

SPECIAL CANADIAN WOMEN'S HEALTH NETWORK REGIONAL REPORT ON B.C. AND ALBERTA

Spring/Summer, 1992

\$3.50

# Healthsharing

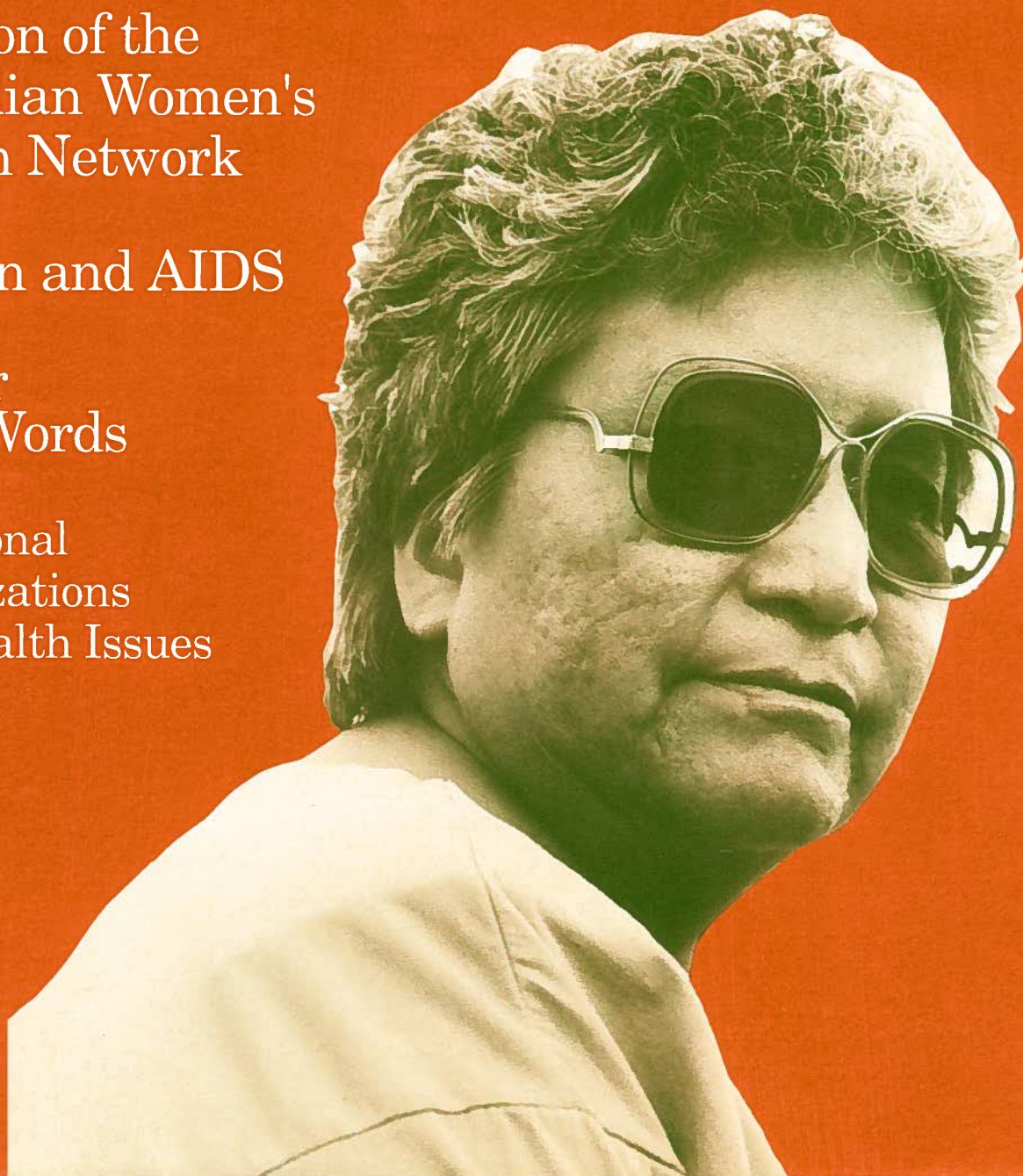
A CANADIAN WOMEN'S HEALTH QUARTERLY

## Community Health Reps

A Vision of the  
Canadian Women's  
Health Network

Women and AIDS

In Our  
Own Words  
Profiles  
of Regional  
Organizations  
and Health Issues



# HEALTHLINES

## A Dream Comes True

The Canadian Women's Health Network has taken off! This special issue of *Healthsharing* is the first of six issues we will bring to you from six different regions in Canada. We begin with British Columbia and Alberta.

Building a health network for women across Canada is an ambitious undertaking. But we are inspired by the comments from the women, groups and organizations contacted in compiling the content for this special report, indicating that such a network and indeed these issues, will be useful in increasing our knowledge of the work of other groups across Canada; and, in sharing resources and information.

It is always difficult to be the first at anything. And this report is certainly no exception. It has taken months to put this issue together. What has made it less difficult were some of the wise choices we made along the way. One, in particular, if not most importantly, was hiring an enthusiastic, committed regional animator to locate and contact groups working in women's health in B.C. and Alberta; to solicit information and articles from them; and to compile a resource listing of those groups contacted. Anne Fraser has already made this part of the project a success. Working in somewhat isolated conditions (geographically and otherwise) she managed to help design an issue which is inclusive of the diversity of Canadian women. The responses to Anne's call for articles was tremendous and we wished we could have included all the information received, but space being limited, we could not. What is included is a compilation of women's stories, of concerns and issues which affect women's lives, of organizations and support groups working to better the quality of life and healthcare for women.

There are many people to thank: the writers, artists, photographers, Anne, Jill Weiss and Rachel Grant for their support for this special project. Special mention to the *Healthsharing* staff members Susan Elliott, Nicci Cohnstaedt and Lisa Huncar, Amy Gottlieb,

and editorial committee members Helen Armstrong, Pam Bristol, Virginia Mak and Megan Williams for the incredible amount of work they contributed to this issue. Thanks must also be extended to Health and Welfare Canada for providing the financial support to the Canadian Women's Health Network project, making this issue and the five others to become a reality.

I share "Healthlines" with Anne for this special report so she may have an opportunity to reflect on the process, the content, and our dream for a Canadian Women's Health Network.

Hazelle Palmer

This first regional issue of *Healthsharing* marks an important step in the development of the Canadian Women's Health Network. Hundreds of women and organizations in Alberta and British Columbia were contacted to see if they wanted to be part of a Canada-wide women's health network. The response was overwhelming and exciting: the network will be formed by women working in many ways to improve personal and community health, whether community is defined by geography, race, culture, gender, sexual orientation, disability, income, class, and/or age.

Many women suggested goals for the network. Sharing resources was most commonly called for, though many women suggested research, lobbying, providing support, networking, developing a resource bank and publicizing specific health issues.

This is just a beginning. To make the network really useful, we need to form regional steering committees, determine priorities, seek funding, and devise ways to have real and ongoing contact between interested women.

This regional issue of *Healthsharing* profiles some of the work being done in B.C. and Alberta and some of the pressing health concerns here. Of course, much important work was left out due to space and time constraints: think of this as a sampling from a very diverse

region. We are pleased that many of the writers are writing for a feminist publication for the first time.

We intended to include a resource bank listing regional organizations and print, tape and video resources in this issue, but there is not room to list the varied work which is being done. The resource bank will be published separately.

While much useful work is being done, many challenges remain. Work is often accomplished despite great obstacles including discrimination, isolation and lack of resources and funding. The women's movement is broadening to represent women from many cultures, races and abilities but very few organizations or resources exist for young or old women in this region. Older women are predominantly working in mixed groups which often do not address women's issues, and almost no resources or support exists for teenage women.

Funding is an ongoing problem for many groups. The new B.C. government is beginning to fund some feminist organizations, but the Alberta government remains conservative. Most of the federal programs which fund health projects do not target women as a priority group. The only federal program which still has women as a priority group, Secretary of State, is currently undergoing a review process; it is important that we mobilize to ensure that their mandate continues to include the improvement of the status of women. Changing funding priorities to improve funding for women's health could be a goal for the network.

We want to thank all the women who took the time to fill out questionnaires, suggest ideas, write articles, or produce graphics. Special thanks to Rachel Grant and Jill Weiss for all their work.

Finally, we encourage you to think about the future of the Canadian Women's Health Network. What are the most important goals for a Canada-wide network? Which activities are best done locally or regionally and which are most effectively accomplished at a Canada-wide level? How can we best share our stories and strategies and organize to effectively represent our diversity? How can we speak together when we are united on issues and support our separate projects when we differ? Barbara Mintzes and I share some of our ideas for the Canadian Women's Health Network in this issue. We invite you to join in the discussion.

Anne Fraser

# LETTERS

We encourage readers to write. Your comments are just as important as the original articles and columns published in the magazine. Please take the time to share your opinions with other readers.

Healthsharing reserves the right to edit letters for length, and print them, unless they are marked "not for publication."

## Been Looking

I cannot begin to tell you how long I have been looking for a magazine just like this. Thank you!

G. Hepworth  
York, Ontario

## Enjoy Reading

Thank you immensely for publishing this journal. I enjoy reading it.

N. Carroll,  
Boston, USA

## Telling Our Own Stories

Ten years ago I was involved in organizing "Women and Words", a bi-lingual, pan-Canadian, women-only conference in Vancouver which brought together 750 women of words. I can

remember one issue which came up and which in my head I understood and supported. This was the demand by women of colour and first nations women to speak for themselves, to tell their own stories.

Now I understand in my heart why this was an issue of such importance for them because I now have the same concerns. As a woman with a disability, I am getting really tired of non-disabled women speaking on my behalf. I am specifically referring to the article, "Women with Disabilities Challenge the Body Beautiful" [Healthsharing, Winter/Spring, 1992].

The first problem that I have with the article is the disparity between the topic of the article, self image, and the fact that two non-disabled women wrote this article about the self image of women with disabilities. How do non-disabled women think that they have the right to speak for us? Even as I ask the question, though, I know the answer. These women are highly qualified by virtue of their

long experience and familiarity with issues concerning the disability community. And they wrote a pretty good article. But women with disabilities can write good articles for and about ourselves. Just ask.

The next thing that I found fairly offensive was the faint praise that damned DAWN Canada. DAWN is the voice of women with disabilities in Canada and it got one sentence. Nothing about the fact that DAWN produced the first national position paper on self image and Canadian women with disabilities, (other position papers in this series are on mothering, violence and employment). Nothing about the first ever national symposium on self image that DAWN held in Toronto in 1990 called "Who Do We Think We Are?: Self-Image and Women with Disabilities" (proceedings are available). One wonders at advice which recommends that readers "talk to other women with disabilities and share success and things you would do differently" and neglects to recommend an obvious thing to do to facilitate this process: get in touch with a DAWN affiliate.

To be fair, my need to write this letter comes from a frustration that has been brewing for some time. When DAWN Canada began, it was partly because no one was paying any attention to these issues concerning women with disabilities, neither the disability community (male-dominated for a long time and feeling just a tad threatened by women organizing autonomously - sound familiar?!) nor the women's movement (largely inaccessible). This is changing and people are beginning to pay attention. The way that it's changing, however, causes me misgivings.

Hardly a week goes by

that I don't get a call (as the Past-Chair of DAWN Canada) from some eager, non-disabled student who has just stumbled upon the notion that the depths of issues concerning women with disabilities have yet to be plumbed. Think of all those juicy, original thesis and dissertation topics just ripe for the picking. I guess I shouldn't complain about the ones that call. At least they indicate good faith by checking in in the first place. Goodness knows what the other ones are doing. And saying. And turning into "experts" about. And getting consulted on. And getting funded for.

I fear that the real experts, women with disabilities, will become (or continue to be) marginalized and colonized. I fear that the funders will continue to seek the advice of and find funding for the academics - rather than us. I fear that, after a brief moment in the sun, women with disabilities will be forced to take a back seat to those "experts" who do not value or validate our experience. What do they know?

I am not speaking rhetorically. As many of you know, the four-year federal funding initiative on family violence prevention is well into its second year. DAWN Canada had a project proposal on the desks of the bureaucrats the week after the announcement was made (I know this because I'm the Supervisor of Violence Projects for DAWN). In spite of the fact that the initiative identifies women with disabilities as a priority, we're still waiting to see any project funding (although some has been approved) and its 15 months later. Some priority. Women with disabilities continue to be violated and abused, continue to be denied access to support

**Pat Paula Rayman M.Ed.**

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services and continue to be invalid/ated by the police and the judiciary while the bureaucrats fiddle.

If DAWN Canada had not formed and had not done the initial research which indicated that disabled women are twice as likely to experience abuse as non-disabled women and that almost no transition houses in Canada are accessible to us, no one would have known of the critical need for more work. We do have one wonderful and supportive bureaucrat who has had to fight with her colleagues in order to convince them that they shouldn't just fund a bunch of academics who, no doubt, are more methodologically

correct. We can always get better on methodology; they can never know about disability the way we do.

There are many women with disabilities who are capable of and interested in telling our stories. Let us speak for ourselves.

Joan Meister  
Vancouver, B.C.

*No one can ever dispute the contribution DAWN Canada has made to the lives of women with disabilities. It is with regret that we, at Healthsharing, did not insist that the writers include more information on this organization. We understand, as you admit, that your letter is partially based on "frustration*

*that has been brewing for some time." We are pleased that you have used Healthsharing as your forum to vent your frustration, but more importantly your letter serves to remind us of the right for women with disabilities to have a voice, to tell their own stories.*

*To be fair, Healthsharing has given women with disabilities space to be heard. In the same issue*

*(Winter/Spring 1992), we published an article by Shirley Masuda, a staff person at DAWN: BC. And, we should also mention that before publishing the article "Women with Disabilities Challenge the Body Beautiful," we consulted with*

*DAWN in Toronto, for comments and feedback. They were both positive.*

*We hope to continue to be a forum for ALL women to discuss their health and health concerns. We know women with disabilities can write good articles for and about themselves. Their words, their voices are always welcome.*  
HP.

#### Thanks

Thanks for "The Politics of Breast Cancer" - answered all my questions re: mammography.  
C. Ferguson,  
Caledonia, Ontario

## UPDATE

### Midwifery in Alberta ...almost, but not quite

Midwifery supporters in Alberta await the introduction of legislation anxiously, after years of government studies, meetings with politicians, and letter-writing and telephone campaigns.

A recent cabinet shuffle in the Conservative government has left the issue uncertain. While the former Solicitor General, Dick Fowler promised to introduce midwifery legislation in the spring session, his successor, Steve West, has made no commitment to adhere to timing of the new law. However, after a recent meeting with the Solicitor General, Sandra Botting, president of the Alberta Association of Midwives

said that West is "supportive of midwifery and understands some of the issues."

The Liberal and New Democratic Parties endorse the legalization of midwifery, and are pressuring the Conservatives to act. Pam Barrett, the NDP health critic denounced the delay by saying that "there is no reason the government can't act now."

As recommended by Alberta's health disciplines board, a Midwifery Services Review Committee (MSRC) was created. The committee included consumers and representatives of the Alberta Association of Midwives, the College of Physicians and Surgeons, the Alberta Association of Registered Nurses,

the Alberta Health Care Association, health units and non-voting representatives from three government departments. This group met weekly from October 1991 to January 1992 and prepared a report that detailed the benefits of midwifery care.

The MSRC report, released April 6, 1992, recommends:

1. midwifery be established as an autonomous profession;
2. midwives provide primary care for women with uncomplicated pregnancies throughout the childbearing cycle;
3. midwifery be publicly funded, under the Canada Health Act;
4. midwives practice in all settings including hospitals, healthcare units, free-standing birth centres and homes;
5. a four-year baccalaureate program in midwifery be established for new midwives, with an evaluation program for current midwives;
6. home births take place with a back-up system to handle emergencies no more than 30 minutes from a hospital.

The report reflects the desires of midwifery supporters, while some details need to be renegotiated. Sandra Botting said the report "recognizes that many women in Alberta want midwifery care. And it represents a concerted effort to define midwifery." Now Albertan women have



to ask "What is the government going to do about it?"

For the MSRC report, contact Dan Charlton at the Professions and Occupations Bureau, using the toll-free government switchboard (the RITE number) at (403) 297-6161 or directly dialing (403) 427-2655.

*Midwifery legislation was introduced on June 23, 1992.*

Laura McKinnon

# B.C.'s abortion clinics get government funding

On March 20, British Columbia's NDP government announced it would provide funding for the province's two free-standing abortion clinics. This victory is a result of years of work by pro-choice activists who argued that the pro-choice movement in B.C. should not only fight for increased access to abortion, but also help provide those services by opening and operating abortion clinics.

"We did not want a private, doctor-run clinic. We wanted a woman-run, non-profit, community-based clinic. And we believed that the way to get that clinic was for the B.C. Coalition for Abortion Clinics (BCCAC) to open it," says

Marg Panton, a coalition activist and staff member at Everywoman's Health Centre.

Deciding to open a clinic like this was one thing, but finding the funding to make it a reality was quite another. However, once the coalition promoted its intention to open the clinic, donations poured in. Says Panton: "The only reason this clinic opened was because of the absolutely incredible support from the community."

When the Supreme Court of Canada struck down the existing abortion law in January 1988, action boosted the campaign to establish the clinic since what the coalition was proposing would no longer be illegal. Furthermore, the anti-abortion stance of then premier, Bill Vander Zalm also helped to fuel the campaign. According to BCCAC spokesperson, Joy Thompson, Vander Zalm's threats to reduce access to abortion in the province, mobilized large numbers of women who had not previously been active in the pro-choice movement.

"The consciousness of people had been raised by the attacks on choice and really kick-started the campaign," says Thompson. Within nine months they were able to raise enough money for a down payment to buy a building and to purchase the medical equipment.

The clinic, called the Everywoman's Health Centre, opened its doors on November 1988. "In the beginning the financial constraints and working conditions were tremendously difficult," says Marg Panton. In its first few months, the clinic faced constant harassment by the anti-abortion group, Operation Rescue. Eventually, repeated arrests

and a court injunction wore the protesters down to a manageable level.

But there were other hurdles. One of the biggest battles for the centre was the fight for a charitable tax number. All donations made to the clinic had not been tax deductible. Although the clinic applied for charitable tax status, Revenue Canada stalled the application for so long that the centre was eventually forced to take legal recourse. After a three-year battle, the centre finally won the case in the Federal Court of Appeal in late 1991.

The most recent victory was obtaining funding from the B.C. government for two abortion clinics — the Everywoman's Health Centre and Elizabeth Bagshaw Women's Clinic. Securing this funding means that women entitled to B.C. medical coverage no longer have to pay for an abortion performed at a clinic. "The funding is a tremendous victory for all women because it acknowledges [that] abortion and reproductive health are not something to be ashamed of. It also means that women who prefer the respectful treatment provided in clinics [like these] will no longer be penalized," says Thompson.

Treating women with respect and providing them with support as well as information about their bodies is at the heart of the philosophy of the Everywoman's Health Centre. It begins when a woman first telephones for information or an appointment. It continues throughout the time she spends in the centre. Every woman speaks with a counselor about her decision, the procedure and contraception. The counselor also

accompanies the woman into the procedure room and provides support during the abortion. Before she leaves, each woman is asked to complete an evaluation form so the staff can continue to improve the quality of care they provide. A large majority of women rate the centre's services as excellent.

Panton says it is not difficult to treat women with respect. "We treat women the way we want to be treated and the way we deserve to be treated. This could be the norm [but] what's shocking is that it's not. Women are so surprised at the treatment they get in our clinic and that's a really serious indictment of the kind of healthcare women receive."

Everywoman's Health Centre operates with a collective structure. There are seven core staff positions with one part-time position and nine staff who are on call. There is also a 13-member board of directors with staff representation.

For Marg Panton the biggest accomplishment is that the centre exists at all. "We would like to expand our service to encompass all aspects of reproductive health," says Panton, "and basically that spans most women's lives from pre-teen to post-menopause."

There is hope that things will continue to improve in the area of reproductive healthcare for B.C. women. In addition to funding the two clinics, the B.C. government has established a task force to report on access to contraception and abortion, examining how barriers to these services can be removed. The report will be published at the end of August.

ERIN MULLEN

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# Reproductive rights in Alberta

The opening of two private abortion clinics in Alberta has tremendously improved abortion accessibility for women. In mid-September 1991, the Morgentaler Clinic opened in Edmonton, and the following January, the Kensington Clinic in Calgary began operating.

Prior to the clinics' opening, only three hospitals in the province performed abortions: the Royal Alexander Hospital in Edmonton, and the Peter Lougheed Hospital and the Foothills Hospital in Calgary. According to Denise King of Abortion Rights Edmonton, the Royal Alexander Hospital turned away 50 women each week before the establishment of the Morgentaler clinic. The Calgary Birth Control Association (CBCA) referred 60 women each month to the United States for abortions.

Since the clinics began operating, the waiting period in Edmonton is down to one to five weeks from six to eight weeks. In Calgary, the waiting period has dropped from four to five weeks to one to two. This is a critical improvement for women because of the 12 week pregnancy limit set by Alberta hospitals. Clinics have a 16-week limit, after which a woman must travel to the U.S. for an abortion.

Although there are other hospitals where individual doctors will perform abortions for their own patients, in many parts of the province access to abortion is non-existent. When it is available, confidentiality cannot be guaranteed. Consequently, most northern and rural women bear the financial and time costs of travelling to the city. Debi Kalinin, a resident of Fort McMurray and long-time volunteer with the Canadian Abortion Rights Action League (CARAL), says,

"Women can't take all their support systems with them. That's the saddest part."

The cost of an abortion at the clinics ranges from \$300 to \$550 depending on how pregnant a woman is. Both clinics have a policy, however, that no woman will be refused an abortion for financial reasons.

A current campaign being waged by CARAL and the Pro-Choice Coalition demands that Alberta Health Care fully fund abortions in clinics. Presently, AHC covers less than 25 per cent of the actual cost.

Access problems are not limited to rural areas. Gerri-Lynne Benoit of the CBCA reports that immigrant women who are not fluent in English often do not know how to access pro-choice information or doctors. Furthermore, because many of the family planning agencies do not represent their community's cultural diversity, women of colour do not find it easy to approach the agencies. Teenagers, too, are often misled and may end up at an anti-choice group which falsely advertises as an "abortion counseling" centre. For poor women, travelling to the U.S. for an abortion is impossible due to travel costs, childcare or extra-billing.

Jaqueline Preyde, a volunteer with the Lethbridge Alberta Status of Women Action Committee, stresses the importance of pro-choice supporters speaking out about the range of reproductive choices being promoted, including contraceptives and sex education. The CBCA, Planned Parenthood Alberta affiliates in Edmonton and Banff and some local health units offer services such as contraceptive counseling and education.

Unfortunately, in some

communities there are often active anti-choice groups such as Birthright, who offer no contraceptive counseling and use guilt and shame to limit women's choices.

On the surface, anti-choice groups appear fairly quiet at present in Alberta. Both abortion clinic directors praised the police for the effectiveness in enforcing injunctions against protesters. Nonetheless, the clinics and some staff continue to receive bomb and death threats from the Pro-Life Death Squad.

Three groups which are making sure the pro-choice voice is heard in Alberta are Abortion Rights Edmonton, and in Calgary, CARAL and the Pro-Choice Coalition. Their activities include publishing pamphlets and posters, public education and conducting letter-writ-

ing campaigns.

The Association for the Right to Choose has formed in Calgary to facilitate access to the new Kensington Clinic. They supply in-clinic volunteers, provide over-night accommodation for rural women, raise funds to cover abortion, legal and security costs for poor women, and if necessary, they will mobilize escorts and clinic defence.

Abortion Rights Edmonton has been collecting stories of Albertan women who have had abortions. These stories, highlighting problems and areas for improvement, will be published as a book. Any woman wishing to tell her story can write to P.O. Box 4098, Edmonton, AB, T6E 4S8.

LAURA MACKINNON

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## The Vancouver Women's Health Collective lobbies for core funding

The Vancouver Women's Health Collective (VWHC) is lobbying the provincial NDP government for core funding. The government has set a health mandate to improve community access to healthcare, to improve preventative health programs and to provide reproductive health and abortion services. The VWHC has fulfilled this mandate since 1973. In our 20 year history, the VWHC has promoted women's active participa-

tion in and control of their own healthcare. The collective's resources give women an understanding of the ways in which the conditions of women's lives create ill health and comprehensive information on prevention and treatment options. With this information women are better able to make informed decisions about their healthcare needs.

The Vancouver Women's Health Collective has led

the way in providing a model for community-based women's health education and advocacy. We want to share our experience with individuals and organizations developing new community programs. Core funding will ensure that this unique resource will thrive.

Our work straddles the mandates of both the Ministry of Health and the Ministry of Women's Equality. As the Ministry of Women's Equality will not provide funding because we deal with health, we asked the Women's Equality Minister, Penny Priddy, to start a dialogue with Elizabeth Cull, the Minister of Health, to ensure VWHC does not fall through

the cracks of bureaucracy. We are providing the Health Ministry with an opportunity to demonstrate its commitment to its mandate.

VWHC hosted a panel discussion on teenage pregnancy on May 28th, in Vancouver, which brought together various community groups working in this field to get an overall picture of the issue.

We look forward to being recognized by the new government as a vital part of a new era in community and women's health.

ALEXA BERTON



## A report from the Midwifery Association of B.C.

The move towards legislation of midwifery is fast becoming a reality in British Columbia. We have been successfully educating the public and the government about midwifery. Discussions now centre on the model of midwifery to be chosen and its implementation.

Bill 31, The Health Professions Act, was passed in March 1991, allowing previously unacknowledged professions to seek recognition. A Health Professions Council was appointed in April. This Council receives applications to determine which professions can practice in B.C., including midwifery.

Thanks to the financial assistance of the Midwifery Task Force, the Midwives Association of B.C. (MABC) applied to the Health Professions Council for recognition.

When the Royal Commission on Health Care and Costs in B.C. recommended the speedy implementation of midwifery, but proposed a plan authorizing the Regis-

tered Nurses' Association of B.C. (RNABC) to regulate the practice of midwifery until a College of Midwives could be established. We found this policy contrary to the concept of autonomous midwifery. We issued a press release and met immediately with the Minister of Health, Elizabeth Cull, to discuss these recommendations. We also asked national and international midwifery organizations to write to the minister supporting our position.

As a result, a resolution requesting that the Registered Nurses' Association of B.C. support the World Health Organization definition of "midwife" was accepted for discussion at the Annual General Meeting of the RNABC. A committee was created consisting of members of both the MABC and the RNABC. It will develop future policies for the RNABC.

The change in attitude towards midwifery also appears in the media.

Sensational headlines with negative overtones have been replaced by positive images of midwifery as a valuable profession. Midwives are portrayed as courageous women, rather than as pariahs who prey on and serve a lunatic fringe.



We find this change in attitude most encouraging.

One of MABC's major projects during this last year was the 23rd Triennial Congress of the International Confederation of Midwives (ICM). Midwives from all over the world will discuss midwifery-related issues. The theme is: "Midwives hear the heartbeat of the future". The Congress will take place in Vancouver on May 9-14, 1993. To financially assist midwives from the Third World, "Sponsor-a-Mid-

wife Programme" has been organized.

MABC activities for this year included a requested presentation to the Midwifery Committee of the College of Physicians and Surgeons; a presentation to the Cesarian Task Force supporting the integration of midwives into the present healthcare system so as to reduce the Cesarian-section rate; a celebration of International Midwives' Day at Grace Hospital; the inclusion of our organization in the telephone directory, which raised our profile; the opening of a new midwifery chapter in Victoria; and an informative exchange with midwifery organizations in other provinces.

The coming year will be challenging as legislation of midwifery draws closer. Midwives in this province need moral and financial support to continue our work. We hope that midwives and friends of midwives will become involved and help ensure access to midwifery care for all women in this province.

JEAN COOPER

## Anne Fraser and Barbara Mintzes

# Visioning

## the Canadian Women's Health Network: Sharing Information is Essential

*This article is intended to stimulate debate about directions for the Canadian Women's Health Network. Readers are invited to send comments on the ideas presented here to Healthsharing for a column we will introduce in the remaining five regional reports. This column will be used to continue a cross-Canada discussion on the need for building a Canadian women's health network.*

In Halifax, a women's centre writes a book on menopause. It is well-researched and interesting to read, and includes an overview of the pros and cons of medical treatments and personal stories by women about their experiences with menopause. Women who come to the centre, to the local women's bookstore, or to women's centres in nearby towns find it very helpful. In Vancouver, a woman's health centre, unaware of the book just written in Nova Scotia, finds many women coming to their centre need information on menopause. They use a small grant to write a booklet. This fictitious scenario could easily happen anywhere in Canada. It highlights problems which could be addressed by the Canadian Women's Health Network (CWHN).

Unnecessary duplication wastes scarce resources. Our women's centres and feminist health groups are chronically underfunded. But if we were to change the scenario described above, both groups could have coordinated their resources; they could have produced one nationally distributed booklet or two different locally relevant versions. Or they could have produced booklets on two different women's health issues.

We reach relatively few women against great odds. Our feminist centres and health organizations distribute thousands of booklets, books and magazines. This is a drop in the bucket compared to the thousands of women who receive uncritical information on hormone treatment for menopause from the popular media and from their doctors, who have been pumped by the pharmaceuticals with promotional information on drug treatment of menopause.

We are still struggling to achieve our far-reaching political goals. Both groups in the scenario above produced their booklets because of strong political goals: they question the over-medicalization of

women's lives and believe that most women do not need to experience menopause as a disease and do not need drug treatment. They are also consciously working towards women's liberation. These booklets are an important step towards these goals.

But, both groups realize that many of the women they reach already have resources, information and a critical perspective. The groups want to reach a broader range of women, and they also want to stop the other actors in this scene: doctors who prescribe unnecessary and potentially harmful treatment, the pharmaceutical promoters and the Ministry of Health Protection Branch which doesn't have strong enough regulatory controls on medicines or on promotion to doctors and the public. Similarly, they want to pressure provincial governments whose policies contribute to women's poverty as they grow older; the employers who discriminate; and the advertisers who promote a flat ideal of youthful beauty for women.

This is just one example of a situation in which a cross-country network of feminist health organizations could help these groups achieve their goals. The CWHN could encourage joint political action, shared information, coordination of resources and a wider distribution of feminist health publications.

### Joint Political Action

A network for joint political action could allow us to swiftly react to events with a common strategy or to launch simultaneous campaigns using the various strengths and contacts of local groups. We need to develop quick, organized ways for member groups to consult one another, listen to our many voices, reach decisions and carry out coordinated action. Two fairly recent examples of feminist national campaigns are the campaign to prevent legalization of Depo Provera in



Canada and the ongoing struggle for abortion rights.

When communities of women have different health concerns and priorities, we could also use the network to tell each other about our issues and to support our separate projects.

### Shared Information

We strongly believe one goal of the Canadian Women's Health Network should be to provide health information to women, to help us care for ourselves and our children. Critical information allows us to make informed choices about preventive health, diagnosis and treatment options. It counteracts the over-medicalization of our lives and empowers us when dealing with doctors and other healthcare workers. Sharing and distributing health information in everyday language is also the backbone of political action on women's health. We need accessible and critical information in order to get media coverage, to lobby government agencies, to convince professional

short summaries of complicated articles to make them accessible. Hence, the information is inconsistent: on some health issues it is excellent; on others it is outdated and incomplete.

Groups in other locations run health information services similar to the VWHC with similar problems. While the information at the VWHC and other local centres is incomplete, most women in Canada have almost no access to critical and supportive health information. Many women have only two sources of health information: doctors and the popular media.

We suggest two main strategies for the Canadian Women's Health Network to provide health information to women:

- an extensive on-line data base with information on women's health topics and available resources - a short-term goal.
- a women's health publishing house or clearing house to promote and distribute feminist women's health information - a longer-term goal.



organizations to change and to counteract the myth of the "expert". Our thoughts on this topic grow out of 12 years of experience working at the Vancouver Women's Health Collective (VWHC) although neither of us work there now. The VWHC is a small, feminist, grass-roots collective which runs a health information centre for women.

The VWHC has a library and clipping files with information on health concerns. The information, often hard for women to find on their own, comes from a variety of sources including medical journals, women's stories, and books on herbology, homeopathy, and other alternative treatments. The VWHC has also published many articles and books on women's health which critically examine this often contradictory and complicated material from a feminist perspective. They are written in straight-forward, accessible language.

The VWHC does not have money for someone to read the main medical, popular press and feminist publications on women's health issues, to pay for a news clipping service, or to subscribe to enough periodicals to have a complete overview of events in women's health. Nor can it periodically do computerized searches for new articles on a topic and have someone decode the medical language and write

We do not think the network should provide counseling or set up support groups. This more personal support can best be handled at local or regional levels, although information on counseling, support groups, popular education techniques and more should certainly be collected for the data base.

The CWHN project has already started a resource bank which will list individuals and organizations across Canada working on women's health issues. It will allow a woman to quickly find out about work being done across Canada on topics from poverty to endometriosis and to find Canadian resources.

The resource bank could expand to include more extensive health information. The database should be divided into women's health topics, and each topic should contain three components:

- an easy-to-read overview of the health topic, which includes a description, diagnosis and treatment options, and alternatives to medical treatment, if they exist.
- an annotated bibliography, or list of available print, video, and tape resources, with short descriptions of these resources.
- a list of organizations and individuals, by region, able to provide support, experience or counseling or who are politically active on the issue.

The work of building up and maintaining the database could be contracted out to groups or individuals across Canada with a critical feminist perspective such as the Canadian P.I.D. Society, or D.E.S. Action who have already written extensively on their topics. They could refer to a variety of sources. The overviews could be updated every one to three years, with notes on new information added when needed. Resource lists could be updated on an ongoing basis.

A woman anywhere in Canada could contact the database, either through a modem, or by phoning or writing to ask for printed material to be sent to her. This information could help her get involved locally.

Since the system would be on-line, women's centers, health information centers, such as the Vancouver Women's Health Collective, and healthcare workers, such as community health representatives, could have immediate access to information. They could have copies of many books listed in the bibliographies, and could provide much needed support

Similarly, many individuals and organizations want to produce crucial health resources but can not obtain funding. A national feminist publishing house would help with both funding and distribution problems. It would need to function in English and French, and support communities wishing to publish in other languages. At present, translation, like publishing, is carried out in a piecemeal way and is very expensive.

### Funding This Project - A Challenge

This project could eventually make critical information on women's health much more accessible to women throughout Canada. It could cut down on unnecessary duplication and provide support to groups receiving funds from local, provincial and federal sources.

We suggest beginning with the goal of finding funding for a national information database. The set-up would require a librarian and an editor and consultation with a computer programmer and/or with organizations already running similar information ser-



for women trying to make difficult decisions. They could also use the database information to develop regionally or culturally specific resources as needed.

To be useful across Canada, this database should function in English and French, and be translated into many languages. Anglophone and francophone groups could meet and discuss whether it would be more effective to have one data base or set up two independent databases, but share resource lists and information.

A national British organization, Women's Health (formerly WHHRIC), in London runs an information centre with a similar computerized database. They list organizations, resources, and bibliographies kept up to date with help from regional centres. They counsel women on the phone, looking up basic information on the computer then send a list of references, organizations, or contacts. Their reference library contains files with recent articles on each health topic.

Many women's health resources in Canada are produced on short-term project grants. Sponsoring organizations do not have the time, finances, or expertise to effectively promote and distribute them. Most Canadian women thus do not have resources even when they exist.

Health activists and organizations would be hired to develop resource material for the database. Once the system was set up, computer maintenance costs would decrease. The major costs would be for the manager/editor, contracted writers, data-input and translation. Some new equipment would be needed, as well as funding for some subscriptions, reference materials, library literature searches and a clipping service to keep up with new information on women's health. We need to think seriously about how to fund this, and maintain feminist control. Does anyone have any ideas? However it is funded, the work to set it up would need to involve women's health centres which already run information services to incorporate their information.

Of course, information is only one component of women exerting control over our healthcare. The network also needs to become an active political force, able to effectively express the voices of many Canadian women, to improve our healthcare, choices, and eventually the health of our society.

*Anne Fraser was the regional animator for this issue on B.C. and Alberta.*

*Barbara Mintzes works at Health Action International.*

## Beth Easton

*AIDS is a women's issue. Currently in Canada women and youth constitute the fastest growing groups of HIV positive people. Not only are we infected in greater numbers, but increasing numbers of HIV-infected youth who rely on us as primary caregivers means many of us are additionally affected through our families and communities.*

# W omen & AIDS

Women have lived with and died from HIV/AIDS since the early 1980s when the pandemic was first recognized. Of the women who have died of human immunodeficiency virus (HIV) related infections, many never received an acquired immunodeficiency syndrome (AIDS) diagnosis, proper treatment, care or support. This is because HIV, which causes a syndrome of illnesses known as AIDS, affects women differently than men. The dominant medical definition of the disease has been based on the illnesses common to men.

Treatment and education strategies are determined and made available through the lens of this male-oriented definition and consequently women's needs are usually not met. Yet the World Health Organization estimates that 250,000 women in the world have AIDS and 3 million of us have HIV. At the beginning of 1992, 289 adult women in Canada were reported to have AIDS, representing approximately five per cent of all reported AIDS cases in the country. Transmission through heterosexual contact accounts for 60 per cent of Canadian women's cases and two-thirds of the women with AIDS worldwide.

However, reported AIDS cases do not represent an accurate picture of

HIV infection in women. Anonymous HIV testing done on blood samples of pregnant women in British Columbia, Ontario and Quebec revealed higher numbers of HIV positive women than previously indicated. The studies found that in Vancouver and Victoria one woman in 1,300 was HIV positive; in Toronto one woman in 1,976 was HIV positive; and in Montreal one woman in 616 was HIV positive. Based on these figures an estimated 2,900 women of child-bearing age in Canada are HIV positive, an estimate that is considered conservative.

Despite our experiences and the reality of our risk, the dominant AIDS agenda is white and male. This means that medical treatments, preventive education strategies, media content, and government policy; the social, medical and educational responses which constitute the dominant campaign against AIDS, reflect male needs and experiences. The reasons for this are diverse and complex. Key is the fact that in North America where the dominant AIDS agenda was set, large numbers of men were first affected, and first responded to the disease. AIDS emerged in a world governed by patriarchal ideology and institutions and the response has been primarily defined by male-biased attitudes and values.

White, male domination of the struggle against AIDS renders invisible those HIV positive people whose needs and experiences are not the same. The strong male association with AIDS, specifically white gay males, and intravenous drug users thwarts many people in their ability to recognize their possible HIV risk behaviours if they don't identify with either of these groups. And treatment and education strategies developed according to a male model are often not effective with other individuals or groups.

In response, women must work to create our place within the AIDS agenda to ensure that our specific treatment and prevention requirements are met. However, we must be careful not to unwittingly contribute to the maintenance of a hierarchical strategy against AIDS which may deal with discrimination based on gender, but continue to discriminate according to race, class, sexual orientation and ability. All marginalized people whose needs and experiences are different, need to be able to access and develop treatment and education strategies of their own.

The women's movement has always tried to broaden social agendas and make them more representative and responsive to the needs of marginalized people. We have been forced to develop inno-

## Vancouver Native Health Society

Deborah Mearns

As Andrew Nikiforuk charges in a series of articles in the *Toronto Star* in 1991, AIDS is not the "sanitized epidemic presented by bureaucrats or the democratic epidemic promoted by the Czars of political correctness," but a very discriminating disease that primarily attaches itself to "communities" that are for one reason or another marginalized by society. The AIDS pandemic has severely impacted the gay and bisexual population and has now found fertile ground among communities that harbour poverty, substance abuse, homelessness and a high incidence of other sexually-transmitted diseases (STDs).

Unfortunately, governments, striving not to further "stigmatize" the already disenfranchised, have embarked on a campaign that is resulting in the further spread of the disease by promoting educational programs with a "one size fits all" philosophy.

The health status of Aboriginal people in Canada is far below the national average and the introduction of AIDS has further highlighted the failure of the healthcare system to meet the needs of this community. The prevalence of substance abuse problems, the high rates of STDs, poverty and overall poor health in the Aboriginal community means that AIDS poses a significant threat to this population. AIDS has the potential of affecting Aboriginal communities to the extent that the tuberculosis and small pox epidemics have; all the routes of transmission are present. Although the number of women with AIDS is small, according to official statistics, the majority of them come from those communities most at risk. The offering of generic educational programs targeting "women" may meet the criteria of government but miss the mark when meeting the needs of those women that are already victimized and most at risk.

The social malaise that has afflicted Aboriginal communities has been fostered both knowingly and unknowingly by a succession of governments. The results have been devastating, leaving behind a myriad of ailments including family violence, sexual abuse, high rates of STDs and family and community dysfunction. In this context how do you advocate "safe sex"? How does a woman who holds no power in her relationship or her community hold this out as an option?

In Vancouver, with an Aboriginal population estimated at 50,000 there exists only one Aboriginal AIDS educator, despite the findings of a study that found that Aboriginal street-involved people exhibit higher infection rates than non-Aboriginals. As well, Vancouver's needle

exchange, the largest in Canada, has recorded that 40 per cent of its registered users are Aboriginal. Despite the glaring need that is illuminated by these findings, the provincial government defended its "Native AIDS strategy", a couple of years ago, citing with precision that the conveyors of its message had reached 1,899 Aboriginal people in the province during that preceding year. It is therefore not surprising that other AIDS-related services have not been developed or promoted targeting this community.

So what needs to happen? As has been the case all along, the most effective programs are those that originate in the community they intend to serve. Communities must be given the resources and the support to develop programs and services that meet their unique needs and embrace the values and cultural ideals that can create an atmosphere conducive to long term behavioral change.

The cultural diversity of Aboriginal communities is only one factor in determining that there is a need for specific, community-based programming. Within the Aboriginal population itself there exist groups that occupy an even more tenuous position. These groups demand special attention as they are often isolated from their own communities and represent the most at risk individuals. For these reasons it is not even conceivable to consider a universal "Aboriginal AIDS" strategy.

Communities most affected by this pandemic must wrest the power from the bureaucrats and publicity-conscious politicians, to make the tough decisions so that our communities can come to grips with this disease. In the Aboriginal community it will mean facing issues that are terrifying and difficult; it will demand an examination so intimate that many will weep. But only through such a process will Aboriginal people reclaim their dignity and self respect thereby opening the way to once more controlling their own destiny. If this challenge is not undertaken the future of a whole generation could be threatened as well as the survival of many communities.

*Deborah Mearns is the president of the Vancouver Native Health Society. She is on the B.C. Medical Association Committee on Aboriginal Health. She is also an active board member for AIDS Vancouver and Downtown Eastside Youth Activity Society and is involved with the B.C. AIDS Network.*



## Women and AIDS in the Latin American Community

Adriana Tweedlie

**W**ithin our local Latin American Community in Vancouver, AIDS is still far from being a main concern. To understand why, it is necessary to look at sexual and cultural identity, gender roles and educational approaches towards HIV/AIDS.

The Latin American community is a very diverse and heterogeneous community. The differences among us are defined by many factors besides country of origin: political and social class differences, religious beliefs, socio-economic and educational level, the reasons we had for leaving our countries of origin, the specific problems pertaining to our settlement process and legal status in Canada, and the degree of identification we have in relation to the mainstream society and our commitment to stay in Canada permanently.

Most of us who immigrated to Canada brought traditions, language, values and a cultural heritage with us which continues to influence our way of looking at the world. The family is one of the most influential institutions, passing on traditions and attitudes and defining gender. Traditional female roles that define the position of women in Latin American societies are being duplicated in the new country. Centred around domestic chores, reproductive responsibilities, raising children and caregiving, traditions perpetuate a passive role for women. A woman's worth is measured by her ability to procreate, care for a family and make a home. Wives are expected to be submissive and obedient.

Topics like sexuality, homosexuality, AIDS or condoms are often quite difficult to discuss among family members and even couples because of the strong influence of religion in our lives. Virginity, purity and chastity are concepts still prevalent in Latin American society. Women are divided into two groups; the "good" women and the "loose women", that is, women who have a more assertive attitude towards sexuality.

Communication is only one of the problems that affect our understanding of AIDS. The dichotomy that we experience between identity with our own culture and mainstream Canadian culture can influence our understanding of issues like AIDS. For many of us who left our countries of origin recently, AIDS was not an issue until we came here, and even now we do not see ourselves at risk, mainly because we still perceive AIDS as a

"white" disease that only affects specific groups of people.

Programs to educate and prevent the spread of AIDS in the community are still few and underfunded, making it difficult to consistently provide help and services. Printed materials in Spanish are hard to find and access to mainstream services is in many cases blocked by language barriers. Another problem we face is the "ethnocentric North American" approach taken by mainstream services towards education and prevention, which doesn't necessarily include "multicultural" differences.

Currently there are two AIDS programs which work with the Latin American community. The AIDS Awareness Project of the Downtown Eastside Youth Activities Society (DEYAS), provides education and counseling services for the downtown eastside area of Vancouver. The other project is sponsored by the Women and AIDS/HIV Support Network and provides education about AIDS/HIV and prevention strategies as well as support and counseling for women. The known identified cases of HIV/AIDS amongst Latinos are very few. Although there are no specific statistics on the number of HIV/AIDS cases in the Latin American community, one can only assume that they are bound to increase.

Communication and education are the ways to understand our own responsibility to ourselves and to each other in order to grasp the magnitude of the disease. But understanding will not be enough unless we get rid of our own ambivalent morality, fears, prejudices and prudishness, and design HIV/AIDS programs to reach and satisfy the specific needs of the ethnic and cultural minorities that make up the diverse Canadian population.

*Adriana Tweedlie started as a volunteer at AIDS Vancouver and now works at the Positive Women's Network where she provides an education workshop for the Latin American community on AIDS prevention.*

vative strategies for our voices to be heard. Key to our empowerment has been the permission and opportunity we have given each other to speak in safe, supportive spaces. The diverse voices that emerge from these spaces are voices of power capable of prompting change.

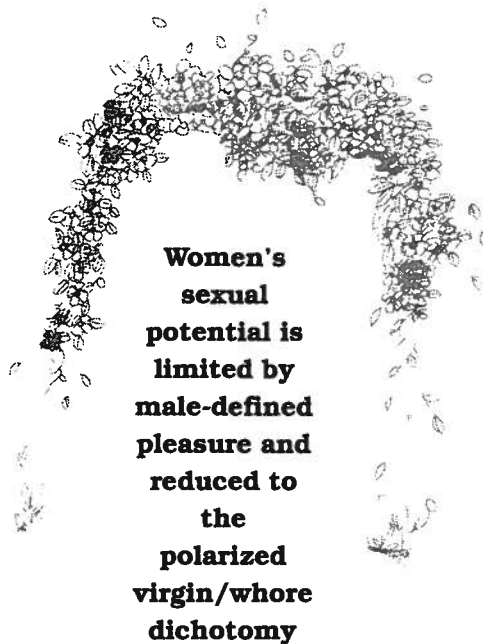
The Vancouver Women and AIDS Project is an example of a community based AIDS education and prevention initiative which reflects this philosophy of empowerment and change. Begun by a group of women who saw the inadequacies of available AIDS education resources for women, the mandate of the project has been to raise public awareness about women and AIDS and to provide women with relevant HIV/AIDS resources. The project was funded by the Health Promotion Directorate, Health and Welfare Canada and sponsored by the Vancouver Women's Health Collective.

The cornerstone of the project was the development of a safer sex education model relevant to women. Available HIV/AIDS safer sex models have often not been useful for women because they reflect male experiences of sexuality and power. For example "Just say no" a once popular HIV/AIDS prevention slogan is not realistic advice for many women who have sex with men and fear the threat of violence for saying no, or for asking male partners to use condoms. Another slogan "negotiate safer sex" is an insufficient strategy for women who broach the subject of safer sex from a lesser position of power than their male partners. Such strategies offer nothing for women who desire a healthy, pleasurable sexuality in a society where this can be difficult, if not dangerous. For women who have sex with women these models do not address their experiences. Educators often wrongly assume that lesbians are not at risk for HIV/AIDS because they don't have sex with men. Yet some women do have unsafe sex with men and still identify as lesbians. Women can be at risk regardless of how we identify sexually.

Because most women's experiences have not been reflected in

contemporary education models these models are not adequate tools for us. To be successful, safer sex models must address all women's sexual realities.

The Women and AIDS Project Workshop was developed to promote positive changes in behaviour and to reduce women's risk of HIV and other sexually-transmitted diseases. It represents



two years of working with women who identify as heterosexual, lesbian and bisexual and who come from diverse social, cultural and economic backgrounds. For example, workshops were conducted with women who were pregnant and parenting, in drug and alcohol rehabilitation facilities, students in post-secondary institutions, street involved, staff and clients of health clinics, in women's and community centres, sex trade workers, health care and social workers and in penal institutions. The Women and AIDS Project Workshop is unique because of its specific emphasis on women's needs and the workshop format ensures physical and emotional safety for the participants, helping them to obtain information and explore attitudes and values about HIV/AIDS and safer sex.

The workshop exercises were developed and adapted for women. Although some are similar to exer-

cises used in other HIV/AIDS education models, their grounding in a feminist framework makes them unique. The exercise rationales and objectives address the safer sex obstacles women face and explore ways these obstacles may be overcome.

A key exercise explores the reasons women have for being sexual. To help make sex safer for ourselves, and to more effectively offer support to other women who want to practice safer sex, we need to be aware of the various reasons that we have for being sexual. This awareness can help us understand that the motivation for sexual expression is personal and complex and that safer sex practices can be significantly impacted by them. The exercise acknowledges that safer sex practices need to be within the power of the woman to implement without fear for her health or safety. They must reduce risk and be easily maintained and to be most successful, they should be conducive to a women's pleasure. By exploring ideas about what sex means to us we are in a better position to confront difficulties which occur when we attempt to practice safer sex.

The *Language Comfort* exercise recognizes that people need to feel comfortable and confident when talking about sex and sexual health issues. Taboos surrounding sexuality can often limit honest and accurate discussion. Many words which describe the human body and sexual activities are stigmatized, contributing to a climate where opportunities to give and receive accurate information about sex are few and prohibitive. This exercise gives participants an opportunity to learn about and become more comfortable with words and phrases relevant to safer sex.

The *Sexual Activities* exercise addresses misinformation and controversy about which sexual activities are risky for HIV transmission and other sexually-transmitted diseases. The mass media commonly frames AIDS in a manner that is more frightening than factual. Overwhelmed with information many people deny their risk and become frightened believing that sexual expression can no longer be



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For women this situation is particularly distressing as our sexuality has long been restricted and influenced by a negative sexual climate. An unequal power dynamic between women and men results in a debilitating double standard for male and female sexuality. Women's sexual potential is limited by male-defined pleasure and reduced to the polarized virgin/whore dichotomy. Male-centred heterosexual expression is the acceptable norm against which all sexual expression is measured. Sexualities which do not emulate or support male-centred heterosexual sexuality are at best devalued and stigmatized, and at worst legally restricted and violently opposed.

To challenge this negative sexual climate and begin to make it safer for women, we need to consider the possible range of sexual expressions, identify safer activities, and strategize to create safer sex activities. The *Sexual Activities* exercise provides women with a non-judgmental environment in which to acknowledge and evaluate our sexuality and sexual risk. This exercise will help to alleviate fear and enable participants to consider positive sexual change.

The *Eroticizing Safer Sex for Women* exercise attempts to compensate for the emphasis of other HIV/AIDS models. The concern has been that they have emphasized the danger of transmission and contribute to the sex-negative climate while neglecting the empowering discussion of erotic expression and safer sexual pleasure. Sex for us can and should be a site of pleasure and empowering self-expression.

The *Latex Comfort* exercise addresses the fact that using latex barriers is hindered by complex factors. Traditionally, safer sex practices have not emphasized disease prevention, but rather the prevention of pregnancy. Not until we perceive safer sex as including measures which prevent disease, will the use of latex barriers seem necessary. The situation is compounded by the fact that birth control and safer sex practices are still generally considered the woman's responsibility. Because women

who have sex with men approach these relationships from an unequal position of power, many of us lack the power to effectively and safely insist that our male partners use condoms. And if women use oral contraceptives, condom use may seem redundant when conception control is not accompanied by concern for disease prevention. Because oral contraceptives have been touted as emancipatory because they are women "controlled", use of male controlled condoms may seem like a step backward.

Attitudes about the possession of condoms and latex barriers also hinder safer sex practices. The commonly held misconception

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condoms

that people who carry and use condoms are "promiscuous" and therefore at risk prevents people from protecting themselves and their partners. People are afraid of being judged negatively for instigating the use of latex barriers.

Finally, the discomfort caused by inexperience and improper use and the belief that latex reduces sensation and sexual pleasure also hinder the use of latex barriers. By teaching participants how to use latex barriers to ensure safety and pleasure, this exercise provides women with an opportunity to familiarize themselves with latex in a safe and educational environment, and gives participants an increased sense of confidence and control over safer sex practices.

The Safer Sex Discussion Scenarios are designed to give women the critical experience of



## AIDS and Disability Action Project

Ann Daskal and Beth Easton

Women with disabilities are particularly vulnerable to HIV and sexually transmitted disease (STD) transmission. Visual and hearing impairments, physical, learning, psychiatric and mental disabilities or chronic illness can lead to circumstances which put them at risk. Despite their presence in all communities, women with disabilities remain some of the most physically, socially and emotionally isolated among us, adding to their vulnerability. They tend to be seen as sexually inactive and disinterested, without potential to be otherwise. This further deprives women with disabilities who live in a society where standards of beauty, sexuality, and acceptable sexual expression are rigid, stifling the diversity of the sexual needs and interests of women with disabilities. Sexual rights, sexual information and sexual health education, including AIDS information is often not provided.

In response, the AIDS and Disability Action Project (ADAP) was created by the British Columbia Coalition of People with Disabilities, a cross-disability organization committed to promoting self-help and independence. Funded in part by the Health Promotion Directorate of Health and Welfare Canada and the VanDusen Foundation, one of the main tasks of the project was to develop educational materials with and for the different disability communities that address basic AIDS information needs, using content and formats that are accessible. This was done by committees, comprised of members from disability communities and some service providers. These working committees also helped develop distribution and promotion strategies and played a crucial role in enabling project members to gain permission for speaking engagements and AIDS educational workshops.

The reluctance of many disability organizations, be they peer or professional, to address AIDS, parallels that of non-disability organizations. In addition, the tendency of service providers, caregivers and family to deny or overlook the needs, rights and activities of people with disabilities, especially regarding taboo areas such as sexuality and drug use, makes it especially difficult to make changes within organizations and institutions. AIDS education, even in peer-based disability organizations is slow to be implemented or not seen as necessary. This is why appropriate materials and trained resource people within the community are crucial.

The materials resulting from the AIDS and Disability Action Project reflects the interests and input of all the working committees. For example, the booklet created by the Deaf and Hard of Hearing Working Committee raises their concern for the general lack of sexually-transmitted disease information in their often residential-school educated community. Their booklet, as well as being written with American Sign Language-style grammar and having many graphics, has extensive STD information. The pamphlet for the physically-disabled community

provides standard information with an additional section about transmission via contact with personal caregivers. A low literacy version and audio tape were also created. The Blind and Visually Impaired Working Committee, after reviewing materials read to them, selected several existing pamphlets and a national resource list of AIDS organizations to be translated into Braille and put on audio tape. The Psychiatric Working Committee requested a printing of the pamphlets for people with physical disabilities, minus the caregiver section. Working with the Committee for People with Mental Handicaps a set of materials was created that includes two booklets, "Let's Talk About AIDS", "Let's Talk About Condoms" and an eight-page Support Worker's Kit.

Because of funding limitations and the importance of establishing ongoing community-based activities, the AIDS and Disability Action Project encouraged the creation of networks for AIDS information dispersal and links to AIDS-related organizations, while educating the latter about the issues and needs of disability communities. One outstanding development is the beginning of a Deaf Outreach Project based at AIDS Vancouver, similar to the one at the AIDS Committee of Toronto. It will provide AIDS prevention education and support services to the local Deaf, hard of hearing and deaf/blind communities.

ADAP has always operated from the assumption that AIDS is a disability and that shared concerns, discrimination and the protection of rights necessitates a close working relationship and sense of mutual support between all disability groups. As part of the project, a joint conference "AIDS as a Disability" was held last October in Vancouver, and was well attended by both people living with AIDS and people from the "traditional" disability communities.

Our concern is that fear of AIDS and lack of appropriate information will foster a return to the promotion of restrictive sexual, social and physical environments for people with disabilities, especially women. The best resources are those which help make all people's sexual environments safe for maximum independence and choice.

*Ann Daskal was a staff member of the AIDS and Disability Action Project and has been active in women's issues for over two decades. She continues to be involved with AIDS and other disability concerns, especially chronic environmental illness.*

*Beth Easton is a member of The Positive Women's Network.*

Educational materials and a conference report are still available. For specific materials or a sample set, contact AIDS and Disability Action Project, B.C. Coalition of People with Disabilities, #204-456 West Broadway, Vancouver, B.C., V5Y 1R3. Contributions for materials are appreciated.



## Women and AIDS Project - Edmonton

Nancy McPherson

In September, 1991, the Edmonton Board of Health took action on women and HIV/AIDS. The Health Promotion Division developed the idea of a Women and AIDS project during discussions with women's shelters, transitional apartment programs and women's assault services. The Alberta Council of Women's Shelters and the Edmonton Women's Shelter became co-sponsors of this innovative project.

More than one-third of HIV transmission for women in Alberta is by heterosexual contact (Alberta AIDS Surveillance, May, 1991). Sexually transmitted disease rates are high among women in the province and many women find it difficult to set the conditions for their sexual practices. When AIDS educators and activists speak of "negotiating safer sex," we must also consider how realistic the idea is in terms of violence against women. Even when a physical assault does not happen, many women may not have the power to insist on condom use or sexual activity that is not high risk.

In Phase I of the project, we focused on expanding the services already provided by organizations working with women in abusive situations, increasing healthcare workers' knowledge of HIV in women and assisting women in protecting their own health.

To be effective, health protection strategies need to be delivered by community agencies, such as women's shelters and transition houses, working directly with women facing social and economic barriers to health. These agencies can provide support through open discussions about sexuality and appropriate educational materials. Community agencies which serve women in abusive situations also provide women with a supportive environment by offering physical safety and opportunities to build communication skills.

The project facilitator began by visiting seven women's shelters and transition homes in the Edmonton area to become familiar with each agency and the services provided. During this time, it became obvious that not all shelter and transition home staff supported the project. The discussion identified the concern that yet another issue, HIV/AIDS, would be added to the demands of their current workload. Staff members voiced feelings of being overwhelmed with the prospect of addressing HIV-related issues with their clients. The focus for discussion was then shifted to examining the implications of HIV for battered women. Staff identified the threat of HIV within a relationship as a form of abuse and they became aware that a client's risk of HIV infection is directly related to their level of power within the relationship.

Enthusiasm for the project was generated among the staff by recognizing the limitations within the agencies to handle HIV at the present time.

We had originally planned to begin staff education with "AIDS 101" sessions followed by a presentation by a woman with HIV, but the shelter directors identified a strong need for sexuality-related issues to be

addressed before attempting to address HIV. This need was later confirmed by shelter staff members. Several very successful sexuality workshops have been held. They provided the opportunity for staff members to examine their personal attitudes and values and explore personal phobias. The challenge now is to incorporate this awareness into the work setting.

A major issue facing women is that many physicians do not recognize the symptoms of HIV in women. It was decided during the planning phase of the project to design a physician referral system to assist the agencies in helping clients identify knowledgeable practitioners. Discussion among the co-sponsors of the project identified a need to expand the referral system to include dentists, counselors and pastoral care workers. A questionnaire was sent to various practitioners in the Edmonton area to introduce the project, generate interest in women's health issues and obtain feedback on the services provided by the practitioner. Completed questionnaires will be made available in each agency for client use. An educational package containing current information about women and AIDS is being assembled to distribute among health care workers through their professional associations.

There is, without question, a lack of resources to support women and children living with HIV/AIDS. To help fill the gap, we developed a video depicting a conversation between a shelter director, a childcare worker, the project facilitator and an HIV-positive woman. As well, audio interviews were conducted with four HIV-positive women. We felt these personal experiences would provide a greater understanding of HIV-related issues for women.

A review of the current HIV educational material for women made us realize that much of the generic AIDS material is not suitable for women in abusive situations. A poster message such as, "If he doesn't have a condom, you just have to take a deep breath and tell him to go get one," is not helpful for a woman who does not hold any power in her relationship. We chose to develop a poster that is supportive, not offensive, to the reality in which many women live. The message we selected is, "AIDS... it's safe to talk about. Learning is one way to help protect yourself." As well, we have developed a condom case that will hold six to eight condoms, contains visual instructions for condom application, and describes reasons for HIV antibody testing as well as testing sites in Edmonton.

The Women and AIDS project has been very successful so far. We will begin Phase II shortly with the focus on risks of HIV infection through intravenous drug use. A number of exciting activities are in the planning stage including a public forum on Women and AIDS.

*Nancy McPherson is a Women and AIDS Project Facilitator in Edmonton.*

discussing safer sex. Few of us have adequate skills or an opportunity to communicate constructively about sex. The scenarios are applicable to both lesbian and heterosexual activities with the goal of provoking discussions that will better prepare women to communicate these issues.

The Women and AIDS Project Workshop empowers women by providing a supportive place and an educational framework to encourage them to consider their safer sex needs, explore possible strategies, and identify realistic safer sex solutions. For many women participating in such a workshop, it is the first opportunity they have had to discuss and explore these issues. It is also important that women know about other resources available to them in their communities which can offer ongoing support and information if required. AIDS education for women is as much about developing a sense of empowerment as it is about providing access to information. The Women and AIDS Project does both.

Because the project is one of the first of its kind, with few available and relevant resources and experiences to build from, and with a mandate to address the broader issues around women and HIV/AIDS, it has not focused on the specific needs of any one group of women. Yet our experience demonstrates unequivocally that the most successful education and prevention strategies are those which reflect the specific needs of the individuals they target. Hence women and HIV/AIDS work must continue to be community-based and preferably generated from within specific communities. It will be these strategies, developed by women, that will prove the most responsive to our needs.

Women's needs and experiences are just beginning to be heard and addressed in the AIDS agenda. However, women are no more a cohesive community than are the citizens of a nation and we must continue to work to promote the needs and experiences of the more marginalized and vulnerable among us. Race, sexual orientation, class, and able-bodiedness all influence our

vulnerability to HIV transmission, and cause us to have needs and experiences different from some of our sisters. Those of us who are more privileged must offer resources and support to the women among us whose needs and experiences are different from our own so that all women may find their specific voices, strategies, and solutions to deal with our diverse HIV/AIDS and safer sex issues. Education for women by women equals power and women's increased power will mean our decreased risk for HIV/AIDS and other sexually transmitted diseases.

Copies of the 'Safer Sex and Empowerment' workshop manual are available from AIDS Vancouver, att: Beth Easton (604)-687-5220. For information about support services for HIV positive women contact The Positive Women's Network (604)-255-9858.

*Beth Easton was a coordinator with the Vancouver Women and AIDS Project and is a member of The Positive Women's Network.*



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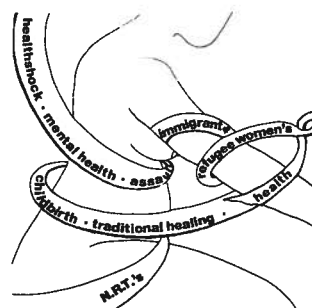
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# IN OUR OWN WORDS

Profiles of organizations working to better women's health

## *Advocates for Care Reform*

While many B.C. nursing homes work hard to ensure that residents are well cared for, there are still many unresolved issues which affect the quality of care for the health-impaired and adults with disabilities living in these homes. The vast majority of nursing home residents are women; most are over eighty years of age. Advocates for Care Reform (ACR), is a group of family members and friends of nursing home residents dedicated to improving the quality of care and life in residential care settings.

Issues such as the disregard for resident's rights to dignity and independence, over medication, non-functioning or ineffective residents councils, liberal use of restraints and staff-resident miscommunication—all impact negatively on the lives of residents many of whom may spend up to 15 years in a nursing home. Some concerns are never reported because residents are unaware that anyone can help improve matters, or because they or their family are reluctant to complain about a facility which they are dependent on. Other residents are unable to advocate for themselves and have outlived relatives who might act on their behalf.

ACR helps establish family councils and family support groups in nursing homes, speaks about the quality of care issues to professional and government groups, and publishes a newsletter containing

news of nursing home advocacy issues and government policy in B.C. and elsewhere.

Readers interested in the work of ACR, or other Canadian groups with similar goals are invited to contact us at: Advocates for Care Reform, Box 18015, Vancouver, B.C. V6M 4L3.

*Shelagh Nebocat*  
*Advocates for Care Reform*



## *Take Time to Talk*

Women with disabilities, especially those of us living in remote communities feel isolated and disconnected. The DisAbled Women's Network (DAWN) B.C. decided to develop and present a workshop for women with disabilities and their children throughout B.C. to talk, without inhibition about the pertinent issues which many of us deal with in isolation.

We received funding from the Health Promotion Directorate of Health and Welfare Canada for a project called "Take Time to Talk." During the project, which ran from March 1990 to April 1991, we created a two-day workshop and a facilitation manual.

The first day of the workshop focused on the anger raised by having a disability and ways to

manage that anger. The second day focused on increasing self-esteem. A children's workshop was also designed to run concurrently using peer-support, role-playing and other techniques to explore problems and responsibilities.

Workshops were held in seven towns throughout B.C. Local women's centres, self-help groups focusing on disability, and groups concerned with services to women with disabilities were contacted and asked to help with promotion, accommodation and providing accessible meeting rooms.

Fewer women participated than we had anticipated. We think this was due to the isolation that women with disabilities have to contend with, the reluctance they have about admitting their disabilities and the fact that we were from "outside" the community. Unfortunately, the children's workshop was not requested by the workshop participants in any of the regions.

However, the women who did attend the workshops were enthusiastic and the evaluations were favourable. An exciting result of the project is that self-help groups are now in place in four of the towns. We are keeping in touch with the workshop participants because they are actively campaigning to reach other women with disabilities in their communities.

A manual was designed to be used by facilitators in their communities to continue the work started on the project. This 70-

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OUR  
OWN WORDS

page workshop guide has sections on facilitation, anger management, self-esteem and communication. The manual is available for the cost of postage (\$2.04) from: DAWN B.C. 10846 141 Street, Surrey, BC, V3R 3J4, (604) 584-4449. *Gem Wirzilas*  
*DisAbled Women's Network B.C.*

### **Chinese-Canadian Women's Council**

The Chinese-Canadian Women's Action Council (CWAC) of S.U.C.C.E.S.S. (United Chinese Community Services Society) is a women's organization which advocates for Chinese-Canadian women. Throughout the last seven years, CWAC has initiated and delivered a multitude of services to Chinese-Canadian women living in Vancouver and the Lower Mainland.

We work to advocate and promote the advancement of Chinese-Canadian women, to encourage community participation and leadership development, to identify social issues that affect women and to lobby for policy changes.

In 1991 we completed a video project on family violence prevention and received positive feedback. This project was initiated to raise public awareness on the issue of family violence within the Chinese community. The video shows vignettes depicting child, wife and elder abuse and includes commentaries on this issue.

After the showing the video, the number of counseling cases at S.U.C.C.E.S.S. increased by 20 per cent. This year, CWAC will launch the second phase of the project which includes the production of a six-series radio program in Cantonese, the printing of three pamphlets and organizing four seminars for women in the Chinese community.

Another recent initiative was the implementation of a needs survey of Chinese immigrant women that was launched last year in Richmond, B.C. The results of the survey and recommendations pertaining to language training, childcare, employment problems, orientation and support programs have been released and forwarded to various

government departments and social services agencies for review. Special submissions and presentations were made to the minister of women's equality and the First National Conference for Chinese Canadian Women in Toronto.

CWAC has also created a sub-committee to focus on the needs and problems faced by many foreign graduate nurses currently having difficulties with the local nurses' accreditation and registration process. This sub-committee will carry out a needs survey to identify and explore the underutilized human resources among Chinese immigrant women.

At present, we are planning to introduce a community awareness project regarding healthcare, employment and the legal system. This project will encourage increased awareness and understanding of the range and depth of current issues affecting Chinese-Canadian women.

We hope through all our efforts and with continued cooperation with other organizations, we can work towards the advancement of all women.

*Celina Luk*  
*Chinese-Canadian Women's Action Council*



### **Action North Recovery Centre—“The 35-Day All Women's Program”**

My name is Ruby Elizabeth Firth, but my close friends call me Rube. I work at an alcohol and drug treatment centre called Action North Recovery Centre in High Level, Alberta. I want to tell you about the journey that got me here and the awesome types of programs that we run at the centre, specifically the 35-Day All Women's Program.

I am an Inuvait/Dene woman

from Aklavik, Northwest Territories, and if you have heard of this place, my hat is off to you. I am a recovering alcohol and drug addict and have been in recovery for almost nine years. I started working in this area eight years ago at a treatment centre in Calgary called Sunrise Residence Society. Through a Canada Employment and Immigration project I was able to take Nechi training on alcohol and drug education.

I have been working at Action North Recovery Centre since October 1989. During my time here, the centre has been changing and growing in a positive, constructive manner. Our program has been changing from a co-ed, 28-day treatment program to four different types of programs which includes programs for women, men and families, each running 35 days, as well as a 10-day follow-up treatment program.

These magnificent programs have evolved out of staff development sessions which involved working on a number of issues such as sexual abuse, adult children of alcoholics, co-dependency, residential school syndrome, alcoholism and other dysfunctions.

I would like to specifically talk about the 35-Day Women's Program. From April 8 to May 13, 1992, we held our third 35-Day Women's Treatment Program. From the responses of women who completed the first and second program, it has been a very successful process. During the first program a baby was born and was in treatment with her mother and in the second, another baby was born; both mother and baby stayed until the program was over and this in itself was very uplifting.

Women from all over the Northwest Territories and Alberta come to our Women's Treatment program. While here they have the opportunity to deal with very painful issues in their lives. Many of these issues are still having a traumatic effect on how they are living their lives. Instead of living in the present where all the power is, they continue to live in the past and use alcohol and drugs to escape the pain.

While in treatment, most of the



women have a very difficult time and some end up withdrawing from the program. Others stay and trust Action North Recovery and the process to help them. In this very painful process, staff and clients examine many issues, such as sexual abuse (which has happened to the majority of the women in treatment), grief, physical, mental, emotional and spiritual violence (particularly if such violence has been directed toward the individual) as well as the issues surrounding those issues.

We also look at the issues associated with growing up in alcoholic or dysfunctional families. This concern alone can be related to a great deal of the problems a client experiences today. They are taught that not trusting, not talking and not feeling are normal ways in which to deal with their problems. Naturally, they carry this learned behaviour into their adult lives and this creates obstacles in the treatment process.

I and many other counselors at Action North Recovery Centre are survivors of many of these problems. We continue to overcome the many daily problems in life one day at a time. Most follow the few 12-step programs that teach us new ways of life. As for me, I am grateful to the people who saw hope for alcoholics. Alcoholism is a disease which is progressive, permanent, chronic and fatal.

The work we do here at the centre is very important to me because the more women who confront and deal with their problems, the sooner they will be able to achieve their goals in this country. Then, Canada will be a better place in which to live.

*Ruby E. Firth*

*Action North Recovery Centre*

### ***The Philippine Women's Centre***

In 1988, a group of Filipino-Canadians started to work within their Filipino community to gain insight into the community and the working conditions and challenges facing a number of Filipino domestic workers in B.C.

As the group learned more about the community, they saw the

need for an organization that would help address the concerns and issues facing Filipino women, especially domestic workers. Most of these domestic workers are newcomers to Canada and non-immigrants (i.e., they have been granted permits only). Within the Filipino community, there is a low regard for domestic work because manual labour in the Philippines is inexpensive. The restrictions imposed by having non-immigrant status in Canada further compounds the low regard for this work. Many domestic workers feel homesick and lonely. They are



insecure about their status and working conditions. And, their unfamiliarity with Canada and, in some cases, difficulties communicating in English, make an already stressful situation even worse.

At first, two members of the group and a former domestic worker tried to help domestic workers by working with an existing domestic worker organization. This failed because of differences in perceptions and ideas about how to go about organizing and empowering domestic workers who are mostly women of colour.

In 1989, six women from the group who are also members of the B.C. Committee for Human Rights in the Philippines met and discussed alternative ways to address the concerns and issues affecting

Filipino women. In the course of their meeting and discussions, they realized that the problems of the domestic workers were not peculiar to this group alone, but were also concerns of other women. Upon further discussion, many in the group felt a need to form an organization that would address not only concerns of domestic workers as a distinct group, but all women's issues as well. The result was the birth of the Philippine Women's Centre.

One of the major objectives of the centre is to promote awareness of common interests, issues and problems among Filipino women as an ethnic minority in Canada. The centre also aims to help foster feminist values emphasizing their experiences as women of colour and to promote and study the perspectives of Filipino feminists. The centre disseminates information about the Filipino community and relevant events affecting women as well as establishing links with other groups which share common interests.

The Philippine Women's Centre was officially registered with the province of B.C. in January 1991.  
*Cecilia Dioscon*

*The Philippine Women's Centre*

### ***The Beyond Love Project***

Communities across Canada are being challenged by a devastating increase in the number of persons experiencing primary dementing illnesses, such as Alzheimer's disease. Ten to 12 per cent of persons over 65 will suffer from a dementing illness, as will 18 per cent of persons age 75 to 84, and 48 per cent of persons 85 years of age and over.

Over 70 dementing diseases cause loss of functions such as short-term memory, as well as the ability to retain and use new information to communicate and to perform basic activities of daily living.

Some studies suggest that only 20 per cent of the known dementia population is treated in a medical or chronic-care facility. This small percentage translates into at least 70 per cent of the population in long-term care facilities. These persons are being cared for in facilities that

IN  
OUR  
OWN WORDS

were designed and built to address different medical problems. This presents staggering difficulties in terms of the redesigning of environments, the training of staff for this new specialty and organizational adjustments within the healthcare system. Professional caregivers, working in this environment, are struggling with the transition needed to affect an appropriate health-care model for this new institutional population.

The remaining 80 per cent of persons suffering from Alzheimer's and related dementias are cared for in their homes. For every person at home there is at least one lay caregiver, and possibly more. These caregivers are the shock troops of our current healthcare system in Canada. On a voluntary basis, they provide care for the growing numbers of mid-life and elderly persons who are experiencing chronic dementia illness.

A Chicago study suggests that 70 per cent of caregiving is provided by women—mid-life women, daughters and daughters-in-law. The caregiver's role is coming under increasing scrutiny, as healthcare planners realize that without this voluntary family contribution, particularly in the area of dementia care, community-based healthcare will flounder and cast an unmanageable burden on the existing formal healthcare system.

If we hope to keep mid-life and elderly persons with dementia in their homes as long as possible, it is important that we understand and support the role of lay caregivers.

In an effort to address this and other issues associated with lay caregivers, Health and Welfare Canada, through a Seniors Independence Grant to the B.C. Community Care Association provided funding to develop the Beyond Love Project. Over the course of the project, between 1989 and 1991, caregiver needs were identified in several urban, rural and remote areas of B.C. In designated regions, advance teams contacted a wide range of community organizations and invited them to participate in the project to raise awareness of caregiver issues.

A public forum was held in each community and participants were

invited to attend a further two to five days of intensive education. The course curriculum, presented by professional specialists in dementia care and senior family caregivers, included information on dementing illness, strategies of care, stress, communication, grief, death, community development, to name just a few of the topics. The objective of the educational component was to empower participants to become leaders in their communities. Approximately 500 representatives from 87 communities in B.C. participated in the Beyond Love experience.

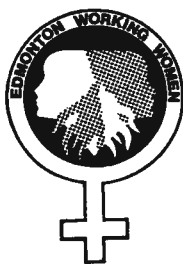
The project also produced a resource book for caregiver education and support. *Beyond Love: A Resource Book for Caregiver Support and Education* contains material used in the educational sessions, an extensive resource listing, as well as a step-by-step outline of how to develop similar projects in other organizations, facilities and communities.

A limited number of copies of *Beyond Love* are available for \$13.50 (GST and postage included) from Beyond Love, 8264 Burnlake Drive, Burnaby B.C., V5A 3K9.

For information on how to bring the Beyond Love Project to your community, write to the address above or telephone (604) 421-1680; fax (604) 936-4988.

*Gil Ludeman*

*Beyond Love Project*



### *Edmonton Working Women*

**T**ina worked in a male-dominated, non-traditional industry for five years and during that time she was a victim of harassment—sexual and other forms. Some of it was subtle but most of it was overt. Her job sometimes required her to live and work in camps where her quar-

ters were often isolated from the other workers, usually substandard and sometimes unsafe.

Tina was harassed by co-workers as well as her supervisors. One foreman continually pressured her to let him impregnate her. On one occasion, her co-workers picked her up and tossed her onto some nearby equipment. Despite Tina's repeated attempts to submit a grievance through her union, the union ultimately refused to support her.

She then turned to Edmonton Working Women, a group which helps women and groups of women with work-related problems. Tina's case is still outstanding and is being mediated rather than settled in court. It has been two years since her case became known. In that time she's been isolated by the industry and relations with her family have deteriorated because she would not succumb to pressure to drop her case. She is disillusioned, and in some ways offended, with the way in which the Alberta Human Rights Commission dealt with her case. But, Tina continues to stand up for her rights. However, she has less self-confidence, increased insecurities and experiences anxiety attacks, stress-related cold sores around her mouth and mild agoraphobia. She has not worked in over 13 months.

Sexual harassment in the workplace is not new. Edmonton Working Women (EWW) has helped women with this problem since the inception of its hotline in 1986. In fact, sexual harassment is one of the most common complaints the EWW receives. One distressing aspect of the sexual harassment calls is the number of women who are already at a crisis point by the time they find EWW. This may be the direct result of subsequent harassment or retaliation women suffer after reporting an incident. We hear from women like Tina who are totally frustrated with the formal complaint bodies such as the Human Rights Commission, management and unions. We encourage groups of women to create informal options such as picketing the harasser or the workplace or using the media to respond to sexual harassment. Such informal

options seem to work better for some women than turning to the formal bodies for help.

Edmonton Working Women provides information, referral and advocacy to women experiencing problems at work. The organization is currently working on a project that will provide information on work-related issues to immigrant women's groups. EWW has produced a labour law handbook and a pamphlet on sexual harassment for women with low literacy skills. We can be reached at 9930-106 Street, Suite 50, Edmonton, AB T5K 1C7, (403) 429-3370.

*Mary Bell*

*Edmonton Working Women*

JOINT  
EFFORT



## *Joint Effort*

The lack of healthcare has been a serious problem for women in prison since prisons were first developed in the 1700s in Europe. The security and care of women's bodies has been used against women in prison as a tool of punishment, control and to break their spirit.

The justice system does not convict and incarcerate all transgressors of the law; "justice" is carried out in discriminatory ways. For example, almost all women who are incarcerated experience poverty and Native women make up a disproportionately large percentage of the prison population relative to the general population. Also significant is that approximately 70 per cent of women prisoners are incest and/or sexual abuse survivors. Having a job, an education, being white with a middle-class background will lessen a woman's chances of serving a prison sentence. The health issues of women prisoners begins with the poverty, racism and victimiza-

tion they experience in society at large and the discrimination and lack of access they face as a consequence.

In prison women face many threats to their health and well-being. Having to go to prison can be a psychological and emotional trauma possibly involving the loss or separation from their children, family and friends as well as social stigmatization and rejection. In prison women's behaviour is closely monitored and controlled.

Women are treated as though they are unable to care for themselves. There is a lack of adequate programs so most women are bored; the primary employment for women in prison is sewing, cooking, cleaning and hairdressing. There is no protection for the women against abuse by individual guards.

Common healthcare grievances at women's prisons are that doctor's visit are too infrequent and in most cases the care and diagnosis are "incompetent". There is a distinct lack of respect for the clients, women are told that their ailments are psychological and proper treatment is not given, if at all, until symptoms become severe.

Joint Effort is a women prisoners' rights group, which grew out of the B.C. Federation of Women nine years ago, lobbying on behalf women in prison and to improve the conditions of prison life. On a larger scale, Joint Effort's broader goals are to advocate for the abolition of prisons, to increase public awareness of the demographics of the prison population (including the recognition of connections between economic oppression, racism, misogyny and incarceration), to inform the public about the conditions inside Canadian prisons, to provide inmates with education, entertainment and sport opportunities and to advocate on inmates' behalf.

Joint Effort organizes weekly discussion groups inside the prison, shows videos, organizes cultural events, teaches line dancing and brings in speakers. We are actively lobbying the B.C. Correctional Institute for Women in Burnaby, B.C., and the provincial

and federal governments to adhere to their own laws on prisoner's and human rights. For more information about Joint Effort's work and information on women in prison write to: Joint Effort c/o The Vancouver Women's Bookstore, 315 Cambie Street, Vancouver, BC V6B 2N4 (604) 872-7407

*Kim Jackson*

*Joint Effort*

## *The South Asian Women's Action Network*

Within the multicultural context of Canadian society, the depiction of South Asian women usually conjures up stereotypes. The media portray us as being constrained by repressive cultural traditions, as being unnecessarily submissive and as putting our own interests last.

The realities of South Asian women's lives contradict these depictions. South Asian women have a long history of resistance. We have carved out our own strategies to defy the patriarchal structures of oppression. The history of South Asian women is filled with examples of this resistance, and yet, according to the overriding patriarchal and oriental history of the western colonizing nations, this is disregarded.

The South Asian Women's Action Network (SAWAN) is continuing the tradition of resistance. We are a collective of activists engaged in battling the issues of representation at all levels of social life. Our experience is mediated by the sexism, racism and classism we experience in every facet of our lives as we struggle to survive in an environment that seeks to render us invisible. We are feminists; recalling our heritage of struggle against oppression.

Despite these obstacles, we have not remained silent or inactive. Our collective is made up of women who are personally committed to breaking down such barriers in their every day lives and includes women who are active with a wide variety of women's organizations at a local, provincial and national level. Our network transcends linguistic, cultural and

IN  
OUR  
OWN WORDS

religious affiliations while recognizing and nurturing our diversity.

Our strength is in numbers. Together we can raise our collective voice above individual cries for recognition. For too long, South Asian women have suffered the isolation and alienation imposed by mainstream institutions which tend to be mono-cultural, patriarchal and racist. Our cultures have been denigrated and contained within these parameters. SAWAN is committed to changing these conditions.

In light of all this, our first aim as a collective is to actively work towards the creation of a South Asian women's centre. This centre will be a site of inclusion, embracing the diversity of our community and providing a space where we can draw upon our collective strength to affect social change; a cultural space where we can come together and engage in critical dialogue, create new definitions and revive ourselves to continue the ongoing struggles.

*Seema Ahluwalia and Yasmin Jiwani  
The South Asian Women's Action  
Network*



### **Orientation Adjustment Services for Immigrants Society (OASIS)**

Through 5000 years of civilization, Indian people have learned to survive. This legacy of survival has been used to help them settle in their newly-adopted country. However problems developed: the extended family system was not understood by their neighbours; a male-dominated society with its severe restrictions was to run afoul of the law; teenagers in school wishing to be accepted by their peers met strong opposition from their parents; love marriages

rather than the traditional arranged marriages divided families; and, unequal discipline imposed on girls and boys had painful results. All of these problems had serious repercussions.

In 1975, an immigrant services centre opened to provide a coordinated approach to immigrant services, particularly services to people of Indian origin from different parts of the world. For the first seven years, the centre was administered as a branch office of the Immigrant Services Society of B.C. But in 1983, OASIS was registered as an organization separate from the society to provide preventive and remedial services to the immigrant population, but specifically the Indo-Canadian community. OASIS helps the mainstream community to understand and appreciate immigrant cultures and works with people to modify attitudes, to absorb the new environment and to create a blend of cultures.

There are a number of areas in which OASIS works: providing information and referrals, responding to requests for interpretation and escort/accompaniment, counseling and assistance in a number of areas such as physical and sexual abuse. We also run a number programs including a support group for women, one for youth and a social adjustment program for seniors.

In addition to ongoing work, OASIS undertakes short-term projects when funding is available, such as the Women's Health Education Program. This program provided information on nutrition and immunization, taught health promotion skills and increased women's social support networks. The program also included pre-and post-natal classes. Another program, designed for socially-isolated women and youths, provided social interaction to help ease them out of isolation. The groups offered emotional support for people going through crises, provided instruction for acquiring or improving economically valuable skills, built self-confidence and encouraged participation in mainstream society. OASIS is now exploring two projects related to

women's needs in the area of family violence and childcare.

We have produced two books: Health Education for Immigrant Women: A Manual and Resource Guide and a health manual in Punjabi. We are currently investigating funding for writing and translating a series of brochures on family violence into Punjabi and Hindi. For information write: OASIS, 8165 Main Street, Vancouver, B.C., V5X 3L2, or call (604) 324-8186.

*Shalen Rai*

*Orientation Adjustment Services for Immigrants Society (OASIS)*

### **Equal Justice for Women**

In April 1991, a prominent doctor in Prince George, B.C., charged with 16 counts of sexual assault by 12 women, was found not guilty on all counts (*Regina vs. Clark*). Included in the reasons for dismissal were the past history of incest, past emotional trauma, irritability, moodiness and excessive weight problems of the women who brought forward the charges. Their testimony was rejected and their credibility disregarded. The dismissal outraged the community.

A group of concerned citizens decided to focus their anger into action and formed Equal Justice for Women in May 1991. We are determined to speak out against the treatment of women within the legal system and the lack of protection and resources provided to women sexually abused by healthcare professionals. Our goal is to seek changes within the justice and medical systems which allow women access to fair and equal treatment when reporting sexual misconduct by a health professional. Our objectives include: identifying gender bias in the medical and justice systems; supporting and encouraging change in the medical and justice systems to eliminate gender bias; and educating and informing the public on gender bias.

Over the past year, Equal Justice for Women has been active in pursuing these objectives. Subsequent to the *Regina vs. Clark* trial and the formation of EWJ, a rally was organized in June at the B.C. Supreme Court building. Advertisements



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were placed in the local newspaper asking anyone sexually assaulted by a healthcare professional to contact EWJ. As a result of this ad. campaign, several women came forward including one woman who wrote to the College of Physicians and Surgeons with a new complaint against Dr. Clark,

In June 1991, EWJ submitted a proposal to the College of Physicians and Surgeons regarding the college's intention to establish a committee to examine sexual misconduct by doctors. We believe our proposal helped the college to change the structure of their committee from a closed to open forum and one that would include non-medical persons.

This committee, called The Committee on Physician Sexual Misconduct sought public input by creating a toll free "hotline." Phone calls were answered by experienced female counselors — not doctors. This initiative, though commendable, was not widely publicized. An informal brochure distributed to all doctor's offices within the province (and other related locations such as pharmacies) was never displayed. Not one copy of that brochure was seen in Prince George. So, although the college appeared to be taking steps to examine the issue, their efforts, for the most part, were ineffective.

Last October, we made a presentation to the Gender Bias Committee of the Law Society of B.C. As a result of this presentation, Ted Hughes the Chairperson of the committee is personally reviewing the *Regina vs. Clark* trial. A report from this committee is expected in June this year.

Women who have been sexually assaulted by a health professional are often very fearful to see their male doctor for routine pelvic and breast examinations. Often these very important examinations are not done because the women are unable to obtain a female doctor. In Prince George, for example, a city of approximate 70,000 people and located in the northern interior of B.C., there are few female doctors—there are only three gynecologists, all male. In Prince George a

doctor often refuses to accept you as a new patient if you have already been a patient of another doctor. If an individual feels uncomfortable with the way their present doctor conducts examinations, or for any other reason, it is very difficult to change doctors.

Several women involved in the *Regina vs. Clark* trial have not been to a doctor's office since. Their physical and emotional health remains threatened. But, Prince George offers no alternatives.

In April 1992, we organized another rally. Organized in only eight days, approximately 120 people turned out to march in front of the courthouse to protest minimal sentencing by judges. One case concerned an offender, convicted twice before for assault causing bodily harm to his common-law wife, who violated a court order to stay away from her and sexually assaulted her. He was given an 18-month probation order by a Supreme Court judge in Prince George. The second case concerned a man who attacked a woman with a metal pipe, inflicting cuts and bruises to her head and shoulders and causing her to have part of a finger amputated. He pleaded guilty to assault and was sentenced to 90 days in jail, to be served intermittently on weekends.

Support for the aims of EJW has been received from government: A local N.D.P. MLA pledged his support for our goal for fairness in the justice system adding "a zero tolerance" of sexual assault abuse by health professionals must become the norm in our society; and a N.D.P. MP addressed the House of Commons in March and asked Justice Minister Kim Campbell to initiate mandatory sensitivity training for judges at all levels.

It is time for government officials to put their words into action and legislation. Women must have control and choice over our own healthcare. Equal Justice for Women believes it is time to lobby governments to provide alternative healthcare for women. For more information about EWJ write to P.O. Box 2966, Prince George, B.C. V2N 2T7.

Carol Mooring  
*Equal Justice for Women*

The federal government policy document *Striking A Balance: Mental Health for Canadians* defines mental health as, "...the capacity of the individual, the group and the environment to interact with one another in ways that promote subjective well-being, the optimal development and use of mental abilities, the achievement of individual and collective goals consistent with justice and the attainment and preservation of conditions of fundamental equality." For women, there are several factors that make this definition of mental health difficult to achieve.

Meet Gerri-Lynne Benoit and Michele Butot. Both are counselors, on a part time basis, at the Calgary Women's Health Collective. Gerri-Lynne is also the Counseling Coordinator at the Calgary Birth Control Association where she trains and supervises 28 volunteer counselors. Michele and Gerri-Lynne both identified the primary mental health issues for women as systemic discrimination, poverty, violence against women, depression and self-esteem and connected them completely to women's oppression in this culture. "Basically, we live in a society that devalues women, systemically discriminates against us and subjects us to incredible amounts of violence. Of course women have mental health needs in this society," says Michele. "There is a direct correlation between the degree to which your society values you or devalues you, and your mental health."

The key issues in determining the scope of a woman's need for mental health services seems to be availability, affordability and appropriateness. Available and affordable services that are inappropriate don't work. Michele feels the more appropriate the services are for women the longer the waiting list, because the bulk of the services are not specialized towards the needs of women. They come out of the traditional mental health system and a lot of them are still coming out of medical model kinds of interventions.

The clearest example of the cri-

sis in availability is the issue of waiting lists. In Calgary the largest counseling agency is the Calgary Family Service Bureau. Other smaller agencies include the Calgary Jewish Family Services, Catholic Family Services and the Pastoral Institute. The waiting list at the Calgary Family Service Bureau is now four months long for day time appointments and the waiting list has been closed for evening appointments. They operate with a sliding scale fee and there are about four or five feminist counselors working from that agency. Waiting lists at the other agencies are similar although there are fewer feminists working at them.

"Even in a lot of the large agencies that do exist and that are supportive of having woman-identified women to work on their issues with them, I don't think they even recognize the significance and very often will funnel women in to see male counselors and very often that can be incredibly detrimental. Not necessarily in the first or second or third session, but down the road when you find out the underlying issues include incest, sexual assault or whatever it is that happens to come up," says Gerri-Lynne.

The waiting list for adult survivors of childhood sexual abuse at the Calgary Sexual Assault Centre is six months long. Gerri-Lynne believes that the issue of funding for agencies that provide mental health services for women is urgent. She argues as well for a reorientation in the post-secondary faculties that train professionals and believes that courses dealing with these issues should be required and should be taught by feminists with activist experience.

#### **Feminist vs. traditional therapy**

There are few choices for women who do not want to be caught in the traditional mental health system. They can go to one of the few feminist counselors operating from the larger, generic counseling centres. They can go to one of the feminist services offering specialized, issue specific services. Or

Anne McGrath

# Mental Health Services for Women

Inadequate.  
Unavailable.  
Inappropriate.  
Unaffordable.

they can see a feminist therapist at the Calgary Women's Health Collective. Michele says, "There are feminist women doing counseling who aren't doing what I would call feminist therapy. To me, and certainly to the rest of the members of the collective one of the things that defines feminist therapy is having a class analysis and working on a sliding fee scale. There are lots of private practitioners doing work at \$90 an hour for upper middle class people."

There are many examples of just how negative the traditional male-

dominated mental health system can be for women. The Canadian Mental Health Association (CMHA) document, *Strategies for Change* describes the mislabelling of women's behavior in ways that blame and devalue women. Victim blaming and misdiagnosis are entrenched in the system and the mental health community has absolutely failed to acknowledge the prevalence and impact of violence against women. In addition, recent work about the abuse rate among therapists has been refuted by some parts of the established professional community with blatant self-serving and sexist defenses.

A key feminist criticism of traditional mental health services has been the pattern of pathologizing women's experiences and reality. The fact that so many women are prescribed psychotropic medication (68 to 72 per cent of all psychotropic medications are prescribed to women) and that most of these prescriptions are made by general practitioners, points to the tendency of doctors to interpret women's legitimate mental health issues as 'sick' and in need of intrusive treatment. Many early feminist health publications including the Boston Women's Health Collective's, *Our Bodies, Ourselves*, cautioned women about the dangers in the male dominated medical and mental health systems. In their newest publication the collective writes: "Women must approach psychotherapy with caution. Most mental-health professionals, especially male psychiatrists and psychologists, have distorted ideas about women based on their training, their personal experiences with women, inadequate information about women's psychological development as it differs from men's and the reality of most women's lives."

In a presentation in Medicine Hat, Alberta on *Women and Mental Health*, Michele Butot said, "Traditional therapy has failed to recognize that it is depressing and anxiety producing to be underpaid, undervalued, overworked and face contradictory expectations, and has sought instead to help women clients adjust to these unjust situations."

### Evaluating the quality of care received

The issue of standards and qualifications inevitably comes up when we acknowledge that we need publicly funded, multidisciplinary women's health clinics and that the services provided should be free. Of course this means that there is tension between that need and the government control and intervention that accompanies it. While I understand the caution around government involvement, I also feel strongly that there must be some way of ensuring standards and accountability. Michele and Gerri-Lynne agree that there must be standards, but that these should not be imposed or monitored by either the government or the medical professions. "Standards are absolutely essential, but I think the criteria for those standards have to be determined by the women who need the services," says Gerri-Lynne. "I think that there has to be accountability, you have to have someone monitoring your work and you have to be evaluated by your clients. I think there has to be some way that people know that you're doing the job that needs to be done."

Michele believes that in terms of standards and qualifications we need to look at value base, at both formal and informal education, at experience and at personal characteristics. She says that we do know some things about what makes a good counselor. In *Choosing a Therapist*, a booklet written by Michele and published by the CMHA, Alberta South Central Region, helpful therapists are differentiated from harmful ones: "...the most helpful therapists are genuine, willing to share information about themselves (only when that is helpful and appropriate for the client), have respect and a high positive regard for their clients, are warm and empathic, responsive and active, firm but not authoritarian. Helpful therapists also have a good grasp of technical skills which are used to promote the well-being of the client; they are aware of the inherent power imbal-

ance in the therapeutic relationship and work at all times to facilitate the empowerment of the client; they see the client as an expert on their own lives and see the client as an active partner in the healing process. In addition, they are aware of their own biases and the limits of their skill, and will refer you to other professionals if necessary."

Based on this, the qualifications and skills necessary to provide appropriate mental health services for women then, are somewhat removed from the traditional formal degree basis used in our current systems.

### The self-help model

Self-help models of care are perhaps the most underdeveloped, undervalued and underresourced. Although there has been an increase in the number and variety of self-help groups in recent years they continue to receive very little credibility and support from institutions with the power and resources to support them. Often self-help groups, by their very nature, do not fit into the bureaucratic structures designed even by community agencies and are thus rendered ineligible for assistance that could establish them more firmly. Indeed, many of the community services that do exist began from a self-help model and were gradually professionalized to the point where it is arguable that some have become as institutionalized as the mainstream, traditional services.

Self-help groups are, despite the difficulties in maintaining an under-resourced group, still one of the most effective ways of working for women's mental health. They are de facto available, affordable and appropriate. The issues and methods of operation are determined by the group and the expertise comes from within the group. They acknowledge women's skills and experience and work to empower women who have often been disempowered by the system. Aside from resources, or maybe even tied in to the issue of resources, as the critical issue that most self-help

groups have to come to terms with is power. We all know that just saying that you are operating as a collective does not mean that power is not present and used or abused. Many women have been as devastated at the hands of a collective as they have in a hierarchy.

Talking about some of these issues Gerri-Lynne says: "Women in the feminist community struggle just as hard as anybody else to deal with power issues because I think that power issues arise regardless of what your basic philosophy is and I think that that's the greatest underlying reason why those kinds of centres first of all don't spring up, and last if they do, and why peer support groups and other kinds of support groups don't last for very long as well because I think the power dynamics eventually tend to destroy them." However, Gerri-Lynne is hopeful that we are at a place where it will be possible to deal with some of these issues constructively. "We're at a place in our understanding of feminism and in the way we live feminism where those gaps can easily be bridged now. I think there are a lot more people with a different kind of commitment to feminism. It's not just the dogmatic intellectual analysis. There's a spiritual analysis. There's a real different bent that's moving through the movement that's really healthy. It's starting to see the individual as a whole person rather than just valuing women's minds. I think that's a really significant change that really can benefit not just the feminist movement."

### Feminist Therapy at work

The Calgary Women's Health Collective has been working almost exclusively to provide feminist therapy since 1987. There are eight women working at the collective. Two are full time therapists and the other six work part time. In addition to feminist therapy, the collective conducts public education on women and mental health, feminist therapy and collective models of work. They have a small library and provide some information and referral. There are also a

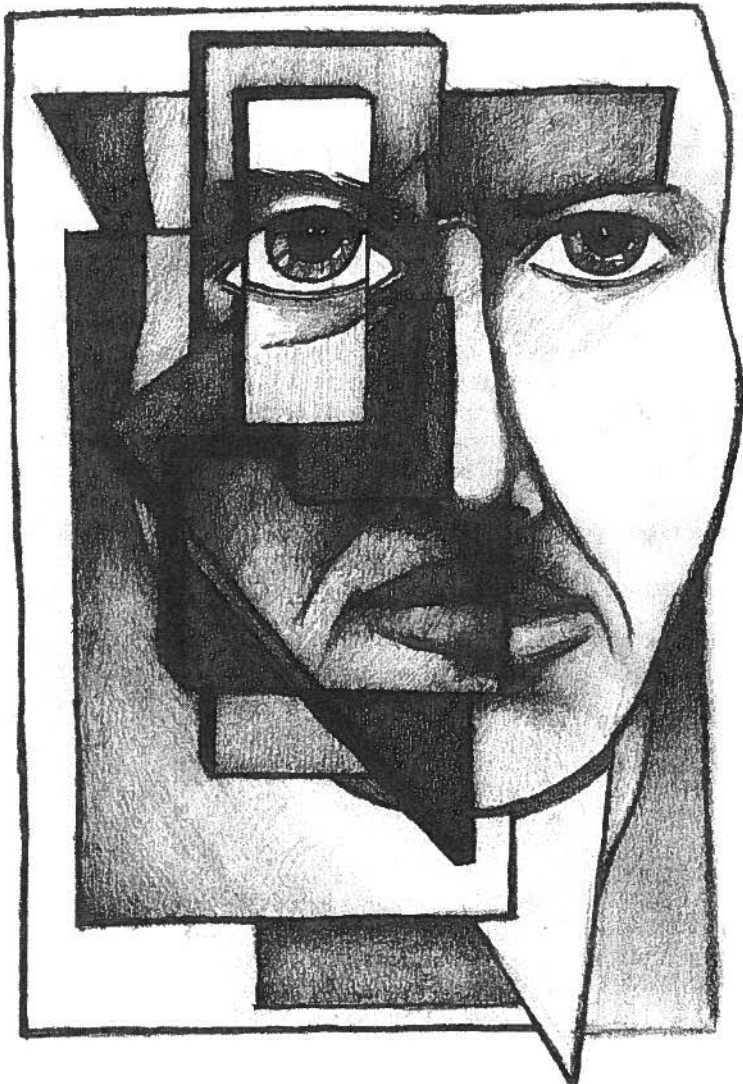
few kits on women's health issues such as lesbian health, menopause, and reproductive issues. None of the workers at the collective receive a salary. They operate on a sliding fee scale and their waiting list is at best six to eight weeks long. It is currently about four months long. They consider their counseling role to include roles as facilitators, advocates, educators and healers.

Michele feels that they do a lot of long-term work at the collective. Many of the women going to see counselors at the collective have already been in the crisis system and have a lot of long-standing issues. The therapy at the health collective is an alternative to traditional therapy. It is, "...based on a presumption of health," says Michele, and it, "...acknowledges that women's 'symptoms' are actually expressions of our attempts to cope as well as we can. It recognizes the impact of society on the development and maintenance of the distress women experience, and sees necessity for social as well as individual change." The ethical principles of the collective are outlined in the *Feminist Therapy Institute's Feminist Therapy Ethical Code* copyrighted in 1987. The code of ethics is divided into categories of cultural diversities and oppressions, power differentials, overlapping relationships, therapist

accountability and social change. Gerri-Lynne and Michele feel that their work helps to demystify the process and puts the primary emphasis for women's health concerns at the level of society's treatment of women. They are very committed to being only one part of the process in women's healing. Gerri-Lynne says, "Lots of professionals that don't have a feminist analysis are unaware of the significance of women acting as mirrors for women's lives and how that impacts on our self-esteem and how just amazingly empowering it is for women to be able to share their experience with someone that can identify at really deep levels."

### Farm and Rural Women

The mental health needs of farm and rural women in Alberta are dif-





ferent from those of urban women even though there are similar issues and causes which are completely related to our status as women in this society. However, there are special issues that are particular to both farm and rural women.

The financial crisis in the farm community has had a devastating impact on many women who are committed to farm life. Issues of status, workload, financial and role stress, isolation and loneliness, violence against women and depression are all part of the equation in rural communities.

Following the publication of *Strategies for Change* the CMHA, Alberta South Central Region undertook a participatory research project to determine the mental health needs of women in the rural regions of southern Alberta. The researcher, Lorraine Kupfer, talked to 214 women about their experiences and the reality of their daily lives. The resulting report *Through the Eyes of Women, Through the Eyes of Love*, documents vividly the joys, frustrations and tragedies that are part of being a woman in rural Alberta. "Our process began with a commitment to seeking ways that would create caring and empowering opportunities for women to offer their experiences, their learnings and their hopes. Our task would be one of learning from women in rural areas to see what worked for them and what they view as effective for creating mental health and emotional wellness," writes Kupfer.

Not surprisingly, rural women focus their mental health needs on support groups, both formal and informal, and self help. Writes

Kupfer, "In talking with a diverse mix of women throughout rural Alberta, a pattern seemed to emerge: women identify the ability to share themselves with and feel understood by at least one other person as the single most critical factor affecting a woman's sense of feeling able to manage her world. They identified this whether or not they felt they had access to it. For women who had one or more persons with whom they could and would share personally, they felt it was tops on the list of what kept them sane. For women who did not have such a support person(s), it was what they yearned for most and what they felt would be the most helpful addition in their lives."

Women were also very adamant that there is a critical need for childcare services that are sensitive to rural needs. Rural childcare must be flexible, high quality and accessible. Reliance on family and friends has serious limitations even though it is the most frequently mentioned method of providing childcare. It is very difficult to meet women's needs for support when childcare is so difficult to arrange.

The few formal mental health services available in rural communities are difficult to access for very similar reasons as those given by women in urban centres. They are unavailable, unaffordable and inappropriate. Rural women had concerns about over reliance on diagnosis and treatment, particularly medication. For those women who wanted to access formal mental health services the waiting lists were seen as an almost insurmountable barrier.

"In every region people spoke of waiting lists as a very real barrier to service. A six to eight week wait was reported as usual. This functions as more than an inconvenience to the women in rural areas. If they reach for service and find it unavailable at the time they need it, they tend not to try again." Waiting periods seem to reinforce the belief that nobody cares.

In both urban and rural communities in Alberta there seems to be little to gain from the formal mental health system. It is an institutionalized, bureaucratic, paternalistic system that functions to deepen the oppression of women and blame us for the circumstances that have led us to express our need for mental health care. I support the recommendation in the CMHA document *Strategies for Change* which states: "At this time, perhaps the most promising forms of service for women are feminist therapy, self-help groups, and a variety of support services that have arisen in response to indices of women's oppression that have been identified in the recent decades of the women's movement. These services share certain features that include an understanding of the many dimensions of women's oppression, a desire to alleviate that oppression and to empower women, and a new understanding of the nature of women's distress as largely arising from the effects on women of social, political and economic forces."

*Anne McGrath is a feminist and activist formerly working for the CMHA in Calgary. She is presently at OXFAM Canada.*

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Rita Manuel

## The Story of the Community Health Representative

*Community health representatives (CHRs) are primary healthcare workers in Native communities. Most of us work on Native reserves and a few work in urban areas. Our role parallels that of the "foot doctors" in China — we are front-line health service providers.*

*Each province and territory in Canada has community health representatives but most are located in British Columbia where we have at least 200. This may sound like a lot of positions but they are sparsely scattered throughout the province in half-, quarter- and full-time positions. The Medical Services Branch of Health and Welfare Canada divides British Columbia into four zones: Northeast, Northwest, South Mainland and Vancouver Island. Four articles written by CHRs from each of these zones are part of Healthsharing's special report on B.C. and Alberta.*

The CHR program has been in existence since 1960. It was set up to meet four major needs. First, the need for greater involvement of Native people in their own health program, and greater participation by them in the identification and solution of their health problems. Second, there is a need for greater understanding between the Indian people and the Medical Services staff at Health and Welfare Canada. Third, the desire to improve cross-cultural communication between the Native community and the providers of healthcare. And fourth, the need to increase basic healthcare and instruction in Native homes and communities.

CHRs have proven to be "made to order" health resources in our communities. Our roles are very diverse because each CHR responds to the particular needs of her or his community. There are many factors which affect our roles: the age and size of the population, the location of the community (e.g., rural, urban, or isolated), the awareness of community mem-

bers of health concerns, the availability of employment, the creation of Native-operated schools from pre-school to colleges/technical institutes level and the availability of health institutions such as clinics and hospitals.

### **Band Control versus Medical Services Control**

Of the 200 CHRs in B.C., there are five of us, working in Merritt, Salmon Arm and Kispoix, who are still employed by the Medical Services Branch. At one time the federal government, through Medical Services, employed all the CHRs and determined their job descriptions. Over the years however, the Native Bands have agreed to the transfer of the CHR program from the federal government to the Bands. This has its pros and cons.

Native Control of healthcare can promote self-determination which is very important for our communities. To be successful, a transfer

like this requires much preparation. A Band needs to learn how to meet their own healthcare needs and they also require sufficient dollars to be able to do the job efficiently. Unfortunately, sometimes the transfer happens without enough preparation or proper funding. This makes the CHRs job extremely difficult.

With the transfers, CHRs working conditions and benefits have sometimes declined. For example, little or no benefits accompany some transfer agreements with the Bands. Pension plans are included in some agreements and not in others, leaving some CHRs wondering what will happen when they retire.

In B.C., there are two Health Boards that have signed transfer agreements with the federal government for control of their entire healthcare programs. These are the Nisga Valley in New Aiyansh and Nuu-Chah-Nulth in Port Alberni. The situation of the CHR in these communities is more secure in that their jobs are not threatened with the change in

Band leaders, which occurs in a few instances, and benefits are an integral part of their contracts.

### A Varied Vocation

Job descriptions for CHR's vary. Our job is focused on prevention rather than treatment. Ongoing programs we administer include providing complete health services to our Band Operated Schools, conducting pre- and post-natal visits, heightening AIDS awareness (including dispensing condoms), serving high-risk children from birth to three-years-old and house visits. Flu clinics, baby and elder clinics, follow-up on chronic patients, diabetic in-service and follow-up, collecting of water samples, medic-alert and Vial of Life Programs are encouraged where possible.

CHR's may also act as liaisons and possibly interpreters to the Band members in dealing with health personnel or finding resources. Many CHR's attend Band meetings to give reports on their work and to get support for the community's health programs.

Often, especially in isolated areas, the CHR is required to arrange for patient transportation to hospitals, clinics, or a specialist. This may be by air ambulance, boat, bus or private vehicle. In remote areas, such as the Nemiah Valley where there is no telephone communication, the CHR would communicate with a c.b. radio.

There are preventive healthcare programs planned for the communities. However in situations where the CHR is the sole health resource person for the Band, this often gets put on the back burner. They are so busy dealing with critical issues that little time is left for program planning.

Where neither Band nor Medical Services has a community health nurse or resource centre nearby, the nearest health resource for these CHR's would be the provincial health nurse and health unit. This applies to CHR's working on reserves in Penticton, Oliver and Squamish, who not only have to perform their health services duties but have clerical responsibilities as well.



"Throughout my 20 years as a CHR, I have seen many positive changes in our roles in our communities, in our job descriptions, and in our daily responsibilities."

The most extreme situation exists where the CHR has neither federal nor provincial health nurses and is the sole health resource in her/his community. This exists in the communities at Oweekeno, River's Inlet, Bella Bella and Nemiah Valley. The responsibilities that fall on these CHR's are enormous. Regardless of their work hours and statutory holidays, they are on-call 24-hours-a-day. The word "overtime" has no significance. There's no such thing as payment for overtime worked.

As public servants and CHR's we do support what we believe in. When the Public Service Alliance of Canada Union went on strike last September, we supported the

strike and walked off our jobs. For CHR's the strike was unsuccessful. However in April 1991, a decision was rendered by the Human Rights Commission that CHR's, as members of the Hospital Services Group in the Public Service Alliance of Canada, qualified for a reclassification effective from 1987. This was good news for us. It has not happened yet, but when it does, we hope that both government and Band-employed CHR's will receive the same benefits this reclassification will provide.

### Training

CHR training has been a mixture of everything. Medical Services Branch initially allocated training to their "health educators," who did so to the best of their abilities given the short time they had. Generally, training ran from several weeks to several months and occurred in provinces outside of British Columbia.

Today, there is ongoing training for CHR's through various educational institutions throughout Canada. In some instances, CHR's train new CHR's. Medical Services has a contribution agreement with a private educational institution that is concentrating on standardizing the CHR training. Recognized accreditation is the ultimate goal. Perhaps one day a CHR will be able to use her or his training as the first step towards further training to become a registered nurse, public health nurse, or other health-care worker.

Our work as CHR's is challenging and sometimes rewarding. Too many times CHR's are the victims of "burn-out"; we are constantly on-call because the majority of us reside in the same community we service. Throughout my 20 years as a CHR, I have seen many positive changes in our roles in our communities, in our job descriptions, and in our daily responsibilities. It is this change that keeps you going.

*Rita Manuel is a community health representative with the Medical Services Branch, in Merritt, B.C.*

## Community Health Representatives: A report from the South Mainland

Charlotte Phillips

**M**y name is Charlotte and I am the community health representative (CHR) for the Tobacco Plains Indian Band in Grasmere, British Columbia. This is a small reserve, located approximately 60 miles southeast of Cranbrook and 40 miles southwest of Fernie. As a small ranching and logging community there are not many services available in this area.

As the CHR, my job is to serve the local Native population on the reserve. In emergency situations, I also respond to the community off the reserve. Through the work of the CHRs some of the health problems on the reserve have been worked out, but there are still many left unsolved.

When I first started working as a CHR, workshops on prevention were the main focus of my work. Over the last six years I've done workshops on a range of issues: alcohol and drug abuse, safety, home care of the sick, communicable diseases, firearms, bicycle safety, nutrition, and emergency first aid. Letting the people on the reserve know what their medical plan covers and the healthy things they could be doing to make life easier are among the things we do regularly.

When I started to work here, many people on the reserve did not want to see a doctor for their health problems. In one case, a woman suffering from lower abdominal pain and severe menstrual bleeding would not return to see the doctor. When asked why, she told me that the doctor believed her problem was caused by alcoholism and in describing her condition he would use such big medical terms that she did not understand anything he would be telling her. She allowed me to accompany her to the next appointment to hear what the doctor had to say. I explained to him that she did not understand the terms he used, and rather than



*"If you can do your best to make changes to the system and help your community enjoy a safer and healthier life, then you are doing a good job."*

appear dumb, she had shook her head in agreement but went home with no further understanding of what was wrong with her. After this visit she was able to communicate with him intelligently and he used terms she could understand.

A doctor's attitude can have an enormous effect on our lives. It takes a lot of work on the part of the CHR to convince doctors that the client he or she is seeing is not just another "drunk Indian," but a sober Native person with a health problem. Some doctors cannot overcome this prejudice, so you have to go to another medical person and educate them, hoping that the nature of the illness is taken at face value and taken care of in the future.

Native women face particular problems because doctors seem to lump women's illness into five categories based on a condition or their age: PMS (premenstrual syndrome), menopause, pregnancy, adolescence or old age. It also seems that their diagnosis will always fall into one of these areas. Women suffer from many more illnesses, but this is not taken into consideration in some cases and many diseases are overlooked. CHRs can be helpful in getting doctors to focus on the real concerns.

Mental health is another problem area. There is not much funding available to meet the needs of the people. Medical Services covers only 20 hours of counseling per year for each client. We have no counseling for our children, many of whom need it very badly as survivors of sexual abuse and family violence.

One of the big health problems on this and other reserves, is that there is so much anger and hurt inside of people and they are not dealing with their inner problems. We all know healing from inside cannot begin until we are ready to talk about those feelings and deal with them. Most of the time it takes many hours of counseling in order to start the healing process. In the meantime, alcohol seems to be the painkiller many people use to solve their problems. As health workers, we know this only makes things worse and affects their health, both mentally and physically, to the point where the whole process takes longer and is harder to work with when they do decide to seek help. There is only so much you can do as a CHR during this period. You can be there for them, to listen when they need to talk. You can remind them that there is help and where to go for it when needed, but, you cannot force them to seek help. All you can do is give them support and be there.

As CHRs, we have many problems in dealing with Medical Services and the Department of Indian Affairs. It takes many months before we can get medical supplies into our band offices. The process is very unique in that we have to place the order with our respective health units. The order then goes to Medical Services



where it is queried as to whether it is needed or not, then the order goes to the supply houses. It is finally sent to the health units where we have to go to pick it up. This is a very lengthy and frustrating process.

The five bands in this area are now finishing the first phase of a Fetal Alcohol Syndrome project (FAS). In this phase, assessments of all the students of the area were done to see where they stood in the learning process and if any of them have learning disabilities.

Following the assessments, a pediatrician was brought in to do a complete physical examination on the children with learning disabilities and on those with no disabilities to see if symptoms of FAS could be detected. The second phase will address the education and other social needs of children and teens affected by maternal alcohol abuse. This is a much needed study on the reserves and hopefully a lot of good will come out of this project.

Workshops are now being organized for the five bands called "Healing Circles for Adult Children Who Attended Residential Schools." The residential school experience has left many problems behind that are yet to be addressed. This healing experience will give people a chance to share their pain and anger and begin the healing process.

CHRs and band members have recently attended a two-day workshop on family violence hosted by the Women's Resource Centre in Fernie, B.C. Health and Welfare Canada have provided funding for us to publish five special edition newspapers on family violence (spousal, child, elder, emotional, physical and sexual abuse) through the Ktunaxa/Kenbiskit Tribal Council.

These newspapers will be mailed to all families in the five bands in the tribal council. Following the release of these five newspapers, we will hold workshops to review the material and information gained, answer any questions that have arisen, and plan for support groups and prevention programs.

At the tribal council level, we have a Wellness Committee that

"The life of a  
community  
health  
representative is  
not easy, but it is  
rewarding."

includes CHRs, alcohol and drug workers, education and social service workers, chiefs, family support workers, courtroom workers, and a representative from each of the five bands. At this meeting, we bring together the problems in our communities and discuss ways and means to solve them. We do not discuss confidential information, but focus on specific issues or concerns as they arise and find ways to proceed. Having a forum like this to discuss pertinent issues has proved to be an important part of our work.

For example, last year, without notifying or advising the CHRs, the Department of Indian Affairs changed the system which we have been using to get prescription drugs for band members. The department decided that Natives could only receive prescription drugs when they presented their status cards to the pharmacist. Not only were the CHRs not notified, but only one pharmacist received the package containing information detailing the new process. He passed on the information to me. I took photocopies and gave them out at our Wellness Meeting. It was at this meeting that we decided to prepare band lists with each band member's name and band number on it to give to the pharmacists so they had the information on hand. This was better than having hundreds of people trying to get status cards done before they could receive their prescriptions.

The life of a community health representative is not easy, but it is rewarding. If you can do your best to make changes to the system and help your community enjoy a safer and healthier life, then you are doing a good job.

## Community Health Representatives: A report from the Northwest zone

Diane Brown

**M**y career as the community health representative (CHR) for Skidegate, Haida Gwaii, British Columbia began in March 1970 when I attended a six-week Family Aid training program in Prince Rupert. There were 15 of us from the northwest zone. The only stipulation made by Medical Services was that those taking the course had to be over 25 years old. That was the first rule I broke. I was much younger, but I won't say how much.

We were taught St. John's Ambulance First Aid treatments, the fundamentals of home nursing, basic sanitation and general guidelines for improving family health by maintaining proper nutrition.

We had the same nurse in Skidegate for 40 years. She was a registered nurse, but more like a doctor. She delivered almost all the babies born in Skidegate; she nursed people through flu epidemics and pneumonia when there were no antibiotics. I had quite an act to follow as the elders thought I was a nurse as well. Because I was so young I was teased a lot. I wasn't prepared for what awaited me. I was called for all emergencies, all accidents, dealing with sick babies to sick elders, seven days-a-week, 24 hours-a-day, and \$70.00 a month. I was supposed to be working half-time, but it was more like time-and-a-half.

When I began working on the reserve over 20 years ago, many of our elders did not speak English and had no confidence in the medical system. I had to liaise between the doctors and my people—often translating from Haida to English. I worked out of a small room in my own home. A Medical Service nurse flew in once a month from Prince Rupert to immunize infants. We had a different nurse every month and that in itself made things very confusing.

Back in 1971 when I first began this work, I realized that a dentist

hadn't visited the reserve for over two years. The major problem in those days was toothaches and some elders needed dentures. I made home visits to every house in Skidegate and examined everyone's teeth. I wrote down exactly how many cavities each person had, if they needed dentures, etc. and sent the letter to the zone office. Somehow my letter got to Ottawa because I received a reply from Monique Begin who was then Federal Minister of Health. Shortly after, a dentist came to Skidegate and relieved our dental problems for awhile.

It is interesting that the main health problem then was dental. Now, 20 years later, it is alcohol, drug abuse, diabetes, heart conditions and arthritis, in that order. Skidegate's population in 1970 was 279; today it is 525. Of those 525 people, 125 have a chronic illness and 35 are diabetics who have many other chronic diseases. Our most recent area of concern is sexual abuse.

In 1976, I received a letter from the zone office saying there was Nechi training (Nechi is a Cree word which refers to an alcohol and drug training program offered to and designed for Native counselors) available for community health representatives. I knew nothing about Nechi but went anyway. I arrived in Vancouver with a huge hangover and went to the first session where I found out that the training was for alcohol and drug counselors. I told the group that I felt I was definitely in the wrong place. They told me to stay for three days and if I felt the same way I could go home. I stayed for the full six-week program and have not had a drink since. In 1977, we put in place our first alcohol and drug program in Skidegate.

The main role for CHRs is to promote a healthy lifestyle and to educate people to take care of themselves. With the heavy workload in Skidegate, we are just barely managing to keep up and care for our chronically-ill patients. My co-worker completed her CHR training three years ago and came home with great insights into the causes of our community's health problems. She was able to see



**"When all your power has been taken away for 200 years, your spirit begins to die. You do many things to avoid the pain—drinking, taking drugs, inflicting self-abuse, overeating."**

what I could not—that our people were too dependent on the CHRs or Band Council. We both see now that it was the history of white society pushing their values on us that has led to many of the illnesses that plague us now. For 200 years we have heard that our traditional values are wrong and that our language was not to be spoken; we have seen our sacred ceremonies stopped and our way of living in harmony with Mother Earth ended. Then came the Department of Indian Affairs making all decisions in every aspect of our lives. All of this, along with the repercussions of the residential school (when children at ages five or six were removed from their homes to be "educated" by church-run resi-

dential schools), has had devastating effects on First Nations People. When all your power has been taken away for 200 years, your spirit begins to die. You do many things to avoid the pain—drinking, taking drugs, inflicting self-abuse, overeating. I feel this is where we are at today.

One of the major tasks for caregivers is to empower people. This is a slow process, after all it took 200 years for us to get this way. We are at the beginning of this process of self-empowerment. The spiritual, physical and mental aspects all have to work together, at everyone's individual pace. My co-worker and I can see this starting. However, in order to get the healing started, we need trained therapists. There are some available, but no funding to hire them. If Medical Services provides the funding, they have a long list of rules attached.

If you asked me six months ago if I had hope, I would have said "No!" But today, I am very hopeful that there will be some changes for our people. The suffering has gone on long enough. I see a future where our children will be singing our songs and speaking the Haida language with pride.

### **Community Health Representatives: A report from the Northeast Zone**

Linda Morris

**I** am a member of the Nadleh Whut'en Band (people of Nadleh) and have been employed for 10 years, working 20 hours per week as a community health representative (CHR) in the Northeast zone.

Our reserve is 100 miles west of Prince George; our band has 308 members. The nearest town is Fort Fraser which is three miles away. We have 90 per cent unemployment, except in the spring and summer when our people have short-term jobs. When there are no jobs available there is a lot of alcohol and drug abuse.

As a community health representative, my job is to make sure the

health on the reserve is up to standards and to advise and assist individuals during home visits and clinics. I suggest different approaches to problem solving, facilitate individuals and families to initiate the process of helping themselves, and teach them to be more responsible to their families. I provide a family-centered health service based on planned clinics and home visits. I arrange and conduct health education sessions and workshops (using different teaching methods, slide presentations, films, posters, games, flannel board presentations and demonstrations). I provide treatment services by carrying out first-aid and emergency treatment to the best of my ability. I also do reporting, liaison activities, clinic duties and work on cross-cultural understanding. Every day is different for me.

One thing that makes my job difficult is that there is no medical clinic on the reserve. This means that I have no space to work out of.

Just recently we hired a community health coordinator who works out of Northern Native Family Services in Prince George. This really makes a difference in my job, as she is always looking for educational training which may be of interest to all CHRs.

In addition to the support from the community health coordinator, a nurse employed by the federal government comes from Burns Lake at least twice a month to provide all types of health services to our community, such as pre-natal and post-natal care, immunization, flu shots, and workshops on various health issues. A few years back, we had a tuberculosis outbreak on our reserve. The medical nurse came to our area every week. We had 20 people on medication and I had to monitor them very closely to be sure they were taking their medication properly. It was quite a difficult situation for me because I had no time to deal with other health issues. At the time of the out-break, Medical Services agreed to fund the making of a video on T.B. The video will be released soon through Medical Services in Vancouver.

In March, the community health representatives in our Tribal



" One thing that makes my job difficult is that there is no medical clinic on the reserve. This means that I have no space to work out of."

Council area started a CHR training program at the College of New Caledonia in Vanderhoof. This training program consists of a basic understanding of the human body and common diseases and disorders, safe medication use, the life cycle, a safe environment, communication skills and community development.

This training continues for 16 months, one week per month. At the end of the training program we will be receiving certificates and credits from the college.

I participate in quarterly meetings at the reserve which include all human service workers from the Carrier Sekani Tribal Council Bands. We get together to exchange ideas and the names of

resource people for workshops on different health and social issues.

We also have a Human Service Committee where we offer each other support and help solve social problems within our community. Our Family Care Worker and a representative from the Ministry of Social Services and Housing (MSSH) are also in our Human Service Committee. Native Family Care Workers are being trained by Northern Native Family Services in a joint venture with the MSSH. These workers are available to the bands in the Carrier Sekani Tribal Council area to help prevent child apprehension and teach parenting skills.

There is also an Elder's Committee which makes recommendations on all social problems, housing, recreation and band politics. They encourage our traditional culture.

The Nadleh Whut'en Band has a special pilot project funded by Medical Services which is in its second year. This service provides counseling in the community for offenders and victims of family violence and other related issues.

We also have another pilot project under way called the Job Re-entry program which includes the participation of 13 women. The overall goal of the program is to improve a person's employability by combining academic up-grading, life skills, and pre-employment training (job search and job retention techniques). Adding life skills and job search strategies, helps the participants to deal with the stress of training, home-life demands, and employment requirements. The program lasts 22 weeks and an additional four weeks are spent on the job, training for what could be permanent employment.

We have constructed a Learning Center on Nadleh Reserve. In 1990-91, we had 38 adults participate and this year we have 45 (which includes non-natives). This program aims at increasing the educational levels of adults. Adults enrolled in this program have the option of working towards a regular diploma or an adult diploma, both of which are recognized as secondary school graduation cer-

tificates. Most of the women on the reserve go to the Learning Center. The elementary and high school students go off reserve to school, but come to the Learning Center in the evenings for studying and tutoring.

Many thanks to the Canadian Women's Health Network for providing me with the opportunity to share information about our community health in the North.

### **Community Health Representatives: A report from Vancouver Island**

Charlotte Williams

**T**he Cowichan reserve is a combination of eight villages, which make up the Cowichan Band population of approximately 2,609. Our community is located on Vancouver Island, in the heart of the Cowichan Valley. Our area is considered urban, as we have a hospital, medical and dental facilities, schools, shopping centres and human services within a few miles of our villages. The reserve skirts the city of Duncan, as our boundaries surround the town. Approximately 75 per cent of our population is under the age of 24.

The Cowichan people are known for the famous Cowichan sweaters. This cottage industry forms a large part of our peoples' livelihood—knitting sweaters, toques, socks and scarves.

The Cowichan Band employs about 85 of our people in all areas of service to the community, but there are still a large number of people unemployed. Forestry and farming are seasonal work for many. Recently with the introduction of the natural gas pipeline to the island, additional jobs have been provided. There are also a number of our families that are self-employed, owning their own businesses.

Many of our people live off the reserve either due to land or housing shortages or overcrowding. There are five urban Native housing projects in this area, under the Makola Housing Society.

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There are currently three full-time community health representatives; each of us has our own geographic area to service. We work with nurses in maternal and child health and in chronic care and elder programs. We do regular CHR duties and specialize in different areas of the healthcare program—such as hospital liaison, workshop facilitation, interpretation or translation, and home care. I supervise the CHRs and serve on the Band's management staff as a supervisor.

One of our key projects is Project C.H.I.L.D. (Cowichan Holistic Intervention and Life Development), a four-phase education and awareness program which focuses on issues of child sexual abuse and the

impact such abuse has on our community. Three phases of the project have been completed, focusing on training, heightening community awareness, research and developing materials specific to the people in our area. We are now in the final phase of the project which will provide a community workshop for our Band Council.

Another program is the Kwunatsustul Counseling Services. Staffed with four counselors and one supervisor, Kwunatsustul Counseling Services runs several programs such as the children's program. This is a six-week program offered to our families with children between the ages of nine and 12 which concentrates on the physical, mental and spiritual growth of our children. The children participate in group activities developing their own problem-solving techniques, communication styles and social skills. Elders are invited to participate in the program by telling stories and teaching the customs of our people to the youth and their parents. The children's program has proved to be an excellent program for our young people.

Our lifestyles have changed over the years. Women are becoming the main support for their families. A sedentary lifestyle has led to more diabetes amongst our people. The change of eating habits to more processed foods instead of the traditional food preparation of the past has had a significant impact on the health of Native people. The stresses of every day survival causes a lot of mental health concerns as well.

We live in a bi-cultural society today. Natives and non-Natives have different values and systems. For our people this means always trying to adjust to two worlds. Our children face the strongest demands by going to school daily and learning new things. As parents we have to bridge the gap and somehow bring that world into ours.

As a CHR, I often see our work as having a bridging function as well—helping our people and non-Natives to live side by side and to better understand each other.



# MY STORY, OUR STORY

## My Environment Turned Against Me

Eve Horne

I aged 40 years in a matter of minutes. I still looked like a 30-year-old woman but my physical and mental capabilities had plummeted to the level of an ailing 70-year-old. What seemed to be minor injuries in a car accident triggered a series of health problems which appeared to have no logical cause. No cause, until I looked more closely at the environment in which I lived.

Before the car accident my life had been hectic and full. I was married with two active boys, ages five and nine. I worked part-time as a nurse and was a full-time student at a college 40 miles from my home. In our spare time, my husband and I built houses.

Then it happened. As I was driving home on the freeway, a truck swerved into my lane. I hit it head on, bounced through the median and landed on the other side of the freeway with traffic coming towards me. I remember thinking to myself that I was either going to die or be in a wheelchair for the rest of my life. Luckily no one hit me and I managed to get my car onto the shoulder of the road. I walked away from the accident with whiplash and all my muscles torn from my neck down to my waist. The initial prognosis was that I would be back to normal within four to six weeks. I was grateful to be alive and even more grateful that it was apparently a minor injury.

After the accident I was forced to reorganize my life. Student ser-

vices at the college gave me an assistant to do all my writing. Because I couldn't drive, I rented a hotel room near the school so that I could rest between classes. On the weekend someone drove me home. I missed my family, my job, my busy life and most of all my independence. I was in so much pain that I had to take a break between washing my face and brushing my teeth. But I kept telling myself that it was only going to last six weeks.

After six weeks, there was no improvement and I began to get uneasy about my injuries. I requested that my doctor send me to a specialist. I saw a neurologist and an orthopedic surgeon. Both specialists agreed that my injuries were not serious and I would be back to normal in six to eight months.

A year after my car accident, the healing from my injuries was minimal and my physical and mental well being had deteriorated drastically. I suffered from constant fatigue, overall achiness, restlessness, hot and cold flushes, and lack of coordination. I was falling down, bumping into things and dropping everything. I experienced uncontrollable shaking and tremors. I was drowsy and my attention span and concentration were virtually non-existent. Facial pain, pressure in the head, dizziness and vicious headaches put me in bed for days and sometimes weeks. I was emotionally sensitive and depressed. Restless sleep and insomnia left me totally drained. I

had problems with my vision, my throat, and speech. I had difficulty breathing and painful muscle spasms. My list of symptoms went on and on, and yet no doctor could find any physical or neurological explanation for them.

Two and a half years after my car accident, I had seen at least half a dozen specialists and was feeling neurotic and beyond help. My frustration level was reaching the breaking point when I met a doctor who told me that he suspected what was wrong with me. He had been seeing patients for five years with symptoms very similar to mine. Finally, after two and a half years someone was actually acknowledging my pain and telling me that I wasn't alone.

After he finished examining me, he asked if I had ever been exposed to chemicals. Without hesitation I automatically said no. But he continued to tell me that he felt that patients like me were highly sensitive to something in our immediate surroundings. I left his office thinking that what he told me couldn't possibly be true. I lived in a clean, new home in the country away from big-city pollution. I went through a lot of fear and denial in the next year. I knew that if the doctor was right and I was highly sensitive to something in my environment, my life would never be the same. There would be no pill or miracle cure and even time would not heal my illness.

I lived alone with the denial and confusion for seven months without telling those close to me about the doctor's diagnosis. I just could not believe that my environment was responsible and especially that the government would allow it. The government has standards for everything—you can't buy a toaster without the government's stamp of approval on it.

As I emerged from my state of denial, I started to examine my previous life and realized that I had been exposed to chemicals from an early age. I had picked heavily sprayed berries. I lived most of my life in a farming community that used chemicals. My area was sprayed every year for mosquitoes.

In March of this year I discovered that there is little monitoring of pes-

ticide application in the Fraser Valley where I live. One field inspector monitors all pesticide application, all public land spraying, aerial forest spraying, mosquito control, farm pesticide and general pest control. This inspector's territory for inspection runs from Powell River to the Fraser Canyon. There have been traces of pesticides found in the Abbotsford aquifer: the government did a water study but the results were never released. A carcinogenic chemical from a train derailment in 1986 is still venting into the area's atmosphere. I have now lost my faith in the government.

During the past year, I have discovered that chemicals are everywhere and a lot of them are right in our homes. Our homes are built with chemically loaded materials. Then we clean our homes with chemical cleaners. Water, soap, shampoo, perfume and make-up all have varying amounts of chemicals. The food we eat is all heavily sprayed and then preserved with chemicals. Material in our clothing has chemicals and then we wash or dry clean the clothes with chemicals. Most home owners handle a multitude of chemicals, sprays to kill weeds or unwanted bugs, and fertilizers.

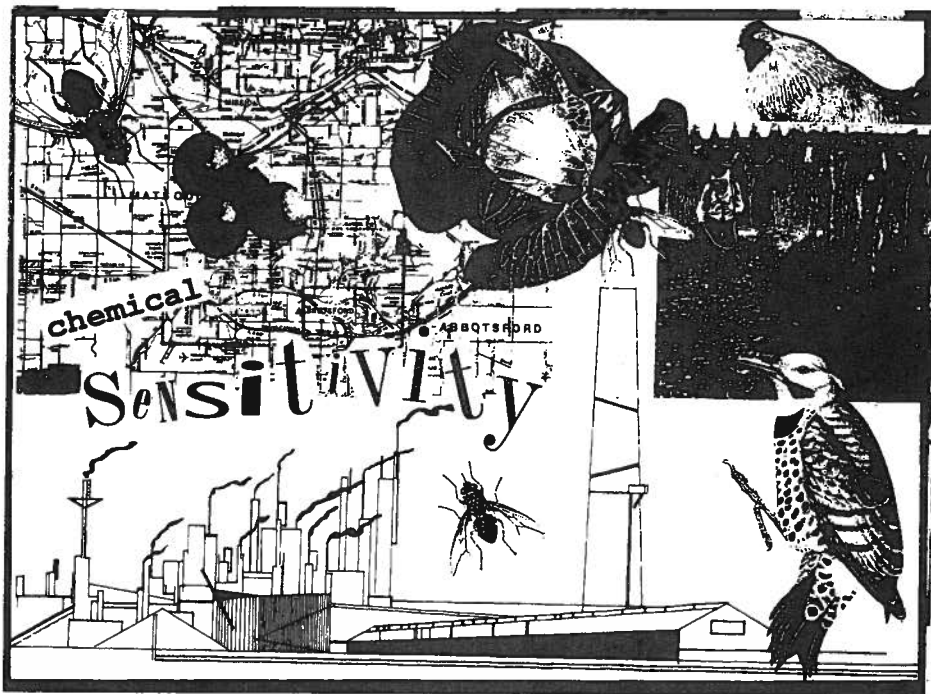
Once I looked at the total picture and realized how many chemicals were entering my system, I could understand why my body was breaking down and screaming for help. Multiple chemical sensitivity has many names and the symptoms go on forever. The support group I joined calls it S.C.I.D.S. (Somatic Chemically Induced Dysfunction Syndrome). It has been frequently termed "the mystery disease" because it is like no other disease that human beings have come across. It affects every system in the body and is virtually impossible to pin down. "The mystery disease" makes sense if we realize that each person is a unique blueprint and that each person is bombarded with different chemical combinations. Man-made chemicals are not one of the five requirements for life to exist—they help destroy life. Our approach to nature is to beat it into submission. We have been beating nature for far too

long—our wildlife is dying and human beings are sick and dying. Our eyes must be opened, and we must understand what we are doing to every living thing as well as even our land.

Multiple chemical sensitivity is not a sudden development; it has been slowly creeping into our world unnoticed for more than 100 years. D.D.T. was synthesized in 1874, but its properties as an insecticide were not discovered until 1939. Isn't it amazing that it took 65 years to partially understand one single chemical? A more recent

impairment, disruption of species balance and behavioral alteration. Why are we not learning from our past mistakes—are we so greedy, lazy and demanding of instant perfection in nature?

Multiple chemical sensitivity is not selective in any way. It affects every living thing all over the world to varying degrees. According to various studies, people living in cities or suburbs are now exposed to heavier doses of pesticides than farmers spraying their crops. In 1989, Soviet Central Asia had an ecological catastrophe that crip-



chemical—agent orange—was proclaimed to be harmless but we know from its use in Vietnam by the U.S. Army and in other wars how deadly agent orange is. Chemicals are a multi-million dollar business, yet many that hit the market are not properly tested. The U.S. Department of the Interior, Fish and Wildlife Services' special scientific report #119, 1968, states that organochlorine pesticides may last years in the environment and be carried great distances by wind, water and animals. As a result, most living organisms now contain organochlorine residues. This report states the horrific impact of these organochlorine substances on the environment: death, reproductive

ple and killed thousands of people. Years of chemical fertilizer and pesticide abuse seeped into the water supply poisoning tens of thousands. An American CBS news report, March 28, 1990, *Danger in the Yard*, reported that widely used products designed to give your lawn a healthy look are making people sick. Symptoms range from rashes to severe breathing difficulties and have included incapacitating headaches lasting two weeks.

Why are we not realizing and questioning what is happening to us? Have we become a world full of pill poppers? "I have a headache—take two aspirins. I can't breathe—where is my inhaler. I have a rash—throw on some cream." We need to listen to our

## Lesbians Face Unique Healthcare Problems

**I** WAS RECENTLY ASKED TO GIVE a lecture on lesbian healthcare, a topic I thought I was familiar with because I am both a lesbian and a family physician. I was surprised by some of my findings. The realization that up to 10 per cent of female adults may not be getting the healthcare we deserve prompted me to write this article.

How many physicians personally know a lesbian? Only 25 per cent of heterosexuals surveyed in the U.S. reported that they know a homosexual. Lesbians are thought to make up five to 10 per cent of the general female population, although we can be an invisible group and difficult to quantify. Still, the reality is that any physician who treats a woman has likely treated a lesbian, although many doctors swear they have not. Of 110 gynecologists surveyed in a Florida study, 50 per cent said they have never seen a patient whom they thought to be a lesbian.

It is important that physicians talk about and increase our awareness of lesbians. Naming something brings new concepts into existence, not naming something renders 'it' invisible and nonexistent.

The system that finds lesbians unacceptable is heterosexism, which assumes that there is only one way to be - heterosexual. Heterosexism is backed by institutions and establishments such as governments and the medical profession, which assume that everyone is heterosexual.

Interestingly, until 1897 "lesbian" referred to a resident of the Isle of Lesbos. During the first wave of feminism in the 19th century, when men were threatened by women who refused to get married and who loved each other more openly, sexologist Havelock Ellis defined lesbianism as a sickness,

which he claimed he could cure. The word "heterosexual" entered our language after the word "lesbian" because society had assumed that everyone was innately heterosexual. The word wasn't needed until a conceptual contrast was formed.

Although we can minimize homophobic responses by appearing conventional - heterosexual in our behaviour, dress and mannerisms - try to imagine what this is like.

Imagine a world where nothing fits your reality. Imagine that almost every magazine you look at every television show or movie you see, every advertising image, novel and song, constantly shows a way of life that is not yours. Imagine living with another person sometimes for decades, and not being able to go together as a couple to your family's celebrations. Imagine always having to change pronouns and having to lie to protect your job, your home, your children and your life.

One of the main issues affecting lesbians is our emotional well-being. In such a homophobic world, there has to be some self-doubt in all but the strongest women, and if a community doesn't validate a couple's relationship, the individuals don't either.

A lesbian couple, patients of mine, had been living together for years and it did not occur to either of them to bequest personal belongings to one another - they did not know that this could be done. Instead, their personal effects had been left to their families.

Little medical research is done on lesbians. "Lesbian" is not a medical subject heading in Index Medicus; researchers assume that because we're all lumped together as homosexuals, our concerns will be similar to those of gay men, so

**The articles  
presented  
in this  
section  
highlight  
the  
work of  
individuals  
and groups  
around a  
specific area  
of health  
or illness**

people seeking information are directed to "homosexuality." Most of the articles listed concern AIDS and problems affecting gay men, and only a fraction mention lesbian concerns. In reality, lesbians differ from gay men in the same way that heterosexual women differ from heterosexual men.

Most books on general health-

because there are differences between heterosexual women and lesbians. For example, lesbians are at the lowest risk of being infected with HIV of any group, including children. Lesbians are generally healthier than heterosexual women, particularly gynecologically, and there are no medical problems specific to us.

gynaecologic care only when a problem occurred.

Problems can arise at any time. One woman called her local women's health clinic to ask about services provided to lesbians and was told that "the woman who deals with that stuff" was away. She asked: "Shouldn't everyone there deal with it?"



care say nothing about us. One recent book on the Canadian healthcare system had no index listing under lesbian and only two under women: one regarding healthcare reform and the other under the ubiquitous category of drug overprescription. Of course, men are not listed in the index either - the entire book is about men and the patriarchal system. A listing of "Men" is rare in any index, since most articles and books assume the male focus.

Society's assumption of heterosexuality is so strong that lesbians almost always have to volunteer information about our homosexuality to doctors. A 1981 study revealed that less than one per cent of the lesbians surveyed had been questioned about their sexual preference by doctors; a study released in 1985 found that 9.3 per cent of lesbians had been asked.

When patients volunteer the information, they usually regret it. "The minute that you say you're a lesbian, whatever minimum sympathy, interest, or concern was coming through is immediately shut off," said one patient. "It's transformed into clinical interest - you're all right as an exception to the general rule of lesbians as long as you act nice."

But the information is important

Although our health problems are mostly, but not entirely, the same as heterosexual women's, our experiences with the healthcare system are much different.

The most significant risk is that we avoid routine healthcare. Forty percent of lesbians surveyed reported they feared that if they told their doctor they were lesbians, they would receive inferior care. Eighty-four per cent of lesbians surveyed had experienced a general reluctance to seek healthcare, finding it non-empathic. This study revealed that 96 per cent of lesbians "anticipated situations in which it could be harmful to them if their healthcare provider knew they were lesbian."

This fear of the healthcare system can have a definite impact on care. Lesbians may not receive early warning of abnormal Pap smears, endometrial cancer or breast cancer. Although such screening is simple, women who feel ill-served by the system may not seek it. A 1981 U.S. study showed the average time between pap smears for heterosexual women was eight months, for lesbians, 21 months. Lesbians are more likely to orient healthcare around a specific crisis rather than a routine evaluation. In one sample of lesbians, 58 per cent sought

Another lesbian went to Planned Parenthood to investigate a suspicious lump in her breast and was told that choosing some type of birth-control method was a mandatory part of the visit.

"After I knew for sure that I was a lesbian, I went to a doctor to get my IUD (intrauterine device) taken out," another woman recalled. "He told me I was just going through a phase and refused to take it out."

"An individual is assumed to be heterosexual unless proven otherwise," observes one writer. "The assumption of heterosexuality is so strong that it overrides all contradictory evidence, no matter how vehemently asserted."

Another study looked at healthcare professionals' reactions after patients stated that they were lesbian. It revealed that 89 per cent of the professionals had negative reactions: 12 per cent were cool to the news, 30 per cent were embarrassed, 25 per cent responded in an inappropriate way, either by offering mental health referrals or asking voyeuristic questions, and 22 per cent rejected their lesbian clients overtly by leaving the examination room and having their nurses finish taking the health histories.

In a 1985 survey of 37 physicians and 91 nurses, more than 30 per cent said their feelings about



homosexuality have grown more negative since the onset of AIDS. A survey of 1,009 physicians in San Diego revealed that 30 per cent of respondents felt highly qualified homosexuals should not be permitted to enter medical school. More than 40 per cent had stopped referring patients to a paediatrician or psychiatrist who was known to be gay or lesbian.

The American Medical Association advises practitioners to at least mention to patients that therapies for "reversal" exist. Of course, nowhere does it say to tell patients the therapies don't work: there is no cure for lesbianism because there is no illness.

In the past, psychiatric professionals assumed we were mentally ill. Lesbians and gay men lobbied the mental health establishment, and now we are no longer deviants, but variants. No other well-adjusted group has had to prove its sanity, but it wasn't until 1988 that activists were able to convince the World Health Organization to remove homosexuality from the International Classification of Diseases.

"Established medicine has a virtual monopoly on healthcare," commented one observer. "Thus doctors have the exclusive right to define disease and to prescribe its treatment. Very often this is done without any understanding of the cultural, religious, or social context of the patient. When people are denied their right to decide what's best for them, they can end up feeling vulnerable and powerless."

Lesbians are often denied access to their partners in emergency rooms or intensive care units. One patient of mine went to the emergency room and although she stated that she lived with the patient, the nurse would not allow her to see her partner because she was not "family". She then sat down in the waiting room until shifts changed, identified herself to another nurse as the injured woman's niece, and was allowed to visit.

Lesbians do not want special rights or privileges — just the same rights as anyone else living in Canada. But we do not have them. We can be fired, evicted and harassed on the basis of our sexual

preference, and no legal recourse is available to us.

A friend of mine recently had to see a locum physician because her regular doctor was away. Because she was seeing him about a gynecologic problem and felt it was relevant information, she told him she was a lesbian. He stared straight ahead for a while until she asked him if there was anything wrong. He smiled at her and said: "I'm trying to find a nice way to write it in your chart."

If a woman tells her doctor she is a lesbian and the doctor responds that it does not matter, the doctor has missed the point. If it did not matter, the issue would not have been raised.

Once, lesbians were seen as infantile in Freudian terms, stuck with immature sexual desires. Now, liberal therapists tell lesbians it does not matter what we do in bed, as though our sex lives defined our existence. This attitude is homophobic because it makes our struggles and our distinct lesbian lives invisible.

As Suzanne Pharr notes in her book *Homophobia: A Weapon of Sexism*, "To say that lesbianism is just a bedroom issue is to deny the wholeness of sexual identity and its social expression and it denies the presence and effects of homophobia."

It is important that healthcare providers not assume we are heterosexual. This can involve as simple an act as asking us whether we are lesbians or whether we need birth control, and accepting our responses. Instead of asking if we are married, ask "Who do you live with?" The partners and friends of lesbian patients should be included in medical discussions. When one of our "family" members, albeit extended family, has a medical emergency or otherwise enters the healthcare system, we must be recognized as family and allowed to participate in the recovery.

The medical profession needs to reconsider the healthcare it provides to lesbians if we are to receive the care we deserve and doctors are to provide the care we should.

*Ruth Simkin is a lesbian and a family physician living in Vancouver.*

## Je Sais/I Know

*On February 27, 1992, the I Know Breast Implant Information Association met in a Vancouver hotel to raise awareness about implants and offer support for the women who wear them. When women from the audience approached the microphone, they spoke of swelling of their joints, pains in their chest, fatigue and numbness in their feet. They spoke of going from one doctor to another in search of answers, only too often to be told that their complaints were psychosomatic, that it was "just nerves". On the stage, a panel of women nodded their heads as they listened to the stories. "I know," they said, "I know."*

**B**USINESS WOMAN LINDA Wilson of Delta, B.C., received silicone-gel breast implants in 1985 following double mastectomies. After suffering chronic infections and severe disfigurement from the implants, resulting in several further operations and three new sets of implants, she began to wonder if other breast implant wearers had similar complications. Wilson found it difficult to contact other implant wearers. She found little sympathy among doctors for her pain. "I was always told I was the exception," she says. "Listening to the doctors, it seemed all the other women were perfectly happy with their implants."

Then the Meme scandal broke. The Meme is a silicone-gel breast implant with a polyurethane foam covering. Approximately 17,000



Women examine a Meme breast implant at a I Know Breast Implant Information meeting last February in Vancouver

Canadian women have them. Last April, however, the American Food and Drug Administration imposed a moratorium on the Meme after testing indicated the foam was a potential carcinogen (cancer causing substance). Canada followed suit. The press coverage of the scandal resulted in an important development for Meme recipients: women came forward with their stories of horrendous complications and discovered there were others with similar problems.

The moratorium on silicon-gel implants has since been lifted, however, many women have found themselves in a state of panic and confusion. Should they have their implants removed? The dilemma is compounded by the fact that little information is available to doctors and patients about the possible side-effects of the implants. Doctors' common advice to "ignore the media hype" has failed to reassure many women.

Some steps, however, can be taken. Dr. Linda Warren, Clinical Professor in the Radiology Department at the University of British Columbia, says mammography can detect most ruptures. "The escaped silicone can be seen very well against the rest of the breast tissue," she says. A xero-mammogram can help check the edges of the prosthesis and document minor irregularities or ruptures. Although the technology is not 100 per cent accurate, she recommends both procedures.

Dr. Pierre Blais, former Health and Welfare scientist, recommends

women have their implants checked regularly: every two years after implantation and once a year, after five years. The mammograms should be performed gently, he emphasizes, to avoid damaging the implant.

If the implant has ruptured, a woman must seek surgery within two to three months. She should refrain from any strenuous activities. Blais recommends that surgeons remove the fibrous capsule (a wall of scar tissue which forms around all breast prosthesis) as well as the implant. Although this procedure, called a "capsulectomy," is more complicated than simply removing the implant, it is vital the capsule be removed in order to avoid future complications.

Some women are choosing to have their implants removed even if they are not experiencing side effects. Dr. Urve Kuusk, a breast surgery specialist in Vancouver, has removed two to three implants a month since the moratorium. She says that removing the implant is a more complex procedure than implanting one and suggests women choose a surgeon they're most comfortable with.

"Find out as much as you can about the silicone implants," advises Linda Wilson, "and don't automatically assume your doctor or surgeon will know more than you do."

She urges women to form or join support groups, to share information, and make their voices stronger.

*Heidi Walsh is a freelance writer for several feminist publications.*

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## An 'Epidemic' in the Workplace: Repetitive Strain Injuries

**S**UNERA WORKED FOR twenty-five years at the same job in a garment factory. She was employed as an invisible mender, required to sit in a hunched position over a magnifying glass and do fine and intricate stitching. Sunera was highly skilled, viewed by her company as an expert. She was thus sent garments for fine mending from other factories in Canada and the United States.

Ten years into her job, Sunera had pain in her arms, shoulders and neck. She did not think the pain was from her job duties. Two years later, her pain became severe and Sunera sought medical treatment.

Her treatment began with injections in both shoulders. The treatments continued over a 12-year period, involving eight surgeries. She returned to work after each treatment, but 14 months ago, her doctor finally advised that she no longer work.



Sunera filed for Worker's Compensation and appealed, but was turned down. Workers' Compensation says there is no medical evidence to show her condition is work-related.

Sunera's story is one of several that are used to begin the booklet, "Repetitive Strain Injuries in the Workplace," recently published by

Women and Work Research & Education Society of Burnaby, B.C.

The society is conducting a three-year national project on Repetitive Strain Injuries, funded by Health and Welfare Canada. Project Co-ordinators, Lois Weninger and Lynn Bueckert, discovered there was a critical need among clerical workers for information on Repetitive Strain Injuries (RSI) which has become North America's number-one occupational health problem.

Repetitive Strain Injuries (RSIs) is a term used to encompass a number of physical problems that result when muscles, tendons and joints are overloaded. Conditions known as tendonitis, tenosynovitis, tennis elbow (epicondylitis), carpal tunnel syndrome and bursitis occur most often in the neck, shoulders, forearms, hands, wrists, elbows and backs. Such injuries have been recognized in athletics for years, resulting in the growth of the field of sports medicine. However, their role as an occupational health hazard has been slow in gaining similar recognition.

It is estimated that more than 50 per cent of the workforce is at risk from RSIs. The high-risk occupations are those which involve rapid, repetitive motions and awkward posture, such as cashiers, assembly line workers, bindery workers, bank tellers, airline reservation personnel, telephone operators, data processors, hairdressers, mail coders and sorters, musicians and meat cutters or wrappers. In today's workforce, women in particular work in these high-risk occupations.

The introduction of the computer, the wide spread mechanization of work and the demand by employers for more productivity, has created the current epidemic

of injuries. Many women workers ignore their pain and work faster for fear of job loss and of complaints. In the garment and fish industries, immigrant women are afraid to lose their jobs and have fewer employment choices due to language barriers. Women, still more often single parents, cannot risk unemployment. Workers often ignore their symptoms, risking a chronic, serious injury. In the current economic climate of global competitiveness and job shortages, it is little wonder that workers continue to meet unreasonable work demands despite the risk of personal injury.

RSI victims often face particular problems in finding good medical treatment. There are still doctors in the community who are not familiar with work-related repetitive strain injuries. Some doctors have been known to treat female victims as hysterical or simply unhappy with their job or home life. Even with a sympathetic doctor, accurate diagnosis and effective treatment is a problem.

Across Canada, workers' compensation boards vary in their compensation criteria for work-related RSIs. The B.C. Workers' Compensation Board still denies a great many cases, forcing costly and time consuming appeals to review boards, medical panels or the appeals division. This places an unfortunate added stress on the individual worker and taxes union resources and the understaffed Workers Advisors' office. Many workers do not file compensation claims; even more are discouraged from the appeal process when their claims are denied.

The booklet, "Repetitive Strain Injuries in the Workplace," offers information which can prevent injury or help a worker cope with an existing injury and claim for compensation. It is being translated into Punjabi, Chinese and Spanish.

RSIs can be prevented, but only with substantial changes in workplace practices. Employers must redesign workstations and equipment to meet workers needs. Jobs must be redesigned to limit repetitive tasks and eliminate pacing and electronic monitoring. Education and training programs are needed

to provide information on healthy postures and motions and how to adjust chairs, desks, workstations and lighting.

Prevention is the key to dealing with RSIs, but as long as employers, doctors and workers' compensation boards refuse to recognize the problem, prevention programs will not be implemented and workers will continue to be injured.

The RSI Project of Women and Work Research and Education Society hopes to help workers and unions with prevention and education. Over the next two years, the project will develop their booklet for use in Alberta, Manitoba, Ontario, Quebec and Nova Scotia. They will also organize public forums and conferences in each of these provinces. They will focus on RSI-injured workers and bring together unions, workers, women's groups and medical and legal representatives to deal with the epidemic



increase in workplace RSIs. The B.C. conference was held in Vancouver on April 10th and 11th, 1992.

For further conference information, and to obtain the publication "Repetitive Strain Injuries in the Workplace," write or call Women and Work, 4340 Carson Street, Burnaby, B.C., V5J 2X9, telephone (604) 430-0458 or fax (604) 430-0460.

*Sharon Saunders is affiliated with Women and Work. She has been in printing and publishing for 20 years and is active in union organizing and health and safety education.*

*Lois Weninger is one of the project coordinators for Women and Work. She has worked in adult education for 20 years and specializes in stress and closed-air building problems.*

Illustration from Repetitive Strain Injuries in the Workplace

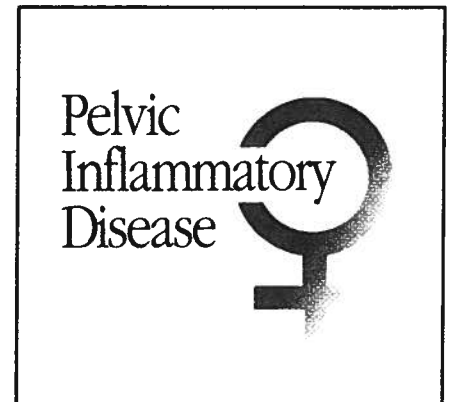
## PID: A Neglected Health Issue for Women

**T**HE CANADIAN PELVIC Inflammatory Disease (PID) Society provides services, activities and education on the most serious yet most neglected health issue for Canadian women. PID is an infection or inflammation of a woman's reproductive organs (the uterus, fallopian tubes, ovaries and the surrounding tissue). It is the leading cause of hysterectomy, infertility, and ectopic pregnancy in Canada. Serious long-term consequences or complications are common after only one episode of PID including: scarring and adhesion of the pelvic organs, chronic pain, perihepatitis (a spread of infection to the liver capsule), infertility, peritonitis (a life-threatening spread of infection to the abdominal cavity), recurring infection, tubo-ovarian abscess (which is life-threatening if the abscess ruptures), ectopic pregnancy, disability and death. After one episode of PID, one in five women will suffer from chronic abdominal pain, one in four women will experience recurring infection, and one in six will be infertile. The rate of ectopic pregnancy has skyrocketed in Canada as a result of PID: One in 66 pregnancies is now ectopic, and the rate is increasing.

The frequency of this illness is alarming. Almost 100,000 Canadian women develop PID each year. By the year 2000, one in four women will have had PID.

The prevention of pelvic inflammatory disease is made more urgent because this illness is extremely difficult to diagnose. A recent Canadian study by John Sellors indicates general practitioners and gynecologists often fail to detect PID. As a result, many women do not receive prompt treatment.

The prevalence of PID, the long



term health consequences, and the difficulty in diagnosis, make PID one of the most serious health concerns for Canadian women. However, neither public education or the prevention of PID is high on our public agenda. There are currently no publicly-funded education or prevention programs. The only education programs for PID are those conducted by the PID Society.

PID is preventable. In countries where public education about PID is widespread, the rate of PID is significantly lower. For example, in Sweden, where public education about PID now begins in elementary school, the rate of PID has dropped 40 per cent in the last decade.

A similar decline in PID could occur here if federal and provincial governments initiated publicly-funded education and prevention programs.

The Canadian PID Society was formed six years ago by women with PID and interested individuals. Our goal is to improve public education and, to prevent and to reduce the incidence of PID in Canada. As well, we provide self-help counseling, information and resource or referral services to women with PID and their families. We facilitate self-help telephone support networks for women with PID. We develop and distribute public education



materials; distribute medical research analysis. Our large resource library stocks over 1,400 research articles on PID and related topics. We coordinate training sessions, workshops and conferences.

We have just published the first brochure on PID in Canada which summarizes information about the disease and prevention methods. Samples of the brochure are available at no cost from the PID Society. Larger quantities are available at discount prices to cover printing and postage costs.

For more information about pelvic inflammatory disease or our society or to order the brochure contact the Canadian Pelvic Inflammatory Disease Society, P.O. Box 33804, Station D, Vancouver, B.C. V6E 1L5, (604) 684-5704

*Jill Weiss is the coordinator of the Canadian PID Society.*

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## Fetal Alcohol Syndrome - 100 % Preventable!

**F**etal Alcohol Syndrome (FAS) is a devastating health concern which is 100 per cent preventable. Medical professionals and governments are beginning to address this issue but it is crucial that the strategies and programs developed support women and their children.

FAS is a pattern of birth defects found in people who were exposed to alcohol while their mothers were pregnant. FAS is the most serious result of alcohol exposure and is characterized by structural facial abnormalities (small eyes relative to the space between the eyes, long smooth area between the nose and the lips, thin upper lip, flat mid-face), hearing and speech disorders, joint and limb problems, small head circumference, heart abnormalities, low birth weight, post natal growth retardation, nervous system dysfunction (i.e. poor coordination, hyperactivity, attention problems, learning disabilities, developmental delays, motor problems) and mental retardation. This syndrome affects people throughout their lives.

A child with a history of prenatal alcohol exposure, but not all the physical or behavioral symptoms of FAS, may have Fetal Alcohol Effects (FAE). Although the outward physical abnormalities of FAS will not be present, the child who is Fetal Alcohol Effected (FAE) will have cognitive and behavioral problems affecting the child's education, social functioning, and future vocational success.

Exposure to alcohol at different times during pregnancy can have different effects on the developing fetus. During the first trimester of pregnancy, maternal use of alcohol can cause major structural malformations of organ systems and bone growth, which can include the skull

and thus the brain. Children with FAS have very similar facial features and look as if they are biologically related. This is due to the effect of maternal use of alcohol upon the developing bones of the face during the first trimester of pregnancy. Unfortunately damage often occurs during the time when a woman does not know that she is pregnant. For this reason a woman would be well advised to abstain from alcohol if she was planning to get pregnant.

Exposure to alcohol during the third trimester of pregnancy can cause neurological deficits which affect higher brain functioning; this appears later when the effected child struggles with learning and behavioral problems. The associated learning problems from this damage effect the child and their parents in many ways. One of the most difficult aspects of parenting a FAS/FAE child is their inability to learn from experience. Cause and effect are not connected for them. Poor impulse control and concentration, hyperactivity and a lack of ability for abstract thinking all contribute to enormous social and life skill deficits.

Women often ask "how much can I drink while I'm pregnant?" The answer is "there is no known safe amount of alcohol consumption during pregnancy." The University of Western Ontario has recorded that after one drink the fetal cerebral circulation of the blood flow to the brain was decreased by about 30 per cent for an extended length of time and showed decreased fetal breathing.

### Crabtree Corner

The YWCA's Crabtree Corner is an emergency and short-term daycare and women's drop-in centre located in Vancouver's inner city area called the Downtown Eastside.

Crabtree Corner works with pregnant women, mothers and children, including children affected by maternal use of alcohol and other drugs during pregnancy. Although one in 1,000 incidences of FAS is often quoted, studies have shown that in some communities in B.C. and the Yukon the prevalence of FAS/FAE is as high as 200 in 1,000 (one in five) in the birth to 18 age group. FAS and FAE may be more common than both Down's Syndrome (approximately one in 600) and Spina Bifida (approximately one in 700) combined. In 1990 in the Downtown Eastside of Vancouver, 15 out of 30 babies born during a six-month period were noted to have a neonatal alcohol or drug-related prob-

**FAS and FAE  
may be more common  
than both  
Down's Syndrome  
and Spina Bifida  
combined**

lem.

The families who attend Crabtree are poor. Most of the women are frequently shelterless, economically and socially disadvantaged and have a physical, mental and educational disability. Many of the women appear to be suffering from FAE themselves and often they discuss this with us. Psychologically they suffer the effects of multiple traumas including multiple family deaths, physical, sexual and emotional abuse, as well as the ongoing strains of racism and sexism. Their health is also affected by lifestyle factors including multiple partners, injectable drug use, and alcohol abuse which puts them at a high risk for HIV infection, hepatitis, sexually transmitted diseases, tuberculosis, and a variety of other health problems.

Most of the women who come to Crabtree are single mothers. They and their children live in hotel rooms, rooming houses or they

share space with several families in one and two bedroom suites: all sub-standard housing. High rent means less money for food; less food means poor nutrition.

Most of the women only access the medical system twice: once for the confirmation of their pregnancy and then at the time of delivery. Many pregnant women who are using alcohol and drugs do not seek medical attention during their pregnancy because they fear possible "apprehension" of their newborn baby if they are identified as an alcohol and drug user. There is therefore little medical monitoring or support during their pregnancies.

The reality is that most of these women do have their babies taken away, and subsequently receive little or no grief counseling.

A high percentage of women get pregnant again within the year to replace their "lost child." Their alcohol and drug use often accelerates to numb the pain of their loss. Each subsequent baby is born more and more effected. Without supportive and appropriate action this pattern will continue.

**Need for a FAS/NAS Project**

In response to a growing concern about the number of developmentally-delayed children in our day-care due to maternal use of alcohol and other drugs, Crabtree Corner successfully applied for a three-year Health Promotion Directorate grant to fund a FAS and Neo-natal Abstinence Syndrome (NAS) prevention project. (NAS means a fetus has been affected by exposure to drugs during pregnancy.)

In 1989, when our prevention project began we contacted detox and treatment centres to determine their protocols for pregnant women. There were none. We also surveyed hospitals and alcohol and drug programs to establish what FAS brochures and information they had available to the public. Again the information was almost non-existent. Our enquiries have produced some changes.

Our FAS/NAS Prevention Project has five goals: to facilitate community educational sessions; to spearhead a community FAS/NAS committee; to develop a



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video/print resource library; to  
provide client resource and refer-  
ral information; and to produce a  
FAS/NAS Prevention manual.

Our community-based FAS/NAS  
Committee is well underway with  
representatives from 35 agencies.  
We exchange current information  
and form partnerships to develop  
comprehensive strategies. Identifying  
gaps in education, prevention and  
treatment are the main issues being  
dealt with by the committee. An ad  
hoc subcommittee has recently been  
struck to develop a FAS/NAS commu-  
nity conference in October of 1992.

We are currently working on a  
FAS/NAS Prevention manual which  
has a strong community focus. Cur-  
rently there are only three FAS  
Manuals in North America. One is  
from the Yukon titled "Alcohol and  
the Unborn." The second from New  
Brunswick "Your Child! Your  
Future," was produced in 1989 by  
National Native Alcohol and Drug  
Abuse Program and is no longer  
available. The third manual  
"Protect our Future Generations" is  
from the California Urban Indian  
Health Council Inc. Our manual will  
be very practical and is designed to  
encourage other community  
groups to benefit from our experi-  
ence and to help them create their  
own projects. The manual will  
include our project outline, infor-  
mation on how to develop an advi-  
sory committee, workshop  
material, an annotated bibliogra-  
phy, a parents section and more.

We urgently need a multi-strate-  
gy education program that reaches  
everyone. An aggressive education  
campaign similar to the "if you  
drink, don't drive" campaigns is  
required. Transit and billboards  
advertisements and media could all  
have an impact on FAS/FAE educa-  
tion. Rather than "anti-alcohol," the  
approach should be "pro-healthy  
mothers and babies." Responsible  
choice should be emphasized.

Schools need to be targeted.  
Children today automatically do  
up their seat belts and teens now  
use designated drivers. These  
habits have developed in the past  
10 years as a result of excellent  
educational programs such as  
B.C.'s "Counter Attack". Young chil-  
dren need to know "when you are

pregnant you don't drink."

Education needs to be done with  
professionals too. Existing curricula  
should be surveyed for FAS infor-  
mation and upgraded. Training  
should be conducted for all service  
providers including the medical  
profession, social workers, teach-  
ers, alcohol and drug staff, correc-  
tions staff, bartenders and the  
hospitality industry personnel. All

**FAS affects women  
from all  
cultural, social,  
and economic  
groups**

family physicians, obstetricians,  
gynaecologists, health providers  
and clinics need a protocol in place  
to complete an alcohol assessment  
on all pregnant women and provide  
them with FAS information. All  
offices should prominently display  
FAS/FAE information.

Strategies need to be varied to  
reach a broad spectrum of women  
because FAS affects women from  
all cultural, social, and economic  
groups. We need to discuss how to  
promote healthy pregnancy and  
avoid victimizing women who are  
addicted to alcohol.

### Treatment Models

Programs and services for people  
with FAS and their families need to  
be coordinated and community  
driven. A treatment model must  
include both services to prevent  
FAS and services for the children  
and families already affected.  
Prevention services assisting  
women struggling with alcohol and  
other drug dependencies and must  
women-specific detox and treat-  
ment centres which include chil-  
dren, affordable, safe and secure  
housing and pre-natal care.

There also needs to be services  
for FAS/FAE adolescents and  
adults. The burden of prenatal  
brain damage from alcohol lasts a  
lifetime. Most young adults with  
FAS/FAE have immense problems  
living independently. This puts a  
tremendous burden on their fami-

lies. Once a child is diagnosed with FAS/FAE, the parent is often left with few, if any, services and support. The lack of awareness of FAS/FAE is a nightmare for parents as they try to advocate for their children in the school system.

As well as coordinated programs and services, there is a need for research. Far too often the health concerns of women and children are on the bottom of research priority lists. In B.C., there is no central collection system or centralized information on FAS/NAS incidence. A registry needs to be set up to study the long-term effects of FAS/FAE and to appropriately allocate resources.

A percentage of alcohol revenue should (by legislation) go directly into alcohol and drug programs, including FAS prevention. Up to this time in B.C., revenue from alcohol sales supposedly designated for alcohol and drug programs has gone into general revenue.

Warning signs are crucial. They need to be multilingual and their message needs to be brief and sensitive to literacy and culture. Currently only seven cities in Canada have mandated a warning sign requirement, but we believe that these signs should be mandatory everywhere alcohol is sold. Our FAS/NAS Prevention Advisory Committee has produced a sign in English, Spanish, Vietnamese, First Nations languages and French. Other languages will be included as we gather translations.

I have great difficulty under-

standing the reluctance of the alcohol industry to label their products. Hazardous products are labelled. People know what the symbols mean on a bottle of rubbing alcohol or a tube of glue. Every woman has the right to be an informed consumer. Every woman should know that there is no known safe amount of alcohol to drink when you are pregnant.

Since August 1991, Yukon liquor outlets have applied labels before the bottles go on the shelves. Their bright yellow labels state "Warning: Drinking alcohol during pregnancy can cause birth defects." If the alcohol industry doesn't do their own labeling, vibrant warning labels applied in the store may be another solution.

In early April, after attending the federal Health Committee's FAS Subcommittee, the Health Minister, Benoit Bouchard, stated in the House of Commons that he would "consider" labelling only if all 10 provincial health ministries unanimously call for it. He further said that FAS/NAS was an issue in British Columbia and Alberta, but not in the rest of Canada. This is untrue! FAS is a Canada-wide issue. The only difference is that activists and healthcare workers are making FAS/NAS a priority issue here. I hope this soon becomes true in the rest of Canada.

*Betty McPhee is the manager of the YWCA, Crabtree Corner; she has been a feminist for many years and is an advocate for women and children.*

*My Story, Our Story continued from page 39*

bodies; their complaints should not be taken lightly. Get to know what you are eating, drinking and using.

The B.C. government recognizes our problems, but it is slow and negligent in helping us. Our support group works strictly on donations—hiring independent toxicologists, counseling people that are sick and educating the public as best we can. We need your support. If you feel that you can help us or if we can help you please contact us at S.C.I.D.S., 12717 Cathy Crescent, Mission, BC V2V 6H5.

*Eve Horne is one of the founding members of S.C.I.D.S., formed last year as a support and advocacy group for people who have multiple chemical sensitivity. Since its formation, S.C.I.D.S. has raised awareness of the illness in British Columbia to such a point that the provincial government is now developing a treatment and management plan for people with the illness and is also tightening up environmental testing in the Fraser Valley area. S.C.I.D.S. now has 300 members and is only one of several such groups across the country.*

# HEALTH WANTED

## Calgary Women's Health Collective

The Calgary Women's Health Collective is interested in expanding our counseling services for women. If you are a prospective or practising feminist therapist/counselor with a working knowledge of feminist therapy and experience in the women's movement, you may be interested in working with us.

The basic principles of the collective include commitment to: 1) the equality of power and value of all people, regardless of gender, race, ethnicity, language, religion, class, age, abilities, or sexual/affectional orientation; 2) the political, economic and social equality of women and men; and 3) the equalitarian relationship between counselor and client. We believe that women are strong and capable, and that with adequate support, can make the decisions and changes within our lives which will allow us to feel like whole, healthy individuals.

The collective is a non-profit organization which offers a sliding fee scale to ensure that all women can have access to counseling at a fee they can afford. Counselors receive pay for services rather than a salary and work in the collective because of their commitment to the equality of women.

We offer flexible hours of work but are currently in need of counselors who can provide evening and weekend sessions to our clients. If you are interested, please send curriculum vitae to: Calgary Women's health Collective, 316-223 12 Avenue S.W., Calgary, AB, T2R 0G9, Tel.: (403) 265-9590



# REGIONAL RESOURCES

*Just A Kiss* is a story on teen dating violence depicted through a series of black and white photographs, with narration in photo captions by the **Vancouver's Battered Women Support Services (BWSS)**. An Instructor's Discussion Guide will be developed by BWSS. *Just A Kiss* is available for \$1 from: BWSS, P.O. Box 1098, STN A, Vancouver, BC V6C 2T1

**The First Mature Women's Network Society** offers support, information and referrals to women 45 and older. Their programs provide social and educational opportunities designed to foster self-development and interaction. They have designed the *Social Health Outreach Program (SHOP)* and are presently distributing two manuals for the health/social service fields. The first: *The Leader's Manual for the SHOP*; the second: *Depression Is a Feminist Issue* is designed to work in conjunction with the Leader's manual. Contact: **Mature Women's Network Society**, 411 Dunsmuir St., Vancouver, BC V6B 1X4

**The B.C. Federation of Labour**, with the assistance of the CUPE National Office, has produced a package, *Ending Workplace Discrimination Against Lesbians and Gay Men*. It includes information on negotiating contract clauses and benefits; legal avenues to redress discrimination; and insurance carriers who recognize same-sex spouses. As well

as articles on homophobia, and community organizations working to advance lesbian and gay rights in B.C., Contact: **The Lesbian and Gay Benefits Committee**, 4279 Canada Way, Burnaby, BC V5G 1H1

Linda Franchi has produced two videos for Deaf youth and adults, done in sign language with voice narration and caption. *Sharing Secrets* (1992) focuses on the facts of sexual abuse and prevention. Available from: **Greater Vancouver Association of the Deaf**, 2125 West 7th Ave., Vancouver, BC V6K 1X9, TDD (604) 738-4644. The second video *Loving Yourself* (1989) is a 3-part drama that deals with sexuality issues. From: **Cumberland County Family Planning**

*Repetitive Strain Injuries in the Workplace* is a booklet produced by **Women and Work Research and Education Society**. It contains information on how to identify repetitive strain injury, what to do next, your legal rights and issues around Workers' Compensation claims.

Order from: 4340 Carson St. Burnaby, BC, V5J 2X9 (604) 430-0458

**The Vancouver Status of Women** has published a *Single Mothers' Resource Guide for Vancouver and the Lower Mainland*. They list services and information on areas such as: housing, childcare, legal assistance, and freebies/

cheapies. They intend on updating the guide this fall. To order or suggest revisions contact: **Vancouver Status of Women** Suite 301-1720 Grant Vancouver, BC V5L 2Y6 (604) 255-5511

*Taking Action A Union Guide to Ending Violence Against Women* is a resource that workers can use to get the information they need on violence against women in the home, the paid workplace and the community. The guide is \$10.00 (plus \$2.50 p&h). Add \$.75 for each additional item. To order: **Women's Research Centre**, #101-2245 West Broadway, Vancouver, BC V6K 2E4

**The BC Coalition of People with Disabilities (BCCPD)** has produced a special edition of their magazine, *Transition*, on violence against women with disabilities (Feb/March issue) BCCPD, 204-456 West Broadway, Vancouver, BC V5Y 1R3 (604) 875-0188, Fax (604) 875-9227

*Law, Liberty and Childbearing at the Turn of the Century: Maternal Liability, Surrogate Motherhood and Donated Genetic Material* is a report on legal implications arising from some of the new reproductive technologies. A bibliography is included on each subject as well as a glossary of terms. This study gives a number of recommendations for law reform and some examples of surrogate motherhood

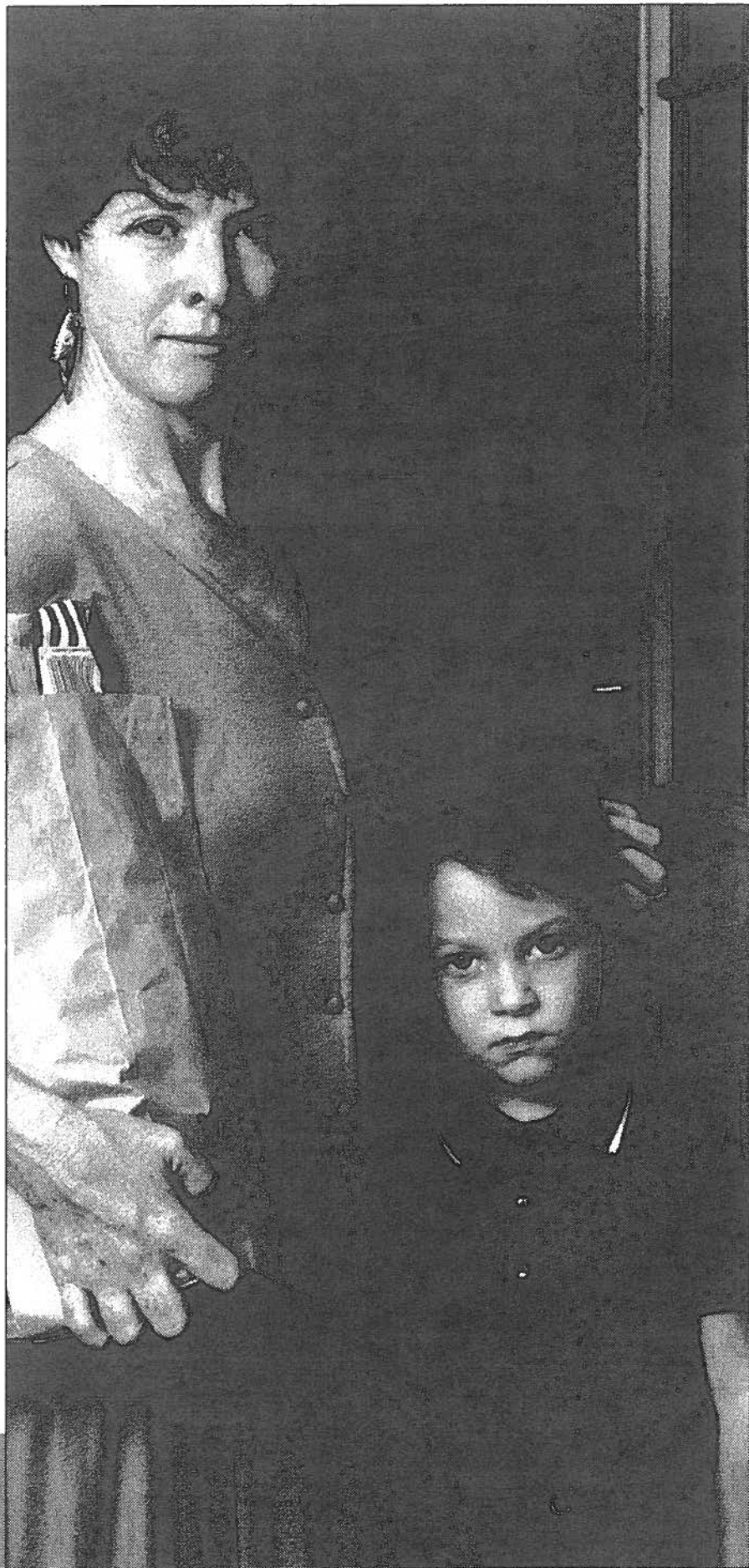
contracts. The report is \$22.00, (includes GST), from: **Alberta Civil Liberties Research Centre**, 310-1167 Kensington Cres.N.W., Calgary, AB T2N 1X7 tel. (403) 283-3643

**The Calgary Status of Women Action Committee** are organizing a conference to be held October 23-24, 1992 called *"Celebrating Diversity, Moving Towards Alliance, Creating Community."* bell hooks will be the keynote speaker and workshops will be held on the three title themes. If you want to submit a workshop proposal or more information about the conference, contact: 319-223 12th Ave. SW, Calgary, AB., T2R 0G9 tel.(403) 262-1873

*OUTrights - Les Droits VISIBLE Canadian Conference on Lesbian and Gay Rights* will take place Thanksgiving 1992. The second pan-Canadian conference on lesbian and gay rights. Bilingual participatory forum to exchange information and work together to develop political, organizational, and legal strategies. Contact: barbara findlay (604) 251-4356 321-1525 Robson St., Vancouver, BC., V6G 1C3

*Two Spirited Gathering*, August 6-10, 1992 an alcohol and drug free gathering for two spirited (lesbian and gay) people and their families, including non-Native lovers and friends. contact: **Vancouver Two Spirits**, P.O. Box 598, Stn A., West Vancouver, BC V6C 2N3 or Michelle at (604) 687-4100

*"Women's Health Across the Life Span - Research Issues"* October 16-18, 1992, **University of British Columbia Centre for Research in Women's Studies and Gender Relations**, 314-2206 East Mall, Vancouver, B.C. V6T 1Z3 (604) 822-9173



# EVERYONE TOUCHED BY VIOLENCE SUFFERS.

OFTEN SILENTLY.  
THE SHAME.  
THE UNSPOKEN.

In the labour movement we speak out against injustice. In all its forms

Even when it is inside our own families. Our own union.

CAW women and men are working together for social justice and human dignity.

Violence. First we must name it. Then, together, we can work to stop the suffering.

If you or your child are being hurt or intimidated, or you know of someone who's in that position, break the silence!

For assistance call your local Wife Assault Helpline, shelter or sexual assault centre.

## VIOLENCE: BREAK THE SILENCE.

CAW  TCA  
CANADA