

## **Community Health Advocate Project**

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

### **The Vancouver Foundation**

#### **Final Report**

*For period January 1, 2001 to December 31, 2001*

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### **EXECUTIVE SUMMARY**

The Community Health Advocate Project (CHA) is an outreach project that focuses on helping women in the lower mainland 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. During the past year the CHA project provided sixteen Patient's Rights workshops. There were a total of 130 participants in attendance from 12 different organizations. The CHA project gave Patient's Rights workshops to ten new groups in the past year.

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).

Through the Vancouver Foundation Grant the CHA coordinator's hours increased from 10 to 20 hours per week. We were able to reach a wider range of women through the sixteen workshops carried out. We were also able to update our CHA Information Kit to be a more 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.

We also continued to carry out the following 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, 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 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

## **RESULTS ACHIEVEMENTS/INSIGHTS/GENERAL OBSERVATIONS**

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 and CHA Information Kit.

The Patient's Rights workshop has been widely received by a host of organizations. From January 2001 to December 2001 eighteen workshops were booked resulting in only two cancellations (due to low numbers). There were a total of 130 participants in attendance from 12 different organizations.

The increase in the CHA coordinator's hours of work has contributed significantly to the growth of the project. Because of the increase in hours we were able to recruit 8 new community hosts and 3 new groups within previous community host organizations. This was achieved through our efforts and referrals by community hosts.

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 the 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 **attached Information Kit**).

Making the design of the Information Kit clear and consistent also came from feedback we received from the women participants. A great deal of time was spent making sure the language of the kit was simplistic in nature and the layout of the kit was easy to read and that it was easy to locate information.

Our evaluation process was put into place September 2001. The findings include: 86% have told us that they strongly agree or agree that they feel better prepared to ask their doctor a question about their health; and all of the 28 women who completed the evaluation (out of the 52 who filled out the evaluation form) stated that the CHA Information Kit would be useful when visiting their doctor.

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. The increase in hours has also enabled us to do supplemental research on community resources, mental health issues and guardianship legislation. This information will be included in the Information Kit.

The CHA project has been promoted through word of mouth, the VWHC newsletter (HER VOICE), the VWHC brochure and the CHA insert (translated into six different languages). As well the VWHC administrator has been promoting CHA through work the VWHC has been doing with the BC Health Coalition. This work has included participating and speaking at public events. All these avenues have been effective tools in the promotion of the CHA project.

The following CHA inserts have been distributed this past year:

Chinese inserts – 74 out of 200 Chinese inserts were handed out

Spanish inserts – 82 out of 200 Spanish inserts were handed out

Vietnamese inserts – 62 out of 200 Vietnamese inserts were handed out

Punjabi inserts – 69 out of 200 Punjabi inserts were handed out

Somali inserts – 55 out of 200 Somali inserts were handed out

English inserts – 1200 out of 2100 English inserts were handed out

The CHA project relies on community organizations serving as “community hosts” for our Patient’s Rights workshop. Working with community organizations in this way has contributed significantly to the success of the CHA Project. The community hosts have promoted the Patient’s Rights workshop within their organizations to women and family programs (see page 12). We have found that utilizing community organizations in this way has made it easier for the Patient’s Rights workshop to reach a range of women. Promoting the project through posterage and word-of-mouth by the community host organizations to their community was effective only if a minimum of 5 participants pre-registered. A broader discussion with community hosts, who want to advertise the Patient’s Rights workshop, will need to take place in order to make this process more successful. Time seems to be the biggest factor in why publicizing a specific Patient’s Rights workshop has not been as successful. The VWHC relies on the community to do its own advertising for the Patient’s Rights workshop. In future it may be viable for the CHA project to involve two or three community host organizations to publicize for a Patient’s Rights workshop. These may help to increase the number of participants.

The organizations’ acting as community hosts, have broadened the diversity of women who access the VWHC and utilize our services. It has given the VWHC a broader understanding of available community services and where we may refer women. The range of women that have come to the workshops has helped us to have a greater understanding of the community outreach services we can provide through the VWHC and CHA. We have found that having a relationship with organizations who offer ESL courses has helped us to look at what we need to be offering in translated documents to help immigrant women access health services. We have learned that translated health documents are necessary while women are learning English. Also ESL training is important and helps women to build the self-confidence they need in order to deal with their health practitioner.

Although immigrant women have served as the largest percentage of workshop participants, we recognize the barriers women of the Downtown Eastside also face. A common barrier is lack of information about services available to women living in the Downtown Eastside. The CHA project still needs to cultivate “community host”

relationships with organizations of the downtown eastside so that we can help bridge this gap.

The Vancouver Foundation grant gave CHA a greater ability to achieve its goals and objectives by increasing the CHA coordinators hours. We were able to provide more workshops, revise the Information Kit, and put in place an evaluation process.

### **EFFECTS ON COMMUNITY AND ORGANIZATIONS**

Through follow-up phone calls to community host organizations, we learned the CHA project has led to greater advocacy skills for women accessing the health care system. The VWHC mission statement states: "The Vancouver Women's Health Collective (VWHC) provides information resources and other support for women to empower themselves to take charge of their own health care." The CHA project does this directly by educating women about how to advocate for themselves which leads to women taking charge of their health care and learning how to use services appropriately. 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. Through information shared at workshops by community hosts and workshop participants, we have found 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.

Again, the increase in the CHA Coordinator's hours has helped the VWHC focus the project. As well, the CHA Coordinator was able to take a facilitators course in August 2001 to help improve her facilitation skills. Through meeting with community hosts, and talking about the issues important to their group, the coordinator has learned to design workshops in a clearer and more direct manner.

### **COLLABORATION/PARTNERSHIP/INCLUSIVENESS/TARGET GROUP**

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 January 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 (**see evaluation process pages 7&8**). This continues to better serve the diversity of women we serve and reflect the needs of specific groups.

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. As well, we are gaining knowledge about how we can better serve our clientele at the Information Centre. 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.

### **FACTORS INFLUENCING OUTCOMES/INNOVATION/DEMONSTRATION**

As stated previously, the CHA project is an outreach project focusing on educating women about taking charge of their health care. The project is set up in a workshop format to educate (train) women on how to advocate for themselves about their health care needs. The strength of the CHA project is the involvement of community hosts. Through access to their programs the CHA project has been better able to achieve its goals and objectives.

Although we did succeed in our goal of providing 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 more 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.

Before and after the bus strike, we became involved with new community hosts or new groups through referrals and VWHC promotion and calls made to organizations by the

CHA Coordinator. Consultation with the community host has been fundamental in the growth of CHA. The evolving workshop design, the Information Kit and the relationships with community hosts has positively influenced the outcomes of this project.

### **PUBLICITY/MEDIA**

Given that the CHA's project focus has been developing relationships with community hosts, and that the VWHC has a small staff, we have not been able to give publicity as high a priority as we would like. This has improved over the past year with the VWHC's involvement with the BC Health Coalition. Caryn Duncan, the VWHC spokeswoman, has spoken at length about the VWHC and the CHA project at numerous public events.

Because it is important that we maintain the confidentiality of the women who attend Patient's Rights workshop it has made it not possible to invite the press to attend Patient's Rights workshops. However this year we will be sending out a press release around International Women's Day highlighting the significant contribution the Vancouver Foundation has made to the CHA project and the success of the Patient's Rights workshops.

### **EVALUATION PROCESS**

The CHA project underwent significant changes in the 1999 – 2000 period, which had impacted the evaluation of the project. The project was heading into a new direction and the funding level, at the time allowed only for a work week of 10 hours for the CHA Coordinator. Therefore, at the time it was decided that 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.

The Vancouver Foundation's extensive documentation on "evaluation processes" helped the VWHC assess the CHA projects evaluation needs based on how the project was currently being administered. The bus strike period helped us to focus on developing a good evaluation process for the CHA project. The evaluation process 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 pages 14, 15 & 16).

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.

### **VANCOUVER FOUNDATION ADVISORY COMMITTEE GOALS**

The CHA project meets the following Advisory Committee goals:

- **To encourage initiatives which support the development and facilitation of inter-agency cooperation.**

Continued cooperation between the VWHC and the community host organizations is essential in maintaining the success of the CHA project.

- **To encourage the development of skills and competencies in individuals, agencies and communities that will build self-sufficiency capabilities.**

The Patient's Rights workshop purpose is to teach participants skills in advocating for themselves. This supports individuals in developing personal skills and also enhances the programming of community organizations.

- **To promote linkages between the social, health, economic and environmental sectors within communities?**

The structure of the CHA project is to work with specific communities. Working with community organizations in the immigrant/refugee communities in the Downtown Eastside, with women of different economic backgrounds has helped us make direct links between health, social and economic sectors.



- **To encourage community creativity and responsiveness in developing programs and facilities that will provide new and enhanced services.**

The Vancouver Foundation grant has helped the VWHC to further its mission statement by providing this innovative project to the Lower Mainland. The grant has enabled us to respond to needs of women who access our services around issues of health care.

### **FUTURE OF PROJECT**

The VWHC does plan on continuing the CHA project if the Vancouver Coastal Health Authority renews our grant for 2002/2003. We have applied to the Canadian Women's Foundation for additional funding to support the Vancouver Coastal Authority funding for 2002/2003. To maintain the project at its current level it will be necessary to secure both grants for the CHA project.

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 hosts such as seniors and youth organizations. The Information Kit is a resource tool which will need to be updated on occasion. A priority by March 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. As well, the workshop teaches women how to advocate for themselves and be proactive around their own health care.

## **SHARED STORIES**

The one thing we would like to add to our description about the activities of the CHA project is to provide a couple of examples of how we have seen the project make a difference in women's lives:

At a September 2000, Patient's Rights workshop, several Somali women talked about their experiences with doctors who told them that midwifery services were not available in the community. Due to religious beliefs and the issue of a health care provider's gender, it was traumatizing for these women to have their babies delivered by a male doctor. The Patient's Rights workshop gave the women information about the midwifery services available in the community and that Medicare covers the cost of the service. As well, the workshop informed the women of their rights within the health care system, and gave them suggestions as to how to assert their rights. Specifically, the women were informed of their right to request that their pregnancy and the birth of their child be by midwife (most midwives are women) or by a female doctor.

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.

## **CONCLUSION**

The CHA project designed and successfully carried out 16 Patient's Rights workshops to 130 participants, for twelve different organizations in 2001. Also a comprehensive Information Kit was designed in a clear and concise manner.

We had a busy year and learned a lot. One thing we know is that the evaluation process is the most important tool for keeping the project on track. Having an evaluation process to ensure we are achieving the results we desire will be a major focus of the coming year. The project also needs to expand to include more women from the Downtown Eastside, seniors and youth. 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 have developed for Health Canada. We will continue to work with community hosts to ensure we are meeting the needs of their community.

We have also 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 the many communities, in the Lower Mainland. So we continue to grow turning our weaknesses in to strengths in order to serve our communities better. The VWHC thanks the Vancouver Foundation for helping us meet the needs of this important and viable project.

## **APPENDICES**

### **Patient's Rights Workshops provided between January 1, 2001 – December 31, 2001**

- Kurdish Women Multilingual Orientation Services Association for Immigrant Communities ( MOSAIC) – Patient's Rights workshop -- February 2, 2001 – 4 participants
- Vietnamese Women, MOSAIC – Patient's Rights workshop -- February 19, 2001 – 9 participants
- Mental Health Women, Strathcona Park – Patient's Rights workshop -- February 23, 2001 – 6 participants
- Leads Group I, Pacific Immigration Resources Society (PIRS)– Patient's Rights workshop -- March 14, 2001- 8 participants
- Aids Vancouver – Patient's Rights workshop -- March 15, 2001 (one participant showed, cancelled)
- 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, 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, 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, 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 participants

### **Community Out Reach January 1, 2001 –June 30, 2001**

- January 11, 2001 – Positive Women’s Network provided resources for their women’s group around Patient’s Rights
- January 25, 2001 – Ministry of Women’s Equality Meeting on Women of Colour and Economic Security
- January 30, 2001 – AIDS Vancouver re: Patient’s Rights Workshop
- March 27, 2001 – Sheree Hudson – Clinical Nurse Downtown Eastside re: Patient’s Rights
- 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 People With 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
- involved training and networking
- 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 – P.A.C.E. – 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 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.”**