

Youth Health Rights in Canada: Discussion Paper

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1. INTRODUCTION

The United Nations Convention on the Rights of the Child “recognize[s] the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health” (UN, 1990, s. 41). As a party to the UN Convention, the Government of Canada has agreed to “strive to ensure that no child is deprived of his or her right of access to such health care services.” In Canada, children and youth have health rights that are protected through various federal, provincial and territorial laws and regulations. However, many young people are not aware of these rights, and even those young people who are aware of their rights may face barriers in seeking to exercise them, particularly in accessing health services.

The Young Canadians Roundtable on Health (YCRH) is undertaking a multi-phase Health Rights and Responsibilities Project¹ to bridge these knowledge and practice gaps. In September 2016, YCRH engaged the University of Toronto Joint Centre for Bioethics (JCB) to establish a research base that would inform subsequent phases of the Health Rights and Responsibilities Project. The specific objectives of this research collaboration were to:

- 1) Describe the legal rights of youth² in Canada with respect to health, and
- 2) Identify key barriers faced by youth in Canada in seeking to exercise their health rights.

The JCB team³ conducted a legal overview and a scoping review of the Canadian academic and policy literature to meet these objectives. The *legal overview* summarized current provincial-territorial legislation in Canada as it pertained to youth health rights noting relevant similarities and differences across federal, provincial, and territorial jurisdictions, particularly related to consent to health care, privacy of personal health information, welfare protections, and protection against discrimination. The *scoping literature review* synthesized what is currently known, as reported in Canadian studies, about practical and normative issues associated with access to health services experienced by Canadian youth. Both academic papers and Canadian policy reports were included. Although the international literature illuminates other potential facilitators and barriers, which may also be relevant to the exercise of youth health rights in Canada, the scoping review was limited to the Canadian literature in order to document the known experience of youth in the Canadian context.

¹ The Young Canadians Roundtable on Health (YCRH) was created by the Sandbox Project, “a national charity working to improve the health and wellbeing of Canadian children and youth through collaboration, public education and evidence-based policy development” (<http://sandboxproject.ca/>). The YCRH Health Rights and Responsibilities Project is supported in part by AstraZeneca Canada’s Youth Health Program (<http://sandboxproject.ca/health-rights>).

² The term “youth” used throughout this report refers to adolescents and young adults (approximately ages 13-29).

³ The Discussion Paper was researched and prepared by: Jennifer L. Gibson, PhD (JCB), Angel Petropanagos, PhD (JCB), Lee Ann Chapman, JD (Sick Kids), Randi Zlotnik-Shaul, LLM, PhD (Sick Kids and JCB).

In this Discussion Paper, we summarize key findings of the legal overview and scoping literature review, identify key gaps in knowledge and practice, and suggest possible future directions for research and practice to inform subsequent stages of YCRH’s Health Rights and Responsibilities Project based on these findings.

2. YOUTH HEALTH RIGHTS IN CANADA

Youth in Canada enjoy health rights protected in federal, provincial and territorial laws and regulations. Such rights are often reinforced by practice standards and guidelines set by professional regulatory bodies in each province (e.g., Colleges of Physicians and Surgeons, Colleges of Nurses) and by policies and procedures established by health care organizations. In Canada, there is no single health care system. Each province and territory has legal jurisdiction over the organization and delivery of health care services for its residents. As a result, although there is great similarity in law and health care services across Canada, there may also be notable differences. The federal government plays important roles related to health (e.g., drug regulation, public health surveillance, health and social transfer payments to the provinces and territories); however, its role as a health care provider is limited to a small subset of populations, including Canadian Armed Forces personnel; First Nations persons living on reserve; Inuit; inmates in federal penitentiaries; and certain refugee claimants.⁴ Federally-funded health care services will be relevant to some youth in Canada. In this section, we provide an overview of youth health rights in Canada by addressing two key questions: i) what health rights do Canadian youth have? And ii) are there any limits on youth health rights?

2.1 What Health Rights do Canadian Youth Have?

2.1.1. *Right to Access Publicly Insured Health Services*

Canadian youth, like all legal residents of Canada, have a right to access publicly insured health services. Provincial and territorial health insurance plans cover the cost of medically necessary physician and hospital services. Dental care, vision care, drugs (except those administered in hospital), or other services (e.g., physiotherapy, psychological counselling) are typically paid for through third-party insurance, such as employee health benefits, or out of pocket. However, most provincial and territorial health insurance plans will cover some or all of these additional health care costs for defined populations such as seniors, persons with disabilities, persons with low income, or children and adolescents. Basic dental care is publicly funded for children and adolescents in many provinces and territories. Vision care may be covered for some youth - for

⁴ For example, the federal government provides: i) “limited temporary coverage of health care benefits to refugees, refugee claimants, and certain other groups” who are not eligible for PT insurance through the Interim Federal Health Program (www.cic.gc.ca/english/department/laws-policy/ifhp.asp); ii) comprehensive health care benefits, including medical, dental, mental health, drugs, and other services, to Canadian Armed Forces personnel (www.forces.gc.ca/en/caf-community-health-services-benefits-drug-coverage/index.page); and iii) limited health care benefits, including drugs, dental and vision care, medical supplies and equipment, mental health counselling, and medical transportation, to eligible First Nations persons and Inuk through the Non-Insured Health Benefits Program (<http://healthycanadians.gc.ca/health-system-systeme-sante/services/non-insured-health-benefits-services-sante-non-assures/index-eng.php>).

example, in Ontario, annual eye examinations are covered by the Ontario Health Insurance Plan for persons under 19 years of age or for those persons of any age who have a medical condition requiring regular eye exams. Some community-based mental health services may be publicly funded as well, particularly if provided by a physician; however, wait lists for such services may be lengthy. As coverage decisions are made by each province or territory, there may be some variability in service availability for youth in different parts of the country.

2.1.2. Right to Consent to Health Care Treatment

Under common law and most health care consent acts, capable persons of any age can consent to health care treatment (see Appendix 1). The province of Quebec is the exception, where there is no consent under the age of 14. A capable person under the age of majority (18 or 19 years depending on the province or territory) is commonly called a “mature minor”. In law, the Mature Minor doctrine states that if a person is capable, they may consent to treatment regardless of age. Having “capacity” means being able to understand the information that is relevant to making the decision about the proposed medical treatment and to appreciate the reasonably foreseeable consequences of a treatment decision or lack of a decision.⁵ In other words, capacity not age is the basis upon which an individual has the right to consent to or to refuse health care treatment. For consent to be legally valid, however, the decision must also be made free of coercion or undue influence. Mature minors with children of their own are legally entitled to make treatment decisions on behalf of their own child.

Capable youth who are 16 years and older may, in some provinces, appoint a substitute decision-maker for health care in the event that they become incapable either temporarily or permanently (see Appendix 1). The substitute decision-maker is not automatically the young person’s parents or legal guardians; a capable youth may appoint someone of their choosing to make treatment decisions should the youth become incapable under a Power of Attorney for Personal Care. The substitute decision-maker must follow the prior wishes expressed of the youth while capable. Where such wishes are not known, the substitute decision-maker must make treatment decisions in the youth’s best interests. A substitute decision-maker may only make treatment decisions as long as the young person is incapable. In addition, some provinces permit capable youth who are 16 years and older to provide an advance health care directive (sometimes called a ‘personal directive’), which is a declaration of their capable wishes should they lose capacity to consent (see Appendix 1). Youth at any age have the right to challenge a finding of incapacity and to retain legal counsel to challenge involuntary commitment to a mental health facility. Under some child welfare legislation, youth can consent to counselling by a service provider at the age of 12 independent of capacity.

2.1.3. Right to Privacy of Personal Health Information

Youth have the right to privacy with respect to their personal health information (see Appendix 1). Personal health information is collected by health professionals to aid in providing appropriate health care services. Professional codes of ethics emphasize the importance of privacy and confidentiality to build and sustain trust between health providers and patients. All

⁵ This is known as the legal test of capacity.

provinces and territories have enacted privacy legislation, which outline rights and duties with respect to the collection, use, and disclosure of personal health information. In most provinces and territories, the right to personal health information privacy is dependent on capacity to consent and to understand the implications of privacy (see Appendix 1). If a young person has capacity, they must consent to the release of personal health information. In Quebec, the age of capacity for privacy is 14 years. In some jurisdictions, parents and legal guardians have a right to access the personal health information of youth up to the age of 18 *unless* the youth has capacity or if the health care provider believes that disclosing the youth's personal health information to parents or guardians may be harmful or potentially harmful to the youth.

2.1.4. *Right to Non-Discrimination*

Youth have the right to not be discriminated against in accessing health facilities or receiving health services. Across Canada, federal, provincial and territorial human rights codes promote equal opportunity and protect people as individuals or as members of a group from discrimination based on factors such as race, age, sex, physical or mental disability, sexual orientation, or gender identity or expression.⁶ Whereas the Canadian Human Rights Code applies to services or facilities under federal jurisdiction, provincial and territorial human rights codes apply to services or facilities under provincial or territorial jurisdiction.⁷ This may include health services or facilities such as hospitals. Some provinces set a minimum age in order to make a complaint. For example, in Ontario, young persons must be at least 18 years old to file a human rights complaint, and parents or guardians may file applications on behalf of children and youth under 18 (Government of Ontario, 1990). Genetic discrimination is an emerging area of law in Canada, which may be relevant to some youth. Bill S-201, *An Act to prohibit and prevent genetic discrimination*, is awaiting Royal Assent as of April 4, 2017.⁸ The Act prohibits someone from “requiring an individual to undergo a genetic test or disclose the results of a genetic test as a condition of providing goods or services to, entering into or continuing a contract or agreement with, or offering specific conditions in a contract or agreement, to the individual” (Government of Canada, 2017). Health practitioners who are providing health services to the individual would be exempt. The Act would also amend the Canada Labour Code to protect employees and the Canadian Human Rights Act to prohibit discrimination on the grounds of genetic characteristics.

2.1.5. *Right to Welfare Protection*

Children and youth are protected by law from abuse and neglect. Each province and territory requires health professionals to report suspected cases of child abuse and neglect to the relevant child welfare authority (e.g., Children's Aid Society, Child Protective Services). Concerns about potential child abuse and neglect may arise in routine medical examinations or

⁶ Gender identity or expression is protected in most provincial human rights codes and in the Northwest Territories human rights code. In May 2016, Bill C-16 (*An Act to amend the Canadian Human Rights Act and the Criminal Code*) was introduced in the Canadian Parliament. If enacted, the Bill would add “gender identity or expression” as a prohibited ground for discrimination in the *Canadian Human Rights Act*. To read Bill C-16, go to: www.parl.gc.ca/content/hoc/Bills/421/Government/C-16/C-16_1/C-16_1.PDF

⁷ Links to provincial and territorial human rights commissions can be found here: www.chrc-ccdp.gc.ca/eng/content/provincial-and-territorial-human-rights-agencies.

⁸ www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&DocId=8185825.

provision of health services. Mandatory reporting ensures that all children and youth are protected from harm. There are provincial and territorial differences in the age requirements for such reporting. For example, reporting is mandatory for persons under 16 years of age in seven provinces and territories, under 18 years of age in four provinces, and under 19 years of age in British Columbia and the Yukon. Having been informed, child welfare authorities are likewise required by law to investigate each case, which may lead to removing the child from home. In some cases, this may lead to criminal charges being placed against the parent or legal guardian.⁹

2.2 Are There Any Limits on Youth Health Rights?

There are legal limits on some health rights. These limits are primarily intended to facilitate provision of health care and to prevent harm to individuals and communities. Provincial and territorial legislation regarding consent to treatment and privacy of personal health information are stringent in their protection of individual rights; however, they also recognize exceptional circumstances where consent to treatment may be waived and where disclosure of personal health information *without consent* may be necessary. In all cases, legal limits on health rights are intended to be a proportional response to competing rights and duties.

Health care treatment may be administered without consent in emergency situations 'if, in the opinion of the health practitioner, a delay in obtaining consent or refusal of treatment would prolong severe suffering or put the individual at risk of sustaining serious bodily harm' and 'if there is no reason to believe that the person does not want the treatment' (Government of Ontario 1996, s. 25). However, if a health practitioner has reasonable grounds to believe that the person would refuse such treatment while capable, then the health professional is not permitted to administer the treatment.

Personal health information may be disclosed without consent in certain circumstances. Some disclosure requirements are mandatory by law; others are permitted based on professional judgment. Such disclosure seeks to strike a balance between preserving a person's privacy and decisional autonomy, on the one hand, and preventing harm to another person or group of persons, on the other. Disclosure of personal health information without consent is *mandatory* with respect to some communicable diseases. Each province and territory maintains a list of communicable diseases that must be reported to the relevant public health authority (e.g., regional Medical Officer of Health). Common diseases listed include HIV, sexually transmitted diseases, respiratory diseases (e.g., influenza, tuberculosis), and others which may pose a risk to the health of uninfected individuals in the community. Health professionals are required by law to report all cases of such diseases to the relevant public health authority and also to report if an infected person refuses treatment, neglects to continue with treatment, or fails to comply with an order issued by the relevant public health authority.¹⁰ Nevertheless, although such

⁹ The Canadian Child Welfare Research Portal (<http://cwrp.ca/about>) is a useful resource for information on child welfare protection in Canada, including links to legislation in each province and territory.

¹⁰ Age requirements may apply. For example, in Ontario, if the person is under 16 years of age, it is the responsibility of the parent or guardian to ensure that the order issued by a Medical Officer of Health is complied with.

disclosure is mandatory, professional colleges recommend that health professionals should inform their patients about the disclosure and seek to support their voluntary participation in a treatment order.

Disclosure without consent is *permissible* where a health professional has “reasonable grounds that the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person or group of persons” (Government of Ontario 2004, s. 40). Health professionals are also permitted to contact parents and guardians without a youth’s consent if this is deemed necessary for the purposes of risk assessment for possible involuntary commitment or of setting up community treatment orders. Although such disclosure may be mandated or permissible by law without consent, professional colleges recommend that health professionals inform their patients about the disclosure.

3. ACCESS TO HEALTH CARE FOR CANADIAN YOUTH

Youth in Canada have interests in exercising their health rights in all health care contexts. However, some areas of health care may be of particular importance to youth. Sexual and reproductive health and mental health were most frequently discussed in the literature. Other key areas identified in the literature include: substance abuse; primary and continuing care; and end-of-life care. Although all youth in Canada may face barriers to health care, certain sub-populations of youth, such as First Nations, Inuit, and Métis youth, youth with gender and sex diversities (including LGBTQ youth), youth with disabilities, and street-involved or homeless youth, may face unique challenges in the exercise of their health rights or in accessing services. As a result, some youth may experience marginalization, discrimination, or other forms of disadvantage in seeking to have their health needs met. In this section, we summarize the findings of our scoping review, including key areas of health care relevant to youth and important practical and normative barriers youth may face in seeking to access health services.

3.1. Key Health Care Issues for Youth

3.1.1. Sexual and Reproductive Health

Access to comprehensive, age-appropriate, and timely information about sexual and reproductive health is essential to support youth in making health-related choices (Hobcraft and Baker 2006; McCabe and Holmes 2014; O’Sullivan et al 2015; Salehi, Hynie, and Flicker 2014; Sharfi 2016). Key areas of sexual and reproductive health include: contraception (Hulme et al 2015; Shoveller et al 2007), sexually transmitted infection prevention and treatment (Sharfi 2016; Shoveller et al 2009; Goldenberg et al 2008; Masaro et al 2012), including HIV/AIDS (Linton et al 2009) and human papilloma virus (HPV) vaccination (Rambout et al 2014), and reproductive choice, including family planning. Access to safe and timely abortion continues to be an important reproductive health service for youth (Downie and Nassar 2007). Although pregnancy rates among Canadian adolescents have decreased in recent decades, about 50% of adolescent pregnancies end in induced abortion. Prenatal care services

for pregnant youth is also essential given evidence of poor prenatal care as a major cause of increased pregnancy complications in adolescents (Leslie 2006). The literature also documents a growing interest among youth in fertility services, such as egg freezing (Petropanagos et al 2015), egg donation, and in vitro fertilization (Havelock et al 2016). Fertility preservation services are especially relevant to youth receiving treatment for cancer (Gupta et al 2013; Roher et al 2017) and to young women wishing to delay reproduction (e.g., until after they have completed advanced education or established a professional career). Gender and sex diverse youth may have unique sexual and reproductive health needs; for example, some youth may face increased risk of cervical or anogenital cancers (Sharfi 2016) or require access gender-affirming health services (Travers et al 2010; Salehi, Hynie, and Flicker 2014). Youth living in northern or remote areas of Canada, including many First Nations, Inuit, and Métis youth, have more limited access to these and other types of specialized sexual and reproductive health services (Yee, Apale, and Deleary 2011; Lys and Reading 2012; also see the [Native Youth Sexual Health Network](#)).

3.1.2. Mental Health

Mental health services, including mental health promotion, assessment, treatment, and other supportive services, are critical enablers of health for many Canadian youth (Ruiz-Caseres, et al 2015; Chen, Kazanjian, and Wong 2008; Barwick et al 2013; Cheung et al 2009). According to the Canadian Mental Health Association, an estimated 10-20% of Canadian youth are affected by mental health concerns, such as depression, anxiety, or eating disorders ([Canadian Mental Health Association](#)). Early intervention is essential because the age of onset for a number of mental health conditions is in adolescence or early adulthood. Youth may also face pressures related to school, work, family relationships, and/or social life, which may increase risk of stress, anxiety, or other mental health concerns. Life transitions may present a uniquely vulnerable time in the life of youth, particular among recent immigrants (Chen, Kaznian and Wong 2008), youth with complex health needs transitioning from paediatric to an adult care setting (Amaria et al 2011), and post-secondary students. A recent US study reported that approximately 65% of college and university students reported feeling overwhelming anxiety in the past 12 months and 45% had felt so depressed that they had difficulty functioning ([American College Health Association](#)). Increased social media use and cyber-bullying has been linked to mental health risks, such as eating disorders and suicide ([Centre for Addiction and Mental Health](#); Mishna et al 2016). On the other hand, social media and other online platforms appear to play a positive role in supporting and promoting youth mental health, especially among gender and sex diverse youth (Jenzen and Karl 2014).

According to Statistics Canada, suicide is the second leading cause of death among 15-34 year olds in Canada (Statistics Canada 2015).¹¹ The Canadian Mental Health Association reports that suicide accounts for 24% of all deaths among 15-24 year olds.¹² “Suicide among First Nations

¹¹ The leading cause of death among youth is unintentional injuries (i.e., accidents). Because death due to natural causes is generally low in this age group, suicide and accidents account for a relatively higher proportion of youth deaths (Statistics Canada 2015)

¹² The highest rate of suicide in Canada is among persons 40-59 years of age, which accounted for 45% of all suicides in 2009 followed by 15-39 year olds at 35% and 60+ year olds at 19% (Statistics Canada 2015).

youth (aged 15 to 24 years) across Canada is five to six times higher than among non-Indigenous peoples” (Crawford 2016), and suicide rates among Inuit youth, particularly young males, has increased dramatically over the few decades ([Nunavut Suicide Prevention Strategy](#)). A 2001 study of Canadian lesbian, gay, and bisexual youth found that 1 in 3 youth had attempted suicide, while over 40% had considered suicide (D'Augelli, Hershberger and Pilkington 2001). At a population level, gender and sex diverse persons are at higher risk of depression and anxiety (Rapid Response Services 2014) and have twice the risk of post-traumatic stress disorder and fourteen-times the risk of suicide and substance abuse as compared to other youth ([Canadian Mental Health Association - Ontario](#)).

3.1.3. Substance Abuse

Substance abuse involves the “harmful or hazardous use of prescription and illegal drugs for non-medical reasons” ([Government of Canada](#)). Youth are more likely than older adults to engage in risky behaviours with alcohol and drugs and to experience greater harms from the substance abuse (Young et al 2011). Alcohol, marijuana, and psychoactive pharmaceuticals are the most commonly abused substances among Canadian youth. Substance abuse is most prevalent in older adolescents and young adults ([Canadian Centre on Substance Abuse 2007](#)), particularly young men (Ialomiteanu et al 2014). A recent Ontario study found that alcohol use is almost twice as prevalent as marijuana use by Ontario adolescents, which is consistent with findings elsewhere in Canada (Young et al 2011). In 2013, the rate of marijuana use by youth ages 15-24 was more than three times higher than by adults ages 25 and older ([Canadian Centre on Substance Abuse](#)). Evidence shows strong correlations between substance abuse and mental health concerns (Ialomiteanu et al 2014). More than 15% of individuals with a substance abuse problem have a concurrent mental health diagnosis (Rush et al 2008). Youth untreated trauma (Ialomiteanu et al 2014), First Nations, Inuit, and Métis youth (Yi et al 2015), and street-involved youth with varying degrees of homelessness (Elliot 2014) are at higher risk of substance abuse and its adverse effects. With the proposed legalization of cannabis in Canada, its potential impact on youth can be expected to be a continuing area of concern for health professionals, policymakers, and youth health advocates. The Cannabis Act, which at time of writing has received First Reading in the House of Commons, outlines a number of specific protections and restrictions regarding youth access to the drug.¹³

3.1.4. Primary and Continuing Care

Primary and continuing care services, including access to family physicians (Bridget et al 2011; Klein, Wild, and Cave 2005; Hargreaves et al 2015; Gahagan, Jason and Leduc 2012) are critical enablers of health for youth. Primary health care services comprise health promotion, disease prevention, and assessment and treatment services for health conditions, some of which may be immediately treatable (e.g., infections requiring antibiotic treatment) and others which may be chronic (e.g., chronic pain (Stinson et al 2013) or allergies or asthma (Stuart et al 2012; Garner 2008). Approximately 15%-18% of youth in North America have a chronic health condition or special health condition (e.g., asthma, heart disease, hearing loss, visual

¹³ To read Bill C-45 (An Act respecting cannabis and to amend the Controlled Drugs and Substances Act, the Criminal Code and other Acts), go to: www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&DocId=8894959.

impairments, musculoskeletal disorders) that causes some limitations on their lives (Pinzon and Harvey 2006; Canadian Paediatric Society 2007) and can be manageable with the assistance of primary care providers. Primary care professionals and institutions are also common providers of sexual, reproductive and mental health services (Bridget et al 2011).

Access to primary care may be a challenge for some youth. As noted in section 2.1.1, some health services are not covered by provincial or territorial health insurance plans and must be paid by third party insurance or out of pocket. Depending on the province or territory, vision care (Noel et al 2016), dental care, fertility services, and some mental health services may be out of reach for some youth. Some studies suggest that gender and sex diverse youth (Sharfi 2016; Travers et al 2010) and homeless and street-involved youth (Guirguis-Younger, McNeil and Hwang 2014) experience unique or compounding difficulties in accessing primary care. Dental disease is common for homeless and street-involved youth because of poor hygiene, smoking, alcohol use and difficulty accessing dental care services (Elliot 2013; Chi and Milgrom 2008). Access to dental care has also been identified as a particular challenge for some youth with disabilities (Koneru and Sigal 2009). Moreover, even where services are available, some youth may be reluctant to consult primary care providers, particularly related to substance abuse, mental health, or reproductive concerns (Anderson and Lowen 2010).

Health needs of youth with chronic conditions, disabilities, or complex care needs in the transition from paediatric to adult health provider settings, including primary and homecare services is widely discussed in the literature (Lindsay and Hoffman 2015; Gorter et al 2014; Amaria et al 2011; Stewart et al 2011; Peter et al 2007). Paediatric care settings are often family-centred with parental involvement in decision-making and care; adult care emphasizes patient autonomy and individual self-management of care (Kaufman and Pinzon 2007). Although the transition from paediatric to adult health care can be a difficult and stressful time for youth and their families, this transition represents opportunities for youth to increase independence in decision-making about their care and planning about how to meet their continuing health needs.

3.1.5. Palliative and End-of-life Care

Palliative and end-of-life care are important health services for youth who have been diagnosed with a life-limiting illness or who are living with a chronic condition that might lead toward death. Access to age-appropriate palliative care has been identified as a challenge for youth in some geographic settings and in health settings where youth experience the deaths of peers with the same disease and the immediacy of their own mortality (Pinzon and Harvey 2006). Conversations about death and dying are often difficult, particularly where children and youth are concerned. As noted previously, mature minors are recognized in Canadian law as having capacity to consent to or to refuse treatment, which may include end of life decisions regarding withholding or withdrawal of potentially life-sustaining treatment. Some youth may experience reluctance from parents and health professionals to accept a youth's capable wishes about treatment options if the likely outcome would be a hastening of death. Current legislation in Canada prohibits persons under the age of 18 years from accessing medical assistance in dying (MAiD). While there is disagreement about whether eligibility should be extended to mature minors (Davies and Shariff 2016; Shüklenk et al 2011) and this issue will be studied by the

Council of Canadian Academies in 2017-18 at the request of the Government of Canada, some youth may seek to explore their values, feelings, and beliefs with respect to medical assistance in dying in the context of a larger discussion with their families and health providers about their end of life wishes.

3.1.6. Other Emerging Areas of Interest

There are a number of other emerging areas of interest that can be expected to have implications for youth in Canada. First, genomics is a growing area of interest for many Canadians. Youth who are involved in genomics-based research trials, such as patients involved with cancer research, may want access to their personal genetic information obtained during the trial. Direct-to-consumer genetic testing, like 23andMe, is also becoming more widely available. Precision medicine envisions tailoring health care to a person's unique genetic make-up. Genomic and genetic technology is transforming health care and, as noted above, it is also re-shaping legislation in Canada. Second, reproductive technologies are also creating new questions and conundrums for youth. Youth who were born from the use of donated eggs or sperm in assisted reproduction may have an interest in knowing their genetic origins or genetic information (Ravitsky 2012). The desire to know information about one's donor can include a desire to avoid medical risks and consanguineous relationships, to connect with one's biological family, to complete one's life history, to understand where one's traits come from, to discover or assess one's defining characteristics and capabilities, to rectify a wrong-doing, or to map out one's ancestral history (Ravelingien, Provoost, and Pennings 2013). Third, climate change and its environmental, social, and health impact is an urgent concern, which is acutely experienced by Indigenous communities across Canada (Yee, Apale, and Deleary 2011). The Truth and Reconciliation Commission's call for change sets the stage for a radically different relationship between First Nations, Inuit, and Metis people and Canadian governments with potentially wide-reaching implications for youth.

3.2. Barriers to Health Care Access

Accessible health care involves “[empowering individuals] to use health care and benefit from services, given their circumstances and experiences in relation to the health care system” (Canadian Association of Paediatric Health Centres et al 2010). Our scoping review findings indicate that youth in Canada may experience practical and normative barriers to accessing health care (see Table 1).

3.2.1. What are the Practical Barriers?

Practical barriers occur at both systemic and individual levels of health care. First Nations and Inuit, and Métis youth face unique jurisdictional barriers due in part to the fragmentation of health care delivery systems across federal and provincial or territorial responsibilities. Although geographic, financial, and time-related barriers were cited most frequently in the literature, our findings identified a wide range of practical barriers that may affect youth either singly or in combination.

a) Jurisdictional Factors

For Indigenous peoples, health services are fragmented in Canada hampering access and leading to health inequities (Lavoie and Gervais, 2011). Unlike non-Indigenous people, whose healthcare is funded by their provincial or territorial governments, there is a complex funding and delivery model for Indigenous peoples. While the federal government is responsible for providing limited primary health services for Inuit living within traditional territories and registered/status Indians on reserve primarily through the First Nations and Inuit Health Branch-Health Canada, Métis and those not registered under the Indian Act do not qualify for these federally-funded services and must seek their health care through provincial and territorial health insurance plans. Further fragmentation happens within First Nations and Inuit communities due to variability in how different provinces or territories fund health care services and transfer accountability to local health boards or regional health authorities for the planning and delivering health services of Indigenous peoples. The result is differences in health care access both between Indigenous communities and between Indigenous and non-Indigenous people (The Jordan's Principle Working Group 2015).

The tragic case of Jordan River Anderson, a young Cree boy who died while waiting for federal and provincial governments to resolve jurisdictional issues, underscores the inequity of health service provision for Indigenous peoples (Blackstock 2009). To ensure that Indigenous children and youth would not suffer as a result of jurisdictional disputes, *Jordan's Principle* obligates the government (or government department) to first pay for those services which would ordinarily be available to other children in Canada and to settle any disputes over payment for services afterwards. While the House of Commons unanimously passed *Jordan's Principle* in 2007, the "denials, delays, and disruptions" and hence health inequities continued. In January 2016, the Canadian Human Rights Tribunal ordered the federal government to immediately implement the full meaning and scope of the *Principle* (First Nations Child and Family Caring Society of Canada et al v. Attorney General of Canada, 2016). Indian and Northern Affairs Canada (INAC) has stated intentions to broaden the scope, increase funding, and end the practice of requiring children to await disputes. In September 2016, the Canadian Human Rights Tribunal ordered remedies, which include applying *Jordan's Principle* to all First Nations children (not only those living on reserves) and requiring INAC to report on compliance (*ibid.*).

b) Geographical Factors

The vast size of Canada and the distribution of its population create geographical barriers to accessing health care. Regional variations in availability of health professionals, hospitals, emergency services, and specialists affect equitable access to and intensity of the services used (Bridget et al 2011). Health care access in rural and remote areas of Canada is typically more restricted than access in urban areas. As of 2014, 18% of Canada's population lived in rural or remote communities (Bosco and Oandasani 2016). Canadian physicians, particularly specialists, are concentrated in urban areas with lower numbers and types of health providers in rural and remote areas (Pong and Pitblado 2005). A recent study found that under 16% of family physicians and 2.4% of specialists resided in rural and remote towns (Pong and Pitblado 2005). The geographic maldistribution of health services is reflected in the differences in the average distance to the nearest physician – from less than a kilometre in the largest urban centres to

just over 200 km in the territories (*ibid*). It is often difficult to attract or retain health care professionals, such as physicians and nurses in rural areas (Hay, Varga-Toth, and Hines 2006). Geographical factors can isolate youth from needed health services, including access to contraception (Hulme et al 2015; Mann 2013), STI testing services, (Shoveller, et al 2009; Goldenberg et al 2008; Hay, Barga-Toth, and Hines 2006), and mental health supports (Ruiz-Casares et al 2015). Youth with disabilities or complex health needs also face challenges in seeking to obtain appropriate home care services outside of large urban settings (Peter et al 2007). Lack of transportation or lack of financial resources for travel may place additional constraints on access for youth living in the suburbs or more remotely (Travers et al 2010; Salehi, Hynie, and Flicker 2014).

c) Financial Factors

Direct and indirect financial costs of accessing health services can pose barriers for many youth in Canada (Hargreaves et al 2015), including costs associated with travelling to and from appointments, medication, and health services not covered by publicly funded or privately held insurance such as vision care, dental care or physiotherapy (Quiñonez 2010; Koneru and Sigal 2009). Cost was identified as the important barrier in accessing reproductive health care (Hobcraft and Baker 2006), including contraception (Hulme et al 2015), HPV vaccination (Rambout et al 2014) and fertility services, such as egg freezing and in vitro fertilization. Peter et al (2007) described how families of youth with complex health may face financial burdens both direct (e.g., out of pocket payment for home care services) and indirect (e.g., costs associated with transportation to appointments or lost and unrealized wages as an informal caregiver). Poverty and low socio-economic status are well-documented as social determinants of health in Canada and internationally ([Public Health Agency of Canada](#); [National Collaborating Centre in Aboriginal Health](#); Marmot et al 2008). Canada Without Poverty reports that 1 in 5 children and youth in the general population and 1 in 2 in status First Nations live below the poverty line in Canada and that youth aged 16-24 years comprise 20% of the homeless population ([Canada Without Poverty](#)). As a result, youth and their families may be food insecure and precariously housed, face challenges affording prescription medications, and higher rates of complex chronic conditions (Yi et al 2015; [Canada Without Poverty](#)).

d) Time Factors

Time emerged through the scoping review as a significant factor influencing accessibility and utilization of health services by youth. Youth may also face competing time commitments, such as work and family responsibilities, which can tend to de-prioritize or to delay accessing health care (Stinson et al 2013; Angus et al 2012). Scheduling of appointments might be constrained by clinic hours, which may only be open when youth are at school (Goldenberg et al 2008; McCabe and Holmes 2014), by logistics of coordinating appointments across multiple referrals and providers (Lindsay and Hoffman 2015; Cook et al 2013), or by practical issues, such as arranging transportation (Rambout et al 2014; Klein, Wild and Cave 2005). Waiting lists are a challenge (Klein, Wild and Cave 2005), particularly for mental health services (Barwick et al 2013; Fikretoglu and Liu 2015; Warren 2016), and may be especially challenging for marginalized youth such as undocumented migrants (Magalhaes, Carrasco, and Gastaldo 2010) and street youth (Salehi, Hynie, and Flicker 2014).

e) Language and Communication Factors

Youth who do not speak English, or have a first language other than English (or French) face difficulties in accessing health services (Fikretoglu and Liu 2015; Hay, Varga-Toth, and Hines 2006; Chen, Kazanjian and Wong 2008). Language barriers may contribute to delays in seeking care, reduced patient comprehension and compliance when care was received, and increased risk of hospital admission (Bowen 2001). Language and communication gaps can result in a failure to protect patient confidentiality and to obtain informed consent. This is especially true when family member or other health care providers are called upon to serve as interpreters. Effective communication between youth, families, and health care providers has been cited as a critical enabler for the successful transition of youth with complex needs from the paediatric to adult care settings (Lindsay and Hoffman 2015). In the research context, communication of research results in an understandable manner was identified as a barrier to children and adolescent participation in cancer care research (Fernandez et al 2009). Language barriers regularly contribute to the exclusion of certain ethnic groups from biomedical research as, for example, in the case where study participants are selected on the basis of their ability to communicate effectively in the researcher's preferred language (Bowen 2001).

f) Informational Factors

Absent, incomplete, and inaccurate information about health or health care resources are barriers to youth access to health services in Canada. This is a serious concern given the critical importance of information for the exercise of decisional capacity and for free and voluntary consent to treatment. On the one hand, this underlines the need for youth-friendly communication of health information; on the other hand, it emphasizes the need for education of youth about their health rights and the availability of health services, including how they may be accessed.

The scoping review revealed a number of critical information gaps about available health services (Gahagan, Jason, and Leduc 2012; Goldenberg et al 2008) and their intended purposes. Shoveller et al (2009) found that young women were less likely to undergo STI testing because they believed mistakenly that such testing occurred as a part of their PAP smears and some young men avoided STI testing because they feared the urethral swab and were unaware of alternative methods of specimen collection. Misinformation has been found to be a barrier to the use of contraception. Many teens are unaware of the existence of emergency contraception or that it is available without a prescription and without parental permission (Katzman and Taddeo 2010); some youth may also have the mistaken belief that contraception is an abortifacient and that it has long-term effects on health and fertility. Some reports suggest that youth and their families lack information about mental health services that are available in their communities (Parents for Children's Mental Health 2011). Low-levels of education may also increase the likelihood that individuals experience barriers to accessing care (Fikretoglu and Liu 2015).

Some youth may face unique informational barriers. Access to accurate and comprehensive information about sexual health has been a challenge for youth in the Northwest Territories (Lys and Reading 2012). Youth with disabilities and their families often lack the information

they need in order to navigate a successful transition from paediatric to adult care (Stewart et al 2011). Physicians and other health providers may also lack sufficient knowledge or training to be effective in caring for some patient sub-populations, such as youth in palliative care transitioning into an adult care setting (Cooke et al 2013) or gender and sex diverse youth (Sharfi 2016; Rapid Response Service 2014). In the adolescent and young adult oncology settings, the need for age-appropriate information has been emphasized (Miedema, Easley and Robinson 2013).

g) Privacy and Confidentiality Factors

Health care providers are responsible for assessing the decision-making capacity of their patients based on their professional judgment or with the aid of capacity assessment tools. A patient's capacity is decision and time specific. Paternalistic health care providers may fail to recognize youth as capable of making their own health care decisions (Hobcraft and Baker 2006). Youth may not access health services due to concerns about preserving confidentiality (Hobcraft and Baker 2006; Gahagan, Jason, and Leduc 2012; Cook, Erdman, and Dickens 2007). Masaro and colleagues (2012) reported STI providers' perceptions of how confidentiality is handled, including some providers who believed youth may be at a higher risk of breached confidentiality compared to adults because some physicians believe they should report youth STI status to their parents. Gender and sex diverse youth have unique concerns related to privacy and confidentiality in the context of sexual and reproductive health (Knight, et al 2014; Yee, Apale, and Deleary 2011). For example, LGBT youth may find it difficult to disclose risky sexual behaviour when attempting to access STI testing services (Shoveller et al 2009). Threats to privacy can also be a deterrent to accessing abortion, e.g., being asked to disclose for personal details to administrative staff before seeing a provider (Downie and Nassar 2007).

h) Environmental Factors

Environmental factors may affect accessibility and use of health services and contribute to overall youth health and well-being. The health care environment may have an influence on youth treatment choices and experiences. Youth are less likely to access health services if they are not perceived to be youth-friendly (Hobcraft and Backer 2006; Stinson et al 2014). Some care delivery models may be better suited to meeting youth health needs than others. Barwick et al (2013) reported higher client satisfaction, shorter wait times, and steeper rate of improvement in psychosocial health among youth who accessed a mental health walk-in clinic compared to a usual care setting. Youth who are hospitalized experience a loss of privacy and may feel 'out of place' sharing rooms with adult patients or with patients much younger than themselves (Findlay et al 2008). The physical appearance of a clinical setting may also influence youth willingness to access a health service. One study found that youth were more comfortable receiving an HIV test in a "colourful, friendly, relaxed atmosphere, as opposed to a highly institutional medical facility" (Wertheimer 2011). Home environments matter greatly for youth with complex health needs (Lindsay and Hoffman 2015). In their study of younger adults with mobility disabilities, Gibson et al (2012) identified key conditions of a 'dignity-enabling' home environment conducive to promoting social inclusion and independence. Youth in foster care and homeless and street-involved youth may have greater difficulty in accessing health services (Stewart et al 2011; Barker et al 2015) than other youth. Bridget et al 2011 found that

parental involvement was associated with increased use of family physician services by youth. Indigenous youth are four times more likely than non-indigenous Canadian youth to be living in crowded housing (Mikkonen and Raphael 2010). Food insecurity and the lack of affordable housing, along with other social determinants of health, also create barriers to youth's ability to exercise their health rights. The natural environment may also play a significant role in youth health and well-being. Industrial resource extraction has had a negative impact on the land and as a result contributed to the erosion of cultural and subsistence activities of First Nations in British Columbia (Booth and Skelton 2011).

i) Health Policy Factors

Publicly funded health insurance is available to eligible youth. However, some youth in Canada may be uninsured. Immigration or refugee status is the most significant factor affecting eligibility for publicly funded health services (Campbell 2011). Immigrants to Canada (i.e., permanent residents) qualify for provincial or territorial health insurance but must normally wait up to 3 months while their eligibility is processed. Individuals who have abandoned or withdrawn their refugee claim, visitors to Canada (e.g., tourists), individuals whose work or student permits have expired, or individuals living illegally in Canada are not eligible for provincial or territorial health insurance (Hillard 2016). Non-status pregnant women may not receive prenatal care or delay seeking care, and some youth who were born in Canada to non-status parents have experienced challenges in getting provincial health insurance, to which they are entitled, because of their parents are non-status (Magalhaes, Carrasco, and Gastaldo 2010). Some health providers may be reluctant to accept non-status persons as patients because their care results in higher administrative demands or obstacles to payment for services rendered. For example, physicians must fill out additional forms for patients, payments may be delayed or they may fail to receive payment from the Interim Federal Health Program, and the physician may need to call ahead for care approval for treatments or services (Caulford and Mayhew 2014). As noted previously, given provincial and territorial jurisdiction over health, there may be differences in available health services from one jurisdiction to the next. Hence, youth in one province have access to some services to which youth in another process does not have access. One example would be access to safe and timely abortion services, which is variable across the country (Downie and Nassar 2007). Another example is that Ontario youth up to the age of 25 will, as of January 1, 2018, have access to publicly funded prescription drug coverage through the Ontario Health Insurance Plan (Government of Ontario 2017).

3.2.2. What are the Normative Barriers?

Normative barriers may also have an adverse effect on youth access to and experience of health services. The scoping review identified three normative barriers: implicit bias, social norms and stigma, and discrimination. As with the practical barriers discussed above, youth in certain sub-groups may be at increased risk of encountering normative barriers in seeking to meet their health needs.

a) Implicit Bias

Implicit bias can be defined as implicit attitudes or associations that have a “distorting influence on judgement and hence behaviours informed by that judgment” (Holroyd 2015) and that may

be relatively unconscious and automatic (Brownstein 2017). When linked to age, gender, race, sexuality, religion, and other perceived attributes of individuals and groups, implicit bias influences how someone is treated. Implicit bias has been recognized in health care (Institute of Medicine 2002) and as a factor contributing to health disparities (Blair et al 2011). On the one hand, a health care provider's implicit biases may influence the health services that are offered to a patient or shape how the health care provider interacts with the patient. On the other hand, an individual patient's own implicit biases and past experiences may inform their understanding of the health care system and their expectations of health care providers. Although implicit bias may be difficult to detect by those who hold such bias, its potential effects can be seen in the experience of Canadian youth as documented in recent studies, particularly related to sexual and reproductive health.

Sexual health may be neglected in the care of youth with complex chronic health needs. If it is assumed by health care providers that youth with complex chronic needs are asexual or less interested in sex than their healthy peers, they may fail to offer information about sexual or reproductive health (Pinzon and Harvey 2006). Some women have also been disadvantaged in the availability of HIV testing because they were viewed as 'good girls' who were not at risk of HIV infection; correspondingly, gay men, sex workers or people who inject drugs may encounter implicit bias because it is assumed that they must be engaging in risky behaviours (Wertheimer 2011). Youth seeking treatment for sexually transmitted infections may encounter implicit biases about their capacity for personal responsibility and feel judged as irresponsible (Masarao et al 2012); similarly, those seeking medication for chronic pain found that they were often not believed by health care providers (Stinson et al 2013).

Street-involved and homeless youth may not trust adults or authority figures and they may have legal or personal problems that cause them to avoid accessing health services out of fear of getting caught (Elliot 2014). Moreover, in their study of street youth, Linton and colleagues (2009) found that both age and ethnicity were significant factors in HIV status and called for changes to HIV prevention intervention programs to reach "other street youth, especially to meet the cultural needs of Black, Aboriginal, and other ethnic homeless youth populations." The need to build cultural competencies in order to ensure culturally safe care for First Nations, Inuit, and Métis people has emerged as an urgent priority in Canada (Yee, Apale, and Deleary 2011). Newcomers to Canada may also face cultural barriers in seeking to access sexual and reproductive health (Salehi, Hynie, and Flicker 2014) or mental health services (Cheung et al 2009).

b) Social Norms and Stigma

Social norms are "the customary rules that govern behavior in groups and societies". They serve to create a sense of shared identity and belonging, to coordinate social activity, and to maintain social order. Social norms are reinforced through their practice in daily life, through social relationships within groups (e.g., families, communities), and through habit. We are often unaware that a social norm is operating except when a social norm is broken or when a social norm is experienced as an unwanted constraint.

Gender norms and expectations may pose barriers to accessing health services (Stewart et al 2011) or to making healthy choices. For example, they may hinder girls' and young women's participation in physical activities (Shea and Beausoleil 2012) or undermine health-promoting behaviours of young men (Gahagan, Jason, and Leduc 2012; Masaro et al 2012) if such activities or behaviours are perceived to be at odds with norms of femininity or masculinity. Gender norms, including sexism, can intensify social vulnerability, making some women feel (or be) silenced during health care encounters and experiencing discrimination by providers (Angus et al 2012). Sexual norms can also shape health care education programs and prevent providers from understanding the health needs of gender and sex diverse youth (Rapid Response Service 2014). Some youth do not disclose their sexual orientation out of fear that it may hinder their care (Sharfi 2016). The degree to which youth feel comfortable disclosing their sexual orientation or gender identity may be influenced by a number of factors, such as the presence or absence of gender and sex diverse positive signs in the care setting; availability of inclusive brochures and educational materials; extent of parental involvement at appointments; and the health care provider's training (Fantus et al 2015). Religious norms may also influence whether youth are willing to access health services or discuss their health needs with health care providers. Social taboos surrounding sexuality may be particularly challenging for some youth. For example, Ali-Faisal (2014) described how some Muslim youth experience feelings of guilt and anxiety around their sexuality. Similarly, health care providers who are themselves adherent to particular religious or other norms may be reluctant to discuss some health topics with youth.

Stigma “refers to a set of negative attitudes and beliefs that motivate individuals to fear, reject, avoid, and discriminate against people” (Corrigan and Penn 1999). Stigma may take a number of forms, including public stigma (i.e., “reactions of the general public towards a group based on stigma about that group”) and self-stigma (i.e., “reactions of individuals who belong to a stigmatized group and turn the stigmatizing attitudes against themselves”) (Rüsch et al 2005). ‘Self-trust’ – an individual’s ability to trust their own voice and judgement in the context of their health care decisions (McLeod 2002) – can be eroded by stigma.

Stigma is a known barrier to accessing treatment and social services, particularly mental health services (Corrigan et al 2009; Hatzenbueler et al 2013). The Canadian Association of Paediatric Health Centres (2010) suggests that “stigma is a powerful barrier to accessing mental health care for children and youth.” It reports that 63% of youth identify embarrassment, fear, peer pressure, and/or stigma as factors preventing them from seeking health services and 38% of Canadians are embarrassed to admit that their children suffer from anxiety or depression. The Mood Disorders Society of Canada (2009) reports that Canadians are more comfortable with persons with physical disabilities than with persons with depression. However, a recent survey of Canadians found that 81% are more aware of mental health issues, 70% believe attitudes about mental health issues have changed, and 57% perceive a reduction in mental illness stigma compared to 5 years ago (Bell 2015).

Stigma, shame and social discomfort have been found to be barriers for access to STI testing. For example, youth working as oil riggers in remote areas of Canada did not feel comfortable

consulting others on where to go for STI testing (Goldenberg et al 2008). For women of all ages, stigma and discrimination were found to limit access to HIV testing because they feared being judged by others, losing their partner, children, or job, or experiencing violence from their partner or community as a result of their HIV status (Wertheimer 2011). One study found that youth were concerned about negative reactions from providers in seeking emergency contraception (Shoveller et al 2007). Participants in this study reported receiving subtle and sometimes overtly stigmatizing messages from providers; Asian and South Asian women were particularly concerned about negative interactions with female providers from their sociocultural community and a fear of being recognized, chastised, or gossiped about in their community (Ibid). Gender and sex diverse youth report fear and feeling stigmatized (Travers et al 2010). Fertility services are often not trans-friendly and cissexism (the assumption of a sex-gender binary, that is, that one's sex matches one's gender) is institutionalized and systemic (James-Abra et al 2015). Cissexism is experienced in non-gender-neutral terminology on clinic forms, in conversations between patients and clinical staff, in an inability or unwillingness to use a patient's preferred name or pronoun, and open refusal by health providers to care for patients based on their trans status (LGBTQ Parenting Network 2015).

c) Discrimination

Discrimination is a behaviour that can result from a negative stereotype ([Canadian Mental Health Association](#)). Some gender and sex diverse individuals delay or avoid seeking services because they have experienced discrimination, such as homophobia, in past health care encounters (Rapid Response Service 2014). Gender and sex diverse youth may face particular barriers in attempting to access fertility preservation services in the cancer context (Fantus et al 2015). For example, if a patient identifies a practitioner as unaccepting of gender or sex diversity, this can foster reluctance to arrange examinations or follow-up appointments. Some women trying to access abortion services may fear being targeted for violence and harassment, including by picketers outside abortion clinics. They may feel pressure or coercion from their family, partner, or friends who may oppose her decision to pursue an abortion (Downie and Nassar 2007). Racial discrimination within the health care context is also a concern for members of visible minority populations. Perceived or actual prejudices from health care providers can hinder communication and deter patients from returning. Systemic racism of Indigenous peoples has a long history in Canada and is made manifest as negative stereotypes related to an individual patient's health behaviours or needs (Leyland et al 2016).

Table 1 Summary of Practical and Normative Barriers

| PRACTICAL BARRIERS | EXAMPLES |
|--|---|
| a) Jurisdictional Factors affecting Indigenous youth | - uncertainty among Indigenous youth about how needed health services will be funded and by whom - fragmentation of/ inequitable access to health services for Indigenous youth compared to non-Indigenous youth |
| b) Geographical Factors | - distance to clinic |

| | |
|--|--|
| | <ul style="list-style-type: none"> - lack of adequate transportation - number of services or providers in the area - nearby physicians offer limited health care services, so youth must travel further for certain health care services or specialists |
| c) Financial Factors | <ul style="list-style-type: none"> - cost of travelling to clinic - costs of accessing private (non-publicly funded) health care services - cost of medication - lack of third-party private health insurance - lost wages or child care related to health care appointments - lack of funding for health care services or particular facility |
| d) Time Factors | <ul style="list-style-type: none"> - long wait lists for health care services - time needed to attend appointments - scheduling inconveniences (including the number of appointments and overlap with school hours or job) - not enough time for youth to speak with health care providers |
| e) Language and Communication Factors | <ul style="list-style-type: none"> - not speaking English (or French) as the home language - certified interpreters not used or not available - ability to communicate information in a developmentally-appropriate manner |
| f) Informational Factors | <ul style="list-style-type: none"> - lack of information or misinformation about health or treatment - lack information about health prevention and health promotion programs - providers lack information about some services - providers lack training related to the needs of sub-populations |
| g) Privacy and Confidentiality Factors | <ul style="list-style-type: none"> - lack of understanding about whether and when parents or guardians should be involved in health care decision-making - youth worry that someone will see them at the facility or that their information will be leaked into their community - lack of anonymous testing and services in the area |

| | |
|----------------------------|---|
| h) Environmental Factors | <ul style="list-style-type: none"> - the facility or program is not ‘youth-friendly’ - youth feel out of place with patients who are much younger or much older - home environment can pose challenges for accessing homecare and continued care |
| i) Health Policy Factors | <ul style="list-style-type: none"> - some differences in the health care services available to youth across Canada and differences in which health services are publicly funded - youth who don’t have a health care or permanent address have trouble obtaining provincial health insurance or accessing health care -some immigrants may not have health care coverage |
| NORMATIVE BARRIERS | EXAMPLES |
| a) Implicit Bias | <ul style="list-style-type: none"> - health care providers make (mistaken) assumptions about a patient’s gender or sexual identity - health care can underestimate youth’s capacity to consent to (or refuse) treatment because of biases related to age - health needs are unrecognized or unmet due to stereotypes |
| b) Social Norms and Stigma | <ul style="list-style-type: none"> - youth feel shame or fear stigmatization in accessing certain services because of their sex, gender, religious or cultural beliefs/ values - youth fear losing (present or future) partner, children, or employment because of their health condition or treatment - youth’s self-trust is compromised - power difference between providers and youth inhibit youth from expressing their needs in the absence of trust |
| c) Discrimination | <ul style="list-style-type: none"> - youth fear violence in seeking to access health services - youth are unjustly denied access to needed care on the basis of their personal characteristic - systemic racism is reinforced through negative stereotypes |

4. GAPS IN KNOWLEDGE AND FUTURE DIRECTIONS

4.1 Gaps in Knowledge and Practice

Based on the legal overview and scoping literature review, we have identified gaps in knowledge and practice related to youth health rights in Canada. These gaps present opportunities for future research, advocacy, and youth outreach by the YCRH and others in the field.

4.1.1 *Gaps in Knowledge*

There is a need for more research on youth health rights in Canada particularly related to identifying and understanding the facilitators and barriers of youth health rights. Currently, the available literature is heterogeneous and uneven, hence we lack a full and complete picture of youth health needs and access in Canada. There is a need for more research on:

1. Extent of youth awareness and understanding of their health rights and its effect on youth health choices and outcomes.
2. Unique needs and experiences of diverse sub-populations of Canadian youth, both mainstream and marginalized, at different stages in their development from adolescence through early adulthood.
3. Regional differences (provincial/territorial; urban/rural/remote) in availability of health services for youth and relevant enablers of and barriers to access, including how these barriers interact or compound.
4. Impact and extent of implicit bias, social norms and stigma, and discrimination affecting youth health outcomes and experience.

4.1.2 *Gaps in Practice*

Our findings suggest that there are key areas of practice requiring improvement, particularly with respect to the practical and normative barriers. Addressing informational needs of youth would contribute toward informed consent and more timely accessing of health services. Capacity-building among health care providers, including core knowledge and competencies, would contribute toward protecting youth privacy rights and enhance care for youth with diverse or intersectional needs. Health care providers need also to have better understanding of the health care (and social) needs of sub-populations of youth that may be marginalized or vulnerable. Hence, what may be described as a knowledge gap (i.e. physician's lack of awareness about or understanding of these sub-populations' needs) is effectively a practice gap with the effect that youth health rights may be hindered.

There are also opportunities for advocacy. Insofar as geographical barriers and time-related barriers are frequently cited in the literature, there is a need to address the distribution of health care services across Canada and the clinic opening hours. There is a need for more youth-friendly care because youth can feel out of place in both the paediatric and adult care contexts. Clinical environments that take the unique health, financial, educational, and social needs of young Canadians into consideration can better serve this population.

4.2 Future Directions

There are ample opportunities for research, member/stakeholder engagement and advocacy in the next stages of the YCRH Health Rights and Responsibilities Project. As YCRH moves into the focus groups and website development phases, we suggest that they consider the following action items:

1. Develop focus group questions that can address the knowledge gaps identified above. In particular, ask youth to consider which barriers they encounter most frequently, which barriers they find most challenging, and what their suggestions are to address these barriers.
2. Develop versions of information about youth' health rights and barriers that can be shared with health care providers or clinics. Also consider future training opportunities for health care providers in relation to youth' health care needs and perspectives.
3. Create an online forum for discussion that is moderated by an expert, so as to avoid the proliferation of false information about health rights, barriers, and services.
4. Establish a list of 'youth-friendly' providers or clinics that is available to your members/ stakeholders.
5. Leverage the Sandbox Project's collaboration in the Canadian Child and Youth Health Coalition (<http://www.caphc.org/canadian-child-youth-health-coalition-ccyh/>) to address the knowledge and practice gaps.

APPENDIX 1. OVERVIEW OF RELEVANT PROVINCIAL AND TERRITORIAL LEGISLATION

This table provides a brief overview of provincial and territorial legislation concerning health care consent and privacy of personal health information, including mature minors. Links to relevant legislation and other sources are provided. This information is educational only. It is neither exhaustive of all potentially relevant legislation or statute nor is it legally authoritative; it is not intended nor should be taken to provide legal advice. Youth and their advocates should seek independent legal counsel in regard to the application and interpretation of any relevant laws to their particular circumstances within their province or territory.

| Province/Territory | Consent to Health Care | Right to Privacy |
|-------------------------|--|---|
| Alberta | <p>There is no healthcare consent specific legislation. The common law ‘mature minor’ rule applies.</p> <p>However, the <i>Personal Directives Act</i> establishes an age limit to make a personal directive: “3(1) Any person who is at least 18 years of age and understands the nature and effect of a personal directive may make a personal directive. (2) A person who is at least 18 years of age is presumed to understand the nature and effect of a personal directive.”</p> <p>http://www.qp.alberta.ca/documents/Acts/p06.pdf (For more information on the contents of a personal directive, see section 7(1).)</p> <p>See also: College of Physicians and Surgeons of Alberta, <i>Consent for Minor Patients</i>. Available at: http://cpsa.ca/wp-content/uploads/2015/08/Consent-for-Minor-Patients.pdf?x91570.</p> | <p>The <i>Health Information Act</i> (2000) and the <i>Personal Information Privacy Act</i> (2003) apply to mature minors, who are capable individuals under the age of 18 years (see <i>HIA</i> section 104 (1)(b) and <i>PIPA</i> section 61 (1)(b)). This includes a right to consent to or to refuse disclosure of personal health information and personal information within the limits set out in the Acts. This includes some exceptions allowing disclosure of personal health information without consent</p> <p>https://www.canlii.org/en/ab/laws/stat/rsa-2000-c-h-5/latest/rsa-2000-c-h-5.html</p> <p>http://www.qp.alberta.ca/1266.cfm?page=F25.cfm&leg_type=Acts&isbncln=9780779762071</p> |
| British Columbia | <p>Under the <i>Health Care (Consent) and Care Facility (Admission) Act</i> (1996), adults over 19 years of age are capable of consent.</p> <p>www.bclaws.ca/civix/document/id/complete/statreg/96181_01#section3</p> | <p>The <i>Personal Information Protection Act</i> and the <i>Freedom of Information and Protection of Privacy Act</i> apply to mature minors if capable. The Acts set out some exceptions allowing disclosure of personal health information without consent (see <i>PIPA</i> section 18 and <i>FIPPA</i> section 33).</p> |

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| | <p>However, under section 17 of the <i>Infants Act</i>, anyone under 19 years old (i.e., an “infant”) can consent to health care if “the health care provider providing the health care: (a) has explained to the infant and has been satisfied that the infant understands the nature and consequences and the reasonably foreseeable benefits and risks of the health care, and (b) has made reasonable efforts to determine and has concluded that the health care is in the infant's best interests.”</p> <p>www.bclaws.ca/civix/document/id/complete/statreg/96223_01#part2</p> | <p>http://www.bclaws.ca/civix/document/id/complete/statreg/03063_01</p> <p>http://www.bclaws.ca/civix/document/id/complete/statreg/96165_00</p> <p>See also: Canadian Bar Association – BC, <i>Children and Consent to Health Care</i>. Available at: https://www.cbabc.org/For-the-Public/Dial-A-Law/Scripts/Health-Law/422</p> |
| Manitoba | <p>There is no healthcare consent specific legislation. The common law ‘mature minor’ rule applies.</p> <p>In addition, the <i>Health Care Directives Act</i> states that:</p> <p>4(1) Every person who has the capacity to make health care decisions may make a health care directive.</p> <p>4(2) In the absence of evidence to the contrary, it shall be presumed for the purpose of this Act:</p> <p>(a) that a person who is 16 years of age or more has the capacity to make health care decisions; and</p> <p>(b) that a person who is under 16 years of age does not have the capacity to make health care decisions.”</p> <p>http://web2.gov.mb.ca/laws/statutes/ccsm/h027e.php</p> | <p>The <i>Personal Health Information Act</i> (1997) applies to mature minors if capable. The Acts set out some exceptions allowing disclosure of personal health information without consent (see section 22(2)).</p> <p>http://web2.gov.mb.ca/laws/statutes/ccsm/p033-5e.php</p> |
| New Brunswick | <p>Individuals over 16 years of age are presumed capable to consent to medical treatment. The <i>Medical Consent of Minors Act</i> (1976) provides that under 16 years of age, consent to medical treatment is effective:</p> <p>3(1) ...where in the opinion of a legally qualified medical practitioner, dentist, nurse practitioner, midwife or nurse attending the minor,</p> <p>(a) the minor is capable of understanding the nature and consequences of the medical treatment, and</p> | <p>According to The <i>Personal Health Information Privacy and Access Act</i> (2009):</p> <p>5. The <i>Medical Consent of Minors Act</i> applies for the purpose of providing the consent of the person to the collection, use or disclosure of personal health information or for the refusal or withdrawal of the person’s consent.”</p> <p>The Acts set out some exceptions allowing disclosure of personal health information without consent (see sections 37-42.)</p> |

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| | <p>(b) the medical treatment and the procedure to be used is in the best interests of the minor and his continuing health and well-being.”</p> <p>www.canlii.org/en/nb/laws/stat/snb-1976-c-m-6.1/latest/snb-1976-c-m-6.1.html</p> | <p>www.gnb.ca/legis/bill/FILE/56/3/Bill-88-e.htm</p> |
| <p>Newfoundland and Labrador</p> | <p>There is no healthcare consent specific legislation. The common law ‘mature minor’ rule applies.</p> <p>In addition, <i>An Act Respecting Advance Health Care Directives and the Appointment of Substitute Health Care Decision Makers</i>, 1995) states that:</p> <p>“7. ...there shall, in the absence of evidence to the contrary, be a presumption</p> <p>(a) ...;</p> <p>(b) that a person who is 16 years of age or older is competent to make health care decisions; and</p> <p>(c) that a person who is younger than 16 years of age is not competent to make health care decisions.”</p> <p>http://www.assembly.nl.ca/legislation/sr/annualstatutes/1995/A04-1.c95.htm</p> <p>See also: College of Physicians and Surgeons of Newfoundland and Labrador, <i>Guideline – Consent to Medical Treatment of Minors</i>. Available at: http://imis.cpsnl.ca/WEB/CPSNL/Policies/Guideline_-_Consent_to_Medical_Treatment_of_Minors.aspx</p> | <p>According to the <i>Personal Health Information Act</i> (2008), as in other provincial and territorial legislation, privacy of personal health information is protected, including for mature minors. For minors who do not have the capacity to consent, the “right or power of an individual under this Act or the regulations may be exercised ... (d) by the parent or guardian of a minor where, in the opinion of the custodian, the minor does not understand the nature of the right or power and the consequences of exercising the right or power; ...” (section 7).</p> <p>https://www.canlii.org/en/nl/laws/stat/snl-2008-c-p-7.01/latest/snl-2008-c-p-7.01.html</p> |
| <p>Northwest Territories</p> | <p>There is no healthcare consent specific legislation. The common law ‘mature minor’ rule applies. The age of majority is 19 years.</p> | <p>The <i>Health Information Act</i> (2015) outlines rights and protections regarding the collection, use, and disclosure of personal health information of individuals, including mature minors:</p> <p>“25. (1) Any right or power conferred on an individual by this Act, including any authority of an individual in respect of the collection, use or disclosure of personal health information about him or her, may be exercised,</p> |

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| | | <p>(a) if the individual has attained 19 years of age, by that individual;</p> <p>(b) if the individual has not attained 19 years of age, but understands the nature of the right or power and the consequences of exercising the right or power, by that individual;</p> <p>(c) if the individual has not attained 19 years of age and does not meet the requirement of paragraph (b), by a person who has lawful custody of, or lawful authority in respect of, the individual;</p> <p>...”</p> <p>https://www.justice.gov.nt.ca/en/files/legislation/health-information/health-information.a.pdf</p> <p>See also: Government of Northwest Territories, <i>Health Information Act Guide</i>, 2015. Available at: http://www.hss.gov.nt.ca/sites/www.hss.gov.nt.ca/files/hia-guide.pdf)</p> |
| Nova Scotia | There is no healthcare consent specific legislation. The common law ‘mature minor’ rule applies. | <p>The <i>Personal Health Information Act</i> (2010) states explicitly that “any capable individual, regardless of age, may consent or withdraw consent for the purpose of this Act” (section 18). It recognizes that the ability to consent may be variable over time and type of the personal health information (section 19). The <i>PHIA</i> also states that “where an individual is deemed to have the capacity to consent to the collection, use and disclosure of personal health information, this capacity to consent includes disclosure to a parent, guardian or substitute decision-maker where applicable” (section 20).</p> <p>https://www.canlii.org/en/ns/laws/stat/sns-2010-c-41/latest/sns-2010-c-41.html</p> |
| Nunavut | There is no healthcare consent specific legislation. The common law ‘mature minor’ rule applies. | <p>The <i>Access to Information and Protection of Privacy Act</i> (1994) outlines the rights and protections with respect to the collection, use, and disclosure of personal information, including personal health information. A request for</p> |

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| | | <p>disclosure of a third party's personal information is "presumed to be an unreasonable invasion of a third party's personal information where (a) the personal information relates to a medical, psychiatric or psychological history, diagnosis, condition, treatment or evaluation" (section 23(2)). "A disclosure of personal information is not an unreasonable invasion of a third party's personal privacy where (a) the third party has, in writing, consented to or requested the disclosure; ..." (section 23(4)(a)).</p> <p>https://www.canlii.org/en/nu/laws/stat/snw-1994-c-20/latest/snw-1994-c-20.html</p> |
| <p>Ontario</p> | <p>According to the <i>Health Care Consent Act</i> (1996):</p> <p>4 (1) A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.</p> <p>4(2) A person is presumed to be capable with respect to treatment, admission to a care facility and personal assistance services."</p> <p>There is no age of consent to health care. The common law 'mature minor' rule applies.</p> <p>https://www.ontario.ca/laws/statute/96h02</p> | <p>According to the <i>Personal Health Information Protection Act</i> (2004), consent to the collection, use, and disclosure of personal health information is based in an individual's capacity to consent (section 23(1)).</p> <p>Section 23 clarifies that:</p> <p>"(2) if the individual is a child who is less than 16 years of age, a parent of the child or a children's aid society or other person who is lawfully entitled to give or refuse consent in the place of the parent unless the information relates to i) treatment within the meaning of the <i>Health Care Consent Act, 1996</i>, about which the child has made a decision on his or her own in accordance with that Act, or ii(counselling in which the child has participated on his or her own under the <i>Child and Family Services Act</i>.</p> <p>(3) If the individual is a child who is less than 16 years of age and who is capable of consenting to the collection, use or disclosure of the information and if there is a person who is entitled to act as the substitute decision-maker of the child under paragraph 2 of subsection (1), a decision of the child to give, withhold or withdraw the consent or to provide the information prevails over a conflicting decision of that person."</p> <p>https://www.ontario.ca/laws/statute/04p03#BK32</p> |

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| <p>Prince Edward Island</p> | <p>According to the <i>Consent to Treatment and Health Care Directives Act</i> (2010):</p> <p>“3. (1) Every person is presumed to be capable of (a) giving or refusing consent to treatment; and (b) making a health care directive, until the contrary is demonstrated.</p> <p>(2) Authority to give consent includes authority to refuse consent or revoke a consent previously given.</p> <p>4. Every patient who is capable of giving or refusing consent to treatment has the right</p> <p>(a) to give consent or to refuse consent on any grounds, including moral or religious grounds, even if the refusal will result in death;</p> <p>(b) to select a particular form of treatment from among those proposed by a health practitioner on any grounds, including moral or religious grounds;</p> <p>(c) to be assisted by an associate; and</p> <p>(d) to be involved to the greatest degree practicable in case planning and decision making.”</p> <p>There is no age of consent to health care. The common law ‘mature minor’ rule applies.</p> <p>https://www.princeedwardisland.ca/sites/default/files/legislation/c-17_2.pdf</p> | <p>Personal health information is protected under the <i>Freedom of Information and Protection of Privacy Act</i> (1988). The Act stipulates that:</p> <p>“71. (1) Any right or power conferred on an individual by this Act may be exercised by other persons if ... (d) if the individual is a minor, by a guardian of the minor in circumstances where, in the opinion of the head of the public body concerned, the exercise of the right or power by the guardian would not constitute an unreasonable invasion of the personal privacy of the minor; (e) if the individual has appointed a proxy to make decisions on his or her behalf, by the proxy if the exercise of the right or power relates to the powers and duties of a proxy conferred by the <i>Consent to Treatment and Health Care Directives Act</i>; or ...”</p> <p>http://www.assembly.pe.ca/index.php3?number=1013950&lang=E</p> |
| <p>Quebec</p> | <p>The age of consent to healthcare is 14 years. The parental authority must be informed, however, if the child’s health requires remaining in a health or social services establishment for over 12 hours. (See <i>Civil Code of Quebec</i>, section 14).</p> <p>http://legisquebec.gouv.qc.ca/en/ShowDoc/cs/CCQ-1991</p> | <p>In general, parents in Quebec have a right to access the medical records of their children under 18 years of age. However, there are exceptions to this general rule depending on the age of the child. For children 14 years old and older, parents cannot access their child’s medical record if the child refuses and if the health institution determines that it would be harmful to the child if the parents were to access this information.</p> <p>See:</p> |

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| | | <p>Éducaloi, <i>Medical Records – When Access Can Be Refused</i>. https://www.educaloi.qc.ca/en/capsules/medical-records-when-access-can-be-refused <i>Civil Code of Quebec</i> http://legisquebec.gouv.qc.ca/en/ShowDoc/cs/CCQ-1991 <i>Act respecting the protection of personal information in the private sector.</i> http://www.legisquebec.gouv.qc.ca/en/showdoc/cs/P-39.1</p> |
| Saskatchewan | <p>There is no healthcare consent specific legislation. The common law ‘mature minor’ rule applies.</p> <p>In addition, the <i>Health Care Directives and Substitute Health Care Decision Makers Act</i> (1997) state that: “3. Any person 16 years of age or more who has the capacity to make a health care decision may make a directive.”</p> <p>https://www.canlii.org/en/sk/laws/stat/ss-1997-c-h-0.001/latest/ss-1997-c-h-0.001.html</p> | <p>According to the <i>Health Information Protection Act</i>, “an individual has the right to consent to the use or disclosure of personal health information about himself or herself” (section 5(1)) if capable (section 6(1)). In addition, it states that: “56 Any right or power conferred on an individual by this Act may be exercised ... (c) by an individual who is less than 18 years of age in situations where, in the opinion of the trustee, the individual understands the nature of the right or power and the consequences of exercising the right or power; ...”</p> <p>http://www.qp.gov.sk.ca/documents/english/Statutes/Statutes/H0-021.pdf</p> |
| Yukon | <p>According to the <i>Care Consent Act</i> (2003): “3 Every person who is capable of giving or refusing consent to care has (a) the right to give consent or to refuse consent on any grounds, including moral or religious grounds, even if the refusal will result in death; (b) the right to select a particular form of available care on any grounds, including moral or religious grounds; and (c) the right to revoke consent.”</p> <p>There is no age of consent to healthcare. The common law ‘mature minor’ rule applies.</p> <p>http://www.gov.yk.ca/legislation/acts/dmspa.pdf#page=88</p> | <p>The <i>Health Information Privacy and Management Act</i> (2013) presumes capacity to consent to the collection, use, or disclosure of personal health information regardless of age (section 40). The Act recognizes that capacity to consent may be variable over time and type of personal health information (section 45).</p> <p>http://www.hss.gov.yk.ca/pdf/hipma-act.pdf</p> |

APPENDIX 2: YOUTH HEALTH RIGHTS – Q&As

The following Q&A document has been created for use by YCRH to post on its website.

Youth Health Rights: Questions & Answers

1. HEALTH CARE TREATMENT- WHO DECIDES?

How Old Do You Have to Be to Make Your Own Health Care Decisions?

There is no age of consent in most provinces and territories in Canada. Under common law and most health care consent acts, people of any age can consent to health care treatment (except Quebec where there is no consent under the age of 14). This means if someone has capacity they can consent regardless of age.

What Does “Capacity” Mean?

Having “capacity” to make health care decisions means being able to understand the information that is relevant to making the decision about the proposed treatment. You must be able to understand the consequences of agreeing to the treatment and refusing the treatment. You must also feel free to make the decision without coercion or undue influence. You may be capable to make some decisions and not others that may be more complicated.

What Difference Does Having Capacity Mean to My Health Care?

It means that you can access health care on your own even if it is not an emergency. It means that no one can tell anyone, not even parents or guardians, about your health care without your consent. In most provinces and territories you have the right to privacy with respect to your own personal health information (PHI). However, it is often helpful if parents and guardians know so they can support you and also help you access things like medication that may not be free with your health card. If you are under 16 years in most provinces or under 18 in other provinces and territories, there is an exception to your right to privacy. Professionals have a duty to report to child welfare authorities if they think you are not safe from abuse and/or neglect. There are also some exceptions with respect to safety concerns, specifically public health reporting of some communicable diseases or to the police to protect individuals from a serious credible threat if they have information that could prevent the harm. There might also be cases where courts order production of health care records for legal proceedings.

Who Decides If I Have Capacity?

Your health care provider who is proposing treatment—doctor, nurse, therapist etc. decides if you have capacity. If you disagree you can challenge that finding. Young people at any age have the right to challenge a finding of incapacity usually before a health care consent board. Sometimes doctors, nurses and other health professionals do not know the law about capacity or have forgotten and may think they have to tell your parents so they can consent to treatment. You may have to tell them or ask them to check on the web pages of their licensing

College. Some may have been treating you since you were very young and had no capacity; they may forget that you are now more mature and can make your own decisions. You may need to remind them that you are now capable.

Who Makes Decisions For Me If I Do Not Have Capacity?

When you do not have the capacity to make a decision, either because you lack the understanding for a complex decision or because you are temporarily incapacitated, for example unconscious, then someone else must make the decision for you. They are called a “Substitute Decision Maker”. That person must make decisions that are in your best interests. Usually that person is your parent or if they are not able another family member. In some provinces if you are over 16 years old you can appoint someone of your choosing to make the decision under a Power of Attorney for Personal Care. You can find the forms on line.

What Happens If They Breach My Privacy Rights?

You can report this to the relevant professional college and the Provincial Offices for Privacy Protection.

2. HEALTH CARE TREATMENT- RIGHTS OF ACCESS

What Happens if a Doctor or other Health Care Provider Refuses to Treat Me Without My Parents’ Permission Just Because I Am Not an Adult?

This would be discrimination and you can report it to your Province or Territories Human Right’s Commission. You can also report them to the Provincial College of Physicians and Surgeons or the licensing college for other professionals.

What Are My Rights With Respect to Mental Health Care?

You have the right to access mental health services. If someone thinks you might be at risk of harming yourself or someone else, they might take you to a hospital to determine if you are a risk. You can be a voluntary patient if you wish to seek treatment or an involuntary patient in some Health care facilities. If you are an involuntary patient, it means that you cannot leave until you have been assessed and perhaps treated if it is found you need treatment in order to prevent serious harm. Treatment orders are not open ended but have time limits. Young people of any age who have been involuntarily committed to a mental health facility had the right to retain lawyers to challenge the commitment.

What about LGBTQ2S Health Rights?

You have the right to be treated with respect. You have the right to determine your gender identity including the pronoun that you would like your health care providers to use. Health records by law must be kept in your legal name for safety reasons, however you do not have to wait until you are 18 to change your legal identity markers. If you feel you are being discriminated against in health care because of your identity you can report this to your provincial/territorial human rights commission.

Gender-Affirming Health Care-What Are My Rights?

Primary health care, such as hormone treatment is not available from all health care providers but you can access lists. In some provinces such as Ontario there is no age restriction for gender affirming surgery. If you want re-assignment (affirming) surgery outside of your province or territory, you will need prior approval from your provincial/territorial health plan.

What Are My Rights to Palliative Care and Medical Assistance in Dying?

You have the same rights to palliative care as any adult. If you have capacity you can decide when to refuse active treatment in favour of palliation. If you feel that you are not receiving adequate palliative care there are organizations you can contact. Youth under the age of 18 years of age who are dying and enduring grievous and irredeemable suffering do NOT have the same rights to ask for Medical Assistance in Dying as adults under the same circumstances, even if they have capacity. This was brought into law by the current federal government.

3. HEALTH CARE TREATMENT- WHO PAYS?

I Am a Permanent Resident or Canadian Citizen:

You have the right to have a health card that entitles you to obtain free health care in your province/territory. You must ensure your health card is up to date and not give it to anyone. In some provinces, it will also cover other health care professionals like physio-therapists, social workers etc. Most provinces/territories have government drug programs, some are free, for others you must pay a portion of the cost (see Resource List). If you get sick in another province or territory your health card will pay for emergency health care services and hospitalization. If you travel outside the country you should get private insurance because your provincial coverage will only pay for a small portion of hospital bills and in some cases will not cover any medical costs. If go to university your primary health care will usually be covered by the university or college plan. Your health card is your personal property and identity card. If you cannot find a physician to treat you there are agencies that can connect you with a doctor or Nurse Practitioner.

I Am a First Nations, Inuit or Metis Person:

Your health care is paid for by the Federal Government through NIHB (Non Insured Health Benefits) but you may also qualify for provincial health care. For on reserve First Nations and Inuit, the Federal Nations and Inuit Health Branch (FNIHB) administers health care. This includes both primary health care as well as hospital, drug and other health benefits. *Jordan's Principle* states that the government of first contact must pay for the services for aboriginal children and later seek reimbursement from the federal government insuring that children do not receive inadequate services because of bureaucratic red tape. If you believe your health care rights have been violated.

I Am a Convention Refugee or Person in Need of Protection:

If you are a refugee you are a Permanent Resident or have the right to apply for Permanent Residency, you can apply for the provincial health card (e.g. OHIP). Interim Federal Health Program will cover you until you have your provincial/territorial health card. This coverage will

generally last for one year. After that you have the same rights as other residents to apply for provincial/territorial drug programs.

I Am a Refugee Claimant

You will have Interim Federal Health Program (IFHP) coverage while your claim is being decided. You will not qualify for provincial or territorial health care. All hospitals and some doctors outside of hospitals will accept IFHP. You must renew this coverage every year. This will also cover extended benefits like prescription drugs and eye glasses. If you lose your claim it will end when all appeals are exhausted. If you win your claim you will be a Permanent Resident and entitled to provincial/territorial plans.

I Am Without Status-Undocumented or Illegal (issued a deportation order & did not leave)

You must pay for health care. Some provinces such as Ontario have community health centres where you can receive free primary care. Some larger cities have free health clinics. Hospitals cannot refuse to treat you for emergencies. Hospitals do not report non status people to Citizenship and Immigration.

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