



## **SUMMARY OF LEGAL NEEDS ASSESSMENT**

Canadian Aboriginal AIDS Network  
Canadian HIV/AIDS Legal Network

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*The Canadian HIV/AIDS Legal Network promotes the human rights of people living with, at risk of or affected by HIV or AIDS, in Canada and internationally, through research and analysis, litigation and other advocacy, public education and community mobilization.*

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*CAAN provides a National forum for Aboriginal Peoples to wholistically address HIV and AIDS, HCV, STBBIs, TB, Mental Health, aging and related co-morbidity issues; promotes a Social Determinants of Health Framework through advocacy; and provides accurate and up to date resources on these issues in a culturally relevant manner for Aboriginal Peoples wherever they reside.*



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## Background

In 2014, the Canadian HIV/AIDS Legal Network (“Legal Network”) and the Canadian Aboriginal AIDS Network (CAAN) began collaborating to produce a series of legal information resources for Indigenous communities living with and affected by HIV and/or hepatitis C (HCV). In support of this effort, a legal needs assessment was carried out to determine priority legal questions or situations arising for Indigenous people living with HIV and/or HCV (PLHIV/HCV), Indigenous AIDS service organizations (ASOs) and other service providers through consultation workshops at CAAN’s Annual General Meetings (AGMs) and a series of key informant interviews with Indigenous PLHIV/HCV and service providers.

Two consultation sessions were held in June 2013 and July 2014 at CAAN’s AGMs (Appendix A), and a key informant questionnaire was jointly developed shortly after (Appendix B). Between 2015 and 2016, the Legal Network conducted five key informant interviews and CAAN coordinated a focus group discussion. Indigenous respondents from diverse communities and nations across Canada provided input.

## Findings

The consultations, key informant interviews and focus group generated a number of themes. Two themes that consistently emerged were (1) stigma and discrimination in the context of health care and other settings, and (2) concerns about privacy and confidentiality related to one’s HIV/HCV status.

Issues that were frequently raised included HIV non-disclosure; access to HIV treatment, drug dependency treatment, harm reduction and other health care services; access to housing, clean water and nutritious food; and rights in relation to prison, HIV and employment, gender-based violence, drug use, child protection services and youth.

In terms of how to convey pertinent legal information to Indigenous communities, respondents suggested the development of legal fact sheets, including resources that include visuals to address an audience for whom English may not be the first language; public legal information sessions for Indigenous PLHIV/HCV; legal information training for service providers/frontline workers; and topical awareness-raising workshops for the broader public. A number of respondents emphasized the need to seek input from PLHIV and position PLHIV at the forefront of all initiatives.

A summary of questions and concerns related to each issue area — and the broader themes concerning stigma and discrimination, privacy and confidentiality that pervade each issue area — is provided below.

### **The criminalization of HIV non-disclosure**

Responses here primarily related to the need for a better understanding of the law of HIV non-disclosure. One respondent indicated that the issue is rarely discussed and that there is misinformation on how HIV is transmitted. The same respondent noted that sexual health education is inadequate within Indigenous communities, in part due to inadequate government

funding. Several respondents stressed that stigma and discrimination against people living with HIV drives people underground when they are diagnosed, and away from care, treatment and support. All respondents noted a pressing need for greater education, support and counseling for Indigenous PLHIV.

Some respondents wanted to know what their responsibilities are as service providers, in terms of reporting clients/patients who do not disclose their HIV-positive status in situations that they feel warrant such disclosure.<sup>1</sup> Respondents also wanted to know when public health authorities become involved in a situation regarding HIV non-disclosure.

### Health care, HIV and HCV

*“In my experience, most people go off reserve to get HIV medication because of access and because of stigma.” – Key informant*

A wide range of issues was discussed in the context of health care for Indigenous people, including access to treatment, care and support. In particular, access to HIV treatment, drug dependency treatment, harm reduction services and mental health supports were cited as essential, although there are significant variations in quality, as well as gaps in availability and accessibility, especially in rural, remote and northern communities. Youth respondents raised access to high-speed internet as an important consideration in access to health care, especially in situations where youth are seeking anonymous support from outside their community. One respondent noted that the health care providers she encountered knew little about HIV.

Understandings of health care included broader determinants of health, such as the need for housing, clean water, a safe environment and nutritious food to accompany medication. The cultural and spiritual aspects of health were also emphasized. One respondent commented that Indigenous people living with HIV should be encouraged to participate in sweat lodges, talking circles or pow-wows without necessarily disclosing their HIV-positive status.

Concerns about privacy and confidentiality were prominent in this area, particularly in health care settings where a health care worker may know a patient personally. In many instances, for example, a family member may work at a health center. Concerns about stigma and discrimination also figured prominently, especially stigma and discrimination perpetuated by physicians and nurses against Indigenous people generally, and particularly against Indigenous people living with HIV, who are assumed to use drugs or sell sex.

### Prisons, HIV and HCV

Respondents emphasized that Canada’s prison population reflects its racist and colonial history, and this situation has led to the over-incarceration of Indigenous people. Given the disproportionate number of Indigenous people entering the prison system, respondents felt Indigenous PLHIV/HCV need a better understanding of their rights in prison. Respondents raised questions about access to HIV testing in prison and concerns about how to protect one’s privacy when accessing HIV or HCV medication and harm reduction materials.<sup>2</sup>

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<sup>1</sup> The Legal Network has produced resources for service providers on this issue, including *HIV Disclosure and the Law: A Resource Kit for Service Providers*, available at [www.aidslaw.ca/community-kit](http://www.aidslaw.ca/community-kit), and *Privacy and disclosure: questions and answers on HIV-related privacy and disclosure issues for women’s service providers*, available at [www.aidslaw.ca/site/privacy-and-disclosure-questions-and-answers-on-hiv-related-privacy-and-disclosure-issues-for-womens-service-providers/](http://www.aidslaw.ca/site/privacy-and-disclosure-questions-and-answers-on-hiv-related-privacy-and-disclosure-issues-for-womens-service-providers/).

<sup>2</sup> CAAN’s research report on *Aboriginal People and Incarceration* is available at [www.caan.ca/national-aboriginal-toolkit/section-six/iv-aboriginal-people-and-incarceration-research-project](http://www.caan.ca/national-aboriginal-toolkit/section-six/iv-aboriginal-people-and-incarceration-research-project).

## Employment, HIV and HCV

Respondents raised several concerns in the context of employment, including employees' requirement to disclose their HIV-positive status to an employer or the employer's insurer (in order to access benefits), the employer's obligation to its employees, and broader concerns about privacy and confidentiality in the workplace.<sup>3</sup> One respondent raised a question on the extent of coverage of an employer-based health insurance scheme.

## Gender-based violence

All respondents cited gender-based violence, primarily directed against Indigenous women, as a significant concern, adding that it is related to historical trauma. Several respondents also noted the threat of violence for Indigenous women in the context of HIV non-disclosure and the need for more research on this issue.

Respondents indicated that Indigenous victims of gender-based violence rarely turn to police for help because they “don't want to tell on a person” and because violence against women and children remains highly stigmatized. In one respondent's experience, police who are familiar with everyone in a community (e.g., an Indigenous officer from the community) may merely advise a woman to return to her home. As a result, victims keep the abuse to themselves or leave the community altogether. A need was expressed for people to know what happens when police are called, including the possibility of being charged.<sup>4</sup>

## Drug use

*“Harm reduction is not an accepted practice [in all Indigenous communities]. People are shame-y about drug use because of the narrative of the ‘need to walk the red road’ and ‘need to be clean’.”* – Key informant

All respondents noted considerable stigma and discrimination against people who use drugs, as well as significant drug use within Indigenous communities. A number of respondents noted the pervasiveness of drug overdose in recent years among Indigenous people. Yet respondents observed a lack of understanding of harm reduction among some Indigenous communities and a consequent lack of access to harm reduction supplies and services for Indigenous people who use drugs. Youth respondents wanted to know if they have a right to treatment (of their choice) for drug and alcohol dependence.

Respondents indicated that individuals living in communities who do not choose to provide harm reduction services and supports must leave the community to access services away from home, a huge barrier for people living with substance use challenges. Some band councils, for example, are reluctant to permit opiate substitution therapy or needle and syringe programs to be offered on reserve.

Several respondents mentioned that some Indigenous communities in Canada have taken a strong stance against drugs/alcohol within a community and have passed, or threatened to pass, Band Council Resolutions (BCRs) against drug or alcohol use in a community. The same

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<sup>3</sup> The Legal Network's series of “Know Your Rights” resources in the context of employment include *Know Your Rights 1: Disclosure at Work*; *Know Your Rights 2: Accommodation in the Workplace*; and *Know Your Rights 3: Remedies for Discrimination and Privacy Violations in the Workplace*. These resources are available at [www.aidslaw.ca/site/kyr/](http://www.aidslaw.ca/site/kyr/).

<sup>4</sup> The Legal Network has produced a resource specific to Ontario on this issue, *Women Living with HIV and Intimate Partner Violence: Questions & Answers*. Available at [www.aidslaw.ca/site/women-living-with-hiv-and-intimate-partner-violence-questions-and-answers/](http://www.aidslaw.ca/site/women-living-with-hiv-and-intimate-partner-violence-questions-and-answers/).

respondents also stressed that Indigenous communities (and their Chiefs in Council) vary greatly in their opinion on drug use.

### Child protection services

On the issue of child protection services, respondents wanted to learn more about the power of child protection services to remove children from their parents by virtue of their HIV-positive status or of the more exceptional scenario of a parent convicted of HIV non-disclosure and being placed on a sex offender registry.<sup>5</sup> Respondents were also interested in the issue of vertical transmission, as well as the variation between breastfeeding guidelines in Canada and in other countries (and specifically whether it is possible that the latter guidelines also apply to rural communities in which many Indigenous people live, given the similarity in conditions).

### Indigenous youth

A number of respondents emphasized the growing number of Indigenous youth and the need to gear resources in the areas of sexual health education specifically towards them. Considerably fewer resources are invested in Indigenous education relative to what other schooling systems receive, and there are few social supports, especially for Indigenous youth who leave their home communities. As a result, few youth are knowledgeable about HIV or the law around HIV disclosure.<sup>6</sup>

Indigenous youth have questions about the age of consent, as well as what it means to be legally emancipated from one's parents or guardians. Youth also wanted more information about their privacy rights, especially online (i.e. social media), and whether one's right to privacy is contingent on age as well as whether a parent, guardian or school always has a 'right to know' when it comes to youth.

Fear of arrest and criminalization is a pressing concern for youth, who are criminalized for everything from 'loitering' to truancy, gender identity and more. Therefore, youth want to learn more about their rights in relation to police.

### Stigma and discrimination

All respondents decried the degree of stigma and discrimination against people living with HIV. Some respondents recalled situations in which people living with HIV were paid by a band council to leave a reserve as a means of HIV prevention or were not permitted to return during the late stages of an HIV-related illness. Several respondents recounted situations in which people were fearful of being in contact with someone who was open about their HIV-positive status. Respondents noted a need for greater education on HIV and how it is transmitted.<sup>7</sup>

As one respondent noted, a person who isn't a member of a community living within a traditional territory can be evicted from a community by order of a Band Council Resolution (BCR), which police can enforce. Communities can enact any kind of resolution to prevent people from certain

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<sup>5</sup> The Legal Network has produced a "Know Your Rights" resource on *Disclosure, Privacy and Parenting* that touches on the powers of child protection services. Available at [www.aidslaw.ca/site/know-your-rights-8-disclosure-privacy-and-parenting/](http://www.aidslaw.ca/site/know-your-rights-8-disclosure-privacy-and-parenting/).

<sup>6</sup> In 2017, the Legal Network will produce a resource specifically for youth on the issue of HIV non-disclosure. For more information on the resource, or to be alerted when it is released, contact [info@aidslaw.ca](mailto:info@aidslaw.ca).

<sup>7</sup> CAAN has produced a resource on stigma and discrimination: *Developing a Policy of Non-Discrimination Including Aboriginal People Living with HIV/AIDS: Policy Guidelines for First Nations, Métis and Inuit communities, businesses and community-based organizations*, March 2005. Available at [http://caan.ca/wp-content/uploads/2012/05/CAAN\\_antidiscrimination\\_e\\_04.pdf](http://caan.ca/wp-content/uploads/2012/05/CAAN_antidiscrimination_e_04.pdf).

activities (i.e. drug use). And as previously noted, stigma and discrimination against people who use drugs is also widespread.

### Right to privacy & confidentiality

*“I think more education needs to be done [on privacy], especially when it comes to health care centers and others within reserves. . . People have to be aware that it’s not OK if [breaches of privacy] happen, and the recourse if it does happen, and what their rights are. People need to be able to hold people accountable for a breach of confidential information.” – Key informant*

Respondents emphasized a need to know what rights to privacy people living with HIV have and wanted more information about when one is required to disclose their HIV-positive status. They also shared a number of scenarios in which issues around privacy and confidentiality emerge. Health care centers, particularly those on reserves, were consistently cited as one setting where breaches of privacy occur. Other settings cited include live-in care facilities and educational and employment settings.

Respondents were interested in learning more about provincial and federal privacy laws and their application in various jurisdictions. In particular, respondents wanted to know what actions one could take if their privacy rights were violated (i.e., the involuntary disclosure of one’s HIV-positive status).<sup>8</sup>

Questions were also posed with respect to limitations to confidentiality: Who can access one’s health information? What are the responsibilities of service providers to respect confidentiality? When, if ever, can someone breach a confidentiality agreement?

### Existing resources

While gaps in legal information resources for Aboriginal PLHIV/HCV certainly exist, the Legal Network and CAAN already have a number of resources available concerning some of the issues identified above. These include the following:

Canadian Aboriginal AIDS Network, *Creating Environments that Respect the Privacy and Confidentiality of Aboriginal People Living with HIV/AIDS: A Resource for Aboriginal HIV/AIDS Service Organizations and other Organizations that Provide Services for Aboriginal People living with HIV/AIDS*, 2010. Available at <http://caan.ca/wp-content/uploads/2010/03/Privacy-Doc.pdf>.

Canadian Aboriginal AIDS Network, *Developing a Policy of Non-Discrimination: Including Aboriginal People Living with HIV/AIDS*, 2005. Available at <http://caan.ca/national-aboriginal-toolkit/section-three/vi-information-sheet-on-non-discrimination/>.

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<sup>8</sup> CAAN has developed a resource on privacy and confidentiality for Aboriginal PLHIV: *Creating Environments that Respect the Privacy and Confidentiality of Aboriginal People Living with HIV/AIDS: A Resource for Aboriginal HIV/AIDS Service Organizations and other Organizations that Provide Services for Aboriginal People living with HIV/AIDS*. Available at <http://caan.ca/wp-content/uploads/2010/03/Privacy-Doc.pdf>. The Legal Network has also produced a series of “Know Your Rights” resources that discuss privacy rights in different environments (workplace, school and health care settings). See [www.aidslaw.ca/site/kyr/](http://www.aidslaw.ca/site/kyr/) for more information.

Canadian Aboriginal AIDS Network, “Section Five: Testing — Part I: Pre and Post HIV Test Counselling Guide,” in *National Aboriginal HIV& AIDS Toolkit*, 2012. Available at <http://caan.ca/national-aboriginal-toolkit/section-five/i-pre-and-post-test-counseling-guide/>.

Canadian Aboriginal AIDS Network, “Section Six: Prisons,” in *National Aboriginal HIV& AIDS Toolkit*, n.d. Available at <http://caan.ca/national-aboriginal-toolkit/section-six/>.

Canadian HIV/AIDS Legal Network, *Criminal Law & HIV Non-Disclosure in Canada* (series of three info sheets), 2014. Available at [www.aidslaw.ca/site/criminal-law-and-hiv/](http://www.aidslaw.ca/site/criminal-law-and-hiv/).

Canadian HIV/AIDS Legal Network, *HIV Disclosure and the Law: A Resource Kit for Service Providers*, 2015. Available at [www.aidslaw.ca/site/hiv-disclosure-and-the-law-a-resource-kit-for-service-providers/](http://www.aidslaw.ca/site/hiv-disclosure-and-the-law-a-resource-kit-for-service-providers/).

Canadian HIV/AIDS Legal Network, *Know Your Rights 1: Disclosure at Work*, 2013. Available at [www.aidslaw.ca/site/know-your-rights-1-disclosure-at-work/](http://www.aidslaw.ca/site/know-your-rights-1-disclosure-at-work/).

Canadian HIV/AIDS Legal Network, *Know Your Rights 2: Accommodation in the Workplace*, 2013. Available at [www.aidslaw.ca/site/know-your-rights-2-accommodation-in-the-workplace/](http://www.aidslaw.ca/site/know-your-rights-2-accommodation-in-the-workplace/).

Canadian HIV/AIDS Legal Network, *Know Your Rights 3: Remedies for Discrimination and Privacy Violations in the Workplace*, 2013. Available at [www.aidslaw.ca/site/know-your-rights-3-remedies-for-discrimination-and-privacy-violations-in-the-workplace/](http://www.aidslaw.ca/site/know-your-rights-3-remedies-for-discrimination-and-privacy-violations-in-the-workplace/).

Canadian HIV/AIDS Legal Network, *Know Your Rights 4: Disclosure and Post-Secondary Education*, 2013. Available at [www.aidslaw.ca/site/know-your-rights-4-disclosure-and-post-secondary-education/](http://www.aidslaw.ca/site/know-your-rights-4-disclosure-and-post-secondary-education/).

Canadian HIV/AIDS Legal Network, *Know Your Rights 5: Disclosure as a Patient*, 2014. Available at [www.aidslaw.ca/site/know-your-rights-5-disclosure-as-a-patient/](http://www.aidslaw.ca/site/know-your-rights-5-disclosure-as-a-patient/).

Canadian HIV/AIDS Legal Network, *Know Your Rights 6: Privacy and Health Records*, 2014. Available at [www.aidslaw.ca/site/know-your-rights-6-privacy-and-health-records/](http://www.aidslaw.ca/site/know-your-rights-6-privacy-and-health-records/).

Canadian HIV/AIDS Legal Network, *Know Your Rights 7: Disclosure in School and Daycare*, 2014. Available at [www.aidslaw.ca/site/know-your-rights-7-disclosure-in-school-and-daycare/](http://www.aidslaw.ca/site/know-your-rights-7-disclosure-in-school-and-daycare/).

Canadian HIV/AIDS Legal Network, *Know Your Rights 8: Disclosure, Privacy and Parenting*, 2014. Available at [www.aidslaw.ca/site/know-your-rights-8-disclosure-privacy-and-parenting/](http://www.aidslaw.ca/site/know-your-rights-8-disclosure-privacy-and-parenting/).

Canadian HIV/AIDS Legal Network, *Privacy and disclosure: questions and answers on HIV-related privacy and disclosure issues for women’s service providers*, 2012. Available at [www.aidslaw.ca/site/privacy-and-disclosure-questions-and-answers-on-hiv-related-privacy-and-disclosure-issues-for-womens-service-providers/](http://www.aidslaw.ca/site/privacy-and-disclosure-questions-and-answers-on-hiv-related-privacy-and-disclosure-issues-for-womens-service-providers/).

Canadian HIV/AIDS Legal Network, *Women Living with HIV and Intimate Partner Violence: Questions & Answers*, 2016. Available at [www.aidslaw.ca/site/women-living-with-hiv-and-intimate-partner-violence-questions-and-answers/](http://www.aidslaw.ca/site/women-living-with-hiv-and-intimate-partner-violence-questions-and-answers/).

## Next steps

Based on the findings of the legal needs assessment and a scan of the existing legal information resources relevant to the issues identified during the assessment, five legal information resources will be developed specifically for Indigenous communities, to be finalized in 2016 and 2017. These are

- HIV non-disclosure for sexual partners
- “Know your rights” in prison
- “Know your rights” to privacy and confidentiality
- Harm reduction
- Gender-based violence and HIV

Once they are completed, the resources will be available on the websites of the Legal Network ([www.aidslaw.ca](http://www.aidslaw.ca)) and CAAN ([www.caan.ca](http://www.caan.ca)) and also distributed to the organizations’ memberships and beyond.

Please contact the Legal Network at [info@aidslaw.ca](mailto:info@aidslaw.ca) or CAAN at [info@caan.ca](mailto:info@caan.ca) if you would like to see additional legal information resources.

The Legal Network and CAAN are tremendously grateful for the input of all the respondents, who generously provided their insight on this assessment.

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## Appendix A

### AGM 2013: “Human Rights, Aboriginal People and HIV: Where are we going?”

#### Participant survey compilation of results

**1. What are the top three legal questions you have as a person living with HIV or someone who works in an AIDS service organization?**

- *What are some important rights that I should know as a poz individual?*
- *What are my rights as an intervention worker in terms of reporting people who are deliberately transmitting HIV? (Note: these are not my clients doing this but rather their partners)*
- *Who do you protect with the law: service users? service organizations?*
- *Government changes and jurisdictional boundaries*
- *People living with HIV/AIDS must be protected or incarcerated for mental or addictive behaviour*
- *Criminal charges for HIV*
- *What public health rules apply on reserve?*

**2. What would be helpful in addressing those questions or issues?**

- *Training for frontline workers that is specific to their respective provinces/territories and specific to on-reserve and off-reserve*
- *Bringing this info to attention by working or workshop*

**3. If you could change one or two things in order to improve HIV prevention in your community, what would they be?**

- *To have a bylaw or rule that stops the talk of HIV, stops the whispers or backtalk you hear, and stops being made fun of by others*
- *Implement/establish a safe injection site*
- *Core funding for Aboriginal HIV prevention programs that are NOT housed in AASOs (i.e., move away from time-limited project funding)*
- *PLHIVs’ leadership for PLHIVs*
- *Dismantle and reconfigure organizations to meet needs of PLHIVs and not organization funding/functions*
- *Stop putting people with addictions in jail*

**4. What one or two things would you like to see happen in order to ensure that people with HIV in your community get access to the care and services that they need?**

- *Justice = more care*
- *Talk to those who are doing the negative talk and making fun of poz people, so as to create awareness*
- *Removal of language laws in Quebec which are creating huge barriers for anglo-Aboriginal people living with HIV*
- *Change across the board, and PLHIVs come first*
- *Better connection to mental health, addiction treatment services*
- *Need to ensure Aboriginal communities, leaders support and include harm reduction services*

**5. What should national organizations such as CAAN and the Legal Network do to address these top priority legal issues or help bring about these changes?**

- *Have a lot more talking, interviewing and sharing by media of the stories of those affected by HIV, of what it feels like to be discriminated against. Target doctors and nurses in health care!*
- *Provide provincially-based and federally-based legal documents/resources*
- *More training*
- *2 days for PLHIVs' caucus*

## AGM 2014: "Questions About HIV Non-Disclosure"

### Human Rights and Prison

#### Non-voluntary disclosure:

- When accessing medication or harm reduction materials
- Without actually disclosing, everyone is aware of a person's status

#### Fact sheet specifically on human rights and prison:

- Prisons are a microcosm of every injustice in society
  - Racism and HIV
  - Testing in prison
- Audience: "What are **my** rights in prison?"
- Understanding rights in context of minor offences, when people are coming in and out of prison

### Human Rights and Homelessness

#### Right to health care:

- Right to a street nurse?
- Services to be offered where people are?
- Clean water, safe environment, food to go with medication?
- Is there a right to medication even if my case is "too hard" or "complicated" (as some doctors reportedly told homeless individuals)?
- What does the right to health mean?

#### Right to housing:

- Navigating systems
- Human right to housing?

#### Right to privacy:

- Some shelters ask people to hand over their medications. Do they actually have to give them?
- Who has access to the medications in shelters? Administrative staff?

### Human Rights and Employment

- What are my rights when and once I'm hired?
- Do I need to disclose my status?
- What are the obligations for an organization towards its employees?
- Do you need to disclose your status to benefit from the company's health insurance?

## Right to Privacy & Confidentiality

### Privacy law

- Where does it apply? Federal, provincial? (patchwork of law and precedents)
- Are the core principles universal?
  - Would they apply the same way to a prison's employees as to a hospital's employees?
- What action can I take if someone breaches my rights (e.g., discloses my status)?

### Jurisdictional issues

- Forced disclosure and medical transportation
- Non-Insured Health Benefits for First Nations and Inuit (NIHB)
- Forced disclosure for medical drivers (disclose or no access)

### Limitations to confidentiality

- Who can access your information?
  - Example of secret coding system & electronic health records (should put in codes of conduct that this is an unacceptable way to share info on files as service providers)
  - When can someone (if ever) breach a confidentiality agreement?

### Service providers

- What can we expect from (Aboriginal) service providers?
- What are their responsibilities to respect confidentiality?
- What can we expect from health insurance providers (e.g., employer's program)?

### Drug use treatment centres

- Gap → they are mostly AA-based
- Can limit what people are able to talk about (e.g., if two-spirit or HIV positive)
- Therefore, the treatment is not holistic
- Is this an infringement on rights?
- When you go to treatment for substance abuse and you are asked, "What are your health issues?" and there's a specific box for HIV, do you have to check that box?

### Family Services & Parenting

- Child protection services taking children away from their parents because they say that a mother who is HIV-positive is incapable of taking care of her children. Does that happen often?
- Vertical transmission: why in Canada are we told that we cannot breastfeed but in developing countries you are told that you can? If reserves have rural conditions similar to developing countries, should people living on reserves breastfeed?

### New Immigrants and Refugees

- Can they access treatment and care the same way?
- What if the transmission happens while they are in Canada on a temporary foreign workers' program?
- Screening?

## Treatment

- Do you have to disclose your status for treatment?
- Do health directors have to tell who is HIV-positive (compelled by Chiefs)?

## Miscellaneous

- Target fact sheets
  - Different audiences (service providers, prison staff, (A)PHAS, employers)
- Understanding the criminalization of HIV and the consequences for non-disclosure when your first language is not English (pictures)
- What is the difference between criminalization of HIV, hepatitis C and other STBBIs? Why is there a difference?
  - Could other diseases be criminalized?
- Reach out to youth and trans people

## Appendix B

### HIV and the Law: What do you need to know?

#### Introduction:

CAAN and the Legal Network have collaborated on projects in the past. For 2015–17 we have agreed to work together to produce some legal information resources for Indigenous people in Canada. We have agreed that we will produce a) an information sheet on HIV disclosure requirements under Canadian State law and b) three other legal information sheets (on topics not yet decided), and we will explore possible topics to research jointly.

In order to determine what legal information the community would most value in the resources we produce, we have engaged in a “legal information needs assessment” process, conducting two consultation sessions in June 2013 and July 2014.

We are now conducting a series of short interviews (6–8 total) to get more details on the legal information needs identified at the consultation sessions. We would appreciate your input to help us decide where we need to focus in order for the resources we produce to be most useful.

We have a series of questions about the legal information needs of Indigenous communities in Canada. Please note that we are not asking you what you know about the law or to tell us about your own experiences with the law. We are asking you to tell us what you need to know about the law and what you think your community needs to know about the law. We are trying to find out what sort of legal information the community needs to be able to determine what information we should include in our resources.

#### PART 1: HIV disclosure and the Canadian State Law

In Canada, the law of the State protects each person’s privacy but also at times requires that people living with HIV reveal their HIV-positive status. In certain circumstances, a person living with HIV could be charged with a criminal offence and even sent to jail for not telling another person of his/her HIV status. The first information resource we will prepare will present information on this topic. The answers you provide to the following questions will help us determine what to focus on when we produce this resource.

1. What questions do you have about HIV disclosure?
  - as a person living with HIV
  - as a caregiver for someone living with HIV (adult or a minor)
  - as a health care service provider

Prompts for the interviewer:

- *Do you know when are you legally required to disclose HIV-positive status?*
- *Do you have questions regarding when you are legally permitted to keep your HIV-positive status quiet/to yourself?*
- *Think about when you might want someone who is positive to disclose to you. Do you think what the law requires matches your expectations? Places where disclosure might come up include, for example, at work, in relationships, at school, while accessing health care and while participating in activities such as sports. If you are a caregiver (for either a child or an adult who cannot speak for themselves), when and what should you disclose?*

- *Do you have questions about what counts as disclosure in law?*
- *Do you have questions concerning how to prove that you disclosed?*

2. What questions do you have about privacy rights?

- as a person living with HIV
- as a caregiver for someone living with HIV (adult or a minor)
- as a health care service provider

Prompts for Interviewer:

- *in order to access services (i.e., medical drives) as a client, referrals to other health care services, entering a shelter, entering a treatment centre?*
- *in order to provide services (i.e., when in residential care); when delivering health care in a health centre/office; in school (as a service provider); activities?*

3. How would you describe the “right to know” vs. “need to know” a person’s HIV status?

## **PART 2: HIV and the law in Canada: other issues**

For the three other legal information resources we will produce, and for future research we may pursue, we have further questions about what other legal information you, your clients or your community need.

1. What do you think are legal concerns or considerations on reserve or in rural or remote settings as compared to urban settings?

- as a person living with HIV
- as a caregiver for someone living with HIV (adult or a minor)
- as a health care service provider

Prompts for Interviewer:

- *Do you know if there are different laws that impact First Nations, Inuit and Métis?*
- *What is the scope of services available in different settings?*
- *How does having fewer or more services affect access? Relationship with health care? Relationships in general?*
- *Do you have any questions related to the authority of police, public health, others on reserve or in rural or remote settings as compared to urban settings?*

2. Are there other questions about the law that you would like answers to?

- Examples of everyday situations where more information about what the law says and how it works would be helpful?

Please let us know if any of the following topics would be important to cover:

- What law applies?
  - Is legislation different on and off reserve?
  - What laws apply?
  - When can I access restorative justice mechanisms?
  - When do Indigenous laws apply vs. State laws?
  - Where can I find more information?
  - What legislation or policy applies in Inuit communities?

- What is the reach or scope of responsibility of Public Health?
  - What does Public Health do?
  - When do public health agencies become involved in a situation regarding HIV disclosure?
- How are electronic records used by FNIH, NIHB?
  - Are prescriptions tracked?
- What does the law say about possessing, using or selling drugs in Canada?
  - How do drug laws and HIV vulnerability relate?
  - Do I have a right to get treatment for drug and alcohol dependence? Can I choose the type of treatment?
  - Is it illegal to give out clean needles and pipes?
- What does the law say about family violence?
  - Violence against spouses, children, etc.

### **PART 3: Demographics**

Self-identified sex?

Place of residence?

Age: (between 15–25, 26–35, 36–45, etc.)