THE HALIFAX RAINBOW HEALTH PROJECT

IMPROVING ACCESS TO PRIMARY HEALTH CARE FOR THE RAINBOW COMMUNITY

June 2005

Sponsored by The Nova Scotia Rainbow Action Project
In partnership with The AIDS Coalition of Nova Scotia and
The Lesbian, Gay and Bisexual Youth Project

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A Executive Summary

A.1 *Project Objective*

To increase access to Primary Health Care for members of the lesbian, gay, bisexual, transgendered, two-spirited, intersexed and questioning community (Rainbow Community) within the Capital Health District, which includes Halifax Regional Municipality and the western portion of Hants County.

This objective was accomplished through research to determine the gaps in services and the needs and experiences of the Rainbow Community as well as Primary Health Care service providers.

Cultural Competency
"The framework which allows us to design research and provide services uniquely tailored to each community or individual by integrating and being responsive to factors that influence attitudes, behavior and experience."
- E.J. Rankow
Applying principles of cultural competency to lesbian health, Journal of the Gay & Lesbian Medical association 1998.

A.2 *Research Methods*

The HRH Project started with informal interviews with Rainbow Community-positive health care providers and individuals working in social services.

This community-based research project used focus groups lasting 1-3 hours. Nine Rainbow Community focus groups were conducted. A total of seventeen service provider focus groups were held, that included: doctors, nurses, social workers, mental health workers, and substance abuse professionals.

An anonymous survey was also used for those Rainbow Community members who could not attend a focus group. Two hundred anonymous surveys were completed and returned.

Participants were recruited through promotional campaigns, mass emails, outreach at Community events, advertisements in local Rainbow newspapers, "snow-ball sampling" and survey handouts at local gay events and doctors offices in the Capital Health District.

An extensive literature review surveyed Canadian and international research documents and journals regarding Rainbow Community health issues.

A.3 *Participant Profile*

The project is limited in scope to members of the Rainbow Community who live within the Capital Health District of Nova Scotia.

There were, in total, 265 people who participated in focus groups or completed a survey. There was an almost even split between female and male respondents (female=94, male=100), with the remaining respondents identifying as transgendered, gender-queer, two spirited, intersexed or unsure.

The majority of respondents identified their sexual orientation as either gay or lesbian (n=110), with the remaining respondents identifying their orientation as bisexual, queer, straight, man who has sex with men, woman who has sex with women, two-spirited, poly-sexual, transsexual or other. Some respondents selected more than one category.

The results of the survey reflect, to a large degree, the experience of people with higher levels of education, with 116 respondents reporting that they have completed post-secondary education and another 65 indicating completion of high school and some university. Nineteen respondents have not completed high school. The majority of respondents were employed full time or part-time or were students. Eleven indicated that they were not employed.

A.4 *Results/Conclusions*

Many of the themes, which emerged from focus groups with primary care providers, echoed the themes heard from the Rainbow Community focus groups and from the surveys.

- Participants in every Rainbow Community focus group spoke about finding it difficult to find primary health care services in the Capital Health District that are sensitive to their issues.
- Members of the Rainbow Community often avoid or delay treatment due to a fear of judgment or discrimination.
- More than half of the Rainbow Community participants said they had experienced homophobic attitudes from primary health care service providers. In fact, 75% of the transgendered participants said they had been blatantly refused service based on their gender identity.
- Participants in 148, of 200, surveys expressed concern over the lack of services in the Capital Health District that meet their unique needs.
- Participants in almost all of the providers' focus groups expressed concern over the lack of support available in order for them to become more knowledgeable and inclusive.
- Participants in every provider focus group identified the lack of educational opportunities, and a shortage of information available on specific Rainbow Community health issues, as the main obstacles to becoming more inclusive.
- Participants in 74% of provider focus groups expressed concern over the absence of culturally competent services available for the Rainbow Community.

A.5 *Recommendations*

Evident in all of the focus groups was a sense of urgency for action and energy to participate in a process of change. Participants from the Rainbow Community and service providers made similar recommendations to fill the gaps and create more inclusive services. These included:

- Educational opportunities for all service providers and the inclusion of Rainbow Community health issues in medical, nursing and social work program curriculum.
- Rainbow Community representation on all working groups and boards within Capital Health District.
- Creation of a directory of all Rainbow Community accessible services within the Capital Health District.
- Creation and implementation of standards of care for providing services to the Rainbow Community.
- Creation of a Rainbow Community health centre.

B Acknowledgements

Numerous individuals have contributed many hours of time and energy to this project and the resultant report. The members of the joint advisory committee that guided the development process included:

- Robert Allan – AIDS Coalition of Nova Scotia
- Dr Sue Atkinson – Physician
- Dawn Archambault – HRH Project Coordinator
- Bob Fougere – Nova Scotia Rainbow Action Project (NSRAP)
- Anita Keeping – Planned Parenthood Metro Clinic
- Karen Pyra – Capital Health Project Manager
- Eric MacDonald - NSRAP
- Brenda Richard – Dalhousie University School of Social Work
- Dr Rob Strang –Physician, Capital Health, Public Health Services
- Leighann Wichman – Gay Lesbian and Bisexual Youth Project
- Dr. Rod Wilson – Physician, Capital Health Project

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The committee also expresses its gratitude to the members of the Halifax Rainbow Health Project, Data Sub-Committee, in particular, Dr Russell Westhaver for his guidance in the analyses of the focus groups and survey data, Adam Dolliver for his help with data entry and coding, Brenda Hattie for transcription, and Tara Ainsworth for the development of a database and statistical analyses.

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1 Introduction

1.1 *The Project*

The Nova Scotia Rainbow Action Project, the AIDS Coalition of Nova Scotia and the Lesbian, Gay and Bisexual Youth Project are three Rainbow Community-based organizations that provide services to gay, lesbian, bisexual, two-spirited, transgendered, intersexed and questioning people (Rainbow Community) throughout Nova Scotia.

All three organizations have a long history of supporting this Community's health in Nova Scotia. They also have substantial knowledge about, and capacity to work with the Rainbow Community. Each of these organizations has a strong commitment to increasing access to primary health care services for the Rainbow Community in Nova Scotia.

These three organizations, in March 2004, came together to combine their collective resources and developed a proposal for a multi-phased project focused on improving access to primary health care services for the Rainbow Community within the Capital Health District.

The project partnership presented the proposal to the Canadian Rainbow Health Coalition (CRHC), in response to the Coalition's call for proposals to support the implementation of the CRHC's Rainbow Health - Improving Access to Care Project. The proposal was accepted in May 2004 and the Halifax Rainbow Health (HRH) Project received its funding.

1.2 *HRH Project Goals*

1. To identify the best way(s) of delivering primary health care services to the Rainbow Community within the Capital Health District.
2. To include Rainbow Community health issues as a regular component in the education of new primary health care providers.
3. To include curriculum on Rainbow Community health issues as part of the continuing education requirements for primary health care providers.
4. To improve primary health care data collection procedures to ensure the inclusion of the Rainbow Community in all communications and statistical reporting.

Coincidental to the HRH Project getting under way, Capital Health was launching a project to develop a proposal for meeting the primary care needs within the District. Dr Rod Wilson, in December 2004, responded to Capital Health's call for Expressions of Interest (EOI) for innovative ideas in primary care. Dr Wilson proposed that Capital Health should develop and implement a model to respond to the unmet

primary care needs of the Rainbow Community.

Capital Health selected Dr Wilson's EOI in May 2004, to proceed to the next phase of development: to complete a proposal for submission to the Primary Care Leadership Forum.

Although the Capital Health proposal development project and the HRH project have different goals, it was agreed by all project sponsors that the two projects were similar enough in nature that they should collaborate, particularly in the data collection phase of the projects. A joint advisory committee was created to provide guidance to both projects and to ensure that the efforts of both projects were synergistic.

2 Theoretical Framework

2.1 *A Population Health Approach*

"Addressing the range of factors that determine health status is called a 'population health approach.' A population health approach aims to maintain and improve the health status of the entire populathion."[2]

Information from a variety of sources is used to assess the health of the population, identify priorities for action and develop strategies to improve identified issues. With consideration to the causes of illness and the conditions that create health, this approach invests resources in actions that address social, economic and environmental factors, which are known to have the greatest impact on health status [2].

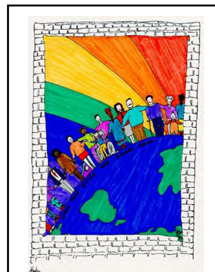
The federal government recommends that the approach to health interventions be broadened. In adopting a population health approach Health Canada has recommended the following key elements:

- Focus on the Health of Populations;
- Address the Determinants and Their Interactions;
- Base Decisions on Evidence;
- Increase Upstream Investments;
- Apply Multiple Strategies to Act on the Determinants of Health;
- Collaborate Across Sectors and Levels.
- Employ Mechanisms to engage Citizens;
- Increase Accountability for Health Outcomes

(For more information on the Population health template see the health Canada web site at: http://www.phac-aspc.gc.ca/ph-sp/phdd/approach/approach.html#health)

2.2 *Twelve Determinants of Health*

Health Canada has established that there are 12 key factors that determine health:
1. Income and social status
2. Social support networks
3. Education and literacy
4. Employment/working conditions
5. Social and physical environments
6. Personal health practices
7. Coping skills
8. Healthy child development
9. Biology and genetic endowment
10. Health services
11. Gender
12. Culture



Population Health focuses on the general circumstances affecting health over which individuals have very little control. [8]

The population health model came out of international research into the factors and conditions that influence the health of populations. 'Fraser Mustard and John Frank of the Canadian Institute for Advanced Research are the main proponents of the population health approach and the related determinants of health. They argue that the complex interactions among the determinants of health have much greater impact on health than any one specific determinant.' [8]

The combined influence of the determinants dictate health status. For example, we know that the most serious health issues occur in the lowest income groups, where factors such as coping skills and a sense of control over life circumstance also come into play.

'Since the inception of the determinants in 1994, Health Canada has expanded the range of determinants of health to include, for example, the determinants of Gender and Culture. The nature and range of the twelve determinants of health will continue to evolve as knowledge in the area grows.'[3]

2.3 *Rainbow Community Health*

The factors that point toward health also operate within the Rainbow Community. In fact, research suggests that the health of this Community is adversely affected because of discrimination when considering each determinant.

It is estimated that one quarter of all street youth are gay or lesbian. [11]

In general, the chronic stress of coping with social stigmatization and societal hatred is the primary negative effect of homophobia. In addition to homo/bi/trans phobia, other types of oppression such as racism, able-ism, sexism, and xenophobia intersect with each other to create serious ongoing health risks.

Well-being and health are negatively affected when members of the Rainbow Community do not have social and family support or a sense of community. Members of the Rainbow Community may feel isolation, alienation and disenfranchisement from the resources and assistance society ordinarily provides in the face of stressors.[9] Educational institutions, employment environments, and social institutions can be dangerously unsupportive and unsafe. Homo/bi/trans phobia experienced in all levels of society can become internalized. This can directly affect the coping skills and health practices of these communities. 'Internalized homo/bi/trans phobia results in lower levels of community integration and social support, lower self esteem, increased feelings of guilt, demoralization, alienation, isolation and other problems.'[9]

The life expectancy of a gay male in Canada is significantly lower than that of a heterosexual male. Statistics Canada reported the average life expectancy of a heterosexual male in 1998 to be approximately 75 years. 'In a study conducted by Cameron, Cameron and Playfair in 1998 found that the median age of death for homosexuals was less than 50 years. There is evidence that this decreased life expectancy is due to increased levels of health and social problems faced by the (Rainbow Community).' [9]

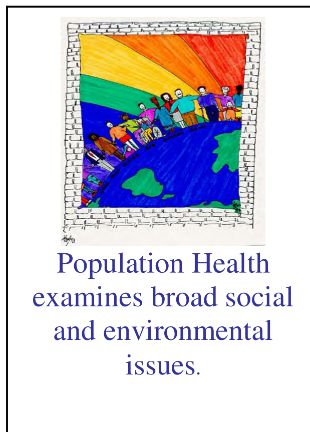
This Community has many sub-cultures that face intersectional levels of marginalization. Youth, for example, who identify as members of the Rainbow Community, are often ostracized from their families, peers and educational systems. 'They can become socially isolated, withdrawn from activities and friends, have trouble concentrating, and develop low self-esteem and depression. These young people, when compared to their peers, experience higher levels of substance abuse, nicotine use, mental health issues and suicide rates.'[10]

Research has shown that gay and lesbian youth are two or three times more likely to attempt suicide than their heterosexual peers. In fact, they account for thirty

percent of all youth suicides. These figures do not include transgendered youth whose rates of suicide are even higher.[11]

'Rainbow Community members living with disabilities or chronic conditions often experience homo/bi/trans phobia and discrimination from mainstream communities, and also struggle for visibility and inclusion within Rainbow Communities.'[4]

Rainbow Community members who are elders face a number of particular concerns as they age. Rainbow elders often do not access adequate health care, affordable supportive housing, and other social services that they need, due to institutionalized heterosexism. 'Many (Rainbow Community members who are) elders experience social isolation and ageism within (the Rainbow Community) itself. These issues are often compounded by racism and other kinds of discrimination.'[6]



Population Health examines broad social and environmental issues.

'Persons who are visible minorities as well as members of the (Rainbow Community) may experience the effects of homo/bi/trans phobia and heterosexism in social and health services more intensely than Caucasian (Rainbow Community) members due to the added discrimination of racism.'[10] Visible minorities may experience additional racism from the Rainbow Community.

The health of the Rainbow Community is greatly affected by the underlying premise behind each of the 12 determinants of health. In order to address the health of this population, all facets of this uniquely diverse Community must be considered.

2.4 *A Population Health Approach to Rainbow Community Health Issues*

Many organizations and communities across Canada (including in Nova Scotia) have adopted a population health approach. This is a vital step towards addressing the needs of the Rainbow Community, although 'there must be an understanding of the implications and an acceptance of the challenges of working with the Rainbow Community as a statistically invisible population with a history of systemic discrimination.'[4]

The following steps, based on an extensive literature review, must be taken to ensure the inclusion of the Rainbow Community in a population health approach:

1. Recognize and incorporate the needs of the Rainbow Community in all structures,
2. Acknowledge and affirm the invisibility of this population,
3. Respect confidentiality at all levels, in all programs and in all services,
4. Include appropriate language in all data collection mechanisms,
5. Provide programs and services that meet the unique needs of this Rainbow Community,
6. Representation and inclusion of the Rainbow Community on all planning committees and working groups,
7. Implement models of care as recommended by this document, and,

8. Develop and implement an extensive evaluation plan for all structures, services and programs to ensure cultural competency.

2.5 *Summary*

A population health approach takes into consideration the factors that indicate health. Focusing on the root causes of problems and incorporating community participation, this approach attempts to find flexible, multidimensional solutions for complex problems.

The main goal of a population health approach is to improve the aggregate health status of the whole society while considering the special needs and vulnerabilities of sub-populations.

This approach is vital to addressing the specific health needs of the Rainbow Community, although special consideration must be taken to ensure the needs of this heterogeneous population are included.

3 Related Research

- The American Gay & Lesbian Medical Association conducted, in 1995, a survey of 2,348 lesbian and bisexual women. Forty percent of respondents felt that, if their physicians knew their sexual orientation, it would negatively affect their health care.
- A Statistics Canada Community Health Survey found, in 2003, that 22% of homosexuals and bisexuals reported they had unmet health needs, nearly twice the proportion of heterosexuals (12%).
- Anti-Gay Discrimination in Medicine, a 1994 report by the American Association of Physicians for Human Rights, found:
  - 91% of respondents reported knowledge of anti-gay bias in their professional environment.
  - 67% of respondents knew of a specific situation in which a lesbian or gay man received substandard care because of his or her sexual orientation.
  - 59% of gay, lesbian, bisexual medical students have suffered personal discrimination.

Recent US surveys indicate that 51%-82% of lesbians and gay men do not disclose their sexual orientation to their health care provider. [11]

3.1 *The Impact of Coming Out on Health and Health Care Access: The Experiences of Gay, Lesbian, Bisexual, and Two-Spirited People. 2002*

Brotman, Ryan, Jalbert and Rowe of the McGill School of Social Work, in partnership with Health Canada, have examined the experiences of Rainbow Communities across Canada in accessing a broad range of health care and social services in the community. They found that health care and social service organizations are often not safe places for members of the Rainbow Community. This is often particularly true for ethnic minorities and Aboriginals who face discrimination based on both their status as members of the Rainbow Community and on their status as racial minorities.

Focus groups respondents, in this study, spoke about feeling the need to 'educate' providers about their unique health issues. The McGill study reports that this was much less likely to have a positive benefit for persons who face multiple oppressions. 'Many (Rainbow Community) members who are subject to intersecting oppression will be more subject to discrimination by health care providers, and as a result, are less likely to be heard, despite a willingness to be honest with their health care practitioners.'[12]

The McGill study recommends that health systems, institutions and providers, in partnership with the Rainbow Community, play an active role in combating prejudice and reducing the barriers to care.

Among the study's further recommendations are the following:
- Healthy policy, both at governmental and institutional levels, should be created that focuses on social justice in health.

- Health and social service institutions should evaluate their ability to provide service to the Rainbow Community;
- Equitable and accessible health care services for the Rainbow Community should be developed;
- Health care policy makers and providers must remain cognizant of the stigma faced by the Rainbow Community and of the impacts of stigma on health;
- The federal government should play an active role in the articulation of best practice with regard to the health and well being of the Rainbow Community. Among such best practice would be the bringing of recommendations for adapting services to provincial health ministers, and assisting institutions in the development of training programs, guides and other materials on Rainbow Community health and health care, and,
- Specialized services that respond to the unique health and social service needs of the Rainbow Community should be developed, including but not limited to:
  - Support for youth who are coming out;
  - Rainbow Community members who are parents;
  - The sensitization of educational services (schools, professional school, health care providers, etc) to the broader Community;
  - The creation of community mental health services, seniors' organizations, and suicide prevention programs.

The Economic Cost of Homophobia

Research conducted by the Gay & Lesbian Health Services of Saskatoon estimates the annual cost of homophobia based on five and ten percent base rates of rainbow population.

- Suicide = $695 - $823 million
- Smoking = $281 - $623 million
- Alcohol abuse = $.29 - $4 billion
- Drug abuse = $119 - $221 million
- Depression = $.54 - $2.3 million

For more information on this study visit the Gay & Lesbian Health Services of Saskatoon at www.gaycanada/glhs

3.2 *Homophobia As a Health Hazard. 1999*

MD's O'Hanlan, Lock, Robertson, Cabaj, Schatz and Nemrow, on behalf of The Gay & Lesbian Medical Association have carried out a comprehensive examination of the effects of homophobia on the health of populations. Their report states that, using the current Diagnostic and Statistical Manual (DSM) IV, homophobia can be diagnosed as a mental disease.

'Homophobia itself is not a named disorder, but since 1972 when the DSM III contained the Ego-dystonic homosexuality, which was described as associated with internalized negative feelings about homosexuality, it has been possible for the clinician to diagnose problems associated with homophobia.'[18]

The O'Hanlan et al. report makes specific recommendations for physicians to reduce homophobia within their practices. The recommendations include:

- The requirement that registration forms and questionnaires in which patients identify themselves should include terms such as 'living together' or 'domestic partner';
- That sexual histories should focus on behaviour rather than on labels of orientation, because many

individuals engage in same sex behaviour but do not identify themselves as Rainbow Community members;

- That patient information brochures must be inclusive to the Rainbow Community;
- That providers should welcome the patient's chosen family, and,
- That physicians, regardless of their own sexual orientation or political or religious affiliation, must provide the highest standard of care to all patients by discarding those views which science does not validate.

3.3 *Healthy People 2010: A Companion Document for Lesbian, Gay, Bisexual, and Transgender Health. 2001*

Coordinated and co-written by the Gay and Lesbian Medical Association, this document is designed to provide a context for educating all possible readers, and for addressing the systemic challenges that must be overcome if persons defined by sexual orientation or gender identity are to be fully understood and their needs met within the health care system.

Healthy People 2010 is intended to highlight or identify the objectives most relevant to populations or groups and to focus on practical strategies to improve the health of the population or better manage chronic disease conditions.

The Healthy People Consortium - an alliance of more than 350 American organizations and 250 State public health, mental health, substance abuse, and environmental agencies - conducted three national meetings. In addition, many individuals and organizations gave testimony about health priorities at five Healthy People 2010 regional meetings held across the USA in 1998. Further, members of the American public were given the opportunity to share thoughts and ideas and to comment specifically on the draft objectives. More than 11,000 comments were received and taken into consideration when developing this document.

> "…Unrecognized homosexuality by the physician or the patients reluctance to report his or her sexual orientation can lead to failure to screen, diagnose, or treat important medical problems…"
> - American Medical Association

The Healthy People 2010 document, when referring to improving accessibility to services, makes the following recommendations:

- Health care systems should create receptive environments for Rainbow Community health care consumers;
- School-based health care centres should offer targeted preventive interventions for Rainbow and questioning youth;
- A national 'health care report card for Rainbow Community consumers' should be created;
- A national resource list of health plans, agencies, and professionals that are Rainbow Community competent, be made available on the Internet;
- A web site should be developed that addresses Rainbow Community health issues, including such information as Rainbow health consumer rights and responsibilities,

self-care, promotion of culturally appropriate standards of care for The Rainbow Community and a compendium of Rainbow health information for health professionals, and;

- The expansion and evaluation of existing programs to promote sensitivity among health care providers to serve Rainbow Community populations.

The document goes on to make specific recommendations for education and training, policies and research.

3.4 *Towards a Healthier Scotland: Inclusion Project Working for Lesbian, Gay, Bisexual and Transgender Health.*

This project, launched in 2002, is a partnership between Stonewall Scotland, representing Scotland's Rainbow Communities', and the Scottish Executive Health Department.

This project reports on current levels of discriminatory attitudes towards the Rainbow Community across Scotland, after having completed a thorough literature review (which included over 150 documents), an audit of existing services, and the inclusion of results from a number of other research initiatives. It also provides evidence of how these issues impact directly on the health of the Rainbow Community. The areas of study include:

1. Health Service Access
2. Mental Health
3. Sexual Health
4. Reproductive Health
5. HIV
6. Addictions
7. Eating Disorders
8. Transgendered Health
9. Domestic Violence
10. Other key social determinants

'The stigmatization, experienced by gay men and lesbians, seriously limits their ability to identify themselves as gay and lesbians to their health and social services professionals.' [25]

The Inclusion Project documented serious gaps in services designed to meet the dynamic needs of the Rainbow Community.

The Inclusion Project, based on evidence gathered, identifies three key areas for action: challenging homophobia and trans-phobia; improving accessibility to, and appropriateness of, mainstream services; and, support for specialist services

3.5 *Health Concerns of the Gay, Lesbian, Bisexual and Transgendered Community: Massachusetts Department of Health. 1997*

A state-wide health care provider survey was used, in 1997, that detailed a serious lack of awareness and understanding of Rainbow Community health issues among providers in Massachusetts.

This study found that the Rainbow Community faces real and significant health care challenges. 'Perhaps the most striking and fundamental finding is that many in the Rainbow Community do not disclose their sexual orientation to their health care providers. The lack of disclosure can limit the practitioner's ability to understand the factors affecting the patients' health and to treat the whole person.'[11]

The project convened a working group of some 60 participants, which included: the department of health, service providers, administrators, community-based agencies, consumers and patient advocates. The group reached consensus, over a ten month period, on fourteen community standards of practice that provide a framework for improving access to care and assisting providers in creating responsive environments of care. The standards of community practice address the issues relating to administration practices and to such service delivery components as:

- Personnel Policies,
- Clients' rights,
- Intake and assessment,
- Confidentiality,
- Community outreach, and
- Health Promotion

(See Appendix 2 for a version of these standards adapted for use in Capital Health)

Jodi Sperber, director of the Rainbow Health Access Project, indicates that the collaboration between the Rainbow Community and service providers was an intrinsic element for the creation of inclusive, workable standards.

The project went on to create a training curriculum and technical assistance to give providers the tools and support necessary to implement the standards within their agencies. The project worked to identify existing Rainbow Community-specific data, improve data collection and address potential problems related to increased data collection in the Rainbow Community.

The Rainbow Health Access Project represents a unique model of public-private collaboration, the success of which is built on leadership by public officials, community-based advocacy and provider commitment. 'Only such an integrated approach can create and sustain systemic change at the health care system level, cultural competence and skill building at the provider level, and the development of advocacy strategies at the consumer level.'[13]

4 Methodology

4.1 *Purpose*

There was a dual purpose of the HRH Project research: to gather information about the experiences of the Rainbow Community in the Capital Health District in accessing a broad range of primary health care services, and to examine the role of health care and social serving organizations in shaping access and service delivery.

4.2 *Process*

The joint advisory committee developed and implemented a communication plan to inform the Rainbow Community and primary care providers about the projects. A series of data collection activities was undertaken to inform the development of the projects, thus providing a better understanding of the primary care issues experienced by the Rainbow Community. Data collection activities included a literature review, site visits to two Rainbow Community primary care models in other communities, and focus groups with primary care providers and the Rainbow Community in the Capital Health District. A survey was also available for completion to provide a forum for those who could not attend a focus group.

The joint advisory committee developed the focus group and survey questions using both qualitative & quantitative measurements. Qualitative research allows the researcher to explore deep meaning in situations and is therefore an excellent method to use when exploring issues related to sexual orientation or gender identity. The use of structured questionnaires allows the researcher to keep the focus of participants to the issues at hand while maintaining the integrity of individual personal experience and expression.

The use of a quantitative measurement tool allowed for the demographics of the focus group and survey participants to be documented.

The joint advisory committee estimated receiving between 30 and 50 completed surveys and was very surprised when 200 surveys were returned .

Nine focus groups were held, for different segments of the Rainbow Community, to ensure that participants felt safe to talk openly about their primary care experiences. Fifteen focus groups were held for primary care providers, including physicians, nurses, public health nurses, social workers, psychologists and health educators.

Focus group discussions were transcribed and then analyzed with the intent of developing common and divergent themes. Each transcript and survey was analyzed section by section, maintaining the integrity of the speakers' comments.

Upon completion of the community based research, an extensive literature review was conducted of Canadian and international research documents and journals that address Rainbow Community health issues.

4.3 *Challenges in Research*

The Journal of the Gay & Lesbian Medical Association[17] outlines specific methodological challenges to studying Rainbow Community health issues. These difficulties include:

1. Defining populations – Populations define themselves, therefore it becomes difficult to maintain consensus among terms. Consensus is required to develop valid and reliable measures.
2. Measuring populations – Existing measures of sexual orientation range from simple dichotomous measures in which subjects report they are or are not homosexual, to the more complex scales as developed by Kinsey et al. 'There is no consensus and virtually no literature discussing when and where each of these measures should be used. Therefore their use and value for research is uncertain at best.'[17]
3. Sampling rare and hidden populations concerning sensitive topics - Due to stigma, violence, or perceived violence, members of the Rainbow Community remain invisible and therefore unaccounted for in most studies. Transgendered, intersexed and two-spirited communities remain the most difficult to sample due to the many levels of marginalization they face.

Measures of sexual orientation and gender identity must take into account racial, ethnic, and age differences among research participants, which may affect measure validity and reliability. [17]

'To better understand and monitor the health concerns of the (Rainbow Community), steps must be taken to standardize definitions, measures and methods.'[17]

4.4 *Recruiting Participants*

Many methods have been used to study the Rainbow Community population; some are more successful than others. Networking or snowball sampling is one method that was successful in the HRH Project research. This method entails the researcher identifying members of the populations of interest, or key informants, who then identify other members of the populations who are consequently contacted and included in the study. These additional individuals can then be asked to identify additional participants and so forth, resulting in a 'snowballing' effect. [17]

The project also used outcropping and advertising sampling methods to find participants, although these methods proved less effective than the snowball method.

4.5 *Summary*

The HRH Project, despite the challenges of defining, measuring and sampling the Rainbow Community, was successful in obtaining a significant amount of information from the Rainbow Community regarding their experiences with primary health care services in the Capital Health District. Although attempts were made to include the intersexed community in the research, representation from this community was very limited. Snowballing, outcropping and advertising were used to recruit participants to take part in structured focus groups and surveys. Using these same methods, the project investigated

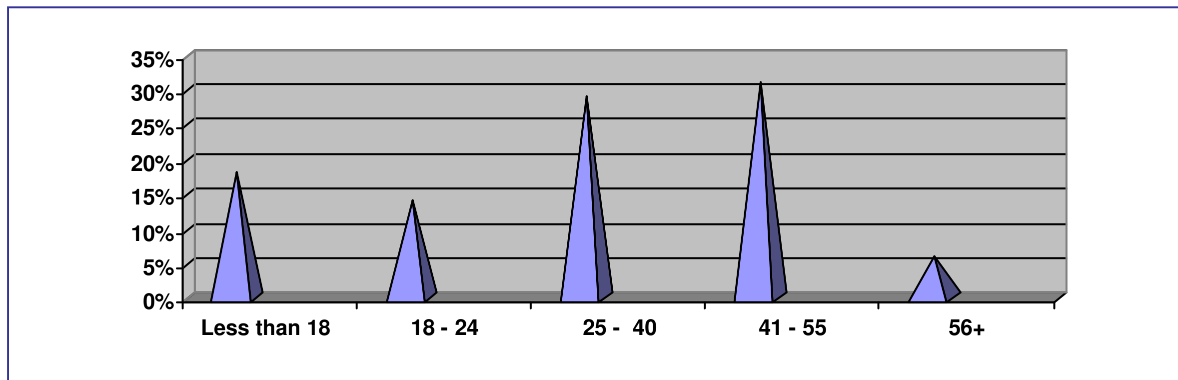
the role that primary care providers and
social service organizations play in
access and service delivery

5 Overview of Participant

The project was limited in scope to members of the Rainbow Community who live within the Halifax Regional Municipality and the western portion of Hants County of Nova Scotia. This area is known as the Capital Health District, which is the largest of nine district health authorities across Nova Scotia. Sixty-five Rainbow Community members participated in the community focus groups and 200 Rainbow Community members completed anonymous surveys. While not represented in the following charts, 145 providers participated in focus groups. The following charts describe the demographics of the Rainbow Community participants in terms of age, sexual orientation, gender identification, employment status, education and ethnicity.

5.1 *Age Groups*

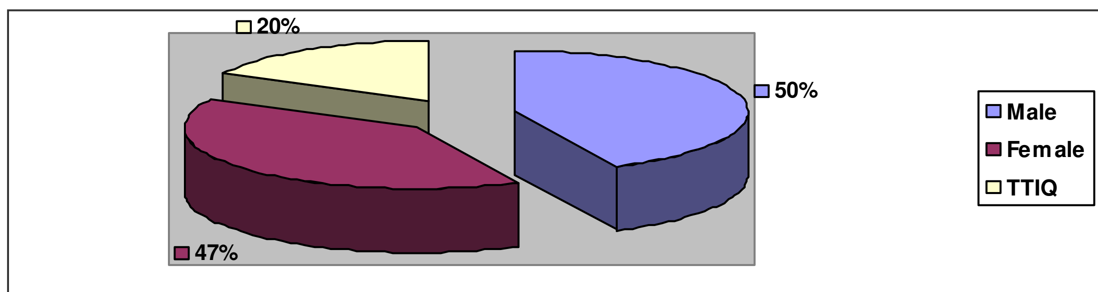
Chart 5-A demonstrates the ages of the focus group & survey participants. The age categories range from less than 18 to 56+. The largest group of participants fall in the 41-55 age range at 31%, followed by the 25-40 group at 29%.



5-A

5.2 *Gender Identification*

Chart 5-B illustrates the break down of the participants in terms of gender identification. It is important to note that many members of the Rainbow Community may choose more than one label when identifying their gender and the statistics reflect this. (For terminology see Appendix 3)

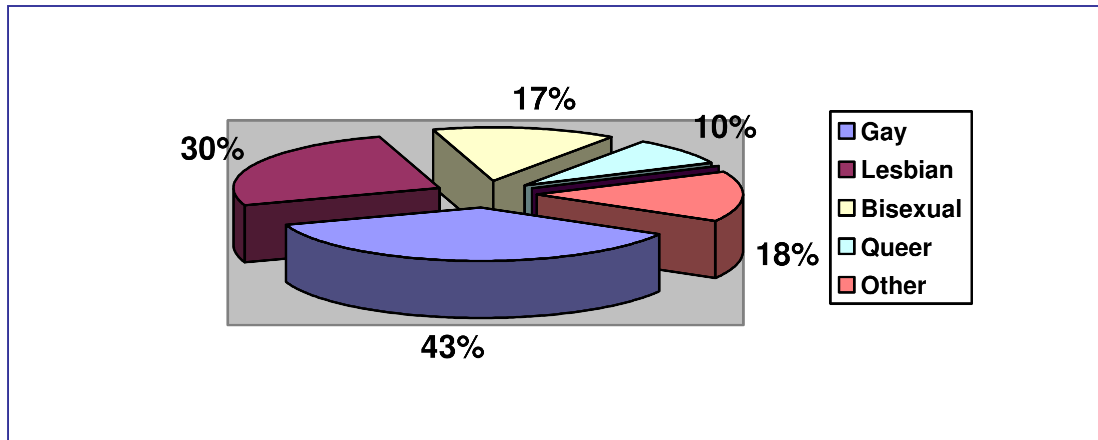


5-B The category 'TTIQ' includes the following identifications and percentages:
- Transgender 1% - Transsexual 4%
- Two-spirited 2% - Intersex 1%

- Questioning 3%

5.3 *Sexual Orientation*

Chart 5-C demonstrates the break down of the participants in terms of identified sexual orientation. It is important to note that many members of the Rainbow Community may choose more than one label to identify their sexual orientation and the statistics reflect this.



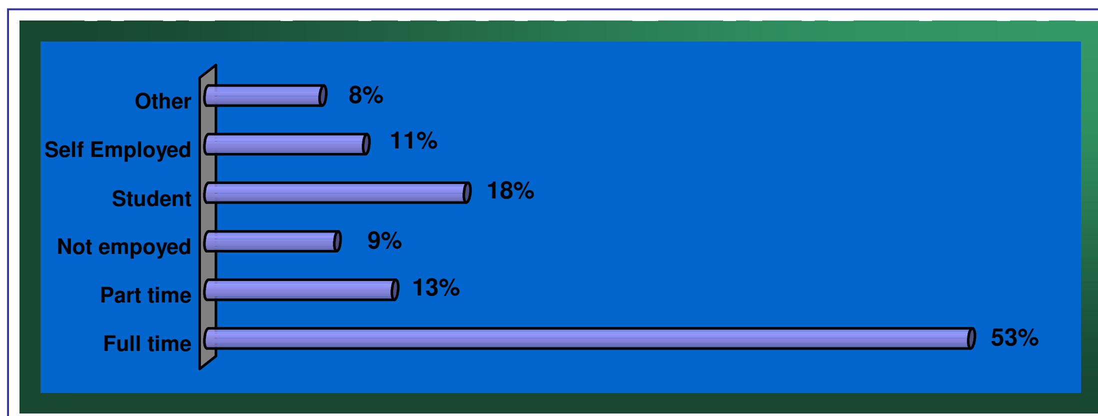
5-C

The category 'Other' includes the following identifications and percentages:

Two-Spirited 2% Straight 5%
WSW 2% MSM 4%
Transsexual 1% Polysexual 3%
Unsure 1%

5.4 *Employment Status*

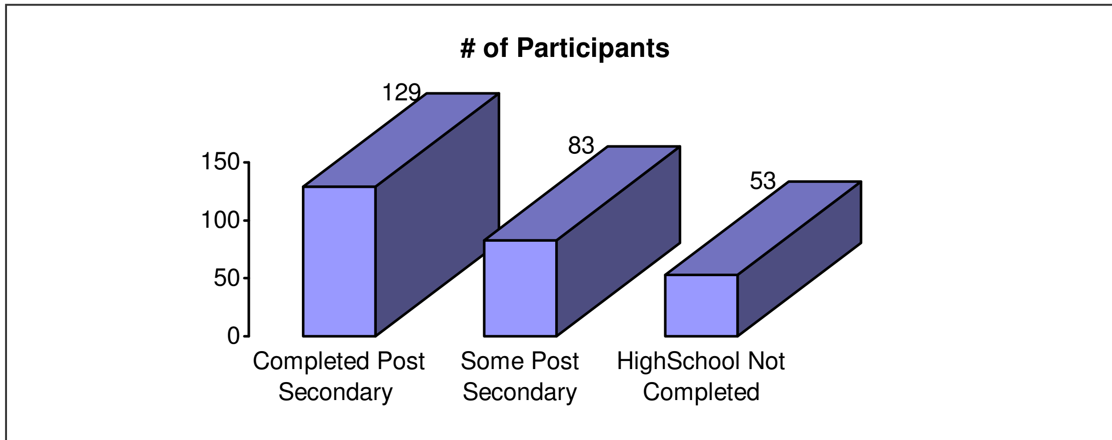
Chart 5-D demonstrates the employment status identified by participants. The majority of participants said they are employed fulltime, however, it is important to note that some individuals may have more than one job or may also be students and the statistics reflect this.



5-D

5.5 *Education*

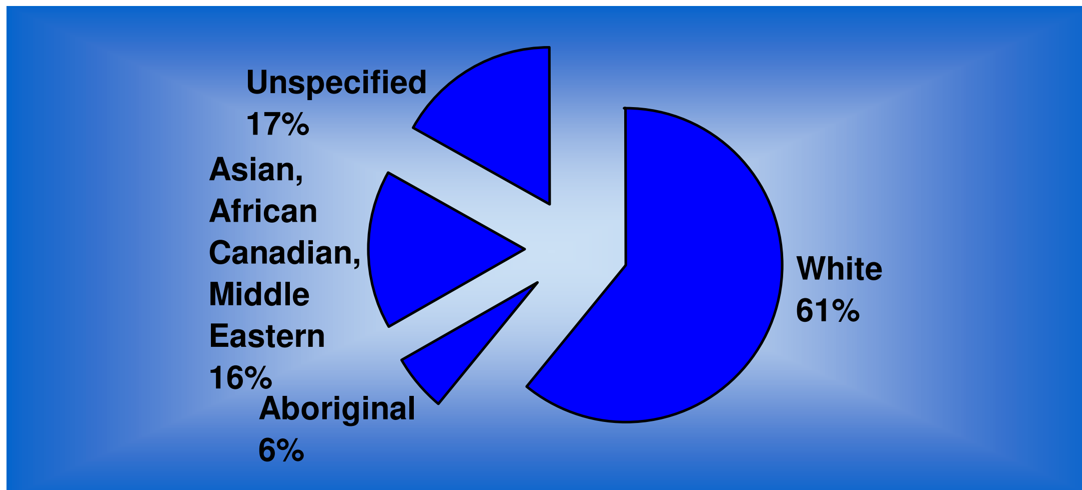
Chart 5-E demonstrates the educational level of the participants. One hundred twenty-nine participants indicated they had completed post-secondary education, and 53 said they had not completed high school. However, of the 265 Rainbow Community participants, 48 were under the age of 18; this may account for the majority of those who have not completed high school.



5-E

5.6 *Ethnicity*

Chart 5-F demonstrates the make-up of participants based on identified ethnicity.



5-F

5.7 *Summary*

Two hundred sixty-five (265) people participated in the Rainbow Community-based research.
Of these, the largest group where white, university educated, employed fulltime, between the ages of 41-55. The most under represented groups were the intersexed, transgendered, transsexual and two-spirited communities, as well as those aged 56+.

6 Results and Observations

To better understand the needs of the Rainbow Community in the Capital Health District, the joint advisory committee conducted a series of focus groups with members of the Rainbow Community, staff of various community agencies that provide primary health care services, and health care providers who provide primary care to the Rainbow Community. Nine focus groups were held for different segments of the Rainbow Community in order to ensure that participants felt safe about talking openly regarding their primary care needs. Fifteen focus groups were held with primary care providers. (The number and type of focus groups held is outlined in Appendix 5.)

"As a gay person, when you seek a service and there's any indication that it's going to be a gay positive space, it really makes you feel good." Community member

The Rainbow Community is difficult to accurately survey and study. Many members of this community remain hidden and would never identify as such to a researcher. Participants in the HRH Project focus groups were required to be open, with at least the interviewer, about their sexual orientation or gender identification. A significant number of people declined this information and were excluded. It is also important to note that people who identify as intersexed are not well represented in the focus group results.

Recognizing that many members of the Rainbow Community would not be comfortable in attending focus groups due to issues of safety, the joint advisory committee designed an anonymous survey, which was made available on the Halifax Rainbow Health Project web site.

There are many people who do not identify with the Rainbow Community but might still identify with a label, or whose sexual behaviours are common to this community. Therefore, the demographic questions reflect a much larger range of possibilities. Notice of the availability of the web site was published in a number of community newsletters, in WAYVES, (a Rainbow Community newspaper), posted at local stores and at Rainbow Community bars. Two hundred and fifty paper copies of the survey were also provided to various venues (e.g. physician offices, gay men's sauna) in the hope of reaching additional Rainbow Community members.

Experienced focus group moderators conducted the focus groups. All sessions were recorded and transcribed, with the exception of two, which were not recorded due to equipment failure. The HRH Project Coordinator coded and analyzed all of the transcripts using data analyses software.

Most of the themes emerging from the focus groups support the issues identified in the literature review. The experiences of the Rainbow Community and providers verify that the Capital Health District is not exempt from the substantial primary care access problems documented in the literature.

6.1 *Results from Rainbow Community Focus Groups & Surveys*

► Eighty-seven percent of the survey respondents, as well as participants in every focus group, indicated that they feel it is very difficult to find primary health care providers who are non-judgmental and/or knowledgeable about Rainbow Community health issues, and therefore avoid treatment.

In total 409 people participated in the focus groups or completed a survey.

"Many of us will avoid treatment at all costs. We only go when it's absolutely necessary, and that's usually 2 or 3 steps beyond where you should be seeking treatment…we have a disincentive to access the system at a time when it's appropriate."
Community Member

► Participants in 8 of the 9 Rainbow Community focus groups expressed the feeling that primary care providers in the Capital Health District assume that all of their patients are heterosexual. These participants expressed concern about disclosing their sexual orientation or gender identification for fear of judgment.

"I haven't told my provider, which is probably not fair to my provider because I haven't given her a chance to respond in any way. But it always throws me off because when I go down there she says 'have you met your prince yet?"
Community Member

► Sixty-six percent of respondents from the survey and participants in more than half of the focus groups indicated they had experienced homophobic attitudes from primary care providers. Almost every transgendered participant said providers, based solely on their gender identity, had refused them service.

"I have spent 8 years of having GPs refuse to treat me – 8 years. And I went through more GPs than you could possibly imagine, being denied, categorically, any discussion of treatment…along the lines of being transgendered."
Community Member

"When my partner and I were looking for a doctor that would help us conceive, we were told a bunch of times by doctors that they don't work with people like us."
Community Member

► One hundred forty-eight, of the 200 survey participants, expressed concern over the lack of Rainbow Community health specific services in the Capital Health District, namely addiction and mental health services.

I found out that I am Bi-Polar last year but I haven't found a counselor yet that knows anything about gay issues. I'm sure there's some out there but I can't afford to pay for it and why should I? Straight people can get help."
Community Member

▶ Thirty-seven survey participants identified cultural sensitivity and language barriers as additional obstacles in primary health care services. Every participant who identified as disabled felt that they face additional barriers to care based on the fact that they are members of the Rainbow Community who happen to be disabled.

"I moved here from (abroad) a few years ago. Its hard enough being a gay man looking for services, add to that someone from a different culture. I experience homophobia from doctors and racism from the Rainbow Community."
Community Member

"A lot of services in Halifax are not accessible for people with disabilities. I find it even more frustrating because I am bisexual. Most services are not sensitive to my needs; I am discriminated against based on my disability as well as my sexuality."
Community Member

6.2 *Ideas From The Community Focus Groups For Making Primary Care More Accessible*

▶ Participants in every focus group, and respondents to 78% of the surveys, agreed that ongoing education and cultural sensitivity training are ways to help providers create welcoming, safe and appropriate health services.

"…you don't want to have to explain yourself every single time. You don't want to have to…try and educate every single person out there who should be the one answering questions. They need training."
Community Member

▶ Participants in 7, out of the 9, focus groups suggested that a directory of culturally competent service providers would help when looking for accessible services.

▶ Sixty-four percent of survey participants suggested that Rainbow Community representation on all working groups and planning committees within the Capital Health District would go a long way toward the development of culturally competent health care services.

Evident in all of the focus groups was a sense of urgency for action and energy to participate in a process of change. The need and desire for collaboration was also expressed.

" I think it would help if the policy makers and those who create services had the forethought to be inclusive. Maybe consulting our Community before creating policies would help. I would love to get involved with something like that."
Community Member

▶ The creation of a Rainbow health centre was mentioned in every focus group, and in 60% of the surveys. The centre would house a variety of services, such as:
- Primary health care services,
- Addiction & mental health services,
- Social support services
- LGBTTIQ Help-line, and
- Educational resources for both service providers as well as the Rainbow Community.

"When I lived (abroad) we had a health centre just for us queer folk, everyone knew where to go and you could just be yourself there. That's what Halifax needs."
Community Member

"I think we need a place of belonging. I would like to see a community centre where I know I will get the health care services that are appropriate to being a trans man who is also gay."
Community Member

6.3 Results From Primary Care Providers' Focus Groups

A wide range of primary care providers participated in the focus groups, including physicians, nurses, public health nurses, social workers, psychologists and health educators.

► Participants in every focus group spoke about the difficulties they face finding non-judgmental, knowledgeable providers to whom to refer clients. Many participants expressed concern that there is an absence of culturally competent services available for the Rainbow Community, namely addiction and mental health services.

"My biggest challenge is knowing who to send people to and that they're safe when they go there."
Provider

"It's skills and it's knowledge base, as well, so how do I treat a gay man?"
Provider

Transgendered people face additional difficulties when obtaining appropriate services where placement in institutions is segregated by sex, for example, shelters, treatment centres and prisons.[26]

► Participants in 13, of the 15, provider focus groups indicated they felt that there is very little support available in order for them to become more knowledgeable. They identified the lack of educational opportunities, lack of information available on specific Rainbow Community health issues, and a lack of guidance, as the main obstacles to becoming more inclusive.

"I'd like to see continuing education across the board, yes, educating students definitely and continuing education across the board whether it's in psychology, social work or other kinds of therapy approaches."
Provider

"I've had to really educate myself . . . sort of had to fly by the seat of my pants for six months. It would be nice to have some support."
Provider

6.4 Ideas From Primary Care Providers

► Participants in every focus group expressed their desire to have more education regarding Rainbow Community health issues. They would like to have guidance on how to create policies and services that are culturally sensitive to the unique needs of this community. They also expressed the importance of including Rainbow Community health issues as a regular component of curriculum for all medical, nursing and social work programs.

"When I was a student I remember we did not learn about the specific health

issues that the Rainbow Community faces. As a health care provider I think this is a dangerous omission."
Provider

Participants, in more than half of the provider focus groups, spoke about the need to have Rainbow Community representation on all planning committees and working groups within the Capital Health District.

"Identify a person …whose sole job it is to pull together these kinds of ideas and find the resources and make some strategies … on a continuing basis and under a kind of statement of commitment."
Provider

The creation of a Rainbow Community health centre was an idea that surfaced in every provider focus group, as it did in the Rainbow Community focus groups. The centre would house the following services:
- Primary health care services,
- Addiction & mental health services,
- Social support services
- LGBTTIQ Help-line, and
- Educational resources for both service providers as well as the Rainbow Community.

"I wonder about the idea of having an outpatients clinic that included nutrition, exercise, counseling, therapy, medical care"
Provider

"It would be really nice if there were some quite specific programs offered to specific groups. I don't think gay males and transgender female to males have anywhere near the same issues "
Provider

Virtually every provider focus group expressed the need for standards of care or best practices.

"As a clinician, it would be helpful to have a set of standards of care. So I know I am providing the best possible care for my clients."
Provider

"I'd like to see our agency move towards the development of some kind of best practices in order to better serve gay & lesbian people."
Provider

6.5 *Key Findings From the Site Visits*

Dr. Rod Wilson from the Capital Health Project was able to conduct site visits to two different organizations working to increase access to primary care for the Rainbow Community.
In June 2004, Dr Wilson visited Gay and Lesbian Health Services (GHLS) in Saskatoon, Saskatchewan. GLHS is a non-profit community-based organization governed by a volunteer board of directors. In existence for over 10 years, GLHS is funded in part by the Provincial government and in part through fund-raising efforts. The fund-raising component of their budget varies annually, making it difficult to accurately plan from year to year.

The organization runs on a drop-in referral model and does not actually offer clinical primary care services on site. They offer multiple support groups that have been established in response to diverse community needs and offer some outreach services. GLHS has 3 full time employees. Similar to experiences reported in Capital Health, one of the

most common issues experienced by GLHS is the difficulty in assisting their clients in accessing supportive and knowledgeable health care providers.

In October 2004, Dr. Wilson visited The Sherbourne Health Centre (SHC) in Toronto, Ontario. The SHC has been in operation for 18 months and was developed in response to the need to develop outpatient models of care with the closure of the local community hospital.

The organization was developed based on a needs assessment of the community that SHC serves. Large portions of that population are members of the Rainbow Community.

The SHC offers a comprehensive range of primary care services provided by a staff of 40, comprised of physicians, nurse practitioners, family practice nurses, naturopaths, health promoters, outreach workers and mental health workers. Four staff members provide services exclusively for the Rainbow Community, including a physician, nurse practitioner, health promoter and mental health worker.

Funding for the SHC comes from the provincial Ministry of Health via a global fixed budget. The SHC is governed by a board of directors and remains autonomous from the health ministry. The SHC has been well received by the community and is quickly becoming established as a teaching site as well as a site for data collection about population health. Partnerships are being developed with numerous organizations, such as the Canadian Breast Cancer Foundation.

6.6 *Summary*

Many of the themes from focus groups with primary care providers echoed the themes heard from the Rainbow Community focus groups, as well as from the surveys. Barriers identified by participants included:

- Scarcity of culturally appropriate services;
- Few services specifically for the Rainbow Community;
- The lack of educational opportunities necessary for service providers to upgrade skills; and
- The lack of guidance to help providers make services inclusive.

7 Recommendations

Participants from the Rainbow Community as well as service providers in the Capital Health District made specific recommendations in order to fill the gaps and create more inclusive services. The literature review revealed similar recommendations from related research.

The following are the recommendations made by the joint advisory committee in order for primary health care providers to become more inclusive to the Rainbow Community. The first of the recommendations describes a model of a Rainbow Health Program that should be developed by Capital Health. The recommendations that follow the model are intended for all organizations that provide health care to members of the Rainbow Community.

7.1 *The Model For Primary Care Delivery by the Capital District Health Authority*

This section describes a model for improving access to primary care services for the Rainbow Community in Capital Health. For a more detailed description of the background and rationale for the model see "Improving Access to Comprehensive and Coordinated Access to Primary Health Care…"[56]

Intended Outcomes of the Model

The model includes the ideas from the focus groups, reflected in the previous section, and is focused on strategies to achieve the following outcomes:

1. Increased access to primary care services for members of the Rainbow Community.
2. Increased health knowledge among members of the Rainbow Community.
3. Creation of a network of existing safe, welcoming and cultural appropriate services for the Rainbow Community.
4. Increased knowledge and sensitivity among primary care providers to enable them to provide culturally appropriate care to members of the Rainbow Community.

Overview of the Model

A common message that was heard repeatedly though all of the provider and community focus groups was the need to coordinate primary care services for the Rainbow Community under one comprehensive umbrella program or service. In response to this message, the joint advisory committee has developed a proposed model that consolidates the various actions required to improve primary care for this community into a coordinated Rainbow Health Program. The Advisory Group envisions the Rainbow Health Program as a centre for expertise on Rainbow Community health issues. It would support all primary care providers in Capital Health in providing high quality care to members of the Rainbow Community.

The Rainbow Health Program model is built on a health promotion approach, recognizing that all of the following five elements are necessary for successful health promotion:

- Building healthy public policy;
- Creating supportive environments;
- Strengthening community action;
- Developing personal skills, and
- Reorienting health services. [57]

The overall vision of the model is presented with the recognition that implementation of the complete comprehensive program would be

incremental.

Component 1: Increased Availability of Accessible and Knowledgeable Clinical Primary Care Services for the Rainbow Community

An urgent need identified by members of the Rainbow Community and primary care providers is access to primary care providers who are knowledgeable about Rainbow Community health issues and who create safe environments for the community.

To increase access to primary care services that are perceived as safe by the Rainbow Community, the first component of the model consists of offering regularly scheduled primary medical care clinics specifically targeted to portions of the Rainbow Community. The clinics would be offered out of a centralized existing clinical setting that provides a safe environment for the community. Primary care physicians would be compensated on a non fee-for-service basis to offer walk-in or scheduled clinics for members of the Rainbow Community several times per month. Physicians recruited to offer the clinics would be knowledgeable about Rainbow Community health issues. The number and type of clinics would evolve over time depending on the needs of the community.

As the model is phased in, the next step in implementing component one would be the development of Rainbow Community specific clinics for mental health and addiction services, possibly co-located with the primary medical care clinics. Partnerships would be sought with existing Capital Health mental health and addictions programs to identify opportunities for offering specific services to the Rainbow Community in safe and supportive locations.

Component 2: Health Promotion/Disease Prevention Outreach to the Rainbow Community

Part of enabling members of the Rainbow Community to take care of their health is providing health education about the specific health issues of the community. Outreach to different portions of the community is an integral piece of this component of the model, so that members of the Rainbow Community are informed about relevant health issues and how they can access various safe resources and supports.

There are currently no culturally appropriate health promotion outreach activities for the Rainbow Community in Capital Health. Educational outreach activities can be coordinated with clinical outreach services such as hepatitis vaccination for men who have sex with men. Outreach entails finding opportunities to deliver health promotion messages in ways and locations that are meaningful to the communities for whom the messages are intended.

Component 3: Professional Development for Providers to Improve Primary Care for the Rainbow Community

Primary care providers have clearly stated through the focus groups that they need access to current information about providing primary care to the Rainbow Community, as well as a directory of primary care providers who are knowledgeable about providing care to the Rainbow Community. A key feature of this component of the model would be implementing a regular mechanism of

keeping providers up to date on health issues of significance to the Rainbow Community; essentially, establishing a centre of expertise on Rainbow Community health issues that providers can draw upon. In addition, a directory of primary care providers who want to be identified as members of a network of providers of care for the Rainbow Community could be created, updated regularly and distributed to primary care providers to assist in referrals.

Opportunities for building a network of providers with expertise in providing primary care to the Rainbow Community could be implemented, such as occasional meetings to discuss current topics of interest or educational sessions. The intention of these activities is to increase primary care providers' knowledge about providing care to the Rainbow Community, as well reduce the sense of isolation that many providers of care to the Rainbow Community feel. These activities will also improve patient access and coordination for existing primary care services in Capital Health.

Component 4*: *Advocacy for Healthy Public Policy

There is no way that the clinical services proposed in component 1 could ever meet all of the primary care needs of all members of the Rainbow Community in Capital Health. Members of the Community will continue to attempt to access the primary care system and continue to experience barriers in doing so unless a concerted effort is made to ensure that primary care services throughout Capital Health are competent to provide the type of primary care required by the Rainbow Community. This component of the model is intended to ensure that resources are dedicated to addressing public policy issues that can lead to the creation of safer environments for Rainbow Community members when they access primary care. An example of accomplishing this objective is through the development and implementation of

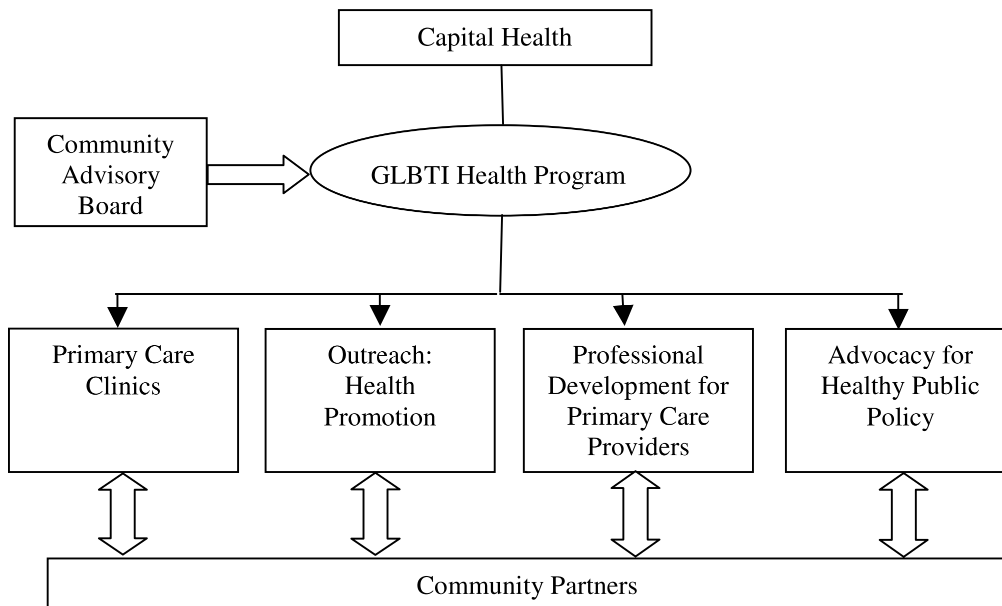


Figure 7-1: Conceptual Overview of the Rainbow Community Health Program Model

standards of care for the Rainbow Community (See Appendix 1 and 2 for more information on Standards of Care). Implementation of such standards would require a significant awareness raising and policy change effort, which is seen as an important function of the proposed model.

Different approaches to implementing the model were reviewed and the solution that offers the greatest opportunity for improvement in primary care services across the Capital Health District is one in which Capital Health shows leadership in addressing the issues by creating a Rainbow Community Health Program within the organizational structure of Capital Health.

7.2 *Recommendations for Organizations that Provide Health Care to Members of the Rainbow Community*

Each recommendation works in partnership with the others. While following only one of the recommendations will certainly help, it is the combination of these recommendations that will address the issues identified in the research and begin the process of inclusion. For example recommendation # 2 addresses educating service providers and the Rainbow Community about specific health concerns. That will ensure that participants on planning committees and working groups (recommendation #3) are able to represent the community in an informed manner. In turn this will help in the creation of appropriate services (recommendation # 4) as well as the development of standards of care (recommendation # 1).

Recommendation 1: The Development, Implementation and Continued Evaluation of Standards of Care for the Rainbow Community.

Standards of care, or best practices, provide a framework to guide long-term improvement in primary health care for the Rainbow Community as well as a foundation for the implementation of new services, where necessary, based on assessment and evaluation.

The literature review has revealed that very little work has been done in the area of developing standards of care for the Rainbow Community. However the LGBT Health Access Project in Boston MA, has developed a set of standards that can be used as a model.

The development of standards of care must be implemented to include the needs of the Rainbow Community in all services and service delivery. Ongoing evaluation of the standards will ensure their effectiveness.

Appendix 1 outlines the process organizations should follow when developing standards of care that relate directly to the services they offer. These have been adapted from the LGBT Health Access Project (Boston).

Recommendation* 2: *The Development and Implementation of Rainbow Community Health Specific Curriculum

Curriculum that relates to the specific health issues and needs of the Rainbow Community must be developed and implemented in the schools of medicine, nursing and social work within the Capital Health District. Primary health care providers have said they want continuing educational opportunities to upgrade their skills to become more inclusive. The Capital Health District

should provide these opportunities and support organizations throughout the process of becoming more inclusive.

Research has suggested that the majority of people who identify with the Rainbow Community are unaware of the specific health issues that affect them. In order to address this issue an informed outreach program should be developed and implemented. Through the efforts of a culturally competent health promoter, the Rainbow Community can become more knowledgeable about their health.

Recommendation 3: Rainbow Community Representation and/or Consultation on all Boards, Planning Committees and Working Groups.

In order to ensure inclusion of the Rainbow Community, the community must be included in the process of change. Community members must be represented on planning committees, working groups and boards that deal with the development of health services or structures specifically for the Rainbow Community.

Consulting with Rainbow Community members on an ongoing basis will help organizations become more inclusive and begin to bridge the gap between providers and the Rainbow Community.

Recommendation 4: The Creation and Continued Evaluation of Services that Meet the Needs of the Rainbow Community.

Services that meet the needs of the Rainbow Community must be created in order to address the specific health issues this Community faces including:

- Primary health care,
- Social services,
- Addiction services,
- Mental health services,
- Outreach and
- Health promotion.

These services must follow specific standards of care that relate to the Rainbow Community. Ongoing evaluation of the services will ensure cultural competency.

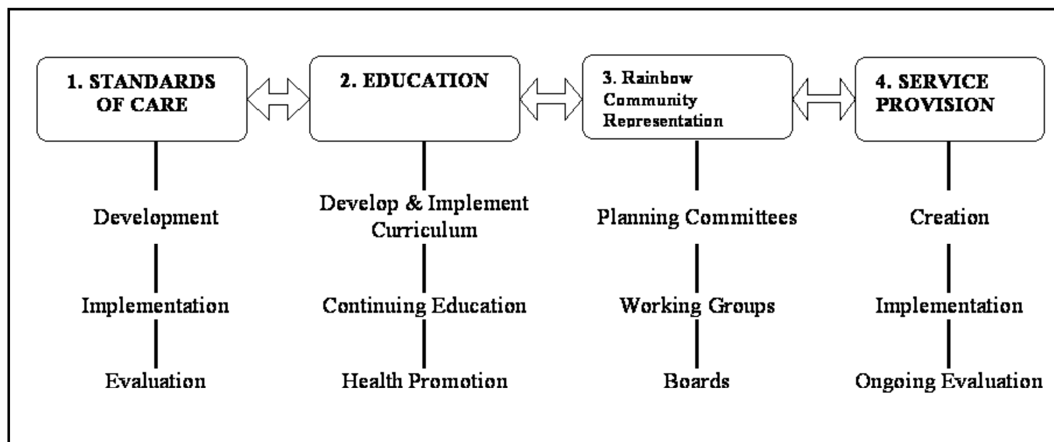


Figure 7-2 Conceptual Overview of Recommendations for Organizations that Provide Health Care to members of the Rainbow Community

8 Conclusion

The HRH Project research has shown that members of the Rainbow Community feel that, not only are their health needs not being met, but many feel unsupported when seeking services. Others have experienced outright discrimination at the hands of those who are responsible to care for their health needs.

The Rainbow Community includes many sub-sets, such as the transgendered and intersexed communities, whose health issues are extremely complex. These communities face many levels of systemic discrimination within the health care system. Members of these communities expressed deep frustrations with the lack of services designed to meet their needs within the Capital Health District, and anguish at the thought of leaving Nova Scotia to seek appropriate health services.

We need to recognize that gays and lesbians from cultural minorities have special concerns and needs, and experience several levels of oppression.[24]

Service providers expressed similar frustrations when trying to find knowledgeable, non-judgmental providers or services that are inclusive, to whom to refer their clients. They spoke about their desire to educate themselves on the specific issues that pertain to Rainbow Community health, and about their frustration at the lack of support and/or guidance to do so. They discussed the need to develop standards of care in order to better serve this community.

There was, during the focus groups, a sense of urgency to take action and a desire to participate in the process of change. Recommendations were made regarding the various ways to increase access to primary health care services. Of these recommendations, the creation of a Rainbow Community health centre that would house a number of health and social services was suggested in every focus group. Other suggestions included education and support for service providers and the inclusion of Rainbow Community health issues in the curriculum for medical, nursing and social work programs.

The results from the literature review and site visits suggest, that while the creation of specific Rainbow Community health services is an ultimate goal, services already in existence must become more inclusive. These services would be greatly impacted by the development of standards of care for the Rainbow Community. Development of standards of care is an individual organizational process. Standards must be implemented that relate to the services that organizations offer, and relate to the unique and dynamic needs of the Rainbow Community.

A population health approach is vital to filling the many gaps that exist in primary health care services in the Capital Health District in Nova Scotia. The creation of standards of care, developed within a population health framework, will ensure the inclusion of the Rainbow Community and its specific, unique health needs.

The Rainbow Community must be represented on all planning committees and advisory boards that are involved in the process of change. Only then can the barriers to obtaining primary health care services faced by the Rainbow

Community be dealt with, and the overall health of this community be addressed.

APPENDIX 1 - Developing Standards of Care

In order to achieve inclusion of the Rainbow Community in practice, it is recommended that agencies and service providers develop and adopt a set of best practices or Standards of Care. Standards provide expectations and outlines for practice. Developing Standards of Care for working with members of the Rainbow Community will allow agencies and service providers to ensure that services, policies, procedures, and environments are inclusive, sensitive, comprehensive and ethical.

Agencies and service providers can develop their own Standards of Care for the Rainbow Community or they can adapt and use some developed by another agency or organization that has a similar mandate and/or operating goals. Standards should outline expectations and sets of practices that are specific, realistic, and measurable. Keeping standards within these limits will allow for quality management and evaluation. Adopting a set of standards will assert that any new practice, policy, procedure or service will be designed to ensure adequate inclusion.

The Gay, Lesbian, Bisexual and Transgender Health Access Project[21] in Boston, Massachusetts developed a process for formulating Standards of Care. This process is helpful in assisting agencies and service providers in ensuring the standards developed are accurate, necessary and meet the needs of the Rainbow Community. Here are some steps to take in beginning the process of developing Standards of Care for an agency. These steps have been adapted from the Gay, Lesbian, Bisexual and Transgender Health Access Project by the Halifax Rainbow Health Project.

1. Administration

Create a standards advisory committee that consists of administrators, staff and Rainbow Community members. This committee will oversee the development process of the Standards of Care for agency approval.

2. Input & Accountability

Hold meetings with stakeholders including government, health care providers and community to discuss what should be included in Standards of Care. Use these meetings to identify gaps, areas of importance and necessary actions.

3. Planning

Create a work plan that identifies timelines, tasks and areas of practice for standard development. Be sure to include both administrative elements such as staffing and policy as well as service delivery. The Gay, Lesbian, Bisexual and Transgender Health Access Project recommends including the following component categories when creating a framework for developing Standards of Care:

- Personnel
- Client's Rights
- Intake and Assessment
- Service Planning and Delivery
- Confidentiality

- Community Outreach and Health Promotion

For each component one or more standards should be developed and accompanied by indicators that specify how each standard will be implemented and measured. It is the indicators that will assist agencies in putting standards into practice and establish a base for evaluation.

4. Development

Create a draft Standards of Care with related indicators. Ensure that the standards address the components mentioned above and reflect the input from the various stakeholders consulted throughout the process.

5. Monitoring

Review the draft standards with those who provided input and assistance. Ensure that the standards and indicators accurately reflect the discussions, advice and decisions that occurred during the planning phase. Continue this process until a final draft is adopted.

6. Impact Assessment

Assess the current practices and policies of the agency and determine what needs to be in place or what resources are needed in order to meet the identified standards and indicators. Present this in terms of time, financial resources, human resources and workloads. Use the impact assessment to adjust any standards or indicators better reflect the reality of the organization, are worded unclearly or need updating.

7. Implementation

Implement the final Standards of Care and begin putting standards into practice. Introduce systems that will accumulate data necessary to measure outcomes as defined by the indicators.

8. Evaluation

Within the first few months or within the first year, monitor and measure the performance of the organization against these standards and related indicators to determine compliance. Develop a plan to improve compliance if weak areas are identified during the evaluation.

It is important to be aware of the models and frameworks in which health care services are established, constructed and theorized. When developing Standards of Care incorporate these frameworks and concepts into standards and indicators so there is congruence with government, professional organizations and community standards. Within Nova Scotia and Canada, it is important to work within a population health framework and to link standards to the Determinants of Health. A population health framework recognizes that health is influenced by a number of individual and societal factors and not just about the presence or absence of disease. The Determinants of Health are the factors that Health Canada has identified as vital to health and well-being.

Establishing accurate and achievable Standards of Care will allow health service providers to better serve the Rainbow Community as well as continually assess and evaluate programs, policies and services to ensure inclusion. Standards of Care for the

Rainbow Community send a perceptible message of acceptance and understanding of the needs of this Community. Standards of Care are also an essential element of competent and comprehensive practice.

"Eliminating barriers to care requires both an educated and empowered consumer base and a skilled, culturally competent, sensitive and welcoming provider community that is openly supportive of gay, lesbian, bisexual and transgendered people and their families. These standards are one tool for achieving greater health care for all."[21]

APPENDIX 2 - Standards of Care for the Rainbow Community

Personnel

Standard 1. The agency shall establish, promote and effectively communicate an inclusive, non-discrimination work place environment for employees who are members of the Rainbow Community.

Indicators:

1.1 Written policies, including but not limited to non-discrimination, diversity and non-harassment policies that explicitly include employees who are members of the Rainbow Community.

1.2 Inclusion of policies in all new employee orientation programs and materials and employee handbook.

1.3 Written sign-off on policies by all employees.

1.4 Discussion of policies with job applicants during interviewing process.

1.5 Posting of policies in all of agency's facilities.

1.6 Annual review of all policies, and opportunities for ongoing employee input and training.

Standard 2. The agency shall support and encourage visibility of employees who are members of the Rainbow Community.

Indicators:

2.1 Active employee recruitment of employees from the Rainbow Community, including outreach to Rainbow Community organizations, and advertising in Rainbow Community media.

2.2 Development and implementation or revision of existing policies to ensure effective procedures for dealing with employee complaints of discrimination or harassment based on sexual orientation or gender identity.

2.3 Written notice to all employees that discrimination or harassment of other employees on the basis of sexual orientation or gender identity is grounds for appropriate levels of discipline, up to and including dismissal.

Standard 3. The agency shall work towards ensuring that employees who are members of the Rainbow Community of all ages are subject to the same terms and conditions of employment, including the same benefits and compensation, as all other employees.

Indicators:

3.1 Written policies explicitly stating that the agency does not discriminate on the basis of sexual orientation or gender identity in providing compensation and benefits, including but not limited to family and medical leave, bereavement leave, and other such benefits as the agency offers employees.

3.2 Written policies explicitly extending the same benefits to all families, including the families of employees who are members of the Rainbow community. Such policies may allow employees to designate who shall be considered their "family" members. If the agency offers health, life, disability insurance and pension benefits to its employees, the agency shall work towards including full and equal coverage.

3.3 Comprehensive ongoing training of all human resource and other appropriate personnel in sexual orientation and gender identity issue with regard to employee benefits.

Client's Rights

Standard 4. The agency shall ensure that comprehensive policies are implemented to prohibit discrimination in the delivery of services to the Rainbow Community and their families. The agency shall ensure that all staff use, and all written forms and policies employ, appropriate language when dealing with Rainbow Community clients and their families. For the purpose of these standards the terms "family" and "families" shall be broadly construed, and shall include but not be limited to relatives by blood, adoption, marriage or declaration of domestic partnership.

Indicators:

4.1 Written policies that explicitly state that the agency does not discriminate on the basis of sexual orientation or gender identity in the provision of services. Such policies shall specifically include families of all clients.

4.2 Conspicuous posting of non-discrimination policies in all languages appropriate to the populations served by the agency, and inclusion of policies in agency brochures, informational and promotional materials.

4.3 Mechanisms to ensure that non-discrimination policies and procedures are appropriately conveyed to all clients, including those with disabilities and those for whom English is not their primary language.

4.4 Explicit sign-off on policy by all employees.

Standard 5. The agency shall ensure that it has comprehensive and easily accessible procedures in place for clients to file and resolve complaints alleging violations of these policies.

Indicators:

5.1 Written complaint procedures.

5.2 Designation of one or more persons responsible for ensuring agency compliance.

5.3 Written notice to all employees that discrimination in the delivery of services based on sexual orientation or gender identification violates standards of good care, and is subject to appropriate discipline.

5.4 Conspicuous posting of complaint procedures, inclusion of procedures in informational materials given to agency clients and their families.

5.5 Translation of procedures into and provision of information in all languages appropriate to populations the agency serves.

Intake and Assessment

Standard 6. The agency shall develop and implement or revise existing intake and assessment procedures to ensure that they meet the needs of Rainbow Community clients of all ages and their families.

Indicators:

6.1 All reception, intake and assessment staff are trained to use appropriate language.

6.2 Development and implementation of intake and assessment forms that provide for optimal self-identification in all categories of gender identity, sexual orientation, marital, partnership and family status, and provide clients with the option and opportunity for further written explanation.

6.3 Develop mechanisms to ensure that all reception, intake and assessment staff is familiar with providers within the agency with expertise in and sensitivity to the issues of the Rainbow Community, and appropriately convey this information to clients.

6.4 Development and implementation of training for all intake and assessment staff to ensure appropriate referrals for Rainbow Community clients and their families to providers within and outside the agency.

Service Planning and Delivery

Standard 7. All agency staff shall have a basic familiarity with Rainbow Community issues as they pertain to services provided by the agency.

Indicators:

7.1 Development and implementation or revision of agency training and programs on diversity, harassment, and anti-discrimination to assure explicit inclusion on Rainbow Community issues.

7.2 Development and implementation of training for all intake, assessment, supervisory, human resources, case management and direct care staff on basic Rainbow Community issues.

Standard 8. All direct care staff shall routinely provide general care to Rainbow Community clients. All direct care staff shall be competent to identify and address, within the scope of their field of expertise, specific health problems and treatment issues for Rainbow Community clients and their families, to provide treatment accordingly, and to provide appropriate referrals when necessary.

Indicators:

8.1 Comprehensive ongoing training provided for direct care staff to identify and address basic health issues within their field of expertise that may particularly or uniquely affect Rainbow Community clients.

8.2 Creation and implementation of mechanisms for identification of staff with special expertise in and sensitivity to Rainbow Community issues.

8.3 Provision of training for direct care staff on how, when and where to make appropriate referrals for Rainbow Community clients and their families.

8.4 Development of a comprehensive resource list for appropriate referrals for special Rainbow Community health concerns.

8.5 Outreach to and development of relationships with other agencies and providers with expertise in Rainbow Community health issues.

8.6 Evidence of agreements or other appropriate mechanisms to ensure cooperation with other agencies and providers to who Rainbow Community clients and their families may be referred for specialized care and treatment.

Standard 9. All case management and treatment plans shall include and address sexual orientation and gender identity where it is a necessary and appropriate issue in client care.

Indicators:

9.1 Provision of training for all case management and direct care staff on Rainbow Community health and treatment issues.

Confidentiality

Standard 10. The agency shall ensure the confidentiality of client data, including information about sexual orientation and gender identity issues. Rainbow Community clients shall be informed about data collection that includes references to sexual orientation and/or gender identity, including what circumstances such information may be disclosed, whether it may be disclosed as aggregate or individual information, whether personal identifiers may be disclosed, and how and by whom such information may be used.

Indicators:

10.1 Written confidentiality policies which explicitly include sexual orientation and gender identity, indicating that such information is to be considered highly sensitive and treated accordingly.

10.2 Designation of sexual orientation and gender identity is at client's option on forms and records.

10.3 Comprehensive training for appropriate staff on data collection and reporting issues as they relate to confidentiality.

10.4 Written disclosure to clients explaining when information may or must be disclosed to third parties for payment or other reasons, and in what circumstances such disclosures may include information regarding sexual orientation and gender identity.

Standard 11. The agency shall provide appropriate, safe and confidential treatment to Rainbow Community minors, unless the agency's services are inappropriate for all minors. All clients who are minors shall be informed of their legal rights, and advised of the possibility and possible consequences of any statutory or otherwise mandated reporting.

Indicators:

11.1 Staff training regarding the legal rights of minors.

11.2 Development and implementation of procedures for intake, assessment and treatment of minors that is sensitive to sexual orientation and gender identity.

11.3 Written and oral notice to minors of various mandated reporting laws and their implications, and of the minor's rights regarding confidentiality and treatment without parental consent.

11.4 Reception staff trained to be sensitive to issues facing Rainbow Community youth.

Community Outreach and Health Promotion

Standard 12. The agency shall include Rainbow Community people and their families in outreach and health promotion efforts.

Indicators:

12.1 Agency advertising and promotional materials clearly indicate nondiscrimination policies regarding sexual orientation and gender identity.

12.2 Agency outreach efforts to social service, medical and other providers promote services available to members of the Rainbow Community and their families.

12.3 Agency outreach and promotional efforts accurately reflect the level and quality of services available to Rainbow Community clients and their families.

Standard 13. The composition of the agency Board of Directors and other institutional bodies shall encourage representation from the Rainbow Community.

Indicators:

13.1 The process for electing or appointing members to the Board of Directors and other institutional bodies include outreach to and inclusion of Rainbow Community candidates.

APPENDIX 3 - Terminology

Some of the definitions are open to debate within the Rainbow Community, reflecting the fluidity of sexual orientation and gender identities and the importance marginalized or excluded groups attach to the process of self-definition and redefinition.

Bisexual
A person who is emotionally, physically, romantically attracted to either male or female persons and can form a loving relationship with either. Someone could be more attracted to men or more attracted to women, but feels they can have relationships with either.

Coming Out
Refers to the experience of some, but not all, Rainbow persons as they explore their sexual identity. There is no correct process or single way to come out, and some Rainbow persons do not come out. The process is unique for each individual, and it is the choice of the individual. Several stages have been identified in the process: identity confusion, comparison, tolerance, acceptance, pride, and identity synthesis.

Closeted
In the closet is where we say someone is before they come out. It can be pictured as a closet, a small, dark, isolating place where someone is hiding a part of themselves from the people around him or her.

Cross-dresser
An individual who wears clothing normally socially ascribed only to members of the opposite sex for the purpose of personal comfort or self-expression.

Female-to-male transsexuals (FTM)
A person born female bodied, but with a male gender who is seeking to correct their physical appearance to match their true gender of male by either taking hormones, undergoing surgical treatment, living life in their true gender, or by undertaking all of the above. This person identifies as a male

Gay
A male/male-gendered individual who is emotionally, physically, romantically attracted to other males/male gendered persons and is capable of forming loving relationships with them.
Often gay is used as a blanket term to refer to gay and lesbian people.

Gender
A person's innate sense of self and of being male, female, both or neither. This could be biological, emotional and sociological.

Gender Identity

A person's sense of being male, female, both or neither. One's gender identity is their innate sense of who they are and how they perceive themselves in their world. This characteristic is an innate trait independent of one's physiology

Gender Queer
An individual whose gender identity does not strictly conform with societal norms traditionally ascribed to either male or female and who defines themselves outside of these traditional definitions.

Heterosexism
The belief that being heterosexual is the only normal and natural way to be and that anything else is abnormal, unnatural or non-existent. Heterosexism is institutional and is about assumptions and invisibility.

Heterosexual
A sexual orientation where a person is attracted physically, emotionally, or romantically to persons of the opposite sex and/or gender-identity and can form loving relationships with them. Heterosexuals are often referred to as straight.

Homophobia
The hatred, ignorance and irrational fear of people who are lesbian, gay, bisexual or behaviours that would be characterized as being homosexual.
Homophobia is linked to attitudes and behaviour.

Homosexual
A sexual orientation where a person is attracted physically, emotionally, or romantically to persons of the same sex and/or gender-identity and can form loving relationships with them.
Male homosexuals are often referred to as gay while female homosexuals are often referred to as lesbians.
This term is disliked by many in the community due to its medical origins and its often negative history.

Internalized Homophobia
Internalized self-hatred that gays and lesbians struggle with as a result of heterosexual prejudice. Persons who experience homophobia internalize it and accept and believe the negative messages of the dominant group as they relate to gay men, lesbians, bisexuals and transgender people.

Intersex
This is a relatively new term to describe someone who is born with ambiguous genitalia or chromosomal anomalies. Often gender is assigned at birth by parents and physicians. The child may or may not grow up to identify with that assigned gender.

Lesbian
A woman or female-gendered person who is physically, emotionally, and/or romantically attracted to other women/female-gendered persons and can form loving relationships with them.

Male-to-female transsexuals (MTF)
A person born male bodied, but with a female gender who is seeking to correct their physical appearance to match their true gender of female by either taking hormones, undergoing surgical treatment, living life in their true gender, or by undertaking all of the above. This person identifies as a female

Men who have sex with men (MSM)
Men who engage in same-sex behaviours but do not self-identify as gay.

Outcropping
A research method, whereby individuals of rare populations are identified and recruited into the sample at locations frequented by the population.

Polyamory
"Loving more than one". This love may be sexual, physical, romantic, or any combination thereof, according to the desires and agreements of the individuals involved. "Polyamorous" is also used as a descriptive term by people who are open to more than one relationship even if they are not currently involved in more than one.

Polysexual
A person who is emotionally, physically, romantically attracted to either male or female persons and able to form a loving relationship or any combination thereof with more than one at the same time.

Primary Health Care
Primary care is the usual first point of contact with the health system - a doctor's office, a health clinic, a community health center, nurse practitioner, calling telephone health information lines, seeing mental health workers, or seeking advice from pharmacists.

Queer
Although historically used as a negative term, queer is more commonly being used by the Rainbow Community, by the academic world and by the media as an inclusive term to refer to people who are lesbian, gay, bisexual and transgendered. However, in our society, it is often still used in a negative way.

Rainbow Community
Term used to refer to those who do not identify within a strictly heterosexual or gender-congruent model of human behaviour/identity. This includes, but is not limited to persons who identify as lesbian, bisexual, gay, transgendered, transsexual, intersexed, two-spirited, questioning and/or queer.

Sex
One’s anatomy, particularly how one is characterized according to their genitalia.

Sexual Behaviour
Sexual behaviour is often confused with sexual orientation. Where sexual orientation is about attraction, sexual behaviour is just about sex. Someone's sexual behaviour does not necessarily tell us someone's sexual orientation or vice versa.

Sexual Orientation
To whom we are sexually attracted, whether it is to men/male-gendered persons, females/female-gendered persons, both or neither.

Snowballing
A research method, where by the researcher identifies members of the populations of interest or key informants who then identify other members of the population who are consequently contacted and included in the study.

Straight
Straight is commonly used to refer to people who are emotionally and physically attracted to the opposite sex. This is a slang term for heterosexual. Some people don't like the word straight as it implies that anything else is 'crooked'.

Transgender
An umbrella term, which defines individuals whose behaviour, manner of dress, or identity, does not strictly conform to societal perceptions of how one fits into a binary gender definition of "male" and "female". This can range from one wearing the attire societally ascribed to the opposite sex, to a person whose gender and sex are in direct opposition.

Transgenderists
Individuals who do not feel as though they fit within conventional societal definitions of either male or female but rather feel that their gender is a combination of both male and female.

Transphobia
The hatred, ignorance and irrational fear of people who are transgender/transsexual or of anyone displaying behaviour that does not fit within societally constructed guidelines for behaviour based upon their sex.
Transphobia is linked to attitudes and behaviour.

Transsexual
An individual whose sex and gender is in direct opposition and who is seeking to resolve this by living in their true gender. This person might seek surgical/medical intervention, undertake hormone replacement therapy, or other associated treatments in order to be seen by others, and themselves, as more closely resembling their true gender.

Two-Spirited
A tradition within many aboriginal cultures, which denotes an individual with close ties to the spirit world and who may or may not identify as being lesbian, gay, bisexual or transgendered. This varies from culture to culture in how it is interpreted and defined, but does overall indicate a duality existent in a person which may or may not include both male and female spirits in one person.

Women who have sex with women (WSW)
Women who engage in same-sex behaviour, but may not necessarily identify as lesbians.

APPENDIX 4 - Rainbow Health Care Charter of Rights

LGBTTIQ people of all ages have the right to full and equal access to all health care services, in a supportive environment, where it is safe for them and for their families to be out to their providers if they choose to do so. They have the right to health care services that are comprehensive, medically appropriate and culturally competent. In order to ensure their access to quality health care, LGBTTIQ persons of all ages have the right:

- to CONFIDENTIALITY of their medical records, including confidentiality about their sexual orientation and gender identity;
- to have their FAMILIES RECOGNIZED, acknowledged and respected by all health care providers;
- to be treated in a health care environment that uses CULTURALLY APPROPRIATE language, including culturally appropriate intake and other written forms;
- to have case management and treatment plans that include and ADDRESS SEXUAL
- ORIENTATION OR GENDER IDENTITY where it is a necessary and appropriate issue in client care;
- to be included and have their needs addressed in prevention and other PUBLIC HEALTH PROGRAMS;
- if a minor, to safe and confidential medical treatment, to be INFORMED OF LEGAL RIGHTS, and to be advised of the possibility and possible consequences of mandated reporting.

Adapted from The Gay, Lesbian, Bisexual, and Transgender Health Access Project, Boston, MA [*http://www.Rainbowhealth.org/index.html*](http://www.Rainbowhealth.org/index.html)

APPENDIX 5 - List of Focus Groups

Focus Groups with Providers of Primary Health Care Services

Primary care providers in Capital Health - 17 participants
Planned Parenthood Metro Clinic- 7 participants
Adsum Centre - 10 participants
Victim Services of the Halifax Police Department - 3 participants
Avalon Sexual Assault Centre - 8 participants
The AIDS Coalition of NS - 5 participants
Healing Our Nations - 6 participants
Public Health - 23 participants
Lesbian Gay and Bisexual Youth Project -5 participants
Millwood High School Gay/Straight Alliance - 23 participants
Family Services Association HRM- 8 participants
Department of Community Social Services - 5 participants
Stepping Stone - 3 participants
Phoenix Youth Programs - 9 participants
Addiction & Mental Health Services, Nova Scotia Hospital - 13 participants

Focus Groups with the GLBTI Community

Gay/Bisexual Men: 2 groups; 13 participants
Lesbian/Bisexual Women: 3 groups; 10 participants
Transgendered/Transexual/Intersexed: 2 groups; 8 participants
GLBTI youth under 24: 2 groups; 33 participants.

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