

Central East **LHIN**

APPENDIX 3:

# FOCUS GROUPS

The Culture, Diversity and Equity Project

# EXECUTIVE SUMMARY

The focus group component of the Culture, Diversity and Equity Project elicited the experiences and perspectives of community members and health service providers in regards to:

- Culture and diversity;
- Health equity;
- Policy;
- Accountability and monitoring;
- Educational frameworks; and
- Services available to marginalized community members.

Overall, the focus groups generated common findings between community members and health and community service providers. Both groups identified many of the same barriers to health equity, for example:

- Substandard service delivery due to cultural stereotyping;
- Inadequate access to services among marginalized groups for financial, geographical, or cultural reasons; and
- Lack of accommodation such as a refusal or inability to provide translation or interpretation services.

The two groups were often consistent in their recommendations as well. Both, for example, advocated recruitment and retention of diverse staff in health organizations; greater cultural competence among staff; consistent, rigorous monitoring of culture, diversity, and equity policies; better outreach and communication to communities; and partnerships with communities.

The 23 focus groups conducted by the project were distributed over the three regions of the Central East LHIN: Scarborough, Durham, and the Northeast (Haliburton, Kawaratha Lakes, and Pine Ridge - HKPR), in geographic locations appropriate to the communities and health service providers involved. Focus groups were conducted with community members and health service providers.

## Community Members

- Youth (Durham)
- People of low socio-economic status (Durham Region)
- People of low socio-economic status (Scarborough)
- Uninsured individuals (Scarborough)
- Sexual and gender minorities (Durham Region)
- Sexual and gender minorities (HKPR)
- People with disabilities
- Visually impaired (HKPR)
- Hearing impaired/culturally deaf (Durham Region)
- Ethno-specific and Linguistic communities (Scarborough)
  - Chinese
  - Tamil
  - African and Caribbean
  - Afghan & Sudanese women
  - French speaking immigrants
- Seniors (HKPR)

## Health Service Providers

- Front-line workers (3)
- Management/leadership (3)

## Sample

In the course of the 23 focus groups, the project spoke to 174 individuals; 134 of these were community members and 40 were health service providers.

Of the 134 **community members**, 34.3% were male, 63.4% were female, and 2.2% identified as transgendered. In terms of age, 13.4% were 18 to 25, 31.4% were 26 to 40, 39.6% were 41 to 60, and 13.4% were over 60. Of the total sample 55.2% lived in Scarborough, 28.4% lived in the Durham region, and 16.4% lived in the Northeast.

Of the total 40 **health service providers**, 77.5% were female and 22.5% were male. In terms of age, 10.04% were under 30, 25% were 31 to 40, 37.5% were 41 to 50, 22.5% were 51 to 60, and 2.5% were over 60. Of the total sample, 37.5% worked in Scarborough, 40.0% worked in the Durham region, and 22.5% worked in the Northeast.

## Community Member Focus Groups

All focus groups with community members reported negative experiences during intake, assessment, and treatment, as well as experiences of discrimination and poor accommodation. They also identified a general lack of cultural awareness, skill, and knowledge on the part of health care providers.

As a result, participants adopt strategies to cope with the inadequacies of the health care system, ranging from self-advocacy (e.g., using two physicians, using community services) to alternative health care approaches (e.g., using home remedies or buying medication on the street).

To improve health services as they relate to culture, diversity and equity, policy, monitoring, health provider competence, and other areas, community members made a number of recommendations:

- Train and retrain staff to show greater sensitivity and provide accommodation;
- Ensure all policies comprise ideas of social justice;
- Involve communities in monitoring;
- Create a complaints body external or internal to the Central East LHIN to act as client advocate, ombudsman, and regulating officer;
- Make services more geographically accessible; enhance outreach efforts; and
- Provide more translators, interpreters, and translated forms.

## Health Service Providers

The six focus groups with front-line health service providers and service care leadership also generated a number of significant findings. All participants agreed that there is a disproportionate burden of illness among marginalized communities, despite the government's policy of universal health care. This is due to barriers to health equity (e.g., discrimination, lack of commitment and competence, lack of internet directories) and to issues related to geography and population change (e.g., unequal access, lack of outreach).

These focus groups also identified, for example, that organizations must be proactively seeking to move beyond current policies. To do so, they must do the following, using a transparent and systematic approach:

- Intertwine diversity committees into all aspects of health organizations;
- Create partnerships in the communities;

- Acknowledge and address workplace discrimination;
- Engage staff in the monitoring process; and
- Set up an external diversity complaints system.

Participants in all focus groups felt strongly that diversity should not only be celebrated, but also invested in. In other words, they hoped to see greater effort and resources from all involved.

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# INTRODUCTION

Twenty-three focus groups were conducted as part of the Culture, Diversity, and Equity Project (CDE Project). They were distributed so as to consider three main categories of interest:

- The voices of marginalized communities;
- The voices of health service providers; and
- Geographic distribution of voices.

The focus groups took place in all three regions of the Central East LHIN and covered the following themes:

- Community member experiences;
- Organizational and clinical abilities;
- Policies;
- Monitoring;
- Education;
- Suggestions; and
- Vision of an ideal health system.



## COMMUNITY MEMBER FOCUS GROUPS

Given the large population of the Central East LHIN (1.4 million), and its geographic vastness (16,673 km<sup>2</sup>), it was important we distributed the focus groups judiciously in order to ensure all the important issues were addressed—those related to the needs of various populations and the needs of the different geographic areas.

Focus groups were held with immigrants, youth, seniors, sexual and gender minorities, people living in poverty, and uninsured individuals. We intentionally conducted focus groups in geographic locations that were appropriate to the communities involved (e.g., immigrants in Scarborough, youth in the Durham region, and seniors in the Northeast).

By distributing focus groups this way, we were able to hear from a range of voices and reflect the distinct realities of urban, suburban, and rural health care provision, as well as issues of culture, diversity, and equity.

Again, it must be stressed that our purpose was to identify the themes and issues that consistently emerge within the communities in question. In each of the focus groups we sought to achieve broad and diverse representation.

### Sample

Of the 134 community members, 34.3% were male, 63.4% were female, and 2.2% identified as transgendered. In terms of age, 13.4% were 18 to 25, 31.4% were 26 to 40, 39.6% were 41 to 60, and 13.4% were over 60. Of the total sample 55.2% lived in Scarborough, 28.4% lived in the Durham region, and 16.4% lived in HKPR.

In terms of highest level of education, 32.1% reported high school, 35.1% reported having attained a certificate or diploma, and 26.1% reported a bachelors degree or higher.

From the perspective of diversity, 25.4% self-identified as belonging to an ethno-racial group, 34.3% self-identified as belonging to a visible minority, 11.9% self-identified as lesbian, gay, bisexual or transgendered (LGBTQ), 15.7% self-identified as having a disability, 26.9% self-identified as belonging to an immigrant and/or refugee group, 10.4% self-identified as seniors, 1.5% self-identified as youth, 2.2 % self-identified as Francophone, 5.2% self-identified as being culturally deaf. In total, 59% of participants self-identified as belonging to one marginalized group and 31.3% of participants self-identified as belonging to more than one marginalized group (e.g., visible minority, immigrant, and LGBTQ).

Overall, 65.7% were born outside of Canada. From this group, 12.7% have lived in Canada for less than three years, 20.2% between four and 10 years, and 34.3% more than 10 years. The regional breakdown is as follows: Of the 74 participants in Scarborough, 77% were born outside of Canada; of the 38 participants in the Durham Region, 47% were born outside of Canada and; of the 22 participants in HKPR, 18% were born outside of Canada.

### Recruitment, Settings, Facilitation, Informed Consent, Reimbursement, and Questions

Participant recruitment and outreach was largely conducted by community organizations that were identified as highly visible and well positioned within their respective communities (e.g., Peterborough AIDS Resource Network for the LGBTQ community in Peterborough). The project team provided administrative support when necessary. A number of different recruitment and outreach strategies were used, with each community organization employing the strategy that was more appropriate for their given community. These strategies included flyers, posters, emails, and direct calls to clients or consumers, social marketing strategies such as Facebook, and approaching existing groups of consumer survivors (e.g., Durham Deaf Accessibility Committee).

When considering locations for focus groups, our first priority was the safety of participants, followed by accessibility (e.g., public transit, distance to town centres, and parking), and the presence of local organizations and their respective communities.

Focus groups were conducted either at apposite community organizations (e.g., the focus group with Chinese speaking individuals was conducted at Hong Fook Mental Health Association) or at general organizations (e.g., the focus group with French speaking immigrants was held at Yee Hong Geriatric Centre).

Each focus group session took approximately 60-90 minutes. Four of the focus groups were facilitated by project staff (also audio-taped), while the 13 others were facilitated by the staff of the same organizations that developed and organized the focus groups. The main themes of all the focus group discussions were documented through note taking.

Prior to commencement of the focus groups, all participants signed informed consent forms, which were available in English (and French for the French group), and which had been explained (sometimes through an interpreter, e.g., Tamil) (see Appendix A). Following an overview of the project, participants also filled in a demographic form (see Appendix B). All community members were given \$25.00 as reimbursement for their expertise, travel, and child-care.

Focus group questions addressed the following points (see Appendix C):

- Conceptualization of health equity;
- Experience with the current health system;
- Coping strategies within existing health system;
- Visions of the health system;
- Issues of intersectionality;
- Knowledge of support for a particular diversity dimension;
- Visions of health equity policies;
- Monitoring and accountability; and
- Education.

## Summary of Findings: Community Member Focus Groups

### Access

Overall, participants access health care services through:

- Family physicians;
- Hospitals;
- Pharmacies;
- Walk-in clinics;
- Psychiatrists;
- Physiotherapists;
- Public Health;
- Telehealth Ontario; and
- Community Care Access Centres.

For services specifically related to culture and diversity, participants access:

- Community Health Centres;
- Alternative practitioners (e.g., Chinese medicine);

- Clinics for uninsured individuals;
- French speaking services;
- Language/culture specific health care providers; and
- Culturally specific websites.

If no specific or community-friendly services exist, some participants travel to Toronto or other areas. In addition to the barriers experienced by the general population—barriers that are often compounded by the experience of marginalization (e.g., finding a GP as a culturally deaf person, or newcomer, or as a person with mental health or addictions issues)—participants said they encounter several other important barriers:

- Lack of local specialized services (e.g., Sherbourne Clinic for LGBTQ);
- Lack of culture/language specific physicians;
- Lack of accommodation;
- Financial constraints (e.g., cost of medicine, travel costs in rural areas, physicians’ notes, some immunizations, ambulance); and
- Lack of free services for newcomers without OHIP.

## Experiences

Participants identified three negative experiences with the health care system, each one closely linked with the other: 1) discrimination, stereotyping, and stigma; 2) lack of accommodation; and 3) negative treatment experiences:

1) Experiences of discrimination, stereotyping, and stigma include:

- Heterosexism;
- Racism;
- Ageism;
- Ableism;
- Intolerance towards cultural explanatory models of illness and treatments;
- Stereotyping according to cultural identity;
- Pathologizing culture (e.g., deafness);
- Denial of access and informed consent to full treatment;
- Lack of interest in marginalized identities (e.g., culturally deaf); and
- Lack of understanding of the intersectionalities of identity.

2) Negative experiences of accommodation include:

- Lack and denial of providing interpretation services (including American Sign Language);
- Inappropriate use of family members for interpretation;
- Lack of transportation (particularly for the visually impaired and seniors);
- Inaccessible facilities (lack of signage and audible elevators); and
- A lack of diverse ways of communication (e.g., culturally deaf re hearing when name called).

3) Negative experiences of treatment are related to consent, intake, assessment, and treatment:

- **Consent:** Participants identified issues with individual rights and family structures (e.g., strong family involvement) and concerns regarding privacy.
- **Intake:** Some participants pointed out that many administrative forms do not reflect diversities (e.g., same-sex families).

- **Assessment:** Participants experienced improper assessments that lead to misdiagnosis and/or treatment based on cultural identity. Clients do not understand the relevance of certain questions, and practitioners and other health service providers do not spend the additional time necessary to ensure full understanding, especially when resulting from language barriers (including ASL). Moreover, health services providers do not understand culturally-based explanations of illness.
- **Treatment:** Participants experienced refusal of services (e.g., blood work, uninsured); lack of affordable medicines and some services; lack of diverse workforce; and sense that health service providers have poor communication and poor relationships with clients of colour.

### Strategies for Dealing with the Health Care System

Participants described a wide range of coping mechanisms, which included: 1) personal coping; 2) self-advocacy; 3) complaints; 4) travel; and 5) alternative health care approaches.

1) In terms of personal coping strategies, participants rely on faith/religion, family and community, and community-based (non-health) agencies. They also choose to avoid the system until critically ill, or to avoid it altogether, and to fill prescriptions but not take the medication.

2) Participants practice self-advocacy in a number of ways; they:

- See more than one physician (sometimes for a second opinion) or change physicians;
- Seek out language/culturally-specific health service providers;
- Bring an advocate to health encounters;
- Behave passive aggressively, with great insistence, or with exaggerated niceness in order to get treatment;
- Leave the service in cases of experiencing racism;
- Educate the health service provider; and
- Make use of community-services and community knowledge to increase access.

3) In terms of using complaints as a strategy, participants said they:

- Speak with organization supervisors, make formal complaints, or otherwise address their experiences to higher levels in the system;
- Seek community supports;
- Lobby politically; and
- Advocate through cultural organizations and bodies (e.g., Canadian Hearing Society).

4) If there is a lack of appropriate services locally, participants said they travel outside for services (and lie about their place of residence) while staying local for acute care.

5) Finally, in terms of alternative health care approaches, participants said they:

- Use over-the-counter medicines;
- Buy prescriptions on the black market (e.g., HIV/AIDS medication);
- Research their health issue online and deal with it at home;
- Use home remedies; and
- Use alternative practitioners.

### Policies

In addressing culture, diversity, and equity, community members see room for improvement in the following policy areas: 1) social justice; 2) anti-discrimination; 3) training; and 4) service delivery.

1) Policies should comprise the idea of *social justice* by advocating equal access and equal treatment, recognizing health as a human right, and acknowledging the broader determinants of health through a client bill of rights and protection of individuals with mental health issues.

2) Participants also identified the need for *anti-discrimination* policies that combat inequity based on gender, race, sexual orientation, age, ability, socio-economic status, and religion.

3) Participants argued that cultural competence *training* should involve not only initial training, but ongoing re-training as well.

4) Finally, participants said *service delivery* should be based on family-centred care and involve culturally specific and/or culturally appropriate services and a client bill of rights. They also maintained that service delivery should incorporate accommodation (including accessibility plans) in regards to:

- Language (e.g., access to translated information, interpreters including ASL);
- Visual impairment (e.g., note takers, non-harassment policy regarding guide dogs, global positioning system, signs);
- Hearing impairment (e.g., alternative means of communication including waiting areas);
- Religion/faith (e.g., diets, prayer times and rooms);
- Culture (e.g., gender matching of health care providers); and
- People living in poverty (e.g., internal and external financial assistance related to health care and treatment).

Finally, participants made the following policy suggestions:

- Involve community in policy development, decision-making, and human resources (e.g., in order to hire more diverse staff); and
- Create clear complaints processes both within and outside of organizations that include good communication with clients.

*"I have been seeing a psychiatrist regularly for the past 10 years but never had a yearly physical check-up because my psychiatrist said it is not his job and I can't find a family doctor that speaks Chinese who takes new patients?"*

- Chinese Community Member

## Monitoring

Overall, community members identified: 1) the role of community; 2) communication of complaints; 3) service delivery as an important means of monitoring organizations' adherence to their culture, diversity, and equity policies, and 4) the need for a complaints body.

1) Policies should take into account *the role of communities* by ensuring community inclusion on diversity committees, focus groups and consultations with community, and client feedback (e.g., online polling, surveys, evaluation forms, focus groups, suggestion boxes, and telephone surveys).

2) The number of *complaints* and the way they are dealt with should play a role in monitoring policy.

3) Also, monitoring of *service delivery* should entail observations, investigations (e.g., sensory and physical space), and monitoring of accessibility plans.

4) Finally, most participants recommended a *complaints body* to address issues of culture, diversity, and equity. This complaints body could be external or internal to the Central East LHIN office and would fulfill the roles of a client advocate, ombudsman, regulating officer (e.g., accreditation), and/or monitor of the organizations' accessibility plans.

## Health Service Provider Competence

Participants identified a general lack of competence related to culture, diversity, and health equity, especially in the areas of awareness, skill, knowledge, and power (imbalance).

It is felt staff lack the ability to recognize difference and diversity (awareness and knowledge), and as a result, the onus is on clients to raise health issues that are related to their cultural and social location (e.g., that people from the Caribbean have a higher incidence of diabetes or issues of transsexual / transgendered individuals).

Participants also noted a lack of sensitivity in various processes, such as intake and service delivery (awareness). Improper assessments and poor accommodation (awareness, skills, and knowledge) are also problems.

Other evidence of this lack of awareness, skill, and knowledge:

- Cultural differences are pathologized (e.g., deafness);
- Different cultural explanatory models of illness are denied;
- Not all methods of communication are respected (e.g., email, interpretation services, ASL interpreters); and
- Broader determinants of health (e.g., immigration and poverty) are neither understood nor addressed.

Participants also referred to experiences of stereotyping, heterosexism, racism, ableism, etc., pointing to a lack of understanding of the basic power imbalances related to diversity and the health care system.

## Service Enhancements

Participants identified four areas for possible types of enhancements: 1) staff; 2) services; 3) information/communication; and 4) systemic.

1) In terms of *staff*, participants suggested that health care providers:

- Spend more time with clients to ensure that all necessary information is being conveyed;
- Build trust and confidence;
- Take on the onus of making accommodations;
- Be more aware of legal issues (e.g., clients rights);
- Represent diversity (language, culture, genders, age); and
- Be knowledgeable, non-discriminatory, and easier to access.

2) In terms of *service* enhancements, participants made the following suggestions:

- Improve intake and assessment tools;
- Identify safe spaces (e.g., stickers for LGBTTQ community);
- Practice cultural and linguistic matching;
- Assist clients in finding specific services (e.g., gender transitioning);
- Increase the availability of translators and interpreters;
- Offer multiple ways of gathering client information (e.g., sending out forms prior to appointment);
- Provide knowledgeable and better skilled staff;
- Clearly display policies;
- Increase general accommodation;
- Increase availability of wellness centres
- Offer more specialized care (e.g., LGBTTQ-specific clinics); and
- Provide services that are geographically accessible, and make services closer together (one-stop shopping).

In order to improve *information sharing and communication*, participants made the following suggestions:

- Use websites, information booklets, service directories, local hotlines, local hubs of information, and email;
- Provide translated forms (including ASL);
- Use vibrating buzzers in waiting rooms (particularly for culturally deaf);
- Make use of videos, flyers, pamphlets, and workshops for communities that also address stigma;
- Educate newcomers on the health system and services;
- Enhance outreach to communities; and
- Clearly display policies.

In terms of *systemic* suggestions, participants discussed 1) costs; 2) kinds of services; 3) accommodations; and 4) general changes in the system:

1) *Costs*: To decrease the burden of medical costs, OHIP should:

- Cover more services and needs for newcomers (including uninsured);
- Cover transportation services in rural areas;
- Provide free medication; and
- Cover alternative services and medication.

2) Recommendations regarding *kinds of services*:

- Make services more locally available and accessible by transit;
- Develop better understanding of the needs of marginalized communities; and
- Gear long-term care towards marginalized communities (e.g., culturally deaf, LGBTTQ, cultural).

3) Recommendations for *accommodations* within the system:

- Include mandatory accommodation provisions;
- Have greater gender-balance of translators and interpreters; and
- Make interpretation and other accommodations more readily available evenings and weekends.

4) Recommendations for *changes* in the system:

- Make the overall system better coordinated;
- Perform a systems analysis of existing services and patterns of use; and
- Allow foreign-trained physicians to practice.

## Youth Focus Group

### Durham

We chose to conduct our youth focus group in the Durham region because of the large and rapidly growing youth population in the region. Moreover, research consistently cites health care access and provider competence issues for youth; therefore, it was imperative for the project to examine these issues directly with the affected community.

The focus group was held at the Ajax Youth Community Health Centre in April of 2009. A health promoter from the organization assumed responsibility for participant recruitment, registration, and parental consent. Facilitation was completed by two of the project leaders.

A total of 10 participants attended the youth focus group in Durham. The group consisted of two women and eight men. In terms of age, 20% were 18 to 25 and 80% were 26 to 40. Of the total sample, 70% were born in Canada and 30% were born outside of Canada. From this latter group, 20% have lived in Canada for less than three years, 10% have lived in Canada between three and 10 years, and 10% have lived in Canada for more than 10 years. All participants lived in Durham.

From the perspective of diversity, 10% self-identified as belonging to an ethno-racial group, 30% self-identified as a visible minority, 20% self-identified as LGBTQ, and 30% self-identified as an immigrant.

Finally, in terms of highest level of education completed, 70% reported high school and 10% reported having attained a certificate or diploma.

### Summary of Findings

Due to the lack of available family physicians in the region, youth most often use walk-in clinics. They feel that the health care system ranges from disrespectful to non-responsive when it comes to their particular needs. They cite a lack of youth-specific services, and feel that those that currently exist—youth mental health services for example—are not outreaching enough. They also express concern about the high costs of some health services (e.g., doctor's note, medication).

### Access to Primary Health Care

Primary health care is available to Durham region youth through walk-in clinics, hospitals, family doctors, the Youth Community Health Centre, and school-based health clinics. Despite the large number of listed services, walk-in clinics are by far the predominant place of access, especially since eight of 10 youths do not have a family doctor (due to retirement and new to the region/country).

In fact, some youth feel that never having had a family doctor negatively affects their chances of securing a family doctor. Apparently, some youth (not in this group) have even been expelled from school for not being able to find a doctor in time to get their immunizations for the school records.

*“Some of them [hospital nurses] are actually kind of rude. Just because you are a teenager they like treat you like ... like you ... are a lazy bum - you are not worth their time and they would rather take in some 30 year old guy.”*

– Community Member

### Experiences with the Health Care System

The youth participants said they generally feel many physicians and other health care providers are disrespectful, non-responsive, rushed, and inaccessible to youth, and that as youth, they are treated with a lack of respect.

Doctors are said to improperly address youth health needs, and to barely perform needed physical examinations; they write prescriptions simply to get youth patients out of their offices, and it is “*virtually impossible*” to book an



appointment within the same week. Finally, wait times in both walk-in clinics and with family physicians are unacceptable.

Several youth told stories of inadequate treatment (e.g., erroneous prescriptions, wrong diagnoses, and false information) which they believe to be the result of inattention due to their age.

### **Treatment Issues**

The youth participants had not received referrals to specialized youth services, which may be due to a lack of youth-specific services, or may simply be a reflection of their good health. Issues related to consent and to individual decision-making versus collective decision-making are concerns for some youth: For example, one youth claimed that his/her mother made him/her stop seeing his/her former family doctor because the doctor had been prescribing anti-depressants, something the mother disapproved of.

### **Strategies for Dealing with the System**

Youth say that using over-the-counter medication is the most common way of avoiding having to deal with an unresponsive and unwelcoming health care system.

### **Mental Health and Addiction**

Youth feel that health care professionals do not adequately address or prioritize their mental health needs and that youth mental health services do an insufficient job outreaching and advertising their services. In fact, some youth claimed to have only found appropriate mental health services by chance (e.g., stumbling upon the offices). That said, several of the participating youth are quite happy with the mental health services offered by one of the local Boys and Girls Clubs.

### **Culture, Diversity, & Equity Competence of Staff**

All focus group youth claim to have never been asked questions relevant to their age and lifestyles (e.g., sexual activity, smoking, depression, peer pressure) by health care providers.

### **Financial Burden**

The high cost of physicians' notes, and of medications/treatments not covered by OHIP, is identified as a problem by youth: One youth told the story of his/her brother's hospital-based malaria treatment, which took place during 3-month OHIP wait period for newcomers; it left the mother with \$5000 in hospital bills.

### **Suggestions**

In short, the youth of this focus group feel there is a need for:

- More family physicians;
- Shorter wait-times (for appointments and during appointments);
- More specialized youth-friendly services, and better outreach;
- Health care providers who are more attentive to their needs and to spend more time with them;
- Services that are more geographically accessible (especially given that they are a population with little access to cars);
- Family doctors who represent different social and cultural locations (including age, language, culture, gender, etc.); and
- More services, particularly for newcomers, covered by OHIP.

## Seniors Focus Group

### The Northeast (HKPR)

We chose to conduct our focus group with seniors in the HKPR region due to the large and rapidly growing senior population. Research consistently cites health care access and provider competence issues for seniors; therefore, it was imperative for the project to examine these issues directly with the affected community.

Originally, the focus group with seniors living in the HKPR region was to be held at the Peterborough Library in Peterborough, Ontario. However, despite planning and advertising by the Community Care Peterborough and the project team, no respondents showed up on the scheduled day.

The focus group with seniors was eventually held at the office of the Peterborough Social Planning Council (PSPC) in July 2009. Focus group members were recruited from among participants of a senior's forum conducted by the PSPC earlier in June. Staff at the PSPC assumed responsibility for participant recruitment, registration, facilitation, and note taking. The CDE Project team provided necessary materials and support to the PSPC.

A total of seven participants attended the focus group for seniors. There were six women and one man. In terms of age, all 100% of seniors were over the age of 60. Of the total sample, 71.4% were born in Canada and 28.6% were born outside of Canada. Of this group, 71.4% have lived in Canada since birth, and 28.6% have lived in Canada for more than 10 years. All participants lived in HKPR.

From the perspective of diversity, 14.3% self-identified as belonging to an ethno-cultural group, 28.6% self-identified as LGBTQ, 14.3% self-identified as an immigrant, and 14.3% self-identified as a woman.

Finally, in terms of highest level of education completed, 35.1% reported having attained a certificate or diploma, 32.1% reported high school, 22.4% reported a Bachelors Degree, and 3.7% reported a Masters degree or higher.

### Summary of Findings

Due to the lack of available family physicians and generally long wait-times, seniors in HKPR are often slow to receive health services and end up in hospitals where they do not receive holistic care. The most common difficulties faced by seniors are transportation to medical appointments (including travel to the Greater Toronto Area), the "one issue per visit" rule by family physicians, the strain posed on family members due to the lack of adequate home care, and language barriers for immigrant seniors.

### Access to Primary Health Care

Seniors tend to use family health teams, after-hours clinics, local family physicians, Telehealth Ontario, and emergency clinics. Due to long wait-times in the HKPR region (around 5 years), a sizable number of seniors visit their family physicians in the Greater Toronto Area (GTA). This puts patients at a disadvantage because GTA physicians cannot order all tests in local HKPR health-care facilities (e.g., Peterborough hospital, Campbellford Hospital), which forces individuals to travel back to Toronto for certain tests such as MRIs, ultrasounds, and CAT scans.

### Experiences with the Health Care System

The biggest issues for seniors are long waitlists for assessments, family physicians, and long-term care. They feel that local physicians do not have enough information about existing community services (e.g., the New Canadian Centre tends to get very few requests/referrals from physicians). Furthermore, due to a lack of physicians, many seniors make use of hospitals, which means they do not have follow up after their health care.

For seniors who are also immigrants, three issues arise. First, immigrants see the three-month waiting list for OHIP as highly problematic and an added stress during settlement. Second, it seems that finding a doctor is even more difficult for new immigrants. Third, lack of language specific services mean that family members can often end up providing translations; many immigrant seniors would rather not address health issues that expose themselves to embarrassment this can cause.

### **Treatment Issues**

Seniors identified poor transportation as a barrier to treatment, and therefore to ageing at home. Community Care Peterborough provides some driving services. Generally, focus group participants said they feel there are not enough wellness programs and supportive housing. They also said that some physicians could be better at assessing people's health needs. Finally, the "one issue per visit" rule is particularly problematic for seniors as health is not a one-issue subject; as a result, they often receive health care that is not holistic.

### **Strategies for Dealing with the System**

Seniors say that being assertive and asking questions is a good strategy. However, they pointed out that this becomes more difficult with age so they require an advocate. In addition, lack of services and wait-times force many individuals to be cared for by family members, which puts an additional burden on the family and the senior.

### **Culture, Diversity and Equity Competence of Staff**

Focus group participants identified physicians' lack of awareness of existing services for immigrants and a lack of cultural sensitivity among staff.

### **Financial Burden**

Limited respite care makes it difficult for seniors particularly if they are living on a fixed income. Transportation to major health care centres also poses a difficult financial burden.

### **Suggestions**

In short, the seniors of this focus group made the following suggestions:

- Create a navigator system that helps individuals access the services;
- Provide increased funding for wellness and the promotion of active living;
- Discourage ghettoizing of seniors through multi-age communities;
- Increase respite care to families; and
- Increase cultural competence of health service providers.

## Low Socio-Economic Focus Group

### Durham Region and Scarborough

The focus group conducted with people living in poverty explored and elicited issues related to health care access, health care competence, and health outcomes.

We engaged the Community Development Council of Durham (CDCD) as well as the Social Planning Council of Toronto to assist us in developing two separate focus groups with people living in poverty—one in Durham region and one in Scarborough.

Originally, we had planned to run only one focus group with people living in poverty in the Durham region, which would include participation with people from across the Central East LHIN region. However, despite planning and advertising by United Way of Durham, no respondents signed up for the scheduled day.

The Durham region focus group was held at the office of the Language Instruction for Newcomers to Canada (LINC), Durham Continuing Education, in Pickering Ontario with an existing group of individuals in May 2009. Staff at Community Development Council of Durham (CDCD) assumed the responsibility for participant recruitment, registration, facilitation, and note taking. The CDE Project team provided necessary materials and supports to the CDCD.

The Scarborough focus group was held in the Scarborough office of Action for Neighbourhood Change (ANC) in June 2009. It was organized by the Toronto Social Planning Council, whose staff assumed responsibility for participant recruitment and registration. A project team member facilitated the focus group.

A total of 19 participants attended the two focus groups. The first group was held in Durham and comprised 11 participants. The second group was held in Scarborough and comprised eight participants. In total there were 15 women and four men. In terms of age, 10.5% were 18 to 25, 31.6% were between 26 to 40, 47.4% were between 41 to 60, and 10.5% were over 60. Of the total sample, 10.5% were born in Canada and 89.5% outside of Canada. Of this group, 21.1% have lived in Canada less than three years, 21.1% have lived in Canada between three and 10 years, and 47.4% have lived in Canada for over 10 years.

From the perspective of diversity, 50% self-identified as a person with a disability, 7.1% self-identified as an immigrant, and 50% self-identified as culturally deaf.

Finally, in terms of highest level of education attained, 21.1% reported high school, 52.6% reported having attained a certificate or diploma, 15.8% reported a Bachelors degree, and 10.5% reported a Masters degree or higher.

### Summary of Findings

People living in poverty make use of a variety of services and venues for their health needs and for health-related information. As expected, several financial issues related to the health care system, including travel costs, are identified as barriers. In terms of policy, participants identified several themes, including commitment, anti-discrimination, service navigation, interpretation, and community inclusion in decision-making.

People with low socio-economic status who are also immigrants said they experience additional barriers; they feel physicians use language that is too technical, and that physicians are often unable to understand cultural explanations of illness. They also identified race and disease as points of discrimination. For all participants, community plays a significant role in helping to deal with the health care system. To address these issues, participants strongly suggest an external complaints body.

## **Access to Primary Health Care**

People with low socio-economic status use family physicians, walk-in clinics, pharmacies, and hospitals to access health services. One participant said he also uses alternative practitioners. For health related information, they make use of the Internet, the YWCA, English as a Second Language (ESL), libraries, and the community.

While some focus group participants say they prefer their physicians to come from the same community and to speak the same language, others worry this can lead to a lack of confidentiality. Those who prefer a doctor from their own community, generally do so because of the difficulties of communicating cultural explanations of illness and, more generally, understanding English-speaking physicians.

## **Experiences with the Health Care System**

Focus group participants said they experience feelings of discrimination due to race and disease (e.g., AIDS), resulting in longer wait times, and poor communication.

## **Treatment Issues**

Some participants see the costs of access to the health care system (e.g., medication not covered by OHIP) and the cost of alternative practitioners / medication as an important barrier to treatment.

## **Strategies for Dealing with the System**

When dealing with the system, participants said they rely on friends, community centres, alternative practitioners, 911, and walk-in clinics for help (and not family physicians). One participant indicated that he /she has lost all trust in the system, and now exclusively uses alternative practitioners.

## **Culture, Diversity and Equity Competence**

Participants with low socio-economic status from different cultural backgrounds said that health care providers are often unable to understand cultural explanations and descriptions of illness. It is felt that physicians and health care professionals use technical language, do not always ask questions that seem relevant, and do not explain sufficiently why they ask particular questions (e.g., about a client's religion).

## **Financial Burden**

Participants mentioned several financial barriers related to accessing health services: cost of medication, cost of alternative practitioners / medication, travel distances to services, and costs associated with specialists.

## **Policy and Monitoring Suggestions**

Participants identified a need for policies that include anti-discrimination provisions, better dissemination of information about the health care system (navigation), culturally diverse practitioners, access to translators and interpreters, and the involvement of community members in policy decisions. Participants also proposed an external complaints body.

## **Suggestions**

Suggestions put forward by this focus group:

- Give health care providers more training in how to deal respectfully with clients;
- Post health equity mandates and commitments in organizations; and
- Offer OHIP coverage on alternative medicine.

## Uninsured Individuals Focus Group

### Scarborough

The focus group with uninsured individuals was held in Scarborough on account of the relatively large number of individuals in the region who, as new immigrants, have no legal status in Canada, or have been without insurance during their three-month OHIP waiting period.

It was imperative that the CDE Project examine the health-care related issues experienced by uninsured individuals in order to assess negative health outcomes.

This focus group took place at the Scarborough Volunteer Clinic in June 2009. A volunteer public health nurse from the organization assumed responsibility for participant recruitment and registration. The focus group facilitation was carried out by one member of the CDE Project team as well as a clinic volunteer.

A total of seven participants attended the focus group. The group consisted of six women and one man. In terms of age, 28.6% were 18 to 25, 14.3% were 26 to 40, 28.6% were 41 to 60 and 14.3% were over 60. Of the total sample, 100% were born outside of Canada. Of this group, 57.1% have lived in Canada for less than three years, 28.6% have lived in Canada between three and 10 years, and 14.3% have lived in Canada for more than 10 years. All participants lived in Scarborough.

From the perspective of diversity, 85.7% self-identified as belonging to an ethno-cultural group, 14.3% self-identified as a visible minority, 57.1% self-identified as an immigrant, 14.3% self-identified as a senior.

Finally, in terms of highest level of education attained, 14.3% reported high school, 18.6% reported having attained a certificate or diploma, and 28.6% reported a Bachelors degree.

### Summary of Findings

All uninsured individuals of the focus group used the Scarborough Volunteer Clinic prior to receiving OHIP. This relieved their sense of being ignored by the Canadian health system. However, they said that the lack of health insurance during the three months was a financial burden, and suggested the government terminate the waiting period and instead assist newcomers in navigating the health care system immediately. In terms of policies, focus group participants said they feel health should be considered a human right, and suggested health be contextualized within the larger determinants of health.

### Access to Primary Health Care

According to the focus group participants, primary health care is accessed mostly through walk-in clinics and family physicians. However, all made use of the Volunteer Clinic in Scarborough during their pre-insurance wait-time. Participants said that during this time, they were more interested in finding an “excellent” doctor rather than a doctor from their own community.

### Experiences with the Health Care System

One participant said he has lost all faith in the Canadian health care system because of its “business” approach, and that he now focuses on disease prevention (e.g., nutrition). Of all individuals in the focus group, only one had been asked by a doctor about culturally specific health issues.

### **Treatment Issues**

Prior to using the uninsured clinic in Scarborough, where they have all had very good health service experiences, participants have the sentiment their health was disregarded by the Canadian health care system.

### **Financial Burden**

All participants agreed that accessing health care services without insurance poses considerable financial burdens, especially since many immigrants and refugees come with few resources.

### **Policy and Monitoring Suggestions**

The focus group spoke of the need to include the statement, “health is a human right,” in all organizational policies, and to contextualize health needs within the broader context of the social determinants of health.

### **Suggestions**

Several suggestions were put forward by the focus group for uninsured individuals:

- Governments should provide information to immigrants and refugees upon their arrival as a means of directing them to services and assisting them in navigating the system;
- The broader determinants of health should be focused on by health authorities;
- Governments should better understand the needs of uninsured individuals; and
- There should not be a three-month wait for health insurance for immigrants and refugees.

## Sexual and Gender Minorities Focus Groups

### Durham and the Northeast (HKPR)

The focus groups with sexual and gender minorities explored the issues related to health care access, health care competence, and health outcomes.

The Project had originally planned to conduct the sexual and gender minority focus group in the Durham region, with participation from across the Central East LHIN. However, during the initial consultation with the AIDS Committee of Durham, it was decided that transportation would be a barrier for people to attend. As a result, we conducted two focus groups: one in Durham region and one in HKPR.

The Durham region focus group was held at the office of the AIDS Committee of Durham Region in April 2009. Staff assumed the responsibility for participant recruitment and registration. Rainbow Health Ontario provided additional recruitment support. Project leaders facilitated the focus group.

The HKPR focus group was held at the offices of the Peterborough AIDS Resource Network (PARN) in March 2009. PARN assumed the responsibility for recruitment, registration, and facilitation. Rainbow Health Ontario provided additional recruitment support. The Project team provided necessary materials and supports to PARN.

A total of 15 participants attended the two focus groups. The first group was held in Durham and had six participants. The second group was held in Peterborough and had nine participants.

In total there were four women, nine men and two transgendered individuals. In terms of age, 13.3% were 18 to 25, 26.6% were 26 to 40, and 53.4% were 41 to 60, and 6.7% were over 60. Of the total sample, 80% were born in Canada and 20% outside of Canada. From this group, 13.3% have lived in Canada less than three years, 6.7% have lived in Canada between three and 10 years, and 6.7% have lived in Canada for over 10 years.

From the perspective of diversity, 6.7% self-identified as belonging to a visible minority, 80% self-identified as LGBTQ, 13.3% self-identified as transgendered, and 6.7% self identified as a senior.

Finally, in terms of highest level of education attained, 20% reported high school, 26.7% reported having attained a certificate or diploma, and 53.3% reported a Bachelors degree.

### Summary of Findings

Sexual and gender minorities living in Durham region and HKPR feel strongly that there is a lack of Lesbian, Gay, Bisexual, and Transgendered (LGBTQ)-friendly/specific services at the regional level. All participants spoke of experiences of discrimination, stereotyping, misdiagnosis, and refusal of treatment, and of heterosexist practices in general.

In order to avoid the health care system, participants buy medication on the black market (particularly HIV/AIDS related medicine). They also articulated an urgent need for a regional LGBTQ health care advocate, and for organizational policies that comprise anti-homophobia and anti-transphobia.

### Access to Primary Health Care

Both Durham region and HKPR participants access primary health care through their family physicians, local HIV specialists, and emergency rooms. Durham region participants also identified walk-in clinics (there seem to be no walk-in clinics in HKPR). Although participants have managed to find some LGBTQ friendly services providers in



the two regions, no LGBTQ-specific services currently exist. In the search for one, a Toronto-based LGBTQ service referred one participant back to his family doctor citing geography (catchment area).

### Experiences with the Health Care System

Very few services are LGBTQ positive or friendly, according to participants. In fact, most local services are heterosexist, with the embedded assumption that everyone is heterosexual. This creates distrust within the community towards the health care system:

Most participants described experiences of discrimination and stereotyping, misdiagnosis, and refusal of treatment. One participant told us that, despite having notified the hospital of his HIV status, was reprimanded by his surgeon, who claimed not to have known in advance; because the client “*could have contaminated the operating room*”.

Another client was misdiagnosed: his doctor said that if he had known the patient was gay, he would have tested for HIV instead of treating him for cancer.

Many participants recounted stories of refusal of treatment. One doctor refused to treat an HIV positive client on the grounds of not being competent. In another case, a surgeon refused a lesbian woman’s request to have a breast reduction, on the grounds that he/she does not perform sex-change surgeries. In another case, a nurse performing blood work left the room and never returned upon finding out that the patient was HIV positive.

*“The clinic near us - they always seem quite surprised that we both go in. Like if we are taking our son for whatever – we both go with him. It’s like ‘is this your sister? No, this is his other mother. Oh, you mean stepmother? No, he has two mothers’ ... you always have to give a little background information first before they click in that it is ok that two people of the same sex come into the appointment.”*

– Community Member

### Treatment Issues

One of the issues identified by Durham region lesbian participants is that most forms do not reflect the realities of LGBTQ families (e.g., listing father and mother on forms for their children). Peterborough participants noted that general health services do not inquire about LGBTQ-specific health issues unless considering sexually transmitted illnesses. They also provided ample examples of inappropriate treatment, even lack of treatment, and HIV-related stigma.

### Strategies for Dealing with the System

Participants said that they travel to LGBTQ-friendly and LGBTQ-specific services in Toronto when needing general services (e.g., Sherbourne Health Centre, Hassle Free Clinic), but stay local for acute care. Other strategies for dealing with the inadequacies of the health care system:

- Seek community support;
- Take their experiences to higher levels in the health care system;
- Remain in a clinic until all health issues are fully addressed;
- Research the issues before accessing the health care system; and
- Lie about one’s home address in order to receive LGBTQ-friendly and specific services in Toronto.

LGBTQ participants feel that their health is most notably compromised by long wait-times. Some individuals, for example, buy prescriptions on the black market rather than wait out the 30 days for an appointment (particularly related to HIV/AIDS); others said they avoid seeking help until more seriously ill, or avoid the health system altogether.

## Culture, Diversity, & Equity Competence

The inability of staff to ask relevant questions was identified as an issue, along with heterosexist attitudes, and very limited knowledge of LGB and Trans issues (the latter being the least understood). When it comes to addressing LGBTQ-specific health issues, there is the feeling that the onus is on the clients rather than the health service providers.

## Policy and Monitoring Suggestions

Participants identified a clear need for anti-homophobia and anti-transphobia policies as well as mandatory ongoing training for all professionals. Online polling/surveys (similar to Rainbow Health Ontario) and a regional LGBTQ health care advocate were suggested as ways of monitoring policy.

*"I had to get blood work done at the hospital. I told the nurse before she took my blood that I was HIV positive. The nurse left the room but said she would be right back. She never returned to take my blood."*

- Community Member

## Suggestions

Participants in this focus group offered the following suggestions:

- Provide staff (physicians, nurse practitioners) who are more knowledgeable about LGBTQ issues and non-heterosexist;
- Establish assessment tools and intake forms that include diverse sexual identity and same-sex families;
- Create informational booklets, websites, a local hotline, and a list of queer-friendly services;
- Provide walk-in clinics in every town/city;
- Set up more LGBTQ-friendly services like the Sherbourne Health Clinic;
- Provide LGBTQ-specific services in Peterborough and anonymous HIV testing;
- Assure shorter wait-times;
- Ask services to use the "safe space" sticker to identify a LGBTQ-friendly service; and
- Lower the barriers to gender transitioning for transgendered individuals.

## **Disabilities Focus Groups- Visually Impaired and Hearing Impaired/Culturally Deaf**

### **Durham and the Northeast**

The focus group with people with disabilities explored issues related to health care access, health care competence, and health outcomes.

Originally, the project had planned a single focus group that would include a spectrum of individuals with disabilities from across the Central East LHIN. However, following a consultation with the Hearing Society of Canada, it was decided that two separate focus groups would be held—one with individuals with hearing impairments and one with individuals with visual impairments.

The Canadian Hearing Society in the Durham region, along with members from the Durham Deaf Accessibility Committee, conducted the focus group with individuals experiencing hearing impairments in April 2009, and used American Sign Language with the assistance of Ontario Interpretation Services (OIS). The regional director of the Canadian Hearing Society facilitated the focus group. The project team provided necessary materials and supports.

The focus group with individuals experiencing visual impairments was conducted by the Canadian National Institute for the Blind (CNIB) in Peterborough in April 2009. The CNIB assumed responsibility for recruitment and registration; two CNIB staff members facilitated the focus group. The CDE project consultation team provided necessary materials and supports.

A total of 14 participants attended the two focus groups for people with disabilities. The first group was comprised of seven individuals with a visual impairment. The second group was comprised of seven individuals with from the culturally deaf community.

In total, there were nine women and five men. In terms of age, 1% were 26 to 40, 64.3% were 41 to 60, and 28.6% were over 60. Of the total sample, 85.7% were born in Canada and 14.3% outside of Canada. Of this group, 7.1% have lived in Canada between three and five years and 7.1% have lived in Canada for over 10 years.

From the perspective of diversity, 50% self-identified as a person with a disability, 28.6% self-identified as a senior, and 50% self-identified as culturally deaf.

Finally, in terms of highest level of education attained, 43.8% reported having attained a certificate or diploma, and 42.9% reported a Bachelors degree.

### **Summary of Findings**

Both visually impaired and culturally deaf focus group participants said they encounter a number of barriers to health care, such as having to travel large distances to receive specialized services, and a lack of sensitivity and lack of accommodation from organizations and staff.

Culturally deaf clients experience a clear unwillingness to accommodate translators and interpreters in the health care system, despite the legal requirement for interpreters, often because they do not recognize sign language as a language.

Both groups expressed a clear need for greater accommodation and sensitivity, as well as ongoing consultations and complaints mechanisms (including an ombudsman).

## **Access to Primary Health Care**

The main access to health services is through family physicians, hospitals, walk-in clinics, and pharmacists. For specialized services, visually impaired participants must travel to Peterborough, Kingston, Ottawa, and Toronto; participants pointed out that travel is particularly difficult for people with diminished vision or blindness. Culturally deaf participants also travel outside their local area to receive deaf-friendly services.

## **Experiences with the Health Care System**

Visually impaired participants identified several positive experiences with the health care system, particularly with family physicians who are well informed of their particular impairments, and with Toronto and Scarborough hospitals. They particularly appreciate hospitals with appropriate accommodation such as signage for low vision/blind clients, audible elevators, and special transportation services. Negative experiences were the result of poor accommodation.

Culturally deaf participants said that, due to indifference in the health care system, they are often discriminated against and stereotyped. They complained that the culturally deaf are considered a linguistic minority, that deafness is pathologized, and that they are not given access to comprehensive information about their personal health issues and care.

They believe this is because health care professionals stereotype them as intellectually deficient.

Culturally deaf participants identified multiple areas of discrimination and complex access barriers for individuals who are deaf and of another culture, and for deaf immigrants who do not speak American Sign Language (ASL). Health service providers often do not recognize ASL as a language, and therefore, despite the availability of the Ontario Interpreter Service (OIS) and the legal requirements, repeatedly fail to provide interpretation services. This leaves clients to communicate in a language that is not their first language. Some participants even feel that health service providers hide behind “red tape” to avoid organizing ASL interpreters, by claiming that they lack the authority to hire an ASL interpreter.

Finally, culturally deaf participants said that waiting for services can be problematic since they do not hear when their names are called, and therefore miss their turns.

## **Treatment Issues**

Visually impaired participants said that questions related to being visually impaired are not asked during intake and assessments.

Culturally deaf participants said that errors in treatment can arise (e.g., following medical directions) when OIS is not available; in some cases, hearing children are asked act as interpreter. In one example, a deaf mother arrived at an appointment with a specialist to check up on her hearing child, who had complex medical conditions. When it became clear that no interpreter was available, the health care professional suggested to the deaf mother that the sick child act as interpreter, not taking into account that this may negatively affect the health of the child.

Participants also noted that many physicians will not take the additional time needed to comprehensively understand the health needs of culturally deaf clients.

## **Mental Health and Addictions**

Visually impaired participants clearly identified a lack of mental health support services.

## **Strategies for Dealing with the System**

Visually impaired participants proposed speaking up, raising concerns, and political lobbying, both at local and provincial level, as good strategies. Culturally deaf participants proposed seeking assistance from the Canadian Hearing Society (CHS) whenever navigating the health care system.

## **Culture, Diversity, & Equity Competence**

Visually impaired participants talked about the insensitivity of health care staff (e.g., asking clients if they did not see a non-smoking sign) and the lack of appropriate intake processes (e.g., asking clients to fill out forms).

Culturally deaf participants feel pathologized by health care providers, who refuse or are unable to provide ASL or to employ all methods of communication (e.g., email).

They also feel that, when it comes to organizing OIS, the onus is on the client, because health care providers are unaware that, according to the Supreme Court of Canada and human rights, all services must be accessible to clients.

## **Policy and Monitoring Suggestions**

Visually impaired participants offered the following suggestions:

- Include the symbol of the white cane in policies (symbolizing independence for individuals with visual impairments and an extra degree of sensitivity within the health care system related to travel time, filling in forms, etc.);
- Ensure that the accommodation needs of the visually impaired are recognized and accepted by organizations;
- Make training part of organizational policies;
- Impel staff to discuss funding opportunities for visually impaired clients who require Ontario disability support program (ODSP) prescription equipment (e.g., orthotics, dental, hearing aids); and
- Provide surveys/evaluation forms, suggestions boxes, and an ombudsman so that issues can be addressed as they come up.

Culturally deaf participants suggested that, beyond organizational accessibility plans, organizations are failing to ensure accessibility and accommodation to the deaf and hard of hearing. As a result, they feel the Central East LHIN service agreements should include provisions for health service organizations to hire ASL interpreters, especially since accommodation for the culturally deaf is a legal requirement.

How these policies are implemented (e.g., sensory and physical components of spaces) and the use of interpretation services could be monitored. Moreover, culturally deaf individuals should be present on diversity committees, and should be consulted on an ongoing basis. They also suggested the establishment of a Central East LHIN complaints mechanism with a clearly identified contact person.

## **Suggestions**

Visually impaired focus group participants made the following suggestions:

- Send forms prior to appointments so that visually impaired clients can have them filled in;
- Give health service providers sensitivity training;
- Improve accommodation in organizations (e.g., signs, call bell in hospital in tactile reach, orientation to new surroundings); and
- Create a hub of services, preferably located close to public transportation for easier access.

Culturally deaf focus group participants made the following suggestions:

- Increase the number of health service providers who are fluent in ASL;
- Encourage health service providers to respect all methods of communication including email, and not rely too heavily on the telephone;
- Instruct health care providers to take additional time to ensure appropriate service delivery, particularly in the absence of OIS;
- Use vibrating devices in waiting rooms to alert clients;
- Train staff to deal with culturally deaf clients;
- Include important educational materials and other information (e.g., flyers, videos) on websites in American Sign Language or with captions;
- Set up a 24/7 online emergency interpreting service; and
- Increase Long-term Care facilities equipped to deal with deaf seniors.

## Ethno-specific and Linguistic Communities Focus Groups – Chinese, Tamil, Afghan, Sudanese, Caribbean, and French Speaking Individuals

### Scarborough

The rationale for the focus groups with ethno-specific communities was the growing recognition of the link between health inequities and the experience of race, ethnicity, and immigration status. This is particularly important as, according to Statistics Canada (2006 Census), out of Ontario's total of 3,398,700 foreign-born individuals (representing 28.3% of the province's population), most live in the metropolitan area of Toronto (68.3%). In Scarborough, immigrants represent 57% of the population; 67% are visible minorities; and 55% have a language other than English as their mother tongue.

In order to ensure a broad representation of voices, the project decided to conduct focus groups with five communities in Scarborough, each one encompassing a certain range of communities and other categories. These categories included: size of community, historical pattern (e.g., recent immigrants), existing or lack of culturally specific services, and language abilities. The project therefore decided to conduct focus groups with: 1) Chinese; 2) Tamil; 3) African and Caribbean; 4) Afghan and Sudanese women; and 5) French speaking immigrants and French speaking individuals.

1) Together **Chinese** languages (e.g., Mandarin and Cantonese) represent the largest mother tongue and home language group after English. Chinese is also the largest group by ethnic origin and the second largest visible minority group in Scarborough (Toronto Community Profiles, 2008). There are several examples of cultural services, notably the Yee Hong Geriatric Centre and Hong Fook Mental Health Association (both of which allowed the focus groups to explore the viability and usefulness of culturally specific services).

*"We recognize that merging these diverse communities into a category called ethno-specific communities has limitations given the diversity of participants and their experiences with the health care system. However, given the focus of this project on the broader issues related to health equity, we believe that structuring the focus groups this way is acceptable."*

- Health Service Provider

A total of 15 participants attended the focus group for the Chinese community. The group consisted of 10 women and five men. In terms of age, 26.7% were 26-40, 66.7% were 41-60. Of the total sample, 100% were born outside of Canada. Of this group, 33.3% have lived in Canada between three and 10 years and 66.7% have lived in Canada for more than 10 years. All participants lived in Scarborough.

From the perspective of diversity, 6.7% self-identified as belonging to an ethno-cultural group, 53.3% self-identified as a visible minority, 60% self-identified as a person with a disability.

Finally, in terms of highest level of education completed, 46.7% reported high school and 46.7% reported having attained a certificate or diploma.

2) **Tamil** is the third largest mother tongue and the fourth largest home language group in Scarborough (Toronto Community Profiles, 2008). There are a sizeable number of health projects and services geared to the Tamil community in Toronto, which enabled the focus group to address these examples.

A total of 12 participants attended the focus group for the Tamil speaking community. The group consisted of six women and six men. In terms of age, 33.3% were 18 to 25, 22.2% were 26-40, and 55.5% were 41-60 years of age. Of the total sample, 8.3% were born in Canada and 91.7% outside of Canada. Of this group, 16.7% have lived in Canada for less than three years, 25% have lived in Canada between three and 10 years, and 50% have lived in Canada for more than 10 years. All participants lived in Scarborough.

From the perspective of diversity, 58.3% self-identified as belonging to an ethno-cultural group, 100% self-identified as a visible minority, 16.7% self-identified as person with a disability, 50% self-identified as an immigrant, 16.7% self-identified as a senior.

Finally, in terms of level of education attained, 33.3% reported high school, 16.6% reported having attained a certificate or diploma, 33.3% reported a Bachelor's degree.

3) **Caribbean (and Bermudan)** is the fourth largest community in Scarborough by immigrant status and place of birth with a total of 5.1%, and is the fifth largest group of recent immigrants. If combined with immigrants from all of Africa, members from the Black community make up the third largest immigrant community and approximately the third largest group of recent immigrants in Scarborough. The Black community also makes up the third largest group of visible minorities in Scarborough (Toronto Community Profiles, 2008). Furthermore, TAIBU Community Health Centre is currently established to develop specialized programs and services to this particular community, and given the small number of health services specific to this group, this focus group chose to concentrate on how directed social services like TAIBU can become exemplars for health services elsewhere.

A total of 20 participants attended four focus groups for the African and Caribbean community. The group consisted of fourteen women and six men. In terms of age, 30% were 18-25, 20% were 26-40, and 50% were 41 to 50 years of age. Of the total sample, 30% were born in Canada and 70% outside of Canada. Of this group 25% have lived in Canada between three and 10 years and 45% have lived in Canada for more than 10 years. All participants lived in Scarborough.

From the perspective of diversity, 45% self-identified as belonging to an ethno-cultural group, 65% self-identified as a visible minority, 5% self-identified as a person with a disability, and 15% self-identified as an immigrant

Finally, in terms of highest level of education attained, 45% reported high school, 35% reported having attained a professional certificate or diploma, and 20% reported and Bachelors degree.

4) **Afghan and Sudanese women** both represent relatively small ethnic communities in Scarborough, making for quite distinct experiences with the Canadian health care system. There are no culturally specific health services available for these communities.

A total of nine participants attended the focus group for Afghan and Sudanese women. In terms of age, 77.8% were 26-40 and 22.2% were 41-60 years of age. Of the total sample, 100% were born outside of Canada. Of this group, 22.2% have lived in Canada for less than three years, 44.4% have lived in Canada between three and 10 years, and 33.3% have lived in Canada for more than 10 years. All participants lived in Scarborough.

From the perspective of diversity, 44.4% self-identified as belonging to an ethno-cultural group, 22.2% self-identified as a visible minority, 66.7% self-identified as an immigrant,

Finally, in terms of highest level of education attained, 44.4% reported high school, 22.2% reported having attained a certificate or diploma, 11% reported a Bachelor's degree, and 22.2% reported having attained a Masters degree or higher.

5) Statistics on **French speaking immigrants and French speaking individuals** within the Central East LHIN are, for a multitude of reasons, limited. This is partly due to the fact that statistics on mother tongue tend to overlook Francophone immigrants, particularly as French is often their language of education or communication in Canada but not their mother tongue (e.g., Haitians may enter Creole as their mother tongue). From an ethnicity perspective, Francophones can belong to any ethnic group, and thus often do not show up in statistics.

Furthermore, within the Central East LHIN, many Francophones are not immigrants from outside Canada but internal migrants from Quebec, New Brunswick and Northern Ontario and may or may not speak English well.



From a legal perspective, Scarborough is a designated area under the French Languages Services Act and therefore the Central East LHIN is obligated to ensure services are available in French. As well as seeking French-specific services like the Centre francophone, most Francophones would, as a second choice accept services in French from a mainstream organization (e.g., hospital). And some service in French is provided by two agencies, the Scarborough office of the Central East CCAC and the Pavillon Omer Deslauriers of Bendale Acres Municipal Home for the Aged.

A total of six participants attended the focus group for the French speaking immigrants and French speaking individuals. The group consisted of four women, one man and one individual who identified as transgendered. In terms of age, 33.3% were 26-40, 50% were 51-60, and 16.7% were older than 60 years of age. Of the total sample, 20% were born in Canada and 80% outside of Canada. From this group, 33.4 % have lived in Canada between three and 10 years and 50% have lived in Canada for more than 10 years. According to region, of the six participants, 26.8% lived in Durham and 71.4% lived in Scarborough.

From the perspective of diversity, 33.3% self-identified as a visible minority, 33.3% self-identified as an immigrant, and 50% self-identified as Francophone.

Finally, in terms of highest level of education completed, 33.3% reported high school, 66.7% reported having attained a certificate or diploma.

### **Implementation of Immigrant Focus Groups**

Given the language barriers of the majority of the focus groups, recruitment, registration, and facilitation were independently carried out by sponsoring local organizations that serve the particular communities. The CDE Project team provided advice, some logistics, and necessary materials and supports. The project team also offered training for organizations on running focus groups.

**Chinese Community:** One staff person from Hong Fook Mental Health Association conducted a focus group in April 2009 with 15 participants.

**Tamil Community:** Two outreach workers of the Canadian Tamil Youth Development (CanTYD) conducted a focus group in Tamil in May 2009 with 12 participants.

**African and Caribbean Community:** One health promoter at TAIBU Community Health Centre conducted four focus groups in May 2009 in English with 20 participants.

**French Speaking Immigrants and French speaking community members:** Two members of the French Language Services Collaborative (both also members of the project committee) conducted a focus group with six participants in French in May 2009 and translated the focus group report.

**Afghan and Sudanese Women:** Two staff of the Access Alliance Community Health Centre conducted a focus group with nine participants in May 2009 with two interpreters.

### **Summary of Findings**

Immigrants tend to use a wide variety of health services and, for the most part, prefer health service providers who speak the same language and/or are from the same culture. However, many of them said that it is almost impossible to find such a health service provider. Immigrants felt that health service providers routinely fail to ask community specific questions. Immigrants also experience discrimination and stereotyping in many forms, which leads them to seek refuge, advice, and services within the community and community-specific service organizations.

From the perspective of policies and monitoring, immigrants would like a recognition of systemic barriers. They also mentioned the need for ongoing staff training, anti-racist and anti-stereotyping guiding principles, ongoing community engagement and consultation, a client bill of rights, and a complaints structure.

### **Access to Primary Health Care**

Despite a preference for local services, almost all participants travel great distances to access health services in their respective mother tongue and/or a doctor or other health professionals with the same cultural background. Several participants noted the downside to having a doctor from the same culture is the risk of confidentiality problems, and further isolation from the English culture and language.

Almost all participants access primary health care through family physicians, hospitals, and walk-in clinics. Chinese participants also identified psychiatrists, Chinese physicians, physiotherapists, and individuals practicing traditional Chinese medicine.

Afghan and Sudanese women also access primary health care in one of the satellite clinics of the Access Alliance Community Health Centre and, most importantly, female physicians.

African and Caribbean participants also use Telehealth Ontario and the Internet for health services—and they find information at local community centres, legal services, churches, through cultural media (e.g., local TV channels), and within the community through word-of-mouth and recommendations.

French speaking participants access health care through the Francophone Community Health Centre, other (Toronto) French-speaking organizations or groups that also offer health services or information, the Scarborough office of the Central East Community Care Access Centre, and Toronto public health offering services in French. They also access Toronto General Hospital services that offer interpretation. Finally, depending on their language ability and their health needs, participants access services offered in English, which can often leave them feeling frustrated: “We were told Canada is a bilingual country - well it is not!”

### **Negative Experiences with the Health Care System**

Nearly all participants recounted experiences of discrimination and/or stereotyping related to their language and/or culture. Tamil participants, for example, sometimes feel health service providers make trite assumptions about them, and misdiagnose based on perceptions of cultural identity.

Chinese participants feel that older Chinese people are particularly discriminated against, mostly if they do not speak English.

One woman in the Afghan and Sudanese focus group described how, in one instance, her medical condition was not properly explained to her during labour because of her limited English abilities, and she was unable to demand her rights as a client.

Participants from the Black community also feel judged for living in poor neighbourhoods in Scarborough.

French speaking immigrants spoke of experiencing discrimination and stereotyping (particularly as new immigrants), and as a consequence, poor assessments of their health issues.

### **Treatment Issues**

Tamil, Chinese, African and Caribbean, Afghan, and Sudanese participants all feel that health service providers tend not to ask questions specific to their communities.

Tamil participants pointed out that medication is not affordable to everyone, and that this is an under-acknowledged barrier to treatment. They also said there are not enough Tamil interpreters in the system to accommodate the need.

Afghan and Sudanese participants also spoke of language barriers when accessing health services, and the financial barriers caused by immigration or temporary visitor status.

Some participants from the Black community said the simple fact of not seeing people from the same culture in the health sector makes it difficult for the community to trust the system. Black immigrants have difficulties navigating the system and accessing interpretation services, especially seniors.

French-speaking immigrants spoke of the difficulty of finding a family doctor as a newcomer, and of the lack of home care services in French for those with special needs.

### **Mental Health and Addictions**

Only Tamil participants called for more mental health services and education, suggesting outreach via different media (newspaper, television, radio, flyers, etc.).

### **Strategies for Dealing with the System**

Tamil, Chinese, Afghan, and Sudanese participants said they use community services (e.g., grassroots organizations, settlement organizations, community health centres, schools, libraries, newspapers, community members, ethnic media, and the internet) to find appropriate health services.

One particular strategy for Tamil participants when dealing with the health care system is to educate health service providers regarding the community. Other strategies include self-advocacy, avoiding the system, and changing physicians.

Chinese participants spoke of going to emergency services for non-emergency issues if they cannot access their family physicians or psychiatrist in a timely manner.

Afghan and Sudanese women turn to faith/religion, friends and family members, the community and community-based agencies when dealing with the health system becomes very difficult.

Participants from the Black community identified a number of strategies:

- Be very nice or very assertive with physicians;
- Use two physicians, and/or ask for a second opinion;
- Conduct research of one's own;
- Use natural remedies;
- Ask pharmacists or family members about health matters;
- Use walk-in clinics instead of waiting to see family doctor;
- Make an official complaint; and
- Fill prescriptions but do not take medication.

French-speaking participants said they change physicians, ask people to advocate on their behalf, or use natural/alternative therapies when dealing with the health care system becomes overwhelming.

### **Culture, Diversity, & Equity Competence**

French speaking participants feel that health care providers should be able to understand clients' cultures.

## **Policy and Monitoring Suggestions**

Tamil participants argued that policies need to recognize the access barriers created through low socio-economic status, and stereotyping by health care providers, and equally, the need for ongoing cultural competence training, equal treatment, and access to translators and interpreters.

Chinese participants argued for clear protection of people with mental illness and the inclusion of family-centred care. They would also like a central complaints body, investigations into incompetence, the use of suggestions boxes (with staff follow up).

Afghan and Sudanese participants made the following suggestions:

- Develop anti-racist policies in organizations;
- Ensure that language barriers do not inhibit access to services;
- Provide interpretation services;
- Provide clients with appropriate cultural and religious diets; and
- Guarantee female physicians for muslim female clients in labour.

Participants from the Black community said there is a need for anti-racist policies, anti-stereotyping, readily available brochures, culturally specific services, engaged community members (e.g., boards), community outreach, cultural representatives, a client bill of rights, and mandatory training and retraining of staff. Monitoring should be accomplished with suggestion boxes, focus groups, observation by regulating officers, and the number of interpretations offered. They also suggested a website for sharing information and experiences, and for filing complaints.

French speaking participants said policies should include:

- The right to receive health care in the language of one's choice regardless of one's nationality, culture, age;
- Culture and language matching; and
- Information in one's language of choice.

In terms of monitoring, they suggested environmental assessments and community consultations to address the health issues of French speaking immigrants as well as the use of client feedback (telephone surveys and focus groups).

## **Suggestions**

Most suggestions were related to language and communication. Tamil participants identified the need for gender-specific translators and interpreters while Chinese participants suggested an increase in Chinese-speaking health service providers. French speaking immigrants suggested more French speaking health service providers who are from the same culture (including in the evenings and weekends), more French services located in Scarborough, more access to health information in French, availability of interpretation services; organizational language and culture matching, a directory listing services in French; and for organizations to encourage staff to identify themselves if they speak French.

Afghan and Sudanese women suggested that community centres always have pertinent information available, workshops for communities, and use language-specific flyers and Internet sites. Afghan, Sudanese, and French participants also said that information related to health services should be provided to immigrants upon arrival in the country.

Participants from the Black community suggested better communication using brochures, outreach, phone lines, and community education.

# FOCUS GROUPS WITH HEALTH SERVICE PROVIDERS

In order to hear from a range of front-line health care workers and individuals in leadership positions, the project decided to conduct six focus groups. The aim for each focus group was to have a broad representation from different health services.

The project team decided to conduct one focus group with front-line workers and one with staff in leadership positions in each of the three regions (Scarborough, Durham region, and the Northeast). This ensured that the six focus groups as a whole would reflect the distinct realities of urban, suburban, and rural health care provision, and the perspectives of various levels of front-line and leadership/governance in organizations.

**Scarborough:** Two separate focus groups with front-line workers and individuals representing leadership among health services were held at the Scarborough Hospital Grace Campus in March 2009. Participants in each individual focus group were recruited through a randomized selection of 15 Central East LHIN funded health service providers in the Scarborough region. Following the randomized selection, participation was solicited through a mailed invitation (see Appendix D and E), email, and by follow-up phone calls. Once selected, organizations independently identified focus group participants and the project team completed registration.

**Durham:** Two separate focus groups with front-line workers and individuals representing leadership among health services in the Durham region were held at the Durham Youth Community Health Centre in April 2009. Given limited responses to the first randomized selections of 15 Central East LHIN funded health service providers in the Durham region for both focus groups, a second randomized selection of an additional 15 CE LHIN funded health service organizations was needed to register a sufficient number of participants. Following the randomized selection, participation was solicited through a mailed invitation, email, and by follow-up phone calls. Once selected, organizations independently identified focus group participants and the project team completed registration.

**The Northeast (HKPR):** Two separate focus groups with front-line workers and individuals representing leadership among health services in the HKPR region were held at the Peterborough Public Library in May 2009. Given that two randomized selections of 15 CE LHIN health service organizations failed to produce a sufficient number of focus group registrants, the decision was made to send an open invitation to all Central East LHIN funded health service organizations in the HKPR region. Participation was solicited through a mailed invitation, email, and by follow-up phone calls. Once selected, organizations independently identified focus group participants and the project team completed registration.

## Sample

Of the total 40 health service providers, 77.5% were female and 22.5% were male. In terms of age, 10.04% were under 30, 25% were 31 to 40, 37.5% were 41 to 50, 22.5% were 51 to 60, and 2.5% were over 60. Of the total sample 37.5% worked in Scarborough, 40% worked in the Durham region, and 22.5% worked in HKPR.

In terms of education, 10% reported a certificate, 27.5% reported a diploma, 35% reported a bachelors degree, and 25% reported a masters degree.

Twenty-seven point five per cent self-identified as belonging to an ethno-racial group, 35% self-identified as belonging to a visible minority, 2.5% self-identified as LGBTTTQ, 5% self-identified as having a disability, 12.5%

self-identified as belonging to an immigrant and/or refugee group, and 2.5% self-identified as Aboriginal. In total, 35% of the participants self-identified as belonging to one marginalized group and 22.5% identified as belonging to more than one marginalized groups (e.g., visible minority, immigrant, and LGBTQ).

Five per cent have less than three years experience in the health system, 25% had three to 10 years of experience, 37.5% have 10 to 20 years of experience, and 30% have greater than 20 years of work experience.

Twelve point five per cent worked in nursing, 35% worked in social work/counseling, 10% worked in health promotion, and 25% in administrative/management roles.

Twenty per cent worked in the addictions and mental health field, 25% in community support services, 10% within the hospitals, 10% in community health centres, and 20% in long-term care facilities.

## **Recruitment, Facilitation, Informed Consent, and Questions**

For each focus group we randomly selected 15 participating organizations. The project team used a formula for distribution of representation from different health care services following the categorization of the Central East LHIN. In other words, one participant from addiction services, one from an after-hours clinic, one from a Community Care Access Centre, and two to three participants each from community support services, hospitals, long-term care facilities, and mental health services.

Participant recruitment and outreach for focus groups of health service providers was conducted by members of the project team. Management and staff from Central East LHIN funded organizations were contacted by phone and email. Management was encouraged to post and distribute flyers developed for participant recruitment.

Each focus group session took approximately 60-90 minutes. Project staff provided the facilitation and note taking of all six focus groups. All focus groups were audio-recorded. Participants signed the informed consent forms and, following an overview of the project and prior to commencement of the focus group, filled in a demographic form (see Appendix F).

The questions of the focus groups addressed the following components (see Appendix G and H):

- Conceptualization of health equity;
- Organizational practices and ability to respond to diverse and marginalized communities;
- Organizational commitment, governance, monitoring;
- Exemplary models;
- Challenges for health service providers; and
- Ideal vision of health equity policies, monitoring, accountability, and education.

## **Summary of Findings**

Most front-line worker participants agreed with the definitions of health equity, health disparity, and cultural competence that were provided as a starting point. However, several members warn that including definitions can create rigidity and encourage stereotypes. Moreover, some members object to the word “competence,” and feel that “cultural awareness,” “responsiveness,” and/or “responsibility” might be more appropriate.

Leadership participants also agreed with the definitions, but found them too academic, making them potentially inaccessible to many individuals. They also pointed out that definitions of cultural competence cannot be static, and will change over time depending on who is affected.

Suggestions that emerged from discussions with front-line workers:

- Create guiding principles rather than definitions (thus moving from the “what” to the “how”);
- Frame these guiding principles as positive and action oriented; and
- Use language that is accessible to all staff and community members.

Leadership participants suggested focusing on the notion of difference instead of cultural competence.

## Health Equity

All front-line worker participants agreed that there is a disproportionate burden of illness among marginalized communities that needs to be addressed (e.g., immigrants with TB).

Leadership participants agreed that health inequity must be addressed, and went further by calling it a civic duty and social justice issue: Health equity is about providing the best possible client-centred care, which entails providing better and more effective services and therefore better clinical outcomes. One participant also argued that ethno-specific services increase the overall quality of the service.

Participants identified the issues of: 1) geographic, population changes, and planning; 2) service barriers; and 3) technology as a barrier.

1) Participants spoke of the lack of planning to deal with the different realities of rural versus urban settings. Scarborough and Durham region comprise great ethno-cultural diversity, while HKPR has a large and growing population of seniors, and increasing issues of age-related illness. One participant spoke of a similar lack of planning to address issues related to First Nations communities.

2) Several barriers to health equity were identified, including:

- Negative experiences (e.g., discrimination)
- Cultural stigmas (e.g., mental illness)
- General stigmas (e.g., Alzheimer)
- Cultural stereotypes (e.g., cultural profiling)
- Low levels of education (particularly in HKPR), and
- The fact that service delivery is tied to the ability to express, demand, and request services.

In fact, those who require the most service are often the ones who do not or cannot express their needs. From the perspective of seniors in HKPR, having to travel to services rather than having services travel to them, is an important barrier to health equity.

Participants in one front-line focus group argued that the alleged universality of both the Canadian health care system and the Central East LHIN’s funding system, is a contributing factor to health inequity, because the notion of universality creates the misconception that everyone has the same level of access to appropriate services, which implies there are no inequities.

According to several participants in several focus groups, health care equity in the Central East LHIN cannot be said to exist, given the unequal funding between the regions, and the fact that most services geared towards mainstream patients, thus creating access barriers. In fact, many wonder if the Central East LHIN’s commitment to tackling culture, diversity, and equity in health care is the consequence of guilt, cynical politics, or a passing trend (“the flavour of the month”).

3) Within HKPR, technology tied to service delivery (e.g., websites for information) creates information barriers for seniors and other individuals, as well as for service delivery (e.g., email systems for volunteers).



Participants offered the following general suggestions:

- Develop brochures in different languages;
- Orient refugees at their time of immigration;
- Outreach actively in order to develop trust among the diverse populations; and
- Engage the office of the central east LHIN in better long-term planning.

## Systemic Challenges

Participants identified a number of systemic challenges, specific to the level of: 1) the individual clients; 2) services providers; 3) organizations; 4) the Central East LHIN; 5) the macro-level.

1) From the perspective of *individual clients*, poverty is perceived as the principal systemic barrier to health care services. In HKPR, for example, clients ignore health issues on account of being unable to pay for transportation to health services, or unable to purchase additional necessary health services.

Another systemic challenge for individuals is a mistrust of mainstream service providers, particularly in Scarborough and Durham region, where diverse clients feel their cultural needs are disrespected. Even though some regions have clusters of diverse communities, many clients prefer to travel to Toronto to receive services. This impacts treatment outcomes.

2) At the level of *service providers*, a number of systemic challenges are identified:

- Prejudice related to the elderly and dying and their quality of life (e.g., seniors with cancer);
- Anti-immigrant sentiments;
- Negative views of first nations;
- Stigma related to clients with mental health and addictions problems;
- Excusing and/or denying racism; and
- Health services staff who are insufficiently prepared during their initial education.

3) At the *organizational level*, participants identified the following systemic challenges:

- A lack of commitment to reaching out to diverse populations;
- A lack of inter-organizational information flow regarding diversity;
- Lack of staff speaking different languages; and
- Lack of culture matching.

*“Language barriers also pose a problem for recent immigrants, as many will use family members as translators when receiving healthcare services – which often times means that health issues of a more private nature can be neglected due to embarrassment.*

- Health Service Provider

Another important systemic challenge mentioned by participants is the lack of diverse representation within leadership: For example, front-line staff represent diversity while leadership continues to occupy a social location of power and privilege. Meanwhile, in HKPR, staff are often more diverse than clients and the spiritual aspects of most HKPR organizations are based on Christianity.

Furthermore, organizational practices perpetuate hiring of non-diverse staff, the use of token “others” (e.g., adding a person of colour to a board but silencing their voice), and the conceptualization of diversity on boards according to skills and professions (e.g., lawyer, accountant, etc.).

4) At the level of the *Central East LHIN*, there is a clear sense of the following challenges:

- Access to financial resources for services is unequal;
- Travel is a priority issue within HKPR;



- Immigrants have the most difficulty accessing general practitioners (in all regions); and
- Lack of human resources and funding related to culture, diversity, and equity.

Limited resources mean there is a deficiency in local research studies to address these challenges. This is partly because of the increase in reporting and investment in Information Technology, which has meant reduced funding for direct service.

Participants pointed out that the limited interpretation services offered within the Central East LHIN force family members to take on the role of translators and interpreters, which in turn can compromise the level of care.

From the perspective of HKPR, due to the large number of individuals without a family doctor and a general lack of walk-in clinics, participants feel that clients with multiple health issues (e.g., seniors, people with mental health and addiction problems) have very little hope finding primary health care (not to mention specialized care which is only accessible through primary care), and therefore end up in emergency rooms with advanced health problems. This complicates health issues even more as emergency rooms tend not to follow up with clients, which results in inconsistency in health services.

This, combined with the lack of long-term care beds, leads to a bottleneck in hospitals, particularly for the frail elderly, who are put into long-term care beds that are often far away from their homes.

Finally, some participants feel that health care is lagging behind other sectors that deal in health equity, and that health equity is at odds with the increasingly corporate structure.

*“We had a [First Nations] man who had a plan in place and requests for his passing and immediately after for ceremony and things. It was time and we had to wheel him outside into the rain and we didn’t actually get all of them – all we were attempting to do was sticking his head out through the doors so we weren’t actually setting off the alarms – the smoke alarms, fire alarms. While we were struggling with the logistics of sticking a glove over the sensors he passed away with his head sticking out the fire exit.”*

- Front-line worker

5) At the *macro level*, participants identify a number of systemic challenges to health equity:

- The larger determinants of health;
- The reality of intersectionality (e.g., youth are not a homogenous group);
- The lack of culture specific disease control; and
- The fact some liability issues and ministry policies can create barriers to providing responsive and client-centred care.

To deal with these issues, front-line workers made the following suggestions:

- Educate service users in the long-term care system to avoid client to client and client to staff discrimination;
- Help clients to better understand the health care system;
- Learn to understand stigma; and
- Avoid reinventing the wheel by sharing experiences from other areas like Toronto (suggested by several members in Durham and HKPR).

Leadership participants made the following suggestions:

- Create partnerships to bust current silos;
- Change initial education for services providers; and
- Acknowledge the existence of racism and discrimination.

## Clinical Issues and Suggestions

The focus groups with front line workers and leadership participants raised the following points:

- There is limited ability among the staff;
- Cultural competence is an issue of time and resources;
- Power differentials are not adequately recognized in clinical encounters;
- The health care system tends to do things *to* people rather than *with* people; and
- Professional colleges are changing their accountability requirements in regards to cultural competence without alerting their own staff.

Overall, participants identified clinical issues related to: 1) language; 2) education; and 3) the health care delivery continuum.

1) Providing health care services to clients who do not speak English is a problem, especially when interpretation or translation services are not available, as it often means relying on community volunteers and family members.

2) A lack of clinical training and education in the areas of culture, diversity, and equity is an issue because, as participants pointed out, it means that an individual's inherited familial values will shape his or her clinical approaches rather than good training and education. Without training, one understands one's own cultural location but not the location of others.

Participants also identified the need for some basic core knowledge and approaches to avoid clinical errors (trial and error is often considered a current learning method), and to better recognize that cultures are not homogenous.

3) Several issues related to the continuum of care were identified:

During *intake*, a lack of knowledge of existing culturally appropriate practices can lead to inappropriate service delivery services (e.g., in the case of drop-ins).

During *clinical assessments*, poor understanding of culture and inadequate information from the clients, including client families (onus should be on the service providers to ask questions), means that cultural and religious needs are not met, even if medical history is taken into account. The challenges related to a lack of cultural understanding and insight include: limited informational flow from assessments to clinical staff, questions purposefully not asked, and lack of time and resources to do comprehensive cultural assessments.

During *planning and treatment*, participants identified the need for culture matching (e.g., physician from the same culture), for non-traditional and family-centred treatment approaches, and for revised treatment plans when cultural issues arise. Some participants further noted that holistic approaches to health care are not adequately practiced.

Finally, during *referrals*, the general lack of culturally competent services, as well as the time required to find appropriate services, are seen as problems. It was also noted that most often it is social workers who refer clients (e.g., in hospitals), meaning that most of the knowledge of alternative services is confined to a small group of staff. Moreover, cultural dimensions are often not shared during referrals.

Front-line workers made the following suggestions:

- Focus on how to ask questions rather than cultural profiling in clinical training;
- Develop a more holistic approach to health care;
- Develop outreach strategies to help communities overcome stigma; and
- Revise assessment tools: use the multicultural calendar, use existing diversity trainings, the blue book, create cultural portfolios, books, and websites to staff.

Leadership participants made similar suggestions, and added the following recommendations:

- Reach and partner with communities and organizations to increase cultural competence;
- Use cultural brokers and community volunteers; and
- Identify cultural competence as a core competence.

## **Organizational Issues and Suggestions**

Overall, participants identified issues related to: 1) policies and commitment; 2) training; 3) communication; 4) resources; and 5) organizational structures.

1) Though there is a general sense that organizations have policies related to culture, diversity, and equity, participants said there is no real commitment to these policies. Some front-line workers feel that the policies are created by people with power and privilege, and that regardless, human resources can block projects and carry on hiring non-diverse staff. The onus, therefore, is on staff (often marginalized staff) to advance diversity.

Leadership also contended that culture, diversity, and health equity are not given priority among the many competing demands and interests. Moreover, because outreach and community partnerships are staff driven, and therefore formalized, they are mostly unsuccessful.

2) All participants agreed that there is a clear lack of training offered by organizations, and this leads to highly inconsistent competency among staff. Front-line workers also say there are few opportunities to share knowledge and expertise among staff and outside organizations (e.g., First Nations organizations).

3) Front-line workers stressed how, throughout the continuum of health care, internal communication creates barriers for culture, diversity, and equity.

4) The failure of organizations to ensure culture, diversity, and equity is due to a lack of resources, according to participants. This often means an absence of translation / interpreter services, especially in smaller organizations and the resulting practice of relying on family members for interpretation can compromise health care, since crucial information may be censored or inaccurate. On the other hand, larger organization, such as hospitals, can offer translation and interpretation between many languages, by pooling their staff. Front line workers pointed out that the Central East LHIN needs something similar to Access Alliance's interpretation services.

5) Finally, leadership participants identified some of the organizational structures that create barriers:

- Failure to recruit and retain diverse staff (particularly outside of Toronto);
- Weak commitment to the issue at certain organizational levels; and
- The difficulty of some large organizations to attend to the specific needs of the populations around their regional offices.

## **Suggestions**

In terms of organizational commitment, participants made the following suggestions:

- Embed culture, diversity, and equity within organizational vision, mission, values, and strategic planning;
- Promote organizational cultures of diversity and tolerance;
- Be proactive rather than reactive, to help organizations move beyond policies;
- Make leadership and staff into role models, to create an environment where individuals can learn from each other;
- Develop multi-lingual services; and
- Create the sense that the onus is on everyone to advance diversity.

In terms of training:

- Train staff in cultural competence using staff orientations;
- Organize diversity weeks; and
- Ensure active outreach to communities that include partnering with communities to create community guidance to organizations.

In terms of structural suggestions:

- Develop a system that is mirrored on the Workplace Hazardous Materials Information System (WHMIS); and
- Ensure diversity committees start off as a focus and then eventually become intertwined in all aspects of an organization.

## Exemplary Models

Most responses to questions about exemplary models in health care were linked to geography.

In *Durham region*, with the exception of the Oshawa Community Health Centre, no other exemplary models in health care were offered. However, culture matching and a focus on identity and intersectionality were identified as possible exemplary practices.

For *Scarborough* participants, exemplary practices included:

- Create satellite locations;
- Hire bilingual staff;
- Target outreach to communities (including media);
- Form active partnerships with communities; and
- Consider mobile service delivery as exemplary practices.

Certain organizations were named as exemplary models: The Hong Fook Mental Health Association, Yee Hong Geriatric Centre, and First Nations addiction aftercare services.

In *HKPR*, participants said the one-stop-shopping model of long-term care was exemplary, as well as certain First Nations services in which care is brought into reserves whenever possible.

## Policy Issues and Suggestions

Several concerns were raised in regards to existing culture, diversity, and equity policies:

- Policies have been mostly developed by staff in management positions and in locations of privilege;
- Policies are proving difficult to implement;
- Certain policies create a culture of fear;
- Current policies only include requirements from the ministry and accreditation; and
- Culture, diversity, and health equity should perhaps not be policies as such, but should instead be included in human rights and other policies and procedures.

Participants suggested the following:

- Develop culture, diversity, and equity policies from the bottom-up;
- Create a code of conduct rather than a policy;
- Make policies action oriented;

- Ensure that policies include components such as:
  - Zero tolerance for abuse;
  - Respect, equality, and sensitivity;
  - Pro-active outreach;
  - Mandatory and ongoing training;
  - Joint service planning with the community;
  - Human resources policies;
  - Diverse boards;
  - Operationalization of policies; and
  - A client bill of rights.
- Make policies accessible, not only to staff, but to support staff (as tools they can use rather than as something that is threatening to them);
- Review, revise, and update policies on an ongoing basis; and
- Include the clients' right to a professional interpreter as part of policy.

### **Accountability and Monitoring Issues and Suggestions**

Participants generally agreed that culture, diversity, and equity policies are not sufficiently monitored, and that the issues are often swept under the carpet, partly because there is a feeling that clients do not know how to complain. What commitment exists is often due more to accreditation and politics than to a bona fide desire to ensure social justice.

Front-line workers argued that internal monitoring is inconsistent and lacking rigour, and that diversity committees fail to focus enough attention on action. Participants working in the long-term care system noted that, for example, ministry inspections do not address culture, diversity, and equity. In the current accreditations system, such as Building Healthier Organizations (BHO), diversity is said to be a mere token—an add-on rather than a focus. Moreover, accreditation is problematic because many organizations hire accreditation services, which to many staff are a conflict of interest.

Suggestions offered by participants related to the: 1) organizational participants; 2) regularity; 3) approach; and 4) a monitoring system.

1) Participants suggested that all organizational levels be included in internal monitoring and implementing organizational policies. Leadership said clients should also be included in the process.

2) Front-line workers recommend strong regularity including monthly check-ups and yearly reports on activities.

3) Participants believe approach should:

- Address actual workplace issues;
- Be rigorous and consistent;
- Include community partners;
- Compare policies with practice; and
- Make use of a standardized system of statistics (e.g., diversity of staff, board, clients; language; referrals; family and client feedback; partnerships; translated materials).

Leadership also noted the importance of measuring quality of care, analyzing trends, and conducting internal performance reviews (including competence).

4) Many participants suggested that monitoring be reported to external bodies rather than internal ones. They also proposed an external system (mirrored on WHMIS systems) with an internal and external diversity complaints system (e.g., ombudsman) that can provide timely responses. Moreover, funding should be tied to Central East LHIN benchmarks.

Leadership added the following suggestions:

- Use a transparent and systematic approach that comprises clear indicators and standards across the Central East LHIN;
- Engage both staff and communities in the monitoring process; and
- Use the Internet as a complaint system.

### **Educational Issues and Suggestions**

With few exceptions, participants feel there is inadequate initial and ongoing education and training in culture, diversity, and health equity. Front-line workers noted a great disparity in the amount and type of training currently given, which ranges from annual re-training to no initial or additional training offered by the organization. In one organization, for example, only managers had received diversity training.

Most culture, diversity, and health equity knowledge is gained by trial and error rather than through organized training options, according to participants. Moreover, the voluntary nature of most training is a cause for concern. Leadership identified a lack of training among board members, and that recent graduates are better prepared to work with diverse communities than senior staff. This reinforces the importance of retraining for long-term staff. It was pointed out that physicians tend not to attend any diversity training sessions.

### **Suggestions**

Most participants feel that there should be mandatory training during orientations for new staff and annual training of up to 8 hours (like WHMIS training). Front-line workers spoke of creating “learning organizations” where situations are used as teachables (rather than using punitive approaches); this would include venues for guest speakers and shared experiences. In other words, training should reach beyond “sessions.” How to ask questions and how to avoid show-casting diversity and entertaining should also be part of training.

Leadership said that training should happen at all levels of organizations as well as between ethno-specific and mainstream organizations. Also, diversity should be celebrated as an opportunity to engage and share experiences, while an awareness of the policies and possible consequences is maintained. Finally, the Central East LHIN should increase resources to ensure adequate and quality training.

# Appendix A: Informed Consent Statement

**Name of Project:** Culture, Diversity, & Equity Project

**Responsible Consultants:** Felix Munger (lead consultant)

Zarsanga Popal (consultant)

Erik Rutherford (consultant)

Eric Hong (Yee Hong)

Project Charter Committee

**Sponsor:** Yee Hong Centre for Geriatric Care

**Purpose:**

The Culture, Diversity, and Equity Project aims to minimize and prevent health inequities experienced by marginalized communities. The project's goals are the development of policy, accountability, and an educational framework for health care organizations in the Central East Health Integration Network (Central East LHIN).

For the purposes of the project, we define marginalized communities as individuals and communities who have experienced systemic oppression and inequity. The process of social marginalization entails factors such as gender, gender identity, sexuality, literacy and educational level, place of residence, mental health, addictions, homelessness, family status, physical and mental disabilities, socio-economic status, legal history, and membership in Aboriginal communities. Cultural marginalization involves issues such as ethnicity, race, immigration/refugee status, and religion.

**What is involved in the Study?**

If you agree to participate in this project, you will be asked to participate in one group interview (focus group). Focus groups will take about 60-90 minutes of your time. The interview will be audio taped and the facilitators will take notes during the sessions. The audiotape will be safely stored in a locked cabinet at Yee Hong for approximately 4 years and will then be destroyed.

Some of the questions are personal and you can refuse to answer these if you wish. The information you provide is for this project only and will remain strictly confidential. The individuals directly involved in your work will not see your responses with any identifying information attached.

**Eligibility:**

To participate in the study you must be working in a health service provider capacity within a health organization funded by the CE LHIN or be a client or potential client of the system.

**Confidentiality:**

- Every effort will be made to keep your personal information confidential:
- Your name will not be used in any reports about the study
- Your consent forms, demographic information and interview notes will be collected by the interviewers and stored in a locked location.
- Interview recordings will be downloaded on password protected computer files.
- While confidentiality cannot be guaranteed within the focus group, participants will be encouraged to not share focus group discussions outside of the group.

The following 4 individuals will be the only people to have access to your data:

Felix Munger (Lead Consultant)

Zarsanga Popal (Consultant)

Erik Rutherford (Consultant)

Eric Hong (Yee Hong)

**Compensation:**

There will be no compensation for your participation if you are a health service provider. If you are a community member we will reimburse you for your attendance at \$40.00 and will reimburse your travel for up to \$30.00 upon receipt of proof of expense.

**Risks:**

Some questions may remind you of unpleasant events in your life experience; therefore, counseling will be made available at your request, if needed.

Some questions may deal with issues that you feel are private. You do not need to answer these questions, and you are free to withdraw from the focus group at any time.

**Benefits:**

It is expected that by participating in the study, your information (and that of many others) may result in changes in health equity within the Central East LHIN.

**Voluntary Participation:**

Participation in the focus group is voluntary. Your participation or your decision to withdraw will not affect your current or future employment or health services. In addition, you can omit any questions or procedures that you wish without any consequence. If you withdraw from the study, your data can be returned to you or destroyed.

**Whom do I call if I have questions or Problems?**

If you have any questions about the project or focus groups at anytime, please call Felix Munger at 519 807 1276 or email at [felix.munger@yeehong.com](mailto:felix.munger@yeehong.com) or Eric Hong at 416 321 6333 x1108 or email at [eric.hong@yeehong.com](mailto:eric.hong@yeehong.com)



Also, if you wish to be sent a final copy of the report, please contact Felix Munger. The report should be ready by June 2010.

**Publication**

The results of this project might be presented at conferences nationally or internationally that aim to address health inequities. The results of the project may also be published in professional association or journal publications.

I consent to allow use of my direct quotations (without your name attached to it) in a published document

Yes

No

**Agreement to participate**

My signature on this consent form means the following:

The Project has been fully explained to me; my questions have been answered

I have read this consent form

I understand the requirements and the risks of the project

I agree to have my focus group audio taped

I agree to take part in this project

**Participant:**

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Name: \_\_\_\_\_

Please Print

Witness:

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Name: \_\_\_\_\_

Please Print

# Appendix B: Demographic Sheet for Community Members

## Demographic Information

This set of questions relates to your demographic information.

Please be reminded that your answers are ANONYMOUS and your responses cannot be tracked back to you.

Please tell us more about yourself.

1. I am  female  male  also Trans

### 2. My age range is

18 – 25  26 – 30  31 – 40  41 – 50  51 – 60  60 +

### 3. I self-identify as belonging to the following groups? (Please check all that apply)

- Ethno-cultural group
- Visible minority
- LGBTQ (lesbians, gays, bisexuals, two-spirit, questioning)
- Transgendered or transsexual
- People with disability (visible / invisible)
- Immigrant / refugee
- Senior
- Other (please specify) \_\_\_\_\_

### 4. My Country of birth is

- Canada
- Other \_\_\_\_\_

### 5. I have lived in Canada

- Since birth
- less than 3 years
- 3 years to less than 5 years
- 5 years to less than 10 years
- More than 10 years

**4. I live in**

- Scarborough
- Durham
- Peterborough, Haliburton, Northumberland, or City of Kawartha Lakes

**5. My highest level of education is**

- High School
- Certificate
- Diploma
- Bachelors Degree
- Masters Degree
- PhD
- N/A

## Appendix C: Focus Group Questions for Community Members

Ensure the informed consent has been explained and signed by participant(s)

### **Introduction and ground rules:**

*Let us establish some ground rules. As a participant in this focus group, you do not have to answer questions that you do not feel comfortable answering. Also, please keep in mind the confidentiality of the information that is being shared with you by the other participants of this focus group.*

### **Recording starts now.**

*Individuals who are marginalized socially and culturally—for example, youth, seniors, immigrants, people with different sexual orientations, gender identities, etc.—tend to experience worse health than the general population.*

*For this reason, as part of a series of focus groups, we have invited all of you here to discuss your experiences with the health system (positive and negative), and help us find ways of addressing the problems and shortcomings that exist in the system.*

*Where do you go to receive health services?*

*Do you search out health services that are directed to your particular community? Do you look for services that are language-specific?*

*If you go to mainstream health services, do staff members (secretaries, nurses, doctors) ask you about some health issues that specifically related to your community?*

*Is there a place you go to when you need information about services that are relevant to your community and that you feel comfortable with?*

*Can you tell us about your experiences with the health system? Do you have examples of positive experiences? Do you have examples of negative experiences?*

*When it becomes difficult to deal with the health system, what do you do to make it easier? How do you cope with the problems or barriers that you face when contending with the health system?*

*What can the health system do to address the particular needs of your community? What is your vision of an ideal health system?*

*In your community/culture/diversity group, is the experience of using the health system very different for young people, seniors, women, or immigrants?*

*In your opinion, what should an organizational policy that recognizes the particular needs of your community include?*

*What should a monitoring system that is respectful of the particular needs of your community include?*

### **Recording ends now.**

# Appendix D: Focus Group Invitation for Front Line Workers

## RE: Invitation to CE LHIN Focus Groups

Dear...

The *Culture, Diversity and Equity – Ensuring Accessibility to Appropriate Health Care for All* (CDE Project) is a Central East Local Health Integration Network project and is intended to address the health issues of marginalized communities within the Central East Local Health Integration Network. This project is funded and supported by the Central East Local Health Integration Network and hosted by Yee Hong.

The CDE Project is running several focus groups and the Project Charter Committee with marginalized communities throughout the CE LHIN and is asking for your assistance in this matter.

### Themes of the focus group

The focus groups will address questions regarding community members experiences with health services, health equity; cultural competence; organizational capacity, commitment, governance, policies and monitoring; exemplary models, etc.

### Staff participant

The ideal participant has experience with working with culturally diverse community members and is a front-line worker.

Please do not send a manager, board members, etc. as there will be a separate focus group for these staff.

Date and Length of Focus group

The focus group will take place on **XXXX** at **XXXX** and will be for approximately 90 minutes hour.

### Location

Once the individuals have contacted the organizer below, we will provide them with the location of the focus group

Please have the individual contact: [cdeproject@gmail.com](mailto:cdeproject@gmail.com) ASAP to register for the focus group.

Felix Munger

Project Leader

Culture, Diversity, and Equity Project

# Appendix E: Focus Group Invitation for Governance Staff

## **RE: Invitation to CE LHIN Focus Groups**

Dear ...,

The *Culture, Diversity, and Equity – Ensuring Accessibility to Appropriate Health Care for All* (CDE) is a Central East Local Health Integration Network project and is intended to address the health issues of marginalized communities within the Central East Local Health Integration Network. This project is funded and supported by the Central East Local Health Integration Network and hosted by Yee Hong.

The CDE Project is running several focus groups and the Project Charter Committee randomly identified your organization and appeals for your organization to send a staff to the focus group in Scarborough/Durham/4 Counties.

### **Theme of the focus group**

The focus group will address questions regarding health equity; cultural competence; organizational capacity, commitment, governance, policies and monitoring; exemplary models, etc.

### **Staff participant**

The ideal participant has an interest and an understanding in issues of health equity, cultural competence, organizational policies, etc.:

- Board members
- Executive Director / CEO
- Manager of Human Resources
- Manager of Programs
- Diversity coordinator/consultants

Please do not send a front-line worker as there will be a separate focus group for these staff.

### **Date and Length of Focus group**

The focus group will take place on **XXXX** at **XXXX** and will be for approximately 90 minutes.

### **Location**

Once the appropriate staff has contacted the organizer below, we will provide them with the location of the focus group

Please have the staff you identified contact: [cdeproject@gmail.com](mailto:cdeproject@gmail.com) ASAP to register for the focus group.

Felix Munger

Project Leader

Culture, Diversity, and Equity Project

# Appendix F: Demographic Sheet for Professionals

## Demographic Information

This set of questions relates to your demographic information.

Please be reminded that your answers are ANONYMOUS and your responses cannot be tracked back to you.

### Please tell us more about yourself.

1. I am  female  male  Also Trans

### 2. My age range is

18 – 25  26 – 30  31 – 40  41 – 50  51 – 60  60 +

### 3. I self-identify as belonging to the following groups? (Please check all that apply)

- Ethno-cultural group
- Visible minority
- LGBTQ (lesbians, gays, bisexuals, two-spirit, questioning)
- Transgendered or transsexual
- People with disability (visible / invisible)
- Immigrant / refugee
- Senior
- Other (please specify) \_\_\_\_\_

**4. My highest level of education is**

- Certificate
- Diploma
- Bachelors Degree
- Masters Degree
- PhD
- N/A

**5. I have worked in the health profession for**

- Less than one year
- One year to less than 3 years
- 3 years to less than 5 years
- 5 years to less than 10 years
- 10 years to less than 20 years
- more than 20 years

**6. My work in the health sector is**

- Nursing
- Social Work
- Occupational Therapist
- Physician
- Health Promoter
- Counselor
- Peer Support
- Administrator
- Board member
- Other (please specify) \_\_\_\_\_



# Appendix G: Focus Group Questions for Front Line Workers

Ensure the informed consent has been explained and signed by participant(s)

Introduction and ground rules:

*Let us establish some ground rules. As a participant in this focus group, you do not have to answer questions that you do not feel comfortable answering. Also, please bear in mind the confidentiality of the information that is being shared with you by the other participants of this focus group. Recording starts now.*

## DEFINITION

*First, please look over the distributed definitions of cultural competence<sup>1</sup>, health disparity<sup>2</sup>, and health equity<sup>3</sup>. Do you, as individuals agree with the definitions?*

## HEALTH EQUITY AS A FOCUS

*Why do you think health equity is an area of concern for the Central East LHIN?  
Can you tell us what culture, diversity, and equity means to you when it comes to health care delivery?  
What does culture, diversity, and equity mean for clients?*

## THE IMPORTANCE OF UNDERSTANDING CULTURE AND DIVERSITY

*Can you give us an example of when understanding culture and diversity mattered?*

## CLINICAL ABILITY & CHALLENGES

*Can you tell us about your clinical ability to address the health issue experiences of the diverse communities you serve?  
What are the main challenges for you when working with individuals from different cultural and social locations?  
Please explain from an individual service provider perspective, an organizational/institutional perspective, and if possible, from a system perspective.  
Can you tell us where you go to find culturally competent services for your clients? Are there particular questions you ask the other organizations when trying to make a referral? Is there anything that is important to you?*

## ORGANIZATIONAL ABILITY & COMMITMENT

*Do you think your organization has the ability to address the health issue experiences of the diverse communities it serves?  
Is there an official commitment?*

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<sup>1</sup> "A set of congruent behaviours, attitudes and policies that come together as a system, agency or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations. The word "culture" is used because it implies the integrated pattern of human thoughts, communications, actions, customs, beliefs, values and institutions of a racial, ethnic, religious or social group. The word competence is used because it implies having a capacity to function effectively".

<sup>2</sup> Health Disparity: A statistically significant difference in a health indicator between groups that persists over time.

<sup>3</sup> Health Equity: 1) Distribution of disease, disability and death in such a way as to not create a disproportionate burden on one population. 2) The absence of persistent health differences over time, between racial and ethnic groups.

*What are some of the barriers that prevent your organization from fulfilling its commitment to issues of culture, diversity, and equity?*

*How much of an organizational priority do you think this commitment is and should be? What are the responses/initiatives you know of in your organization? Does your organization focus on a specific community?*

#### *EXEMPLARY MODELS*

*Can you think of exemplary models of health care delivery (and other social services) to diverse communities (your own or others you have come across)?*

*What do you think ideal health equity policies should include? (e.g., hiring, recruiting, performance appraisal, service plans, supervision, Board membership, management representation of diverse communities, etc.)*

#### *ACCOUNTABILITY*

*How would you monitor organizations and make them accountable to their commitment to health equity? What practical mechanisms would you suggest be put in place?*

*Where would you send uninsured clients? Where would you go to look for services for uninsured clients?*

#### *EDUCATION*

*How much diversity training have you received in your education and how much do you receive from your organization on an annual basis?*

*We have developed a draft flyer for health service providers wishing to find culturally and diversity competent services. Could you give us some feedback?*

***Recording ends now.***

# Appendix H: Focus Group Questions for Governance Staff

Ensure the informed consent has been explained and signed by participant(s)

Introduction and ground rules:

*Let us establish some ground rules. As a participant in this focus group, you do not have to answer questions that you do not feel comfortable answering. Also, please bear in mind the confidentiality of the information that is being shared with you by the other participants of this focus group. Recording starts now.*

## DEFINITION

*First, please look over the distributed definitions of cultural competence<sup>4</sup>, health disparity<sup>5</sup>, and health equity<sup>6</sup>. Do you agree with the definitions provided? Are your definitions different? If yes, what is different and whom do you include in your definitions?*

*Why do you think cultural competence and health disparity are areas of concern for the Central East LHIN?*

## ORGANIZATION

*Can you tell us what culture, diversity, and equity means to your organization when it comes to health care delivery?*

*What are the main challenges for you in working with individuals from different cultural and social locations? Please explain from an individual service provider perspective, an organizational/ institutional perspective, and if possible, from a system perspective.*

## CLINICAL ABILITY OF STAFF

*Can you tell us about your clinical staff's ability to address the health issue experiences of the diverse communities you serve?*

## ORGANIZATIONAL ABILITY TO ADDRESS

*Can you tell us about your organization's ability to address the health issue experiences of the diverse communities it serves? Is there an official commitment? How much of an organizational priority do you think it is and should be?*

*What are the responses/initiatives you know of in your organization?*

*Does your organization focus on a specific community?*

*Are there any factors that are preventing your organization from improving its commitment to culture, diversity, and equity? Please identify any barriers.*

---

<sup>4</sup> "A set of congruent behaviours, attitudes and policies that come together as a system, agency or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations. The word "culture" is used because it implies the integrated pattern of human thoughts, communications, actions, customs, beliefs, values and institutions of a racial, ethnic, religious or social group. The word competence is used because it implies having a capacity to function effectively".

<sup>5</sup> Health Disparity: A statistically significant difference in a health indicator between groups that persists over time.

<sup>6</sup> Health Equity: 1) Distribution of disease, disability and death in such a way as to not create a disproportionate burden on one population. 2) The absence of persistent health differences over time, between racial and ethnic groups.

*EXEMPLARY MODELS*

*Can you think of exemplary models of health care delivery (and other social services) to diverse communities (your own or others you have come across)?*

*POLICIES*

*Can you think of some ways that your organization's policies affect marginalized clients – positive or negative? What do you think ideal policies on culture, diversity, and equity should include?*

*MONITORING*

*How would you monitor your organization's commitment to culture, diversity, and equity? How do you think the CE LHIN should make organizations accountable to health equity?*

*EDUCATION*

*On an annual basis, how much education in diversity do you provide to your clinical staff? How about your board, management, human resources? Are they receiving training, and if yes, how regularly?*

***Recording ends now.***



