

## **Community Health Advocate Project**

*Of the Vancouver Women's Health Collective (VWHC)*

Sharon Martin Community Health Initiative Fund  
For the Vancouver Coastal Health Authority

Date: January 14, 2001

Submitted by: Angela J. Gray, CHA Coordinator

Phone: 604-736-4234 Fax: 604-876-1282

### **EXECUTIVE SUMMARY**

The Community Health Advocate Project (CHA) is an outreach project which focuses on helping women in the Vancouver/Richmond region to educate themselves about their rights within the health care system. CHA was developed to help women protect themselves against disrespect and abuse of any kind within the health care system. This is accomplished through the CHA projects Patient's Rights workshop and Information Kit.

The Patient's Rights workshop is a tool designed to educate women about their rights within the health care system. From April 1, 2001 to December 31, 2001 twelve workshops were given. There were a total of 95 participants in attendance from 10 different organizations. We reached a range of women through these workshops. We also updated our CHA Information Kit to be a user friendly resource. The CHA Information Kit (a take home resource for workshop participants) was updated to include clear language, clear form and design. This document, created with input from "community hosts", highlights hospitals' and clinics' services in Vancouver and the Lower Mainland, questions to ask your doctor about diagnosis and treatment options, and information about the Medical Services Plan.

The project was a great success in the past year due to the increase in community organization participation. The participation of community organizations acting as "community hosts" for the Patient's Rights workshop and being active participants in the design and shaping of the workshop to meet the needs of their group, was a valuable learning opportunity for the Vancouver Women's Health Collective (VWHC).

## **GOALS OF CHA**

- Provide information and support for women accessing the health care system.
- Identify the main issues and problems within the health care system for women in identified communities.
- Help women become the experts and decision-makers around their own health.

Continually providing the Patient's Rights workshop in identified communities helps us to accomplish these goals. The participants of these workshops come from a diversity of backgrounds. They gain knowledge about what respectful health care is, and learn the skills to help themselves. The Patient's Rights workshop includes:

- **an introduction about the VWHC** – including information about the resources we provide and the purpose of CHA
- **information about what it means to access safe, respectful health care** – including information about what a patient's rights are within the health care system, and how to access appropriate health services i.e. when to use emergency
- **self-advocacy skills** – including a definition of self-advocacy, how to stand up for oneself by asking the right questions
- **informed consent** – including information about what a health practitioner must tell a patient before treatment
- **doctor's rights** – what a doctor's rights are as a practitioner in the health care system

## **ACHIEVEMENTS IN MEETING GOALS AND OBJECTIVES AS IT RELATES TO HEALTH OUTCOMES**

CHA is an outreach project that focuses on helping women protect themselves against disrespect and abuse within the health care system through our Patient's Rights workshop. The Patient's Rights workshop is a preventative tool to help women gain self-advocacy skills and make more informed choices about their own health care. A common barrier raised by the women is the lack of language and cultural sensitivities of health care providers. The self-advocacy skills women learn through the Patient's Rights workshop enables women to educate health care providers around the barriers they face. In that way, the CHA project also supports women as a vital force in contributing to improvements to health care. From April 1, 2001 to December 31,

2001 twelve workshops were booked resulting in only one cancellations (due to low numbers). There were a total of 95 participants in attendance from 10 different organizations (see attached page 8 &9).

The CHA Information Kit is a resource tool that is being given out at the workshops. The Information Kit gives women 28 pages of health information including where to access clinics in their community and questions to ask their doctor to help determine what the best choices are for their health care. We have learned that communicating in “clear language” is essential in helping women from a range of cultural backgrounds take charge of their own health care. We have worked extensively on the CHA Information Kit to ensure that it is written in “clear language” with an equally clear form and design.

Although we provided twelve workshops, the bus strike seriously impacted our ability to do more community outreach. This limitation on community outreach did not enable us to meet with organizations to promote CHA. Nor were we able to schedule workshops over the summer months. Because our commitment was to provide most of our workshops to existing women and family programs we were dependant on the women themselves showing up to the group they committed too. Therefore at some workshops the participation was low, and at others the participation was high.

The CHA project underwent significant changes in the 1999 – 2000 period which impacted the evaluation of the project. The project was heading into a new direction and the funding level at the time allowed for a work week of 10 hours for the CHA coordinator. Therefore at the time, it was decided the priority of the project was to set up and establish relationships with community hosts, and design and promote the Patient’s Rights workshop. This focus continued through until the early part of 2001. Unfortunately this meant that we had not allotted time to revise the evaluation process that was in place for the original project.

However, the bus strike period helped us to focus our time and establish the evaluation process that was put in place September 2001. This process consisted of the participants of the Patient’s Rights workshop filling out an evaluation. This evaluation form was based on a scale format. The community host facilitator also filled out an evaluation that had questions, which required written answers. In this early stage of the evaluation process, 52 participants, with 28 evaluations have been filled out. Five community host facilitators filled out evaluations. Although the respondents are still few, 86% of the participants have told us that they strongly agree or agree that they feel better prepared to ask their doctor a question about their health. As well, all of the 28 women who completed the evaluation stated that the CHA Information Kit would be useful when visiting their doctor. Also, 92% of participants said that they agreed or strongly agreed the CHA coordinator was well prepared and easy to understand.

community host facilitators also filled out evaluations, (see attached for comments page 10-12).

We have learned that having an evaluation process in place before your project activities is an extremely important step in project evaluation. Also having participants fill out evaluation forms is another step in communities participating in the development of the CHA project. The feedback we have received has helped us to stay focused and to look at ways to improve the evaluation process in order to help us measure how the CHA project is saving health care dollars.

### **DEVELOPMENT OF PARTNERSHIPS AND FOCUS POPULATION AS RECIPIENTS AND DECISION - MAKERS**

The CHA project works directly with community organizations, which serve as “community hosts” for our Patient’s Rights workshop. This has contributed significantly to the success of the CHA project, allowing us to reach a diversity of women. From April 2001 to December 2001 CHA has worked with 12 host organizations. With each host organization the CHA coordinator made preliminary phone calls to discuss the workshop format. The workshop was then tailored to meet the needs of the specific group. This process ensured that the workshop design was culturally appropriate, sensitive and accessible to the communities served. The CHA coordinator contacted the host organization after each workshop to gain feedback and to schedule a follow up workshop if appropriate. Gaining feedback from both the community hosts and the women they serve has been fundamental in the development of the workshop design and the Information Kit. The CHA project is designed to address the needs of the community. Going to the community through the community hosts to find out what their needs are is a key part of this process. Now that the evaluation process is in place we can design better workshops and fine-tune the information of both the workshops and the Information Kit. This continues to better serve the diversity of women we serve and reflect the needs of specific groups.

Through feedback from our community hosts and the women they serve we found that women were looking for information about local hospital services (including translation services within the hospitals) and local clinics. The workshop participants wanted to also know what services Medical Services Plan and Pharmacare covered. Many participants asked about “what is the College of Physicians” and “how do you file a complaint against your doctor?” The CHA Information Kit is a 28-page resource tool that answers these questions. The Information Kit also provides women with health information and questions women can ask their doctor to help determine what the best choices are for their health care. (see enclosed **Information Kit**)

Our affiliation with these community hosts has broadened the diversity of women who access the VWHC and utilize our services. It also gives the VWHC a broader understanding of available community services and where we may refer women. Having access to the programs available at community host organizations increases the effectiveness of the workshop learning experience and enables us to better promote CHA. Also, through the participation of community host we have translated our CHA brochure into six languages including English.

### **PROGRESS ON ADDRESSING THE HEALTH NEED IDENTIFIED IN THE PROPOSAL**

As stated previously, CHA is an outreach project which focuses on helping women in the Vancouver/Richmond region to educate themselves about their rights within the health care system. CHA was developed to help women protect themselves against disrespect and abuse of any kind within the health care system. This is accomplished through the CHA projects Patient's Rights workshop and Information Kit. The following two examples illustrate the positive effect the CHA projects Patient's Rights has had on women's lives.

A very upset woman attended a Patient's Rights workshop in April 2001. This woman was quite sick, dying from cancer and did not have a doctor. She was being refused care from her doctor, because of the course of treatment she wished to follow (using alternative methods). She had been to three doctors by the time she attended the workshop and all had refused to treat her. The Patient's Rights workshop components on how to find a new doctor and how to advocate for yourself to get your needs met were useful to her. She also learned that if a doctor refused to treat her (which is a doctor's right) the doctor must continue treating her until she has found a new doctor. The CHA coordinator also shared with her that she had the right to use alternative methods of treatment for cancer. This woman did leave the Patient's Right workshop feeling relieved that she had some options and knew more about available community resources.

A woman who had been in a car accident and suffered neurological damage participated in a Patient's Rights workshop recently. She shared the following with the CHA coordinator and other participants: a neurologist had prescribed medication without explaining the possible side effects, one being permanent damage to the eyes. The doctor ordered the medication and set an appointment with her to administer it. The woman felt she needed a second opinion, sought that out, and was advised by the doctor not to take the drug because of the side effects. The woman phoned her neurologist and

explained her concerns as best she could (given a language barrier) and cancelled her appointment to have the medication administered. This upset the neurologist (among other reasons because of the expense of the medication) who made a note on her file that she needed to see a psychiatrist because he felt she had mental health issues. Because of this note on her medical records, the woman felt other neurologists refused to treat her and recommended she see a psychiatrist. The Patient's Rights workshop gave her information about the College of Physicians complainants process, informed her about how to access her medical files, and gave her suggestions about how to advocate for herself. As well, the woman was informed about how to have the information that she felt was preventing her from getting treatment she wants and needs, removed from her file.

In general, information shared at workshops by community hosts, workshop participants and follow up phone calls, we have learned women unnecessarily use costly emergency room services as a first choice for minor ailments, as opposed to using a clinic or visiting a doctor. The Patient's Rights workshop encourages women to access appropriate health services. By giving women information about the range of options available to them in accessing health care, women will make more informed choices about where and how to access this care.

### **SIGNIFICANT CHANGES TO THE CHA PROJECT**

Because the CHA project has undergone significant changes since its original proposal, we felt that it was important in order to put an evaluation process in place. As well, we felt it was necessary to update the goals and objectives of the project, (see attached pages 14 -18).

### **THE CHA PROJECT AS IT RELATES TO THE WOMEN'S HEALTH PLANNING PROJECT RECOMMENDATIONS**

#### **Adopt the framework for women-centred health as a policy:**

The VWHC has been apart of the Vancouver/Richmond region for thirty years. And was founded in order to help women access appropriate health care. All the services we offer have a women-centred approach to health care.

**Address the empowerment of women:**

The services of the VWHC including the CHA project's Patient' Rights workshop are designed to help empower women to take charge of their health care.

**Address the need for information:**

The VWHC provides extensive information about women's health issues. The CHA projects Information Kit provides women with valuable health resource information. If women have information about available health services and information about how to access those services, they will get their health needs met using appropriate services.

**Address women's patterns or preferences in obtaining health care:**

The CHA project works with community organizations who support and help women help themselves, through providing women-centred programming which provides childcare. The VWHC is a women centred space that enables women to access a host of information including complementary therapies.

**FUTURE OF PROJECT**

The VWHC has applied to the Canadian Women's Foundation for additional funding to support the Vancouver Coastal Authority funding for our 2002/2003 fiscal year. To maintain the project at its current level it will be necessary to secure additional funding.

Again, given that the evaluation process is still in its infancy, continued work is still needed in order to find a method that can quantify what we are being told by participants and community hosts. Looking at ways to measure how health care dollars are being saved, because women are accessing appropriate services, will be explored in the context of our evaluation process. We will also be looking at ways to follow up with individual participants who are experiencing immediate challenges within the health care system.

The future of the project will involve establishing new relationships with community host such as senior and youth organizations. The Information Kit is a resource tool which will need to be updated on occasion. A priority before March 31, 2002 will be translating health information for some immigrant populations we work with.

Barriers to accessing respectful appropriate health care services for a diversity of women remains an issue. The CHA project's Patient's Rights workshop and

Information Kit are a valuable way to help women address barriers they face in the health care system. The CHA project teaches women how to advocate for themselves within the health care system and be proactive around their own health care.

We have come to realize that greater integration and promotion of CHA activities and other VWHC activities will increase the understanding of our services in the community and help us ensure our Information Centre fulfills the needs of different communities.

Through this project we have built relationships in the women's community that includes PACE inviting us to be a community partner in a project that they are developing for Health Canada. So we continue to grow turning our weaknesses in to strengths in order to better serve women. The VWHC thanks the Vancouver Coastal Health Authority for helping us meet the needs of this important and viable project.



## **APPENDICES**

### **PATIENT'S RIGHTS WORKSHOPS PROVIDED BETWEEN APRIL 1, 2001 TO DECEMBER 31, 2001**

- Women of the Downtown Eastside – Patient's Rights workshop in partnership with Sheree Hudson of the V/RHB (now the Vancouver Coastal Health Authority) –April 4, 2001 – 4 participants
- The Centre, Queer Women's Health Series – Patient's Rights workshop -- April 26, 2001 – 10 participants
- Traditions Program – Burnaby Family Life Institute – Patient's Rights workshop -- May 10, 2001 – 10 participants
- Raycam Community Centre – Patient's Rights workshop -- May 17, 2001 – 10 participants
- Leads Group II, Pacific Immigration Resource Society (PIRS)– Patient's Rights workshop -- October 10, 2001 – 12 participants
- Vancouver and Lower Mainland Multicultural Family Support Services – Patient's Rights Workshop -- October 31, 2001 – 6 participants
- Vietnamese Women, Multilingual Orientation Services Association for Immigrant Communities (MOSAIC)– Patient's Rights workshop -- November 5, 2001 – 17 participants
- Sex trade workers, Prostitution Alternatives Counselling Education (PACE)– Patient's Rights workshop -- November 8, 2001- 4 participants
- Leads Group III, Pacific Immigration Resources Society (PIRS) – Patient's Rights workshop – November 15, 2001- 9 participants
- Youth and Adults, Gathering Place Education Centre – Patient's Rights workshop -- November 26, 2001 – 7 participants
- Gab Youth Services, The Centre – Patient's Rights workshop – December 11, 2001 - 4 participants
- Youth, Byng Satellite School – Patient's Rights workshop – December 13, 2001 - 12

### **COMMUNITY OUTREACH APRIL 1, 2001 TO DECEMBER 31, 2001**

- May 2, 2001 – PACE re: Patient's Rights
- July 17, 2001 – BC Coalition of People with Disabilities – re: Patient's Rights issues of People with disabilities
- July 24, 2001 – BC Coalition of Disabilities – re: planning for Patient's Rights workshop
- August 5 – 10, 2001- Facilitators Training with Headlines Theatre –the CHA coordinator attended this week long training and networking session
- August 14, 2001 - BC Coalition of Disabilities – re: planning for Patient's Rights workshop
- September 13, 2001 – Vancouver and Lower Mainland Multicultural Family Support Services – re: Patient's Rights workshop
- September 20, 2001 – PACE – re: Patient's Rights workshop
- September 26, 2001 – Community Meeting sponsored by The Centre – networking
- September 26, 2001 – Gathering Place Education Centre – re: VWHC services and CHA
- October 18, 2001 – BC Coalition of People with Disabilities – re: postponement of workshop
- November 10, 2001 – Gathering Place Education Centre – re: Patient's Rights workshop

Community Outreach in this period also involved calling and faxing organizations to inform them about about the VWHC and the CHA project's Patient's Rights workshop.

## **COMMUNITY HOST FACILITATORS RESPONSES TO THE PATIENT'S RIGHTS WORKSHOP**

(These comments to follow are direct quotes from the Community host evaluation forms).

### **What were your expectations of the Patient's Rights workshop?**

"To know what Patient's Rights are. To know what doctors Rights are."

"To inform women about their rights and to make them understand that they also must be proactive as far as health is concern"

"Women be more aware and understand better their rights as patients or as parents of sick children. Women to be more assertive to exercise their Patient's Rights. Women know relevant questions to ask health care providers"

"To get info on community medical services. To get info on women's centred medical services (family planning, abortion clinics etc.). To discuss rights of Patient's/Doctors"

"Wanted info on services covered by MSP. Wanted to know how to make a complaint"

### **Were your expectations met?**

All 28 respondents stated that they felt their expectations were met. One respondent also shared that more workshop time would be needed: "Because of the women's culture and past experience with a number of health care providers, the women need more workshop time to discuss about assertiveness"

"Yes with the help of useful handouts and explanation from Angela"

### **Do you have any concerns about the information provided in the workshop or in the CHA (Community Health Advocate) Information Kit?**

No concerns were raised about the Information kit. Additional information was requested though:

"Would you please add in the Lady's Name and telephone number that Angela had mentioned we can ask for advice from when our Request was rejected by our family doctor"

“No looking forward to the follow up info on age of consent for treatment”

**Workshop content strengths**

“lots of good info”

“information”

“valuable information accessible medical services and clear expectation about Patient/doctor relationship and boundaries”

“very useful information provided our group of women really liked it”

“respectful, organized, fun great advocates”

**Workshop content weaknesses:**

“short of time – 2 hrs including questions will be ideal”

“some activities to break up the talking would be great”

“level of English”

“did not find any”

**Workshop facilitator strengths:**

“friendly, patient and well informed”

“stopped to make sure women understood”

“well prepared, with aid of flipchart, discuss topics were clearly showed”

“clear understanding of the topics, respect and good listening skills to the women, flexibility with the agenda”

**Workshop facilitator weaknesses:**

“speaks too quickly”

“can’t pinpoint”

**Would you recommend this workshop?    Yes                      No                      Why?**

Four out of five responded, yes, they would recommend this workshop. Some of the comments included:

“Important immigrant women understand their rights in Canada. Also need to understand our Health System”

“Very helpful for women. Its good to be aware of their rights, and to be more in control or their health.”

“To let more women know about Patient’s Rights and no more fear about executing their rights”

“Because women in this community are not aware of the Women’s Health Collective and the work they do. If women know what their rights are and what services are available they are more likely to use these services.”

**COMMUNITY HEALTH ADVOCATE PROJECT – GOALS AND OBJECTIVES**  
**UPDATED JULY 2001**

The overall goal of this project is to provide the women of the Vancouver/Richmond region a consistent means to deal with the systemic violence they may experience in the health care system.

**CHA Project Goals Corresponding To The Vancouver/Richmond Health Board (V/RHB)**

The CHA projects initial goals and objectives corresponded with some of the overall goals of the V/RHB.

**The following project goals correspond to the V/RHB Goal # 1**

V/RHB Goal # 1: Promote and advocate improvements in the broader determinants of health.

**The following project goals correspond to the V/RHB Goal # 1**

**V/RHB Goal # 1**

Promote and advocate improvements in the broader determinants of health

- 1. To empower women to take steps to prevent the manifestation of this violence in their own lives (1.1)**

**Outcome measure (s):**

**Old** increased number of women from the identified piloted communities(Somali, Farsi, South Asian, Latin American, Chinese, Women of Colour, Aboriginal, Women of the Downtown Eastside, Mental Health Consumers Women with Disabilities, Lesbian, Bisexual, Transgendered Women, Poor Women) accessing community services that specifically deal with violence against women.

**Update** increased number of women from communities in need accessing community services that specifically deal with violence against women *facilitated through the Patient's Right's workshop, the Information Kit,*

*information sharing occurring within the workshop sessions, and women accessing the Vancouver Women's Health Collective (VWHC).*

**2. Systematically raise awareness of the direct violence women experience from the health care system (1.1)**

**Outcome measure (s):**

**Old** holding 2 community-specific workshops for each identified community around the manifestation of violence in the health care system.

**Update** holding an introductory and follow up community-specific Patient's Rights workshop with each community organization within the lower mainland interested in the Patient's Rights Workshop

**3. Document the region-wide incidence of violence against women in the health care system (1.2)**

**Outcome measure(s):**

**Old** assessed by the Community Health Advocates through a monthly evaluation form, which enables them to collate and categorize the experiences of the women they have dealt with that month. This information will be used by researchers, policy makers and incorporated into educational work.

**Update** assessed by the workshop facilitator who documents, with permission, participant's experiences within the health care system shared during the workshop. As well, space is provided on the Patients Right's workshop evaluation form for women to share their experiences within the health care system. This information is collated and categorized for the evaluation process and funding reports. This information can be used by researches, policy makers and incorporated into the overall educational work of the VWHC.

**4. Build on and strengthen resources that already exist, such as women's centres, community centres, health units and community organizations (1.2)**

**Outcome measures(s):**

**Old** evaluating the success of the Community Health Advocates in working out of these facilities based on the ease of integration and ongoing access to the presenting population.

**Update** evaluating the success of the Patient's Rights workshop being facilitated from these facilities based on the ease of integration and on-going access to the requesting populations.

**The CHA projects goals # 1-4 also address priorities set by the women's PHAC: Women's advisory committee priority #2: Violence against women.**

**The following project goals correspond to the V/RHB Goal # 5:**

**V/RHB Goal # 5**

Ensure greater public participation and responsibility in the health system

- 5. to promote a healthy community by using a community development model of advocacy(5.1)**

**Outcome Measure(s):**

**Old** assessing the increased input into community health plans by the individuals or groups of women that come into contact with the Community Health Advocates.

**Update** assessing the increased input into community health plans by the organizations representatives who meet with the CHA coordinator to plan Patient's Rights workshops in their community as well as during the CHA projects on-going evaluation process.

**The CHA projects goals # 5 address priorities set by the women's PHAC: Women's Advisory Committee Priority # 4: Participation in Health.**



**The following project goals correspond to the V/RHB Goal #6:**

**6. Promote greater choice and control by individuals using the health care system**

**Old** support women in their dealings with the health care system through a variety of advocacy roles(6.6)

**Update** support women in their dealings with the health care system through the Patient's Rights workshop and the Information Kit

**Outcome measure(s):**

**Old** having at least 9 Community Health Advocates trained and working in the community at the end of the pilot

**Updated** providing 3 Patient's Rights Workshops per month held at community organizations which support the CHA project goals and objectives.

**7. To provide consistent health care information around community specified health issues in a format that is community driven(6.3)**

**Outcome measure(s):**

**Old** produce a comprehensive Community Health Advocate training manual in plain English, covering the following topics:

- baseline information regarding access to the health care system – i.e. MSP – what is covered what is not
- common reproduction health issues
- patients rights in the system
- recourse for actions around abuse within the system
- the number of requests for information to the Vancouver Women's Health collective by the Community Health Advocates for issue specific material to be translated

**Updated** produce an inclusive Patient's Rights workshop that is tailored to individual communities

-produce a comprehensive Patient's Rights facilitators training manual  
-produce an Information Kit for Patient's Rights participants of updated basic information regarding access to the health care system (using I information from the Community Health Advocates Training Manual)

- baseline information regarding access to the health care system – i.e. MSP – what is covered what is not
- common reproduction health issues
- patients rights in the system
- recourse for actions around abuse within the system
- the number of requests for information to the Vancouver Women’s Health collective by the Community Health Advocates for issue specific material to be translated

**Goals # 6 & 7 also address priorities set by the following PHACs: Women’s Advisory Committee Priority # 5: Medicalization of Women’s Lives**

**The following project goals correspond to the V/RHB Goal # 7:**  
Respect, recognize and support health service providers as a vital force in contributing to the improvements in the health care system.

**8. By participating in research with the Centre of Excellence for Women’s Health, we can help health care workers and women to work together to develop a system that is respectful of both their needs (7.2)**

**Outcome measure(s):**

**Old** at least one research study linking women with health care workers to develop ‘better practices’ around the issue of power imbalances between women and health practitioners

**Update same as above**

**9. Public methods to deal with these power imbalances to prevent the direct violence women experience from health practitioners and empower women and health practitioners to adopt these ‘better practices’(7.3 and 7.4)**

**Outcome measure(s):**

**Old** 2 day long workshops with health practitioners and women consumers around dealing with these issues

**Update** the continuous promotion and delivery of the Patient’s Rights workshop which helps women give voice to these issues and become educators to their health care professionals. The CHA project works with community organizations working in the area of educating health practitioners on adopting ‘better practices’.

**Goals #8 & 9 also address priorities set by the women PHACs: Women's Advisory Committee Priority # 3: Access to Health Services**