy making work. We also need to use research to evaluate policies once they are put in place to understand whether the policy is being implemented as planned and having its intended effects. This is critical in health care, where many practices remain unexamined.

This issue offers only a taste of what is known about the impact of the program to date. Only a selection of impacts is highlighted here. Literally dozens of other research projects are nearing completion and comprehensive evaluations have been done or are under way in all the Centres to try to capture the diversity of their impacts on policy makers at all levels of Canadian society. I invite you to contact any of the Centres to learn more about what we are learning about women's health every day.

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Making Waves

The British Columbia Centre of Excellence for Women's Health has produced a report on its first five years of activity. *Making Waves* describes key strategies and results of knowledge generation and knowledge uptake employed by the Centre to date. Released in April 2001, *Making Waves* illustrates the productive partnerships of a wide range of academic and community researchers. Over one hundred projects have been completed on subjects ranging from the implementation of midwifery in British Columbia to the health benefits of physical activity to the mid-life health needs of women with disabilities. The report also describes the ripple effects of several projects, from securing program funding to encourage girls' participation in community recreation in the Burnside-Gorge area of Victoria, to the formation of a Gender and Health Institute in the Canadian Institutes for Health Research, to the development of gendered approaches to economic costing. Looking ahead, the unique location of the Centre at Women's and Children's Health Centre of British Columbia, an arrangement that brings the social sciences to the bedside, will continue to provide opportunities for researchers, policy makers, program developers and health care providers to link their work directly to the health concerns of Canadian girls and women.

For a copy of *Making Waves*, visit www.bccewh.bc.ca or contact:

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REDEFINING POLICY MAKING

The Power of Citizen Engagement to Influence Research and Policy

Georgina Feldberg, National Network on Environments and Women's Health

In traditional policy analysis, the power and influence of key interest groups, and their elite membership, is a key explanation for policy change. Thus, for instance, the Canadian Medical Association and pharmaceutical manufacturers are typically considered key actors in conventional explanations of health policy.[1] Critics of the policy-making process suggest that interest dominated policy making creates a "democratic deficit" and erodes the legitimacy of the process. During the past decade, inspired to a considerable extent by the work of Robert Putnam, students of public policy have begun to look below organized interests, and to imagine bottom-up rather than top-down policy making. Analysts have explored the role that citizens and citizen groups can play in making policy, and have tried to "enhance citizen engagement" in an effort to democratize the policy process. Through what is often termed "deliberative dialogue" a broader range of constituents are consulted.[2] Women can be seen as one such constituency and some have sought to add their voices to traditional policy making through standard organizing and lobbying techniques. Other feminist/women's activists and researchers have similarly sought ways to incorporate a diversity of women's positions into a new kind of policy making.[3]

There has been considerable debate over the efficacy and sincerity of the recent governmental push for citizen engagement, but the broader effort to democratize policy making coincides and sometimes intersects with the objectives of feminist activism.[4] Projects funded by the National Network on Environments and Women's Health (NNEWH) provide examples of policy making in which a community group can assume the role of an "institution" that lobbies from the inside out for specific changes related to women's health. Other NNEWH projects illustrate how processes to generate knowledge from the bottom up can allow for more workable policy. In both cases the generation of new ideas and knowledge can lead interested parties and the general public to shift their expectations, behaviours and possibly even votes, and so change policy. The following account of our project, "English Canadian Attitudes to New Reproductive and Genetic Care," provides an example of a "bottom-up" model for policy change that Diane Majury calls "the research arm of the community."[5]

Despite the high public profile of reproductive and genetic technologies, we know little about the ways in which average Canadians think about them. As a result, we don't know how Canadians will respond to regulations and other policies that are developed, and hence whether these policies will be workable. By probing the attitudes of a wide range of Canadians, this project attempted to ground policy in experience. The data that the project generated can inform policy makers in the traditional ways, but the project also facilitated communication between interests: within focus groups, participants educated each other, thereby creating opportunities to reduce the polarization of attitudes between them. The new understanding that resulted increases the likelihood of more workable policy. The various interested parties included a general sample of Canadians, as well as specific communities of women who might turn to reproductive technology (e.g., infertile women, single women, lesbians).

The project used both quantitative and qualitative methods to collect data and develop an empirical framework on which to base statements about Canadian attitudes about the use of reproductive and genetic technology. Briefly, a series of questions were added to the Winnipeg Area Study, a multi-use survey that allows researchers from a variety of disciplines to submit questions related to specific areas of interest. The sample is typically derived through a random selection of working telephone numbers in the Winnipeg area with the household as the primary sampling unit. The sample is intended to be representative of the Winnipeg population. In order to participate in the survey, respondents must be at least 18 years old, reside in the household and meet the pre-designated gender criteria randomly generated for each household. The total sample size in 1999, the year in which we added questions, was 750: 428 women and 322 men between the ages of 18 and 90. The second method for gathering data was focus groups conducted across the country. Participants in both the survey and focus groups came from diverse populations that included, among others, lesbian and minority women.

We recruited participants for the focus groups with the assistance of community groups, ads and flyers, and a "snowball" (having our sources recruit additional participants). All participants were women. The groups proved extraordinarily difficult to schedule. Despite the provision of childcare and incentives, women frequently declined the opportunity to participate. Some agreed, then did not attend. Eventually, after many months of organization, groups were conducted during January and February 2000 in St. John's, Halifax, Toronto and Vancouver. The groups included 37 women who ranged in age from 18 to 69 years. Their educational level ranged from secondary school completion to post-graduate training.

Participants in both the focus groups and the survey were asked to identify the leading cause of infertility. The survey respondents were asked both closed and open-ended questions that inquired about the range of treatments, from high-tech to alternative therapies, that they might consider if they were or someone they loved was diagnosed as infertile. Focus group participants were asked the same open-ended questions. They were also asked how they made the choice and how they assessed the risk of various treatment options.

The survey and focus group data were analysed to provide insight into attitudes about, and the use of, a range of infertility treatments that ranged from high-tech to alternative medicine to behavioural modification. The survey data were also analysed for gender differences. Closed and open-ended responses to the survey and transcripts of the focus group discussions suggest that many Canadians have limited knowledge about infertility, its causes, consequences and treatment. Many respondents identified genetics as the main cause of infertility. Others identified "too much sex" and "too much pop" as leading causes.

In the survey population, women were more likely than men to report having been diagnosed as infertile and they were more likely than men to know someone diagnosed with infertility. In contrast to participants in the focus groups, several of whom had relied on assisted reproduction, none of the respondents to the survey reported having used in vitro fertilization, donated eggs, donated sperm or surrogacy. Most respondents to the survey voiced a preference for low-tech interventions. Women were significantly more likely than men were to consider adoption, but there were also significant gender differences in attitudes towards specific treatments. When asked about their attitudes, both men and women listed change in exercise, change in diet, and ovulation charting with timed intercourse as their preferred

IN FOCUS GROUPS, PARTICIPANTS EDUCATE EACH OTHER, THEREBY CREATING OPPORTUNITIES TO REDUCE THE POLARIZATION OF ATTITUDES BETWEEN THEM. THIS NEW UNDERSTANDING CREATES A FOUNDATION FOR MORE WORKABLE POLICY.

options and use of donated embryos and surrogacy as their least preferred. 5.5% of those between the ages of 18 and 55 reported having used alternative healing as an infertility treatment: 2.3 % had relied on ovulation charting and timed intercourse, .9% undertook a change in exercise.

Both the focus groups and the survey suggest that personal experience fostered greater understanding and concern and that knowing someone with infertility enhanced the participant's awareness of the experience, available treatments and options for treatments. Among survey respondents, those who reported being infertile or knowing someone who has difficulty conceiving were significantly more likely to believe that hormonal imbalances, infectious diseases, age, delayed childbearing, wearing tight undergarments and too much exercise cause infertility. Focus groups sometimes began with participants taking extreme positions on the causes of infertility and the appropriateness of treatment. For example, infertile women were blamed for having "delayed childbearing," and their desire for treatment was dismissed as frivolous or unnecessary. Within the focus groups, women who had personal experience of infertility tempered the discussion and began to bridge perception gaps with narratives that brought to light a range of causes and explanations. In St. John's, for example, "Jane" spoke of her friend who had "pelvic inflammatory disease that caused a lot of scar tissue," while "Mary" identified high costs as a barrier to adoption. In Vancouver, "Katherine," who had attended an adoption support group, commented on the invisibility of infertile women's experiences. "I should know lots of people —I *do* know lots of people who are infertile who never talk about it. It just occurred to me."

This project has obvious relevance to the ongoing debate about the provision and regulation of assisted reproduction. Our responses to draft legislation tabled in 2000 and 2001 are informed by what we have learned:

- Most infertile women don't talk about their experiences. This means that the experiences of those who use the technologies are not reflected in research or policy.

- There is a mismatch between most government policy and public preferences. For example, respondents to our survey indicated that adoption and alternative health were their preferred options for addressing infertility. No one in the survey sample reported ever using in vitro or high tech measures. Yet policy focuses on the control of reproductive technology rather than on the regulation of adoption or the safety of alternative medicine.

Workable policy, that patients and practitioners would comply with rather than resist, must be built upon existing practices and acknowledge the needs of those who would be using the technology.

More significantly, however, the research project itself has implications for policy making. It indicates that recruiting women who have personal experience with a particular condition or disease can be very difficult, which suggests that the voices of such women are not always well represented in the evidence that becomes the basis for policy. Second, we found that when the voices of those women are/can be incorporated, the discussion can become less polarized because the understanding and awareness of other participants is broadened and myths about issues may be dispelled. Third, focus group participants pushed the researchers to use terms that were more reflective of experience. They raised questions about the phrasing of survey questions, such as definitions of infertility and infertility treatment. They expressed unease with the commonly used definition of infertility, "the inability to conceive after a year of unprotected intercourse," which applies almost exclusively to married women, or women in heterosexual relationships. They probed the different meanings of "infertility" to single women, lesbian women, women who were trying to conceive with a male partner, and men. They expressed concern that recurrent miscarriage is conflated with inability to conceive, and that "male infertility," which is more difficult to diagnose, can remain hidden, is less readily treated and still places the burden of treatment on the female partner. The voices of these women, the combination of their experience and the other data gathered from the survey and the focus groups, lays the foundation for policy that is both based in and responsive to population needs.

As the Royal Commission on New Reproductive Technology and its aftermath demonstrated, the policy debate over assisted reproduction is heated and polarized. Hence, efforts to move from recommendation to action have often failed. This research project suggests that focus groups can allow researchers to capture the nuances of women's voices in ways that not only generate new knowledge, but also allow us to move beyond polarized policy alternatives. NNEWH's approach to developing effective policy recommendations has meant engaging "the people" not only as recipients of policy, but as sources of knowledge, influence and power within focus groups as educators and peers, and without as agents of policy.

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NOTES

[1] Tuohy, C. (1999). *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain, and Canada.* New York/Oxford: Oxford University Press.

[2] See for example, A Legacy of Citizen Engagement: The Society We Want Wraps Up Research, *Discovering the Society We Want Newsletter*, Canadian Policy Research Networks, Number 6, March 2001, p.1.

[3] Vickers, J., et al. (1993). *Politics as If Women Mattered: A Political Analysis of the National Action Committee on the Status of Women.* Toronto/Buffalo: University of Toronto Press; Linda Brisken and Mona Eliasson (Eds.) (2000), *Women's Organizing and Public Policy in Canada and Sweden.* Montreal: McGill-Queen's.

[4] Briskin L., M. Eliasson, G. Feldberg, M. Carlsson (2000). Organized for Health: Women's activism and health policy making in Canada and Sweden. In L. Briskin, M. Eliasson (Eds.), *Women's Organizing and Public Policy in Canada and Sweden.* Montreal: McGill-Queen's.

[5] Majury, D. (1998). *Promoting Women's Health: Making Inroads into Canadian Health Policy.* Policy Advice Framework Report to the Centres for Excellence for Women's Health. Ottawa: The Centres of Excellence for Women's Health Program.

The Process Is The Product: Redefining Policy Making

Speaking about the dissemination and policy impact of women's health research, Sandra Bentley, co-chair of the Maritime Centre of Excellence for Women's Health steering committee and senior policy advisor for the Interministerial Women's Secretariat of PEI, says, "Essentially, the process is a significant part of the product." The quality of research partnerships, for example, influences the quality, relevance and impact of the research. Also critical are the ways in which capacity is built in the community and the Centre, and the ways research findings are disseminated. This emphasis on process is particularly important in areas that have traditionally been understudied.

This article highlights three of the Centre's mechanisms to widen the scope of the health policy dialogue, enabling new stakeholders to participate. These initiatives create understanding and momentum and represent investments in health policy knowledge. The first mechanism is a new partnership with researchers who are indigenous to a community that is usually neglected in research, and whose members have less access to health services. The second is a public platform to animate a women's health research agenda and disseminate research findings. Third, a permanent academic research chair on women's health and the environment is described.

Black Women's Health Network

The Black community of Nova Scotia is one of the most vulnerable and high risk populations in the Atlantic region, yet it is routinely excluded from mainstream health research. In order to foster links, new health research and research partnerships with this community, the Centre invited Black researchers to speak at a lunchtime discussion series on Black women's health. The series led to the formation of the Black Women's Health Research Network, an autonomous network of researchers and volunteers from academic, community, public policy and clinical agencies. This group has entered into a partnership with the Centre that has resulted in a research project to examine the current state of knowledge about the health of Black Nova Scotian women and families. In March 2001, 100 policy makers, researchers and community members attended a workshop to discuss the preliminary findings. Recommendations of the study included:

1. Develop health resources for conditions such as Sickle cell anemia that disproportionately affect the Black population.
2. Provide culture awareness training for health professionals and medical students.
3. Conduct research on how to recruit and retain marginalized groups in health care jobs.
4. Build and disseminate evidence-based knowledge about Black women's health.

The way in which this research was initiated, funded and carried out potentially widens the scope of policy making. For example, this project wouldn't have been possible if the Maritime Centre of Excellence had used the standard competitive peer review process as the sole basis for deciding about funding research, and leaders from the Black community would not have become stakeholders as a result. Leaders have supported both the research partnership and the research project because they build capacity and networking within the community, as well as generate new knowledge about the health of community members.

Policy Forum on Women's Health and Well-being

Creating new means to disseminate the findings of research projects may also change the shape of the policy making process. Part of the platform to disseminate the findings of Centre-funded research projects has been a day-long forum held in 1999 and 2000 in each of the four Atlantic provinces. Academic researchers, policy makers, community organizations and women's health activists were invited to attend panel presentations on the research conducted in their province. One-to-one meetings with policy makers (deputy ministers and senior regional health council officials) created another opportunity for Centre staff to give briefings on Centre work, present research findings and distribute copies of Centre publications. Lesley Poirier, former Research Coordinator at the Maritime Centre of Excellence for Women's Health, says, "As well as communicating new knowledge, it's important to point out that the Centre is promoting a new and very specific kind of agenda for women's health research. That is, community-based, applied rather than clinical, and collaborative."

During the 2000 Policy Fora, the Centre inaugurated the annual Leadership Award in Women's Health in Atlantic Canada, an event that honoured 20 women and groups who have made a difference to women's health in their communities. The award ceremonies captured considerable media attention in each of the capital cities where they were held. The Women's Health Leadership Awards make women's health research and women's health community work visible to the public and to policy makers. Apart from providing a stage upon which to animate this work, the Award recognizes, validates and nurtures the community of women's health researchers.

Elizabeth May Chair in Women's Health and the Environment

The Elizabeth May Chair in Women's Health and the Environment at Dalhousie University provides a new, permanent entity for women's health research and a new process for research uptake. The result of two anonymous donations to the Centre totaling $1.6 million, the mandate of the position is to teach, do research, promote debate and ensure that research results become integrated into public policy in the areas of women's health and the environment. The primary appointment is in the Faculty of Health Professions at Dalhousie University, but the appointee works directly out of the Centre, fostering another research partnership. Elizabeth May, Executive Director of the Sierra Club of Canada, was the first chair holder in 1999 and 2000. Sharon Batt has been awarded the chair for the upcoming term. She is currently completing a two-year appointment as the Nancy's Chair in Women's Studies at

Mount Saint Vincent University where she taught and conducted research in women's health. A writer and community activist, her work promoting research and policies to prevent breast cancer through healthy environments is widely recognized. Her book, *Patient No More: the Politics of Breast Cancer* (Gynergy Books, 1994), has won international acclaim.

How do we assess the impact of the three mechanisms described here? New networks of researchers and new research from diverse communities, more stakeholders, including community leaders, lively media coverage of women's health issues where before there was next-to-none, and a growing body of new knowledge about the health of women who have previously been ignored—taken together, *this* is impact.

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TAKING ACTION TO INFLUENCE POLICY

The Mice That Roared: Using Feminist Activist Principles to Influence Policy

Nancy Poole, BC Centre of Excellence for Women's Health

In late 1970s the zany American feminist, Flo Kennedy, offered some advice to feminist activists on strategy. She said that it would always be more problematic for those in power to face 10,000 mice unleashed in a room than a single roaring lion. This image of the unfettered mice may serve to inspire those who are seeking ways to guide research and animate research findings to change the shape of women's health policy. In this article about research on women who are pregnant or mothering and who use alcohol, tobacco and other drugs, the "mice" include community service providers, advocates in government, women who use substances and researchers at the British Columbia Centre of Excellence for Women's Health (BCCEWH). The "roar" comes not from a single lion, but from these multiple stakeholders using feminist organizing tactics and community-based action research methods to influence health policy.

Over the past five years, researchers at the BCCEWH have worked on four such research projects to affect policy related to women who are pregnant or mothering and who use alcohol, tobacco and other drugs. The first project was catalyzed by the legal actions of Winnipeg Child and Family Services to try to force "Ms. G.," an Aboriginal woman who was using solvents during pregnancy, into treatment. As the case moved through the Supreme Court, we started a process of building consensus among those working in the fields of substance misuse, fetal alcohol syndrome prevention and women's health. Our goals were to open up the dialogue and move from narrow, punitive and "competing rights" approaches to the issue, and to use the input of the disparate stakeholders to guide the research direction.

With seed grant monies from the BCCEWH, we researched the legal actions being taken against women who use substances during pregnancy. We also reviewed the literature on the impact of involuntary treatment, barriers to treatment experienced by pregnant and parenting women and effective alternative approaches. We created a media package of this material and held a media conference to coincide with the Supreme Court decision. Women from the BC consensus-building process who worked in government followed up on the media conference. They circulated hundreds of the media kits to provincial governmental policy makers to inform and invite discussion among regional health authorities on how health and social services systems might support rather than punish women in Ms. G.'s situation.

These tactics enabled us to successfully create a context that deterred punitive legislative action against mothers in this province. We helped reframe the public debate surrounding the Supreme Court case and introduce all the stakeholders to the merits of non-coercive, caring support of women during pregnancy to prevent alcohol and other drug-related developmental disabilities.

The Ms. G. case also prompted us to question what barriers pregnant and parenting women face when accessing treatment. Again, we involved those in a position to benefit from and advocate for policy change in the research process. Community alcohol and drug service providers from Prince George and Vancouver helped develop the research questions, conduct the research and disseminate the findings. The report on the findings, *Apprehensions: Barriers to Treatment for Substance Using Mothers,* underlines a key barrier to treatment—that women are afraid their children will be apprehended if they admit to having problems with substance use. Grounded in the pressing policy issues facing substance-using mothers and service providers in communities, this research is being used to guide decision making in a variety of contexts. For example, the Canada Drug Strategy Unit of Health Canada used our report as a basis for discussions held in March 2001 with perinatal and addictions service providers that are involved in training child welfare and other professionals who are in a position to support women's access to care. The findings of this research were also brought to the recent provincial addictions policy development Task Group. As a result, the report of this group, *Weaving Threads Together: A New Approach to Address Addictions in BC* (March 2001), recommends specialized strategies to ensure women can access the services they need.

Aboriginal women's health advocates in BC have also affirmed and augmented our findings by articulating how First Nations and Metis women experience these barriers and supports to treatment. The Spring 2001 newsletter of the Women's Health Bureau of the BC Ministry of Health is devoted to a discussion of ways to improve access to and quality of treatment for Aboriginal women.[1]

In a third research project, BCCEWH researchers worked with the Sheway Project to evaluate their innovative, harm reduction approach to improving access to care for substance-using mothers. Sheway is a program in the downtown eastside of Vancouver that offers supports and care to pregnant women and mothers who are substance users. Our research showed that when care for pregnant women focuses on the broader determinants of women's health, such as nutrition, housing, income support, and reduction of violence, rather than more narrowly on women's substance use, positive outcomes for the women's health and for the prevention of fetal alcohol syndrome in their children can be achieved. Several developments indicate that the research with Sheway is having a policy impact. The BC Children's Commission incorporated our findings into its recommendations to the BC government on the prevention of fetal alcohol syndrome. The Sheway Project's social determinants of health, harm-reduction approach is being advocated as a 'best practice' to programs funded nationally under Health Canada's Prenatal Nutrition Program. The report is also being promoted by the Canadian Centre on Substance Use through their Clearinghouse on fetal alcohol syndrome. Many copies of the research report have been ordered by policy makers from several other provinces working on strategies to improve service provision to high risk, pregnant, substance using women. In order to meet the needs of community-based program providers and others, the BCCEWH wanted to make access to the findings affordable and user-friendly. A short 4-page version of the findings was published in print and web versions (www.bccewh.bc.ca). Four print runs of this short report have now been done, due to high demand for use as handouts in meetings, training sessions and conferences.

In 2000, a multidisciplinary team of researchers at the Centre was funded by Status of Women Canada to undertake an analysis of policy discourses on mothering under duress in three situations: mothers who are coping with an abusive intimate relationship, or with alcohol and/or other substance use, or with mental illness. Preliminary findings indicate that both official policy makers and the media judge women who are substance users more harshly than they do women who are in abusive personal relationships or who have mental health problems. This appears to be because women who use substances while pregnant or when they have a child are regarded as having *chosen* to use these substances, whereas women who are abused by their partners or who have mental illnesses are not held responsible for their situation. This study confirms the challenges facing women's health advocates who support a harm reduction approach to policy and practices for women who are substance users. Developing ways to counter the dominant policy and media portrayals of women who use substances is a formidable challenge, but one that our series of projects on the barriers to treatment and successful approaches equips us to tackle.

In 2001, influencing policy is still by no means an easy task for women's health researchers. But feminist activist principles continue to offer us effective strategies for inclusive research practices, public advocacy and policy change. Mice or lion? We'll stick with the mice that roar.

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[1] For a copy of the newsletter, Vol. 4., No. 1, February 2001, contact the Women's Health Bureau, Ministry of Health, 5-1, 1515 Blanshard St., Victoria, BC V8W 3C8, Tel: (250) 952-2256, Fax: (250) 952-2799.

Promoting Women's Health through Public Consultation

Marléne Dallaire, Le Centre d'excellence pour la santé des femmes – Consortium Université de Montréal

Most of the projects undertaken by the Centre of Excellence for Women's Health, Université de Montréal (CESAF), are designed to achieve practical objectives and, in some cases, develop direct interventions to enhance the health of the Centre's three target groups: women formal and informal caregivers, Aboriginal women and immigrant women.[1] Our goal to bring about concrete improvements to practices and services and to promote the empowerment of women has been supported, in part, by the commitment of a regional health board to provide a training program for home support services staff that will start this fall 2001. Following from a lengthy consultation between CESAF and the health board, the program will teach nurses and social workers at the Local Community Health Centres on the island of Montreal about the special situation of women caregivers, promoting an approach that will directly involve caregivers in decision making.

When CESAF and its partners entered into public consultation with the island of Montreal regional health board, they did so from a knowledge base of five years of research on caregiving. A total of eight research projects have been conducted by CESAF and by partners that include the Montreal Informal Caregivers' Association, the Caregivers' Support Centre at the René Cassin Local Community Health Centre and feminist researcher, Nancy Guberman. One CESAF project that examined the policy documents of regional health boards, the Quebec Health and Social Services department and the Local Community Health Centres, revealed that scant attention has been paid to the situation of caregivers. These government agencies have adopted a utilitarian model —giving support to informal caregivers only to forestall burnout and maintain caregivers' involvement in work. Respite care may be given, or some financial aid, but this limited model fails to acknowledge the complexity and emotional demands of caregiving. Government is transferring the responsibility for caregiving to families, but our studies show that the resources it is allocating to homecare are plainly inadequate.

This scarcity of resources is all the more acute when significant problems are encountered. All of the women caregivers in one CESAF study expressed a negative perception of their own health. They described work overload, stress, isolation and dislocation in every aspect of their lives. Caregivers share common needs for respite, moral support, health information and financial support, but as two other studies demonstrated, their needs also differ. Daughters who are caretakers are at even greater risk than wives are of being perceived as unpaid "resources" by health and social services, yet fewer solutions are adapted to their needs. In a survey of studies, it was found that new immigrants also face unique risks. Although the experience of caring for a sick or dependent relative is similar for families in many different communities, the difficulties of reconciling multiple responsibilities and tasks slows down the process of new immigrants' integration into the host community.

Caregivers develop their own strategies to deal with the difficulties inherent in providing care. These can take the form of religious or spiritual practices, and contact with support networks on an ad hoc basis. The often individualistic nature of these strategies, however, can exacerbate certain kinds of problems, such as the imbalance of power between men and women within the family — between spouses, or between daughters and parents, for example, when the wife or daughter is the caregiver. This problem arises more frequently in situations of isolation.

It is clear that women's personal resources cannot be a substitute for a collective commitment to provide care, but health system restructuring as it is currently proceeding in Quebec does not augur well for collective responsibility. In the spring of 1998, when the regional health board for the Island of Montreal proposed to improve health services, CESAF and its partners took part in the public consultation. In our presentation we noted that "Women caregivers, immigrant women and Aboriginal women are accorded little place in the regional board's proposal, although their living conditions and health status warrant special attention."[2] The

What Would 250 Women Say…

if you asked them to name the social factors that had the greatest influence on their health and the health of women they knew? The Prairie Women's Health Centre of Excellence found out last fall, and their Action Plan for Women's Health in Manitoba and Saskatchewan shares the news. Health care workers, community organizers, academics, policy makers and individuals highlighted 12 areas for priority action in health care and beyond. Released this January 2001, the Action Plan provides direction and strategies to:

1. reduce poverty among women and address the impact of poverty on women's health
2. improve conditions for unpaid and paid caregivers
3. respond to the specific health needs of Aboriginal women
4. address violence against women.

The Women's Health Unit of Manitoba Health has adopted the full 12-point Plan as part of their Women's Health Strategy, but it's too soon to tell what genuine policy impact this will have. The Prairie Women's Health Centre will continue to work with government and communities to track the implementation of the Plan over the next months and years.

For a copy of the full report, or a simplified brochure, visit www.pwhce.ca or contact:

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introduction to the board's revised Plan[3] reflected our perspective, stating that "It is desirable to make specific reference to the female gender in all programs and services." However, the Plan did not set out any concrete measures for reflecting gender, nor recommend any strategies to improve the living conditions of women caregivers. CESAF asked for a meeting with the follow-up committee.

In June 1999, CESAF and interested partners from the research community, the community sector and the health network, presented a joint document of seven recommendations to the committee that included concrete suggestions for implementation.[4] Apart from the findings of the research projects, the document was based on a consultation with caregiver associations from across the province. (In November 1998, 250 people attended a day-long meeting on the situation of informal caregivers that was organized by the Montreal Informal Caregivers' Association and funded by CESAF.) Because regional health boards fall under the purview of the Quebec Health and Social Services department, our recommendations were explicitly in keeping with the department's Status of Women Plan. The Plan talks about the necessity of assessing the impact of health care reform on women, particularly as paid and unpaid caregivers, but the Montreal Regional Health Board was ignoring this direction.

A limited working group made up of health board managers and CESAF representatives was established to examine the short-term feasibility of the recommendations. After discussions with the services involved, and a long consultative process with CESAF and its partners, the board is now prepared to apply one of the proposed measures—a training program for the home support services staff of Local Community Health Centres. To begin this fall 2001, the program will train staff, including nurses, social workers and the Centres' own homemakers to: involve caregivers in decisions about service plans; help caregivers assess their ability to offer care and determine if they have consented to give care; and learn to recognize and respect their caregiving limits. The health board will make the program available to all 29 Community Health Centres. It's our hope that every Centre will offer it to their staff.

Stepping into the realm of public consultation required vigilance and the support of many CESAF partners, in concert with other advocacy organizations. This coalition of groups, the research studies carried out by CESAF and consultation with caregiver associations, provided a means of taking action to influence public policy for the practical benefit of women.

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CESAF has closed. To obtain copies of its publications, contact:
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NOTES

[1] For a summary of CESAF work: Dallaire, Geneviève (2000). *Achievements and Challenges of Knowledge Generation, 1997-2000.* Montréal: CESAF, p. 28.

2 Dallaire, Marlène (1998). *Avis sur l'organisation des services de santé et des services sociaux sur l'île de Montréal 1998-2001.* Montréal: CESAF, p. 14

[3] Régie régionale de la santé et des services sociaux de Montréal-Centre (1998) *Plan d'amélioration des services de santé et des services sociaux 1998-2002. Le défi de l'Accès. (*English version: *Plan to Improve Health Services and Social Services 1998-2002)* Montréal: RRSSSM-C, p.124.

[4] Bernier, Joceyne (1999). *Recommandations concernant l'impact des transformations du système de santé sur les femmes aidantes. (*English version*: Recommendations Related to the Impact of Health Care Reform on Women Informal Caregivers.)* Montréal: CESAF, p. 23.

POLICY FOR RURAL WOMEN

Policy From the Ground Up: Rural Services For Survivors of Woman Abuse

Diane J. Forsdick Martz, Director, The Centre for Rural Studies and Enrichment, St. Peter's College
and Deborah Bryson Sarauer, Mental Health Therapist, Central Plains Health District, Saskatchewan

An abused woman living on a farm who has no vehicle to travel into the city and no money for gas or the bus doesn't stand much of a chance of getting into town for a counselling appointment, or of getting into an overcrowded urban shelter. In Humboldt and the surrounding area where the research study, *Domestic Violence and the Experiences of Rural Women in East Central Saskatchewan* (2000), took place, the only staffed shelter is over 100 kilometers away, a Family Protection Worker comes only when reports are made and phone calls to the RCMP after office hours and on weekends are routed through Regina.

Until the study was done, Mental Health Services, the focus of services for survivors of woman abuse in the area, was using screening protocols to diagnose symptoms such as depression or anxiety, rather than investigating possible underlying causes of distress such as violence. The 19 rural women who participated in the study reported that they had remained with abusive men for years and that the decision to do so had been influenced by a lack of information about abuse and a lack of information about, and access to, adequate support services. These women had been subject to psychological and verbal abuse that ranged from name calling to death threats, and physical abuse from pushing to vicious beatings that resulted in hospitalization, yet the silence and lack of support around them contributed to their belief that the abuse was normal and their fault. Consequently, when they approached support services for help, they did not disclose abuse.

An important finding of the research study was that the detection of woman abuse was determined by chance, a lucky encounter with a worker who was informed and empathic about violence, rather than by service protocols that ensured effective screening and care. This and other service-related findings of the study have resulted in policy changes that have been swift and significant:

1. New service protocols have been instituted at Mental Health Services to consistently and directly screen for violence and to ensure prompt, priority care for victims of woman abuse.
2. Partners for Rural Family Support (PRFS), the anti-violence committee that spearheaded the study, has applied for funding for two new services, a Woman's Advocate and a Rural Family Centre. A third service, a facilitator for a Children Who Witness Violence Support Group, will be supported by a donation.
3. The agencies and individuals that belong to PRFS, including women who have been abused, have become public educators on woman abuse in the region, making the issue more visible.
4. Greater collaboration between agencies in PRFS is being undertaken to facilitate earlier detection of violence.

New Service Protocols

Women in the study concurred that counseling was by far their most pressing need, yet confusion about the mandate of Mental Health Services (MHS) and long waits for appointments, in one case up to two months, were usual. Counselors at MHS, as well as police, clergy, doctors and social service workers often failed to recognize signs of abuse or ask women directly if they had experienced abuse. "We used to see women only through their symptoms," Deborah Bryson Sarauer, a social worker at MHS and coinvestigator of the research study, says. "We taught women about coping with anxiety through breathing exercises, for example, and did not investigate possible causes." Since the study, MHS considers the individual within the context of the family system and her whole situation. "We have a different world-view," Bryson Sarauer says. "We are no longer the experts, the women are." Even before the research was completed, MHS responded by instituting new service protocols:

1. Clients are asked about violence during intake calls, especially if they request couples therapy.
2. If abuse is revealed in couple counseling, therapy with the couple is terminated, the woman's safety is discussed and the abuser is asked if he is willing to address his problem. (Referral to the Alternatives program in Saskatoon is the only resource for abusive men.)
3. Women who have survived violence do not have to wait for counseling appointments.
4. Workers now use an administrative criteria code to denote "survivor of domestic abuse" as the primary reason a client is seeking help, rather than a diagnostic code for mental illness from the DSM IV.
5. The staff team at MHS recognizes that woman abuse cases take more time. Support for counselors who work in this area is provided at staff meetings, and through clinical and administrative supervision.

New Services

A woman in the process of leaving an abusive relationship is under considerable stress. At the same time she must deal with new and complex information and unfamiliar legal and social services procedures. Study participants suggested that an advocate to help guide them through the process of leaving their partners would have been a great help. Partners for Rural Family Support has applied for a Women's Advocate position for the region to help meet this need. A Rural Family Support Centre, where women and families could find information and have someone to talk to about abuse, parenting, health and other issues important to rural families was another idea arising from the study. PFRS has applied for funding to set up the two services but it's not yet known if either proposal will be successful.

Most of the children of the women in the study had witnessed their mother's abuse, and most had been verbally abused themselves. School age children had access to some counseling through school, but a significant service gap that women identified was programming for pre-school children. Mothers had difficulty finding information about abuse in parenting books to help them deal with the behavioural problems their children were exhibiting. Using a donation provided by a charity, Partners for Rural Family Support will be hiring facilitators to work with elementary and high school students who have witnessed abuse. To date, no funding has been found to help pre-school children.

Public Education

Dissemination of the research findings through the media has resulted in a significant increase in requests for public speaking about woman abuse. One survivor is currently writing an article for the local newspaper; the investigators

"WE USED TO SEE WOMEN ONLY THROUGH THEIR SYMPTOMS," DEBORAH BRYSON SARAUER SAYS. SINCE THE RESEARCH STUDY, MENTAL HEALTH SERVICES CONSIDERS THE INDIVIDUAL WITHIN THE CONTEXT OF THE FAMILY SYSTEM AND HER WHOLE SITUATION. "WE HAVE A DIFFERENT WORLD-VIEW."

and participants have made public presentations to the Saskatchewan Medical Association, the medical school at the University of Saskatchewan, the Saskatchewan Women's Secretariat conference, Homecare Services, homecare nurses at a community college and the media. Local and national media have reported on the study, including the local newspaper, *The Humboldt Journal,* which reproduced all 13 recommendations of the study, and the national agricultural paper, *The Western Producer,* which ran an article entitled "Work continues after rural abuse study," and focussed on the funding proposals for the Rural Family Centre and the Woman's Advocate. The local Catholic Women's League paper, *The Prairie Messenger,* published two articles on the study, one of which stressed the need for high school curriculum about family violence. Local and national CBC radio also picked up the story. "With all this attention focussed on woman abuse," Bryson Sarauer says, "what is truly amazing is that not one person in the community has denied that a problem exists."

A Model of Collaboration

Diane Martz, coinvestigator of the study, says that, "From the outset, we wanted the research to be action-oriented. I was searching for a model that would bring together any agency that might potentially interact with a survivor of woman abuse to develop protocols and take action together." This model has manifested in Partners for Rural Family Support. Although PRFS existed before the research was done, it has become a vehicle for the intersectoral collaboration recommended by the study and has grown from a committee into a non-profit association, attracting more agencies and individuals. Now, 50% of its members are survivors of woman abuse. Collaboration within PRFS and between front-line agencies was facilitated by the research study, and by a provincial accreditation process that was taking place at the same time, providing opportunities for discussion about woman abuse and gaps in services. This increased collaboration may help make the early detection of violence more possible. Mental Health Services, for example, now works more closely with a dental health educator, checking evidence of abuse and neglect in children's teeth. Presentations to a prenatal class about changes in the family, including the possibility of abuse when a baby enters the picture, consultation with home care services and a public health nurse all expand the scope for the prevention and detection of abuse. "In rural communities where services are so scarce," Bryson Sarauer says, "it's even more important for us to band together to make an impact."

By putting into practice the hard-won knowledge of the study's participants, and by building on the strengths of close-knit rural communities, Mental Health Services and Partners for Rural Family Support are creating policy from the ground up to more effectively detect, prevent and treat woman abuse. Yet the problem of providing a much higher level of support to rural survivors remains. Social services, health districts and legal aid services in east central Saskatchewan all have different boundary lines, requiring women to travel over an area of two to three hundred kilometres. "In a city, services are centralized," Diane Martz points out. "And there are more agencies to refer survivors to, and more agencies to fill gaps or take overflow." "Mental Health Services in Humboldt is a rural agency," Bryson Sarauer adds, "which means that we have a very broad mandate but a small staff." Martz and Bryson Sarauer agree that the strategies that have arisen from their research study are making a difference, but the rural problem of woman abuse will continue to require innovations in rural services as well as region-wide reform.

For a copy of the full report, visit the Provincial Association of Transition Houses, Saskatchewan at www.hotpeachpages.org/paths/rural or contact:

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POLICY FOR RURAL WOMEN

Seeking a Seat at the Policy Table: Farm Women and the Impact of Program Cuts

Nikki Gerrard, Saskatoon Health District, Gwen Russell, Researcher, and Noreen Johns, Farmer, Educator and Community Worker, the Saskatchewan Women's Agricultural Network

The relationship between farm women's health and reductions in federal and provincial funding were explored in a study sponsored by the Prairie Women's Health Centre of Excellence in 1999.[1] The study found that the enormous challenges faced by Saskatchewan farmers are magnified for farm women. In addition to farming, many of these women care for children and ageing parents and work at off-farm jobs. Programs funded by government and administered by farm women's organizations have benefited farm women by inviting them into the agricultural policy development process, and by providing education, networking opportunities and training. The 11 women who participated in the study reported health detriments of loss of voice and connectedness that resulted when these programs were curtailed or terminated.

The study created an inventory of programming from 1970-2000, identifying five federal programs. The Farm Women's Bureau (FWB), established in 1981 to implement federal agricultural policies, was considerably diminished by 1995. This important organization administered funding for significant educational, training and policy development projects in which farm women participated. It now operates without a clear mandate, is under constant funding pressures and has no capacity to fund projects that would advance understanding of the legal, economic and social issues of farm business women. The Farm Women's Information Initiative (FWII) was established in 1985 as a grant under the mandate of the FWB to provide information to farm women on agricultural policies, programs and legislation. The FWII occasionally carried out informational direct-mail campaigns, and sponsored a toll-free information phone line, but the grant supporting it was cancelled. The objectives of the Canadian Farm Women's Education Council, founded in 1987, were to increase access to farm business training for women, promote professionalism and leadership of farm women, and increase awareness of the status and impact of policy on training. The Council was also terminated in the mid-1990s due to a lack of stable funding. The National Coalition for Rural Child Care existed from 1995 to 1998 to set up childcare centres in rural Canada. A lack of ongoing funding to assist in standardizing regional variations in laws and policies led to the Coalition's demise.

While in operation or when sufficiently funded, these programs offered farm women the benefits of taking part in a broad range of activities, such as lobbying, publishing newsletters or books, carrying out research, conducting

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workshops and providing input into policy. Women in the study reported that these activities raised their awareness, enhanced their sense of community and decreased isolation. Women also benefited from discussing agriculture in a larger context: “All of a sudden I started really looking at the economy, how it affected me and our farm,” one woman said. Most of the women reported health benefits. “Taking action and feeling more in control is the best antidote for depression.” Another woman said that involvement was “Very good for your mental health, and your physical health.”

The erosion of programs meant a return to isolation and invisibility. Becoming “peripheral and voiceless,” as one woman said, had implications for health and well-being. “I miss the collective power and support of working with other women in a specific program or project because that tends to boost your confidence and self-esteem.” Although most women expressed anger over the loss of programming, some noted that the activities had meant considerable time away from home, causing additional strain and fatigue.

Nikki Gerrard and Noreen Johns, two authors of the study report, have presented the report at conferences, including the Saskatchewan Women’s Agricultural Network conference in February 2000, the Association of Women in Psychology, Los Angeles, 2001 and Women in Agriculture in New Brunswick in April 2001. The report was showcased on CBC television, and presented to the former Saskatchewan Minister of Agriculture and to the current Minister, the Honourable Clay Serby.

The study was one of the factors influencing Saskatchewan Health’s decision in the fall of 2000 to establish the Farm Stress Project and to hire one of the study authors, Dr. Nikki Gerrard, as the Farm Stress Consultant to help people identify and manage stress related to farming. Encouraging as this is, serious problems remain. Without the restoration of core funding to the organizations that facilitated farm women’s access to education, training and the policy process, the health of farm women may continue to be detrimentally affected. By cutting funding to these organizations and programs, government has confirmed and exacerbated farm’s women’s relative inaccessibility to economic, political and social power.

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[1] Gerrard, N., G.Russell, N. Jones (1999). An Exploration of Health-related Impacts of the Erosion of Agriculturally Focussed Support Programs for Farm Women in Saskatchewan. Winnipeg: Prairie Women’s Health Centre of Excellence.

WHILE IN OPERATION OR WHEN SUFFICIENTLY FUNDED, THESE PROGRAMS OFFERED FARM WOMEN THE BENEFITS OF TAKING PART IN LOBBYING, PUBLISHING NEWSLETTERS OR BOOKS AND PROVIDING INPUT INTO POLICY. WOMEN REPORTED THAT THESE ACTIVITIES RAISED THEIR AWARENESS, ENHANCED THEIR SENSE OF COMMUNITY AND DECREASED ISOLATION.