

**Washington State Department of Health:
Barriers to Health and Effective Utilization of
Existing Resources**

Final Report

June 2007



By Sita DeGiulio Das

Cross Cultural Health Care Program

Table of Contents

I.	Introduction	3
II.	Focus Groups and Interviews	4
III.	Questions	5
IV.	Participants	8
V.	Findings	9
VI.	Summary	16

I. Introduction

The Cross Cultural Health Care Program (CCHCP) was chosen by the Washington State Department of Health to report on select findings from research conducted for its Cultural Navigator Program (CNP). The purpose was to identify barriers to health and effective utilization of existing resources for patients of health systems targeting populations with limited access to care. A **cultural navigator** facilitates an individual's access to and understanding of the available health and social services in a manner which fosters a deep respect for and an understanding of the individual's culture. The purpose of CNP research is to inform the development of a curriculum to train and support cultural navigators. This training will provide the essential tools needed to successfully navigate cross-cultural interactions while providing health and social services. The CNP curriculum will be rooted in the basic principles of cultural competency, but will expand into such areas as:

- Patient/family centered practice
- Situational indicators to determine if cultural navigation is necessary
- Steps to cultural competency
- Culturally appropriate conflict resolution / Mediation skills
- Understanding different communication styles
- Culturally and Linguistically Appropriate Services (CLAS) Standards
- Resources in the community, health and social services system and surrounding region
- Advocating within the health and social services system / Boundaries for advocating and interpreting
- Self-care for cultural navigators / Support group or network of cultural navigators

There are two goals for the CNP program. The first goal is to create a core curriculum that will provide requisite skills for cultural navigators to proficiently bridge cultural gaps that contribute to ineffective utilization of existing services and suboptimal health outcomes. The second goal is to support professionalizing the field of cultural navigation. This will promote system's change in health and social services institutions, and cultural navigators will then be fully supported by the system in which they work, and will have the capacity to be highly effective.

The method used to collect data was community based participatory research in the form of focus groups and interviews. All of the data is qualitative. The findings of this report are based solely on the opinions and views of respondents. Please refer to section IV of this report for a general description of the participants with respect to each individual's confidentiality.

II. Focus Groups and Interviews

The first step in convening focus groups and interviews for this study involved allocating adequate time for networking and trust building. We established and re-established contacts with many organizations including community clinics and non-profits. This step began our journey of finding cultural navigators, giving them the opportunity to learn about CCHCP, and, in turn, learn about their organizations. The process culminated in receiving their input on the CNP curriculum through focus groups and interviews.

A total of three focus groups and four interviews were conducted between the time period of January 1, 2007 and June 13, 2007. One focus group had eight participants and two had five respondents each. One of the interviews included two interviewees; the other three were single person each. One written response to the focus group questions was also collected and included in the findings. In total, input from 24 individuals is being taken into account for this report.

Each focus group and interview lasted for an average duration of an hour and fifteen minutes and was conducted in English. Participants received \$20 in compensation for his or her time. All interviews took place at CCHCP. Focus groups took place at the respective institutions of the participants. Focus groups were arranged in collaboration with the cultural navigator program managers at institutions identified by CCHCP as mission driven to empower underserved communities. The \$20 remuneration for one focus group was provided to the organization instead of the participants, at the request of the institution.

Participants were given questions prior to each focus group or interview in most cases to enhance the use of time during the session. At the beginning of each session, participants received both written and verbal background information on CNP and CCHCP; they were also given the opportunity to ask questions or express concerns about the process. Two of the four interviews were recorded by cassette. Many participants felt uncomfortable with the idea of being taped; as a result, the last two interviews and all focus groups were written. In most cases, two facilitators/note-takers from CCHCP were present at each interview and focus group session. Participants gave full consent verbally for all sessions. In the case of the two tape-recorded interviews, participants also signed a consent form. Every effort was made by CNP research staff to accommodate the comfort level, needs and schedules of the participants.

All focus groups and interviews were arranged, conducted and recorded by Monica Alfonzo and Sita DeGiulio Das, the two lead research staff members for CNP. CCHCP staff Jennifer Calhoun and Elizabeth Carosso assisted in note-taking and facilitation in instances when one or the other lead researcher was not available.

III. Questions

Two sets of questions were used for focus groups and interviews. The first set of questions was created for the sole purpose of informing the CNP curriculum. The second set of questions was revised to incorporate specific questions from the Department of Health regarding health barriers faced by communities and utilization of resources for the underserved. The second set of questions was utilized for the one focus group with eight participants. The first question set was used for all other focus groups and interviews.

Findings from questions 3, 4 and 5 of the first question set were analyzed for this report. Findings from question set two are derived from question 3, and the last two questions bulleted under question 2. Both sets of questions are included in this report (figures 3-1 and 3-2), with relevant questions highlighted in grey.

All participants were given the opportunity to either answer or not answer each question. Some participants chose to answer each question directly, and some chose to elaborate further on the questions corresponding to areas they determined to be important. In these cases, follow-up questions were sometimes asked by facilitators in order to help clarify statements made. Some focus groups and many of the interviews were more like discussions and less like strict question and answer sessions. Every effort was made to portray comments in a way that corresponded as closely as possible to the amount of emphasis and importance placed on the different aspects of cultural navigation by the participants. The amount of time each participant had to answer questions was not limited, except when hosting institutions placed constraints on the time allowed for the session.



Cultural Navigator Focus Group Questions (Set 1)

CCHCP Introduction:

- About CCHCP
- Background on CNP with our definition of cultural navigators
- What we hope to accomplish with the CNP assessment & focus groups

1. Please share your name and which communities and health/social service agencies you work with...

2. Describe your work as a cultural navigator

Probes: How did you begin your work as a cultural navigator?
 What training have you received?
 What is the most satisfying aspect of your work?
 What's missing?

3. What benefits do you see to having cultural navigators in health/social service systems?

4. Are there any aspects of the health/social services system which make your work as a cultural navigator easier? What about in the community? (Please describe)

5. Describe any barriers you encounter in the health/social services system while working as a cultural navigator? What about barriers in the community? (Please describe)

6. What type of training / information / support would be useful in your work as a cultural navigator?

- Training on advocating within the health/social service system
- Training on overcoming cultural communication barriers
- Training on conflict resolution
- Training on working effectively through an interpreter
- Resources on navigating the health/social service system
- Community resources
- Support group / network of CN's

Thank you for your time and support, your input is greatly appreciated!

www.xculture.org



Cultural Navigator Program Focus Group Questions (Set 2)

CCHCP Introduction:

- About CCHCP
- Background on the Cultural Navigator Program (CNP) and Cultural Navigator (CN) definition
- What we hope to accomplish with the CNP assessment & focus groups

1. Please share:

- Your name
- Which communities and health/social agencies you work with
- How did you begin your work as a CN?
- What training have you received?

2. Describe your work as a CN:

- What is the most satisfying aspect of your work? What's missing?
- What are some of your patients' barriers you've witnessed?
- What key factors/resources/methods have you found to be particularly useful for helping patients better understand and navigate the health care system?

3. Describe any barriers you encounter while working as a CN (in health/social services system or community). Are there any aspects (in health/social services system or community) which make your work as a CN easier?

4. What type of training / information / support would be useful in your work as a cultural navigator? (Please add to the list!)

- Training on advocating within the health/social service system
- Training on overcoming cultural communication barriers
- Training on conflict resolution
- Training on working effectively through an interpreter
- Resources on navigating the health/social service system
- Community resources
- Support group / network of CN's

Thank you for your time and support, your input is greatly appreciated!
www.xculture.org

IV. Participants

Participants included patient outreach workers, promotoras, health educators, case workers and other individuals who work directly with communities in the health and social service fields. Each participant's job description fit CCHCP's description of a cultural navigator (see introduction for definition of cultural navigator). Participation included individuals with a wide range of experience related to the field of cultural navigation. The majority of informants have worked in their respective field for 5-20 years, some of them for longer. There were some respondents who were new to this line of work. Both female and male respondents participated in focus groups and interviews, however, more females than males participated.

Communities represented as identified by informants included:

- Low income
- Migrant workers
- No income
- Low education level
- Limited access to resources
- Immigrant
- Undocumented
- Spanish speaking
- Amharic speaking,
- Tigrigna speaking
- Arabic speaking
- Mandarin speaking
- Cantonese speaking
- Latino
- Russian
- Hispanic
- Mexican
- Caucasian
- Croatian
- Chinese
- Iranian
- Pakistani
- Eritrean
- Ethiopian
- Somali
- Chuukese
- Micronesian
- Vietnamese
- Japanese
- Lao
- Thai
- Filipino

Communities referred to in this report are groups of people generalized by language, country of origin or economic status. These communities reflect some, but not all of the diverse communities present here in King County and Western Washington. Every effort has been made to represent communities and cultures in a manner that mirrors the way in which respondents identified them as closely as possible. Some cultural navigators indicated they sometimes work with communities they themselves are not from. For almost each community mentioned in this report, two or more cultural navigators who represented it were consulted.

IV. Findings

For the purpose of this report, findings were broken down into six general themes:

1. Health System Barriers
2. Systemic Barriers
3. Cultural/Community Barriers
4. Educational Barriers
5. Useful Key Factors, Resources and Methods
6. What is Needed

There is a corresponding chart for each theme depicting areas of focus indicated by respondents, and the number of focus groups and interviews this particular area was mentioned.

1. Health System Barriers (Figure 5 – 1)

Health system barriers were drawn from responses to question 5 of the first question set and questions 2 and 3 of the second question set. There was a total of 15 health system related barriers reported. Three or more participants identified lack of funding and insurance to be major barriers to health care for their communities. Other participants also mentioned programs being cut due to lack of funding, not enough clinics, not enough staff and lack of emergency room care as being barriers; all of which are directly related to funding issues. Two or more individuals discussed lack of time and lack of language services as health system barriers. These barriers likely correspond to funding in some contexts; the latter clearly relates to issues around language access.

Language access appeared to be a dominant reoccurring theme related to health system barriers. At least two participants indicated there is a shortage of doctors who speak the same languages and/or are from the same communities that participants represent. Issues around consent forms and other forms for new patients were brought up by participants in two sessions. Forms are often written at too high of a register for patients with limited English proficiency (LEP) to understand. Some forms are available only in English, creating a significant barrier for patients who do not read and/or speak English.

Two or more participants indicated a lack of updated resources and contact information as being a direct barrier to health. Patients often need to access other resources within the health system, the community, or surrounding region. Internal organizational policies and lack of support for cultural navigators were both mentioned in at least one of the sessions. These issues may or may not be linked to funding. The way in which doctors ask questions was identified by at least one participant as a barrier, indicating a need for provider training in cultural sensitivity.

Health System Barriers	# of sessions mentioned
Lack of funding	3
Lack of language services, patients are turned away	2
Lack of time	2
Lack of insurance/ price of insurance	3
Not enough doctors who speak their language/look like them	2
Not enough clinics	1
Not enough staff	1
When patient is new, they are given a stack of papers	1
Consent issue	1
Programs closing and being cut due to funding issues	1
Lack of updated resources and contact information	2
Internal organizational policies, sometimes the nonprofit structure itself	1
No support for navigators	1
Lack of emergency room care	1
The way in which doctors ask questions	1

Figure 5 – 1

2. Systemic Barriers (Figure 5 – 2)

There were ten systemic barriers identified and discussed in relation to question 5 of the first question set and questions 2 and 3 of the second question set. Lack of transportation, limited or low income, and patients not being legally documented citizens had the highest frequency in responses. Immigration and documentation issues were accentuated by input from at least two participants who mentioned limited public understanding on immigration as a systemic barrier to health and health care. Federal policy in general was pointed out by one respondent as a systemic barrier within itself.

It is significant to note that in two or more sessions, technology was reported as a barrier. Participants stated that although a great deal of information exists on the web that potentially could be useful to patients, most do not have internet access. It was also noted that E-mail is quickly becoming a primary method of communication, replacing telephones and subsequently leaving out a large segment of the population.

Safety in patient neighborhoods, permanent addresses and low-wage jobs were pointed out as crucial systemic barriers. Respondents indicated that many patients either live in neighborhoods that have high rates of crime or lack a permanent address completely. For many services and programs, a permanent address is mandatory to qualify. Due to the fact that many patients have low paying jobs, they are obligated to work many hours in order to cover basic expenses. This impacts both the amount of time patients have to allocate to health care, as well as the amount of flexibility patients have to schedule appointments. According to respondents, these barriers can be linked to poverty, lack of funding, immigration status issues and/or institutionalized racism. Many underserved patients “have more immediate concerns” than accessing the health care

system, a statement that was agreed upon by most participants. Many of these barriers also contribute to why “patients only come to clinics for urgent matters,” as mentioned by one participant.

Systemic Barriers	# of sessions mentioned
Transportation	3
Not legally documented	3
Common use of e-mail instead of phone, info on web	2
To qualify for services patients need permanent address	1
Lack of public understanding on immigration	2
Federal policies	1
Many hours spent at low paying jobs limits flexibility	1
Low income, can't buy medication	3
High crime rates in neighborhoods	1
Only come to clinics for urgent matters	1

Figure 5 – 2

3. Cultural and Community Barriers (Figure 5 – 3)

Cultural and community barriers were addressed also in responses to question 5 of the first question set and questions 2 and 3 of the second set of questions. Cultural differences, religious customs, or beliefs around health that differ from those of the Western Biomedical system contribute to cultural and community barriers. There were nineteen barriers identified in this section. Classification of these barriers as cultural or community is not intended to imply that the responsibility to address these barriers lies solely within the communities where they exist.

Denial was an issue that was pointed out frequently by respondents and identified by at least one participant as being a community barrier. Three or more respondents discussed an aversion to open dialogue and communication around health issues faced by the community as being a barrier. The reasons for this varied; some mentioned specifically were distrust of the system, shame and stigmatization around disease, and the fear of speaking an illness into physical existence. One participant indicated that some patients do not want to be told bad news or hear a terminal diagnosis. In some cultures it is considered bad luck to inform a sick person about his or her disease, and instead the family is informed by the physician and given the choice of whether or not they want to disclose the information to the ill family member. At least one participant indicated that in many cultures there is different language expressed around disease and death. Some believe talking about death, or death-related issues such as a legal will or donating a body to science, will cause death to inevitably occur. Therefore, it is custom to avoid these subjects at all costs.

Another issue that was highlighted in at least two sessions was the issue of time. One participant explained that “patients leave if the wait time is too long.” Many patients work long hours and lack reliable transportation. When put into this context, time spent in the waiting room can cause

a great deal of anxiety. Some patients may not understand why they have to wait so long when they are on time for their appointment, but when they are late, they are left with no other option but to reschedule the appointment. If the patient has traveled far to reach the clinic and made any number of other sacrifices to get there such as taking time off work or arranging child care, it becomes frustrating and demoralizing for the patient to have to reschedule the appointment. In at least one community represented, the action of making an appointment at all is sacrilegious, due to the fact that making an appointment is associated with trying to predict the future, a characteristic ascribed to the Higher Power alone.

Different cultures often have different beliefs around health, disease, body image and prevention. One respondent indicated that in his or her respective community, diseases are associated with spells. At least two participants brought up the idea of disease being a result of karma or destiny, causing the role of a physician to become useless in relation to the disease. Different conceptions around body image, for example the idea that “being skinny is a crime” was also asserted by at least one participant. Cultural differences around mental health specifically were brought up in two sessions. Mental health diseases are often stigmatized or not discussed at all. It was brought to our attention by one participant that in some languages the term “mental health” directly translates as “crazy.” At least two participants reported that many of their patients visit the doctor only when they are sick, which excludes preventative measures that may be available and often leads to late diagnosis. Responses indicate that this could be a result of different barriers besides a different set of beliefs around prevention, such as lack of citizenship, fear of the system or lack of financial resources.

Our research found that a common misconception among at least three different communities is the idea that screening for a disease actually causes the disease in which they are screening for. This mistaken belief becomes its own self-fulfilling prophecy, as patients refuse to get screened until it is too late, and the likelihood of them having the disease is high. Fear is another contributing factor to this misconception, and was mentioned as a cultural barrier by at least two participants. Fear may be caused by many different factors, but in terms of the health system, it is often caused by personal past negative experiences in the health care setting or historical examples of institutionalized abusive behavior (i.e. Tuskegee Syphilis Experiment). One respondent discussed how some patients were easily intimidated or felt patronized by the doctor’s tone of voice. Pride was also brought up as a barrier by one cultural navigator, keeping people from seeking preventative health care and far away from hospitals and clinics. Assumptions, stereotypes and discrimination were all mentioned in at least one session as well. In some cultures, physicians are so highly respected, they may be feared. One participant explained that patients may say ‘yes’ to doctors out of politeness and respect, but end up never following through with what they agreed to do.

Cultural/Community Barriers	# of sessions mentioned
High wait time / anxiety around waiting	2
Idea of appointment goes against God	1
Different language around disease information and death	1
Community doesn't talk about issues it faces, uncomfortable	3
Some patients do not want to be presented with bad news at all	1
Some Muslim men do not want to shake hands because of prayer	1
Perception of disease being associated with a spell	1
Cultural differences in mental health	2
Different perceptions about size and body image "being skinny is a crime"	1
Saying 'yes' out of politeness but not following through	1
Different ideas around prevention, only going to the doctor when you are sick	2
Denial	2
Religion – "Why prevent destiny?"	1
Idea that screening causes disease	2
Idea that disease is result of karma	1
Fear	2
Pride	1
Assumptions, stereotypes and discrimination	1
Intimidated by tone of voice	1

Figure 5 – 3

4. Educational Barriers (Figure 5 – 4)

Educational barriers are both systemic barriers and community barriers. Educational barriers are also health system barriers specifically in terms of health literacy and awareness. Educational barriers are grouped separately from the other categories even though they coincide with the three other types of barriers specified in this report because they were emphasized almost unanimously by all respondents. In the cases in which they were not discussed, educational barriers were inherently implied and referred throughout the session. Educational barriers were also derived from question 5 of the first question set and questions 2 and 3 of the second question set.

Low levels of education, limited English proficiency, low literacy in native language and not knowing when to seek health were all discussed as educational barriers. The first three severely limit the patients' access to written resources as well as the way in which they are able to comprehend information in general. Patients may not know when to seek health if they are unfamiliar with the culture of the health care system and/or are uneducated about healthcare, prevention or navigating the health system.

Educational Barriers	# of sessions mentioned
Low education	2
Low literacy (in native language): limits written resources and the way they comprehend info	1
Limited English proficiency	1
Not knowing when to seek health	1

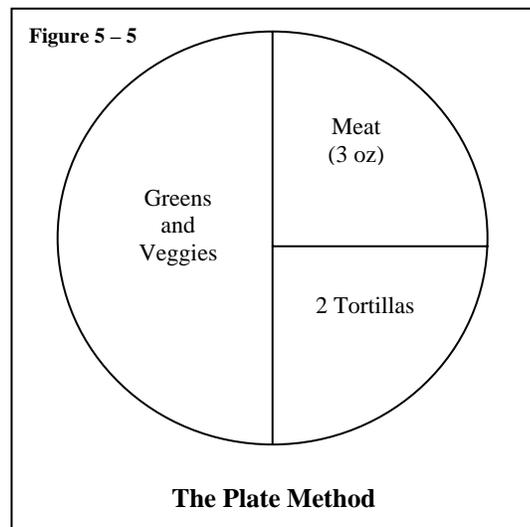
Figure 5 – 4

5. Useful Key Factors, Resources and Methods (Figure 5 – 6)

The findings from this section have resulted from the analysis of questions 3 and 4 from the first question set, and from question 2 of the second question set.

Partnerships and relationships with other institutions and organizations were discussed in five of the sessions as being particularly useful and helpful for assisting patients. There are many factors that impact health but extend beyond the parameters of what is typically considered the ‘health field’ such as transportation and immigration status. Collaboration with other organizations helps to create a network of support for the patient.

Audio and visual materials were clearly expressed by multiple participants as being key functional resources. Both radio and visual materials were mentioned in at least three sessions, and the use of videos was mentioned in at least two. Charts and handouts with diagrams and pictures were said to be commonly used. Food visuals like ‘the plate method’ (Figure 5 – 5) are helpful for patients who are unable to count calories. According to one participant, this model works for all races as long as different foods are substituted into it.



Other useful methods that were emphasized were listening to patients, spending time with patients and trust building. Many agreed that patients are more responsive when efforts are made to make them feel comfortable and welcome in a nonjudgmental atmosphere. One participant expressed, “It works when we don’t just talk and talk, it works when we start with a little chat even if we have [a] certain amount of time in [with] every patient, because you get to know them and you may get them to think in a different direction.” Asking questions to ensure understanding was said to be helpful in one session. Encouragement and repetition from different people in the clinical setting such as nurses, receptionists and health educators helps to reinforce ideas to patients.

Paying attention to key points and other motivational interviewing techniques were also brought up during one session as methods that are particularly useful in ensuring patient comprehension.

Useful Key Factors, Resources and Methods	# of sessions mentioned
Handouts – chart/plan with goals	1
Encouragement	1
Repetition from different staff	1
Videos	2
Radio	3
Visuals materials	3
Food models like “el método de plato” (the plate method)	1
Asking questions to ensure understanding	1
Listening to patients, spending time with patients, trust building	2
Paying attention to key points and motivational interviewing techniques	1
Diffusing tension between groups that may have cultural conflicts by emphasizing common experience	1
Partnerships, collaboration with other institutions, organizations, etc.	5

Figure 5 – 6

6. What is Needed (Figure 5 – 7)

Before the first set of questions was revised to include a question about key factors and methods that are useful, some respondents who answered the first set of questions opted to share some resources they felt were missing but greatly needed. These resources included a citizenship video; medical terms, information and increased literacy in native languages; more awareness in communities; more of a relaxing atmosphere in health settings; and more videos. These needs are congruent with the barriers discussed throughout this report and do not reveal any additional data. They do however, serve to stress other key points mentioned in the findings of this report as well as offer some ideas for possible action towards reducing health disparities.

What is Needed	# of sessions mentioned
Citizenship video	1
Medical terms and literacy in native language	1
More awareness in community	1
Relaxing atmosphere	1
More videos	1
Information in own language	1

Figure 5 – 7

VI. Summary

The Cross Cultural Health Care Program conducted three focus groups and four interviews for the purpose of informing the Cultural Navigator Program (CNP) curriculum. This report was derived from CNP qualitative research to inform the Washington State Department of Health on barriers to health and effective utilization of existing resources. Findings from this report were broken down into six general topic areas which covered different types of barriers faced by underserved and marginalized patients, as well as existing methods that have proven to work well and resources that are still needed.

Barriers reported most frequently include:

- Lack of funding
- Lack of insurance
- Issues around language access and LEP
- Low socio-economic status
- Undocumented citizenship status
- Limited or no access to technology
- Refusal to discuss health issues facing community, stigmatization and denial
- Time constraints for appointments
- Cultural differences around mental health, death, disease and body image
- Misconception around preventive screening
- Low levels of education

Emphasized methods/resources which work well with patients and are needed include:

- Partnerships and collaborations with other institutions and organizations
- Culturally and linguistically appropriate audio and visual materials including the use of videos and radio
- Listening to patients
- Spending time with patients and trust-building
- More awareness and health education in community
- Information in native languages (written, radio and video)
- Increased public awareness on immigration, including a citizenship video available in different languages

The data highlights that health system barriers and other systemic barriers limit access to health care and impact health outcomes. Community and cultural barriers may influence participation in preventive health care and also impact health outcomes. Community engagement and collaborations can contribute to health systems moving towards providing culturally and linguistically appropriate care. Funding and social policy changes are needed to address socio-economic status indicators that impact health.