

7

**Is There A Need For A
Community Based Health Advocate?**

**A report by the Vancouver Women's Health Collective
For the Ministry of Social Services and Housing**

Submitted to Fred Milowsky
Regional Director, Region B
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INDEX

page

Introduction.....	1
Sec A: Availability of Health Advocacy Services.....	2
Sec B: Process For Making A Health Complaint.....	3-6
(1) Personal Barriers.....	3-4
(2) Systemic Barriers.....	4
(3) Consumers lack of knowledge of disciplinary bodies and their services.....	4-5
(4) Self Policing by Health Care Providers.....	5-6
Sec C: User Guidelines on How to Make Health Services Complaints.....	7
Sec D: Link With Community Services to Promote Women's Health.	8
Sec E: Community Health Advocate - Concerns and Benefits.....	9-14
Concerns:	
(1) Funding.....	10
(a) availability & continuity	
(b) impact on other service's funding	
(c) program costs	
(2) Structure.....	11-12
(a) accountability	
(b) role re:existing services	
(3) Access.....	13-14
Benefits:	14
Summary:.....	14

INTRODUCTION

The Vancouver Women's Health Collective received grant funding through the Community Advocacy Program. The moneys totaled \$9,800.00 and were applied to two specific projects. Included are the project summary's for your review.

In November of 1992 the health collective sponsored a conference entitled: 'Leaping Into Health: Women Taking Action.' The conference addressed a variety of women's health issues that included information on menopause, multicultural and native health, eating disorders, and sexuality and disability. We wanted to provide women with a safe forum to learn and share their experiences and discuss strategies for how the health system could better address their needs.

We identified several barriers that could impact on women attending the conference. Cost, language and child care were considered to be key issues. To try to offset these factors portions of the grant money were allocated to the provision of child care and sign language interpreters. There was a sliding fee scale for all conference registrants as well. These considerations allowed women whose information needs are often ignored to fully participate in this event. There were approximately 130 women at this event.

The second project was to determine the need for a community based health advocate and what role(s) this individual would have within the health system. One hundred and forty-two questionnaires were circulated to hospitals, health clinics, women's center's and community groups. A shorter health advocacy survey was available to four hundred and twenty-seven health consumers.

The project goals will be discussed in the following five sections. At the end of each section are recommendations for enhanced service delivery.

Section A: - reviews the availability of community health advocacy services and where there are service gaps and overlaps;
Section B: - reviews the procedures for health consumers to utilize when they have concerns about the care or treatment they have received or can receive;
Section C: - addresses the creation of a health consumers guide about the complaint process;
Section D: - reviews how this project through the VWHC established links with community services to promote the health and wellness of women;
Section E: - identifies potential concerns and advantages to a community health advocate and includes recommendations for further projects proposals about health advocacy;

Concerns raised by respondents about a health advocate were focused on several key areas. These were funding, structure, and accessibility. Each will be discussed separately with proposed solutions.

- 1) Funding a)availability & continuity;
 b)impact on other service's funding;
 c)program costs;

1a)Concern: How will the advocacy service be funded? This was a concern of many of the existing community based services. Many have faced service cuts due to budgetary restrictions and limited outside resources. There needs to be adequate funding for project set-up and delivery for a least one year. If funding cannot be guaranteed for this period it may be advisable to look at service delivery in conjunction with existing services.

Recommendation: We will apply for project funds through the Ministry of Health and Ministry of Social Services And Housing in order to implement a 9-12 month pilot project for a community based health advocacy program. The pilot project would then be evaluated and further funding sought from government, community and other funding organizations if appropriate. If funds are not available we will explore cooperative advocacy education projects with other community and health service groups.

1b)Concern: What type of impact will this program have on funding of existing health advocacy services?

Recommendations: In order to develop this program it is vital that community groups and health services are active participants. The ART is a resource that would offer training and information to individuals and groups. It is not our intent to replicate services, but to build upon what is in existence. The health collective plays an active part in lobbying for adequate funding and support for community based health services.

1c)Concern: Won't this type of program be expensive to operate and how will operational costs be offset.

Recommendations: The program requires a minimum of three full-time paid staff and a large volunteer base. The initial budget will have to include costs to set-up, data collection, computerized data base and development of resource/training materials. Once these steps are achieved there will be a significant reduction in costs. Expenses will then be primarily for salaries and resource information. Costs will be offset by a fee for service to health professionals and community agencies requesting materials and/or training from the ART.

- 2) *Structure:* a) accountable to whom?
b) role re: existing advocacy services;

2a) Concern: Who is the advocacy resource team accountable to and what process would be in place to monitor service delivery?

Recommendations: The advocacy resource team (ART) would be a project under the umbrella of the Vancouver Women's Health Collective. Project staff would be responsible for providing quarterly reports to VWHC on services. They would also provide all funding agencies with a budget summary and analysis of service delivery as required. Comment sheets would be available to users and community agencies. These would be reviewed and incorporated into service development.

2b) Concern: What would the ART's role be in relation to existing services?

Recommendations: The advocacy resource team or (ART) would not be expected to carry out the role or responsibilities of any agency. Client concerns are most appropriately addressed within the agency if the agency ensures it has a clear process available. However in instances where the agency is unable to fulfill that role, the advocate would become involved. Their role is in part a liaison who assists a client(s) identify their needs, review options and clarify the system process. The advocate may also act as a representative for the client and work to bridge systems to promote the client's well being.

The ART would also provide:

public education on client rights & obligations;
provide clients/consumers with the resources and
skills to be effective advocates for themselves
lobby for training of all health, legal and social
services professionals on how to work in partnership
with clients/consumers;
a provincial toll-free information line for individuals
& service providers;

The advocate or ART (advocacy resource team) could accomplish these tasks in several ways:

- community outreach;
- training program & manual available to community groups who then provide materials to client's;
- low literacy/other language information pamphlets;
- video/audio tape information;
- direct 1-1 client service;

In order for these components to be effective and accessible the ART would require the support and involvement of the following:

Community Groups:

- to distribute and promote information;
- to identify potential barriers to information presentation and ways to alleviate or lessen barriers;

Volunteers:

- to assist users develop self help skills;
- to assist in the creation of alternate media resources;
- to translate materials into other languages lower literacy levels;

Health Services:

- to advise ART about available services and program development;
- to provide training to their personnel, possibly in conjunction with the ART about how to work in respectful partnership with clients;

3)Access: a)service provision to individuals or groups with multi-barriers;

b)willingness of health services to offer support and information exchange;

3a)Concern: How will the ART ensure their service is able to meet the needs of individuals who experience multi-barriers that include but are not limited to language, distance, economics and culture?

Recommendations: The ART will try to offset these variables by:

- * ongoing liaison and resource sharing with community groups to ascertain needs of their community, perceived barriers and problem solving strategies;
- * service fees based on ability to pay;
- * service accessible in person, or by phone or mail;
- * budget allowance for interpreter service;
- * information resources in other mediums and languages;
- * cross-cultural training for staff and volunteers;
- * affirmative action hiring;

Provision of any advocacy service must consider the wants and needs of the individuals or community it represents.

3b) Concern: How will the ART garner the support and participation of health services?

Recommendations: The ART would work to achieve this by:

- * providing information to all health services on the role of the advocate and establishing a network of contacts working within the health care system;
- * to direct and inform health consumers about services already in place within the health care system and promote the use of these avenues whenever possible;
- * to provide information to health services re:specific community identified needs;
- * to support health services that place an emphasis on prevention, education and lifestyle management;
- * to support health service initiatives to provide information and training to their personnel on how to work in partnership with clients;

Respondents viewed the following as strengths of a community based health advocate:

System Users

- * *accessible community resource;*
- * *client rights and self-advocacy education;*
- * *client empowerment;*
- * *support;*
- * *non-threatening environment, no bureaucracy;*

Community Groups

- * *gauge community health needs by identifying potential problems and barriers to the ART and health service providers;*
- * *work with health service providers to develop programs that reflect the community's needs;*
- * *members can participate in training's offered by the advocacy resource team (ART) and then present information to own community as per demand;*

Health Services

- * *develop health services and education programs that reflect the specific needs of the community;*
- * *work with ART to develop information and training for health personnel on how to work in partnership with clients;*
- * *health resources information more widely available to system users and care providers;*

Summary: The survey results indicate that there is a role for a community based health advocate or advocacy resource team. This program puts an emphasis on education and skill development for health consumers and health care providers. Communities benefit as their members take a more active role in identifying their needs and working cooperatively with others on problem solving and service development.

May 12, 1993

Dear:

The Vancouver Women's Health Collective received a Community Projects Advocacy Grant in November of 1992, from the Ministry of Social Services and Housing. The money was applied in part to determine the need for and role of a community based health advocate. We have submitted a project summary and our recommendations to the ministry.

From the information compiled there is support for a health advocacy service. Presently we are working on funding proposals to set up a one year pilot project. We will keep you updated on the status of the program.

Attached is a summary of the report's recommendations for your review. If you want more information please contact me at 7364234. Thank you for your participation and support.

Questionnaires were circulated to health services groups, community services and individuals. We wanted to ascertain:

- A. the availability of community based advocacy services and where there are service gaps and overlaps;
- B. the factors that inhibit health consumers from raising concerns about the care or treatment they have received or can receive;
- C. the various processes available to consumers with health service complaints;
- D. potential problems and advantages to a community health advocate and consider these factors in future project proposals;

A. Advocacy Availability

Recommendations

- * Better coordination of existing advocacy services to alleviate duplication of services and to ascertain gaps within present services;
- * To establish an interdependent advocacy system that addresses the needs of the whole person and not just one aspect;
- * Ensure advocates have adequate knowledge of available resources and services and understanding of how to access them;
- * Adequate funding to deliver advocacy services
- * Improved access to advocacy services that are community based, affordable and sensitive to cultural and language needs;
- * Provide users with the skills to become effective advocates for themselves to decrease forced dependence on system whenever appropriate;

- * Set up a community advocacy committee. This committee would include individuals who do advocacy in the legal, social services or health systems, as well as those who work with specific populations such as immigrants, disabled, natives, mentally ill, and the poor. By sharing their knowledge and resources the committee can identify problems inherent in the structure of the various systems, clarify processes and draw on the support and expertise of their peers. Members would be able to bring information back to their agency about community services and work to implement programs and service delivery that are sensitive to the diversity of consumers needs.
- * The community advocacy committee could act as advisors to a community based health advocate or advocacy resource team (ART). Their knowledge and experience are invaluable resources and can provide a framework for future advocacy project development. They have a role to play in health policy review and service recommendations.

B. Factors that inhibit health consumers from raising concerns about their care or treatment.

Section B is divided into four parts. Each part addresses a general concern with specific recommendations.

1) Concern: Personal barriers that can preclude a client making a complaint. These may include fear, culture, language, assertiveness, and knowledge.

Recommendations:

- * acknowledge the validity of the individual's needs;
- * create an environment that is safe, supportive and respectful;
- * cross-cultural training for personnel;
- * easy to read information materials;
- * information on community resources;
- * availability of interpreters;

2) Concerns: Systemic barriers such as complexity of process, failure to inform clients of internal and external complaint process, cost of health records, access to and clarification of chart information inhibit client's from making complaints;

Systemic barriers stem in part from the health agency's philosophy, structure and policies. There needs to be a balance between the interests of the agency and the rights and needs of the client. Health services must be flexible enough to adapt to the diverse needs of those it serves.

Recommendations:

- * recognize where and how the system and the client interrelate;
- * provide this information in a straightforward manner to clients;
- * be alert to problems within the system that endanger the client's interests being served;
- * continue to develop and implement policies and procedures that are sensitive to consumer needs;
- * shift from the best interests of the system to the interests of the larger community by allowing for more shared power and responsibility between health consumers and the health system;
- * provision of information on services and procedures in written, verbal and other formats;
- * specific information on how and where to direct concerns about care or treatment especially in clinics and hospital settings;
- * a liaison to clarify chart information in the health practitioner is unavailable or client feels there are barriers to discussion with the practitioner;

* ongoing service evaluations by clients and personnel and opportunities for the groups to work together on problem solving strategies that reduce systemic barriers;

3) Concern: Consumers lack of knowledge of disciplinary bodies and how they serve health consumers.

Recommendations:

- * educate community on their role and services;
- * circulate information about their consumer services to clinics, health units etc. and encourage that it be available to consumers and practitioners;

4) Concern: Self policing by health care providers.

Recommendations:

- * involvement by non-affiliated professionals and lay people in investigations and disciplinary procedures;
- * client being kept informed about process, time lines, outcome and any other recourse;
- * availability of a support/resource person to advise client about the process and provide support at meetings and/or hearings. This person would operate independently of the college or association;
- * bi-annual review of disciplinary process by an external advisory committee and implementation of proposed recommendations;

C. User Guidelines on How to Make Health Services Complaints

Recommendations:

- * VWHC to continue to gather information from health services about their complaint processes province wide as money and resources permit;
- * VWHC to create a data base that outlines complaint processes that consumers can access province wide;
- * VWHC will develop a series of information sheets for consumers about health services, patient rights, complaint procedures and community support resources;
- * inform client of available processes and other available avenues if not satisfied;
- * make follow-up responses to all complaints;
- * create an environment that promotes information sharing between all parties;
- * asking users to comment on service delivery through use of questionnaires, focus groups, suggestion boxes;

D. Community Based Health Advocate - Advantages and Problems

In order to determine the merit of a health advocacy program we needed feedback from the larger community identifying their needs and service wants. This was done through a questionnaire asking respondents to address the role of an advocate and factors that might impact on service delivery. Community services and individuals were strongly in support of a health advocacy program. Health center's identified certain areas where an advocacy program might be helpful. Included is a summary of respondent's comments and concerns.

81% of respondents wanted the health advocate to provide:

information on the health care system;
public education on client/patient rights;
clients with skills and resources to become effective advocates for themselves;
information and training to health professionals on how to work in partnership with clients;

The consensus between service providers and health consumers on the importance of the above items suggests the growing trend for increased client participation in their own health care. The health system is having to rethink their provision of care and service delivery. System users want access to and information about preventative and alternative care services. They want to make informed choices that consider their lifestyles and health wants and needs.

Approximately 72% wanted the advocate to provide:

individual advocacy;
community outreach;
information on how and where to make complaints;

Approximately 54% wanted the advocate to provide:

group advocacy;
listing of health agencies;
health practitioner directory;
** to participate in the investigative process of health service complaints;*

* There were concerns that the advocate's role would be jeopardized if they participated in the complaint investigation. There is however an identified need for someone not affiliated with the health system to be involved with this process. Refer to Section (B.4) for recommendations.

Concerns raised by respondents about a health advocate were focused on several key areas. These were funding, structure, and accessibility. Each concern will be discussed separately with proposed recommendations.

- 1) Funding:
 - a) availability & continuity;
 - b) impact on other service's funding;
 - c) program costs;

1a) Concern: How will the advocacy service be funded? This was a concern of many of the existing community based services. Many have faced service cuts due to budgetary restrictions and limited outside funding resources. There needs to be adequate funding for project set-up and delivery for at least one year. If funding cannot be guaranteed for this period it may be advisable to look at service delivery in conjunction with existing services.

Recommendation: We will apply for project funds through the Ministry of Health and Ministry of Social Services And Housing in order to implement a 9 - 12 month pilot project for a community based health advocacy program. The pilot project would then be evaluated and further funding sought from government, community and other funding organizations if appropriate. If funds are not available we will explore cooperative advocacy education projects with other community and health service groups.

- 1b) Concern: What type of impact will this program have on funding of existing health advocacy services?

Recommendations: In order to develop this program it is vital that community groups and health services are active participants. The ART is a resource that would offer training and information to individuals and groups. It is not our intent to replicate services, but to build upon what is in existence. The health collective plays an active part in lobbying for adequate funding and support for community based health services.

- 1c) Concern: Won't this type of program be expensive to operate and how will operational costs be offset

Recommendations: The program requires a minimum of three full-time paid and a large volunteer base. The initial budget will have to include costs for set-up, data collection, computerized data base and development of resource/training materials. Once these steps are achieved there will be a significant reduction in costs. Expenses will then be primarily for salaries and resource information. Costs will be offset by a fee for service to health professionals and community agencies requesting materials and/or training from the ART.

- 2) Structure:
 - a) accountable to whom?
 - b) role re: existing advocacy services;

Section A: Availability of Health Advocacy Services

The responses we received indicate there are community services that actively engage in client advocacy work. Their primary focus is on legal, financial, housing and social issues, rather than health concerns.

Other groups outlined that advocacy work is not part of their agency's mandate. Staff may engage in advocacy work on an ad hoc basis. This depends in part on the client's needs, time constraints on the service providers and cost. Several respondents stated they had to refer clients to existing community advocacy services that they believed were already overburdened. These groups saw a need for advocacy services, but were unable to provide the services to the extent demanded.

Recommendations:

- * Better coordination of existing advocacy services to alleviate duplication of services and to ascertain gaps within present services;
- * To establish an interdependent advocacy system that addresses the needs of the whole person and not just one aspect;
- * Ensure advocates have adequate knowledge of available resources and services and understanding of how to access them;
- * Adequate funding to deliver advocacy services
- * Improved access to advocacy services that are community based, affordable and sensitive to cultural and language needs;
- * Provide users with the skills to become effective advocates for themselves to decrease forced dependence on system whenever appropriate;
- * Set up a community advocacy committee. This committee would include individuals who do advocacy in the legal, social services or health systems, as well as those who work with specific populations such as immigrants, disabled, natives, mentally ill, and the poor. By sharing their knowledge and resources the committee can identify problems inherent in the structure of the various systems, clarify processes and draw on the support and expertise of their peers. Members would be able to bring information back to their agency about community services and work to implement programs and service delivery that are sensitive to the diversity of consumers needs.
- * The community advocacy committee could act as advisors to a community based health advocate or advocacy resource team (ART). Their knowledge and experience are invaluable resources and can provide a framework for future advocacy project development. They have a role to play in health policy review and service recommendations.

B. Process For Making a Health Service Complaint

Part of the problem with making a complaint is knowing whom to direct it to and then what if anything has been done. It became clear from health service respondents that the process varies widely and often there are several people or groups involved.

Clinics, hospitals and health units that adhere to a philosophy of customer service and satisfaction made ongoing efforts to encourage feedback from clients. Methods included questionnaires, suggestion boxes and specific support staff to respond to concerns or complaints. All demonstrated a commitment to continually improving service delivery. They kept clients informed about the process, outcome and changes if any that resulted. At all levels was demonstrated respect for a client's needs and supports for the individual to have a voice in their own health care.

In the following section we will examine factors that impede consumers from lodging health services complaints. We have proposed a number of recommendations to help make the process more effective.

1) Concern: Personal barriers that can preclude a client making a complaint. These may include fear, culture, language, assertiveness, and knowledge.

Society recognizes the value of health care services and the respective skills and knowledge of health care providers. The health care system and its members have been given and assumed degrees of power. The resources and information they have imbue them with certain expertise. The client or patient also brings a personal expertise based in part on their value, feelings and experience. Often the individual's personal power is denied or minimized in favor of medical expertise or scientific facts. Relationships that devalue or discount one member's reality impose a power imbalance.

The necessity then becomes how to create a power balance between health care providers and client's. This involves examining how the system structure limits full client participation and potential client barriers to becoming a health consumer instead of simply a health services user.

Health services must work determinedly to develop avenues that foster dialogue between client's and staff. Only then will client's be able to be active participants in their own health care and wellness.

Recommendations:

- * acknowledge the validity of the individual's needs;
- * create an environment that is safe, supportive and respectful;
- * cross-cultural training for personnel;
- * easy to read information materials;
- * information on community resources;
- * availability of interpreters;

2) Concerns: Systemic barriers such as complexity of process, failure to inform clients of internal and external complaint process, cost of health records, access to and clarification of chart information inhibit client's from making complaints;

Systemic barriers stem in part from the health agency's philosophy, structure and policies. There needs to be a balance between the interests of the agency and the rights and needs of the client. Health services must be flexible enough to adapt to the diverse needs of those it serves.

Recommendations:

- * recognize where and how the system and the client interrelate;
- * provide this information in a straightforward manner to clients;
- * be alert to problems within the system that endanger the client's interests being served;
- * continue to develop and implement policies and procedures that are sensitive to consumer needs;
- * shift from the best interests of the system to the interests of the larger community by allowing for more shared power and responsibility between health consumers and the health system;
- * provision of information on services and procedures in written, verbal and other formats;
- * specific information on how and where to direct concerns about care or treatment especially in clinics and hospital settings;
- * a liaison to clarify chart information in the health practitioner is unavailable or client feels there are barriers to discussion with the practitioner;
- * ongoing service evaluations by clients and personnel and opportunities for the groups to work together on problem solving strategies that reduce systemic barriers;

3) Concern: Consumers lack of knowledge of disciplinary bodies and how they serve health consumers.

Many of the health associations and regulatory bodies we contacted to participate in this study did not respond. It is difficult for health consumers to understand the role of these organizations when they seem unwilling to inform the public about their services.

Those that did respond identifies that their role was often not understood by the community. Several were making efforts to become more visible and clarify their functions. A few outlined specifically how they address complaints and other services they have available to health consumers and specific health care providers.

Recommendations:

- * educate community on their role and services;
- * circulate information about their consumer services to clinics, health units etc. and encourage that it be available to consumers and practitioners;

4) Concern: Self policing by health care providers.

The majority of health services and regulatory bodies police their own members. They are involved in the investigation of complaints and any disciplinary action. They also have an obligation to maintain certain standards and ethics. However because there is no external system of checks and balances the public can only hope that the system is responsible and fair.

Many health consumers express doubt that complaints are being addressed adequately and that discipline is appropriate. Whose interests are being served and what safeguards are in place to protect the rights of the complainants they wonder?

Client mistrust is fostered by the system's cloak of silence. There is no validation of a client's feeling or needs when they are denied or provided with restricted information about the investigative process and the outcome.

The hotline set up to report sexual abuse by health practitioners is a prime example. Health consumers were told that this was an issue of concern that the health system intended to address. There were a significant number of complainants and many were told little more than:

"Thank you for calling. We'll look into it."

"How, when and what happened?", the complainants still ask.

This service purported to be concerned about the ethics of their members and the safety of client's. It seemed to do little more than re victimizes the complainant's by reinforcing their sense of powerlessness.

The publication of "Crossing The Boundaries: A Report of the Committee on Physician Sexual Misconduct" looked at this growing problem. Approximately twenty-one percent of respondents stated that they had been told by a client about sexual misconduct by another practitioner. Few reported the concern or offered the client information and support to lodge a complaint?

The structure of self-regulating bodies allow and supports an attitude of protectionism amongst its members. In order to fairly represent the interests of the members and the public we recommend:

Recommendations:

- * involvement by non-affiliated professionals and lay people in investigations and disciplinary procedures;
- * client being kept informed about process, time lines, outcome and any other recourse;
- * availability of a support/resource person to advise client about the process and provide support at meetings and/or hearings. This person would operate independently of the college or association;
- * bi-annual review of disciplinary process by an external advisory committee and implementation of proposed recommendations;

C. User Guidelines on How to Make Health Services Complaints

One of the project's goals was to create a computer data base that outlined the complaint process available and where to direct complaints or concerns within various health services. It was hoped that over time information could be gathered province wide and accessed easily by users and service providers.

We received fewer responses from health service providers than anticipated. Some agencies seemed reluctant to disclose information about their complaint process or the understanding of the process varied widely among personnel. Others advised they did not have adequate time to respond to the questionnaire. The information will be kept on file at present. A data will be developed as we compile information about the complaint process from a larger service base.

Community groups and individual respondents identified the need for understandable information on how to make health services complaints. There was concern especially for immigrants and disadvantaged groups that are not aware of their rights and are subject to poor or limited service.

Over 80% of all respondents agreed there was a need for:
1) education on client/patient rights; 2) provision to clients/consumers with the skills and resources to become effective advocates for themselves;

Recommendations:

- * VWHC to continue to gather information from health services about their complaint processes province wide as money and resources permit;
- * VWHC to create a data base that outlines complaint processes that consumers can access province wide;
- * VWHC will develop a series of information sheets for consumers about health services, patient rights, complaint procedures and community support resources;
- * inform client of available processes and other available avenues if not satisfied;
- * make follow-up responses to all complaints;
- * create an environment that promotes information sharing between all parties;
- * asking users to comment on service delivery through use of questionnaires, focus groups, suggestion boxes;

D. Link with Community Services to Promote Women's Health

This is an objective the Vancouver Women's Health Collective strives for with all their projects. While results are not completely measurable, some patterns emerge. These include:

- increase in community awareness and utilization of the collective's services;
- increase of client referrals from other agencies;
- community groups requesting us to address women's health issues for their clients and personnel;
- participation in joint community projects that address women's health needs and concerns;
- increased availability of community resource information for collective users;
- resource network to access for comments and recommendations for future VWHC programs;

E. Community Based Health Advocate -- Advantages and Problems

In order to determine the merit of a health advocacy program we needed feedback from the larger community identifying their needs and service wants. This was done through a questionnaire asking respondents to address the role of an advocate and factors that might impact on service delivery. Community services and individuals were strongly in support of a health advocacy program. Health centers identified certain areas where an advocacy program might be helpful. Included is a summary of respondent's comments and concerns.

81% of respondents wanted the health advocate to provide:

information on the health care system;
public education on client/patient rights;
clients with skills and resources to become effective advocates for themselves;
information and training to health professionals on how to work in partnership with clients;

The consensus between service providers and health consumers on the importance of the above items suggests the growing trend for increased client participation in their own health care. The health system is having to rethink their provision of care and service delivery. System users want access to and information about preventative and alternative care services. They want to make informed choices that consider their lifestyles and health wants and needs.

Approximately 72% wanted the advocate to provide:

individual advocacy;
community outreach;
information on how and where to make complaints;

Approximately 54% wanted the advocate to provide:

group advocacy;
listing of health agencies;
health practitioner directory;
** to participate in the investigative process of health service complaints;*

* There were concerns that the advocate's role would be jeopardized if they participated in the complaint investigation. There is however an identified need for someone not affiliated with the health system to be involved with this process. Refer to Section (B.4) for recommendations.

how to work in respectful partnerships with clients;

- 3) Access:
- a) service provision to individuals or groups with multi-barriers;
 - b) willingness of health services to offer support and information exchange;

3a) Concern: How will the ART ensure their service is able to meet the needs of individuals who experience multi-barriers that include but are not limited to language, distance, economics and culture?

Recommendations: The ART will try to offset these variables by:

- * ongoing liaison and resource sharing with community groups to ascertain needs of their community, perceived barriers and problem solving strategies;
- * service fees based on ability to pay;
- * service accessible in person, or mail;
- * budget allowance for interpreter service;
- * information resources in other mediums and language;
- * cross-cultural training for staff and volunteers;
- * affirmative action hiring;

Provision of any advocacy service must consider the wants and needs of the individuals or community it represents.

3b) Concern: How will the ART garner the support and participation of health services?

Recommendations: The ART would work to achieve this by:

- * providing information to all health services on the role of the advocate and establishing a network of contacts working within the health care system;
- * to direct and inform health consumers about services already in place within the health care system and promote the use of the avenues whenever possible;
- * to provide information on health services re: specific community identified needs;
- * to support health services initiatives to provide information and training to their personnel on how to work in partnership with clients;

2b) Concern: What would the ART's role be in relation to existing services?

Recommendations: The advocacy resource team or (ART) would not be expected to carry out the role or responsibilities of any agency. Client concerns are most appropriately addressed within the agency if the agency ensures it has a clear process available. However in instances where the agency is unable to fulfill that role, the advocate would become involved. Their role is in part a liaison who assists a client(s) identify their needs, review options and clarify the system process. The advocate may also act as a representative for the client and work to bridge system to promote the client's well being.

The ART would also provide:

- public education on client rights & obligations;
- provide clients/consumers with the resources and skills to be effective advocates for themselves;
- lobby for training of all health, legal and social services professionals on how to work in partnership with clients/consumers;
- a provincial toll-free information line for individuals & service providers;

The advocate or ART (advocacy resource team) could accomplish these in several ways:

- community outreach;
- training program & manual available to community groups who then provide materials to clients;
- low literacy/other language information pamphlets;
- video/audio tape information;
- direct 1-1 client service;

In order for these components to be effective and accessible the ART would require the support and involvement of the following:

Community Groups: to distribute and promote information;
to identify potential barriers to information presentation and ways to alleviate or lessen barriers;

Volunteers: to assist users develop self help skills;
to assist in the creation of alternate media resources;
to translate materials into other languages lower literacy levels;

Health Services: to advise ART about available services and program development;
to provide training to their personnel, possibly in conjunction with the ART, about

2a) Concern: Who is the advocacy resource team accountable to and what process would be in place to monitor service delivery?

Recommendations: The advocacy resource team (ART) would be a project under the umbrella of the Vancouver Women's Health Collective. Project staff would be responsible for providing quarterly reports to VWHC on services. They would also provide all funding agencies with a budget summary and analysis of service delivery as required. Comments sheets would be available to users and community agencies. These would be reviewed and incorporated into service development.

Respondents viewed the following as strengths of a community based health advocate:

System Users

- * accessible community resource;
- * client rights and self-advocacy education;
- * client empowerment;
- * support;
- * non-threatening environment, no bureaucracy;

Community Groups

- * gauge community health needs by identifying potential problems and barriers to the ART and health service providers;
- * work with health service providers to develop programs that reflect the community's needs;
- * members can participate in training's offered by the advocacy resource team (ART) and then present information to own community as per demand;

Health Services

- * develop health services and education programs that reflect the specific needs of the community;
- * work with ART to develop information and training for health personnel on how to work in partnership with clients;
- * health resources information more widely available to system users and care providers;

Thank you again for your involvement in this project.

Sincerely

Laura Sterling
for VWHC