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**AIDS CALGARY**  
awareness association

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**HIV/AIDS and Human Rights  
Needs Assessment  
Equaity Project**

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**A project of  
AIDS Calgary Awareness Association  
(ACAA)**

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## **The Equality Project:**

Imagine a world where you lived in fear that people would discover your deepest secret. Imagine that if certain people found out your secret, you might lose your job, be evicted from your apartment, be refused services by doctors and dentists, or be harassed or abandoned by family and friends. This is a world that many people living with HIV/AIDS do not have to imagine. This is the world they live in.

According to human rights law in Alberta, HIV/AIDS is considered a disability and, within certain areas (e.g. employment), discriminating against people on the basis of a disability is illegal.<sup>1</sup> Despite this legal protection, people living with HIV/AIDS continue to experience stigma and discrimination. In September 2002, after hearing many devastating stories of human rights violations, AIDS Calgary decided that it was time to do something. This marked the birth of The Equality Project.

Funded by the Alberta Human Rights, Citizenship and Multiculturalism Education Fund, the Equality Project is a community-based initiative that focuses on identifying and addressing human rights issues facing people living with, at risk for and affected by HIV/AIDS in the Calgary Region. The initial mandate of The Equality Project was to conduct community-based research for the purposes of creating rights-based educational materials and developing rights-based workshops that would be relevant to service providers and people experiencing discrimination. However, due to the needs of the community, the project soon expanded to include a direct service component to provide one on one education and assistance to people living with HIV/AIDS who are experiencing discrimination.

## **Research Methodology:**

In September 2002, a Human Rights Worker was hired to work on site at the AIDS Calgary office. Throughout Phase I and Phase II of the Equality Project, Jessica Leech acted as the Human Rights Worker and was responsible for conducting the project research. As a community-based initiative, The Equality Project has used community-based research principles to guide the research methodology. The following gives an overview of how the project has evolved:

### **Background Research:**

In response to the immediate needs of individuals in the community for specific rights-based information and support, research on specific human rights law and available community resources and services began immediately and has continued throughout the project.

### **A Preliminary Survey:**

Based on a suggestion from a member of the HIV community, we conducted a survey of people living with HIV/AIDS at the Expanding Your Horizons Symposium in Nordegg Alberta, October 2002. A questionnaire was developed in consultation with community members, including people living with HIV/AIDS. The symposium was attended exclusively by people living with HIV/AIDS, and therefore, the survey was administered for AIDS Calgary by several symposium participants. This questionnaire was filled out by 34 people living with HIV/AIDS (out of a total of 53 people who attended the symposium). The results of the survey were distributed to the community, and were used to guide the development of the next phase of the research. The results of this survey are available on our website at [www.aidscalgary.org](http://www.aidscalgary.org).

### **Research Protocols:**

The research component of this project was designed specifically to gather information for use in developing rights-based educational materials and workshops. As a result, we were interested in identifying:

- What kind of human rights issues people living with HIV were facing.
- What kinds of human rights issues service providers observed in the course of working with people living with HIV/AIDS.
- What people living with HIV/AIDS currently do when they experience discrimination (e.g. Do they complain? Where do they go for help?).
- What service providers currently do when they provide services to people living with HIV/AIDS who are experiencing discrimination (e.g. Do they encourage people to do something? Do they provide human rights supports? Do they refer them to other services?).
- What kind of rights-based information/ education/ resources would be helpful to people living with HIV/AIDS in dealing with discrimination.
- What kind of rights-based information/ education/ resources would be helpful to service providers in providing services to people living with HIV/AIDS.

In order to gather this information systematically, we developed one research protocol to guide focus groups with people living with HIV/AIDS and one research protocol to guide interviews with service providers<sup>1</sup>. We also developed informed consent and confidentiality agreements for use in the focus groups and the interviews<sup>2</sup>. The protocols and consent forms for this research project were not submitted to a Research Ethics Board and, therefore, they did not go through an ethical review process.

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<sup>1</sup> Research protocols are available upon request. AIDS Calgary Awareness Association, [info@aidscalgary.org](mailto:info@aidscalgary.org) or +1-403-508-2500.

<sup>2</sup> Ibid

**The Research:**

Due to concerns for the confidentiality of the focus group participants and the sensitive nature of discussing human rights issues, we decided to conduct focus groups with already existing HIV/AIDS support and social groups. We conducted four focus groups with a total of twenty one people living with HIV/AIDS. Focus group participants were recruited through the administrators of the support groups, through AIDS Calgary's Positive Living Lunch Program, through the promotion of the focus groups by service providers at several agencies and through word of mouth. These focus groups were tape recorded and transcribed.

Due to the time constraints experienced by service providers and concerns for confidentiality, we decided to conduct individual interviews with service providers. A broad cross section of service providers were invited to participate in this research, including service providers from AIDS serving organizations, health organizations, members of the justice system and organizations serving at risk populations. In total, nineteen service providers were interviewed. In addition to notes being taken during the interviews, these interviews were tape recorded (excluding those who requested that no recording be made). Due to time constraints, only half of the interviews were transcribed, although detailed notes of all of interviews were taken.

**Research Limitations:**

Focus Group Limitations: Due to the group setting of a focus group, discussion within such a group may be inhibited by people not wanting to share certain experiences publicly. We attempted to overcome this barrier by forming focus groups out of already existing support and social groups so that people would already know each other and feel comfortable talking with one another. However, due to the way focus group participants were recruited, there was a resulting under representation of certain demographic groups including women, aboriginal people, injection drug users and people from countries where HIV is endemic.

Interview Limitations: Although the confidentiality of the service providers interviewed was guaranteed, the relatively small community of service providers in this field, and the possibility that their livelihoods could be affected negatively if they were seen to be critical of their employers/ agencies may have affected the issues service providers were willing to discuss.

**The Research Analysis:**

As the original mandate of the project was to develop educational resources and workshops, the initial analysis of the data collected involved identifying key themes and areas where discrimination occurs, current barriers to addressing human rights issues, and specific information/ resources/ services requested. Based on this initial analysis, we developed detailed fact sheets to provide rights-based information in most of the key areas (fact sheets are available on AIDS Calgary's website at [www.aidscalgary.org](http://www.aidscalgary.org)). In

order to highlight what discrimination looks like in real life, we also incorporated many examples and quotations from the focus group data into the fact sheets.

### **The Needs Assessment:**

In response to many requests from the community for our research to be made available, and in light of the lack of published information available on the actual experiences of people living with HIV/AIDS regarding human rights issues, AIDS Calgary has decided to make our research results available in report form. The following report is designed to provide:

- A summary of the issues people living with HIV/AIDS and service providers discussed through the focus groups and interviews.
- Anecdotes to reflect the lived experience of people living with HIV/AIDS and observations made by service providers regarding the provision of services.
- Information regarding the barriers people living with HIV/AIDS and service providers face in dealing with human rights issues.
- Information regarding the kinds of resources/ services people living with HIV/AIDS and service providers would like to have available.

As much as possible, this needs assessment incorporates the voices of those people living with HIV/AIDS who participated in our focus groups. This report documents that the primary human rights issues facing people living with HIV/AIDS in the Calgary region are also the most basic: fear/confusion about disclosure of HIV status, discrimination in employment, housing, and accessing services (like health care or dentistry); and barriers to immigration, accessing insurance and accessing adequate economic supports. The following report provides an overview of these key issues.

### **Disclosure:**

#### **Responses of People Living with HIV/AIDS:**

By far the leading issue related to human rights reported by people living with HIV/AIDS during the focus groups was the issue of disclosing their HIV status. The general issue of disclosure came up throughout the focus group sessions and was mentioned in reference to most of the different areas where people felt they had experienced discrimination (e.g. disclosure at work, in housing, in health care settings etc.). Key issues include:

**Stigma:** Due to the stigma attached to having a positive HIV status, there is a general recognition that, in regards to disclosure, the experience of being HIV positive differs substantially from the experience of having other illnesses/ disabilities.

*“It’s funny this disease does that eh? Like if I had cancer, I’d have no problem telling people I had cancer.”*

**Internalized Stigma:** The stigma attached to HIV is often internalized, and in turn, can affect how people approach disclosure.

*“When I was first...integrating all the information of being HIV positive, one thing that was very very predominant in my thoughts and feelings is that I was like a leper. My blood, my fluids, were poisonous. And that affected me on a huge huge level.”*

*“I do it to myself, I discriminate on myself, like I do like little things everyday, like I can't sit down, and I think this is because of my HIV, I can't sit down until my place is spotless, and I wasn't like that before. You know? Or when I'm chopping onions and I cut myself, I'm running into the bathroom because I live with someone and they have to finish cutting the potatoes or whatever it is because I won't go near it because I have a cut finger. You know what I mean, so I'm really, I do it to myself, and even little things, like day after day after day. You know, you lose your self esteem.”*

**Negative Experiences:** The internalization of stigma is often reinforced by the actual experiences of people living with HIV/AIDS.

*“I've been called AIDS junkie whore get off my property before I call the police.”*

*“People call you faggot, you know, you deserve what you got.”*

**Fear of Disclosure:** There is a general fear of disclosing one's HIV status, both on a personal level, and in respect to what a person risks losing through disclosing their status in different contexts.

*“[Disclosing] is like seeing a car in a cross walk and wondering, is it going to hit you or is it going to miss you?”*

*“There's always that feeling when...I'm disclosing my status, that fear of how people are going to react on an individual basis. It's a tightening inside.”*

*“It boils [down] to loss, the risk of loss, and the degrees of it.”*

**Fear of Experiencing Discrimination:** The fear of disclosing one's HIV status is linked directly to the fear of being stigmatized and experiencing discrimination.

*“I don't know if this is exactly the human rights issue, but it certainly relates. I think the biggest thing, the biggest thing to address is people's fear of being stigmatized by, and suffering discrimination by, disclosing their HIV status. I think that's the biggest issue, because its one of those things that it's, you know, it's not mentioned.”*

**Fear as a Barrier to Asserting One's Rights:** The fear and the internalized stigma around one's HIV status can pose a major barrier to asserting one's human rights.

*“It's the person that lives in fear that is not going to be able to stand up for themselves. And that's where human rights comes in.”*

**Disclosure with Family and Friends:** Alberta's *Human Rights, Citizenship and Multiculturalism Act* does not prohibit discrimination in informal areas like everyday relations between family and friends. However, the way a person's family and friends react to one's HIV status may have a large impact on the individual and can affect how a person approaches disclosing their status in other contexts or how a person reacts to stigma and discrimination they experience in other contexts. Key issues include:

- **Fear of loss:** The fear of being rejected, disowned or losing the support of one's family and friends can pose a barrier to disclosing one's HIV status to one's closest relations.

*"I had a lot to lose if my family turned their backs on me at that time. I was in a vulnerable state, emotionally weak. I had no support systems, I had no coping mechanisms...the fear of losing that connection held me back from talking to them when I needed them the most. Yet, I was able to talk to strangers."*

- **Embarrassment/Shame:** Family members, friends and partners of people living with HIV/AIDS may react in ways that express embarrassment or shame regarding the person's HIV status.

*"For the longest time since my diagnosis, [my family] would go to family functions and tell the rest of the family I had leukemia and not HIV. They were embarrassed to even be associated with me."*

*"He said, 'That's another thing we have to talk about, I don't think you should be coming over here taking your pills in here. I think you should be getting up and going to the bathroom and keeping quiet about stuff like that'."*

- **Biased Assumptions:** Disclosure of HIV status has led people to make incorrect assumptions about the person living with HIV based on the mythologies surrounding HIV status (e.g. that HIV is a "gay disease").

A heterosexual man disclosed his HIV status to his father and his father reacted by saying:

*"I didn't know you were gay!"*

- **Stigmatizing treatment:** After disclosing their HIV status to family and friends, people living with HIV may experience a change in how they are treated (e.g. being given a "special cup" to drink out of).

*"I've had a couple say, that's ok, we'll put a cup away in the cupboard and keep it for you. And I look at them and say excuse me, I didn't get it drinking coffee!"*

- **Devaluation:** One result of having negative experiences after disclosing one's HIV status can be a destruction of one's self esteem and sense of value, and a reinforcement of one's lack of power to assert one's rights.

*“Once you're defeated by the family, by the friends, it makes you weaker when it comes to fighting for your rights as far as employment or out on the street. Because when it's so close to home that you don't have value, that you're an abomination and all these things, it weakens the soul as far as being able to deal with the outside issues”.*

- **Onus/ Responsibility:** There is a general concern that when engaging in risk activities there is an onus on the person living with HIV to disclose their HIV status, rather than an onus on the non-positive person to either take steps to protect themselves or to open the dialogue about health status.

*“What I do sense a lot of times is suddenly the onus is on the positive individual, not on the other individual whether they're positive or not, who will allow themselves to go into a risk situation. So suddenly all the pressure, all of the expectations are on the individual who is positive, and I haven't seen that change. I really haven't seen that change”*

**Disclosure at work, in housing and when accessing services:** Alberta's *Human Rights, Citizenship and Multiculturalism Act* prohibits discrimination on the basis of HIV status in employment, housing and when accessing public services. In these contexts, disclosure of HIV status is a key issue as people living with HIV/AIDS must negotiate how and when they want to share information about their HIV status and must weigh the responsibilities and risks of sharing such information in each setting. As each setting presents unique issues, the following sections will provide a detailed discussion of how disclosure is an issue in these different settings.

## **Responses of Service Provider:**

Issues related to human rights and disclosure were discussed by service providers during the interviews. Service providers focused primarily on issues around disclosure in specific settings (e.g. employment, accessing services). The following sections will provide an overview of how disclosure is an issue in these different settings.

## **Employment:**

Issues related to human rights and employment were emphasized by people living with HIV/AIDS during the focus groups and by service providers during the interviews. Key issues included disclosure of HIV status in workplace, discrimination in the workplace and workplace barriers:

**Disclosure in the Workplace:****Responses of People Living with HIV/AIDS:**

**Disclosure in the Workplace:** Due to the stigma attached to having a positive HIV status, people living with HIV have significant concerns regarding the risks associated with disclosing their HIV status in the workplace. Key issues included:

- **Fear of Disclosure in the Workplace:** People reported a general fear of disclosing their HIV status at work or of having their status disclosed accidentally. This fear is directly related to the belief that if people living with HIV disclose their HIV status they will experience discrimination.
- **Confusion about disclosure:** In some cases, people are unsure about whether they legally must disclose their HIV status in the workplace.

*Ryan: "You don't have to legally tell them [your HIV status]."*

*Bill: "Well, I didn't know that for sure at the time"*

- **Disclosure as a Barrier to Returning to Work:** The challenge of managing information about their health in the workplace makes many people living with HIV weary of working/ returning to work. People are unsure of how to explain gaps in their employment history and fear filling out employment related insurance papers that may ask for detailed information about one's health status. People living with HIV also reported that application forms sometimes ask for information about one's HIV status right on the application form. Although the *Alberta Human Rights, Citizenship and Multiculturalism Act* prohibits employers from requesting this information, employers continue to do so, and people living with HIV report being unsure of how to deal with such requests. All of these issues can pose a barrier to people returning to work.

*"I'm afraid to go out and get a job, because they're going to ask why I haven't been working. I haven't been working since 1990, and most of the places, if you go to get a job, you've got to fill out those insurance claims and you've got to disclaim that you're HIV on a lot of them. And even 7-11, I mean, they've got it right on the stupid claim, are you HIV? And you've got to answer yes...its right on the application form...So, if you go out to look for a job, then you have to explain why you haven't been working for 10 or 12 years, and what are you supposed to say? Like, I've got AIDS? HIV? Cancer? How are you supposed to explain it?"*

- **Hostile/ Poisonous Work Environments:** "Hostile or poisonous work environments are characterized by behaviour that is not necessarily directed at one person in particular, however, the actions of one or more people in this environment may contribute to a hostile atmosphere which directly or indirectly

affects a person's ability to work effectively."<sup>2</sup> In some work situations, attitudes towards certain groups of people may be so negative that it is clear that if a person were to disclose information about themselves (e.g. HIV status, sexual orientation) that they would experience discrimination.

*"When I got the job on the seismic crew I told them, I told the foreman that I had HIV and he didn't have a problem with it. That's one time I didn't have a problem. Where I said I don't want to tell the crew, but I'll tell you...I couldn't tell [the crew]...you would be blackballed...If you were gay you would be blacklisted the same way as a seismic worker. If you were gay you would be picked on so bad that you wouldn't be able to work there. The one thing you have to make sure if you're going to disclose you're HIV positive, is that you got it from the needles, not from gay sex, that would be a no-no. You would be teased behind your back."*

- **Perceived Attitudes of Employers Towards HIV:** Many people living with HIV reported the belief that prospective employers would view them negatively if they were to disclose their HIV status.

*"Most employers want you to stick around for a while because it costs money to hire a new [worker] to replace you. So if you're HIV, a lot of people just consider that a death sentence. So, they're going to have to replace you."*

*"I think it's just ,they're worried about a lot of issues. If you get hurt on the job or cut and stuff, they have a lot of other people to worry about... Also, that you'd be a burden."*

*"Are you a compensation risk because you have a challenge?"*

- **Disclosure as a Barrier to Work Advancement:** People living with HIV expressed the concern that even if they did not experience overt discrimination as a result of disclosing their HIV status, if they were to disclose their HIV status they may not advance in their careers due to subtle forms of discrimination.

*"I personally, within my work environment, there are some very subtle forms of discrimination in the hiring practice, in the job advancement practice, and it's just subtle. Employers are very aware of where that line is, of how far they can walk along that line...My company that I work for, the employee handbook includes sexual orientation, same sex is covered, physical handicaps, disabilities are protected under our actual employees handbook. Yet, there is definitely a good old boys mentality. If someone were to have [HIV] status, and there were rumors or whispers, career advancement is definitely halted. There's no, you can't put your finger on it, you just know it's there."*

- **Accidental Disclosure:** Managing information about one's HIV status can be difficult in the workplace, particularly when dealing with coworkers.

*“One of the girls, she worked in the store, and I used to talk to her all the time, we became good friends. And she knew my girlfriend too, and we were all out one time. And I told her [my HIV status], because we knew each other for like a year. And it got around to the boss, which was a lady. She comes back and says, ‘Why didn’t you tell me you were HIV positive?’ and I was like ‘Excuse me?’”*

*“You’d buddy up with somebody [to share a room] and that would be really hard to keep from him, really hard. Especially when you wouldn’t go drinking with him. On your pills the smart thing is to not drink. I mean, why are you on the pills in the first place? To get better... Why drink and make it worse? And that’s the dead give away right there.”*

### **Responses of Service Providers:**

**Disclosure in the Workplace:** Due to the stigma attached to having a positive HIV status, service providers have observed many significant concerns regarding the risks associated with disclosure of HIV status in the workplace. Key issues included:

- **Fear of Disclosure in the Workplace:** Service providers report that the people who use their services have a general fear of disclosing their HIV status at work. In some cases there may be no evidence of discrimination happening, but people are still afraid to disclose their status. According to the service providers, most service users do not disclose their HIV status in the workplace, and some fear that they would be fired if their employers found out. One service provider explained that sometimes people living with HIV are so fearful of disclosure that they quit their job rather than disclosing their HIV status to their employer.
- **Confusion about disclosure:** Some service providers report that they themselves are not sure of the guidelines around disclosing HIV status in the workplace or when returning to work (e.g. on insurance forms etc.).
- **Human Resource Gatekeepers:** Service providers observe that within the workplace human resource gatekeepers (e.g. secretaries) hold information about long and short-term disability programs. In order to get this information, employees must request the forms and the fact that they have requested this information can become known within the office. In order to avoid this, employees can request forms directly from the union or insurance company. However, people worry that once filled out, these forms may not be sent directly from the doctor to the insurance company. Instead, forms may be sent through human resources so they can “sign off” on them, and, as a result, sensitive health information can be very difficult to keep confidential.

- **Accidental Disclosure:** Service providers report that disclosure in the workplace sometimes happens when people living with HIV disclose their HIV status to friends at work and those friends either do not consider the consequences of telling others or they do not think that it will cause a problem so they disclose that information to others in the workplace and this can lead to problems.

### **Discrimination in the Workplace:**

#### **People Living with HIV/AIDS:**

**Discrimination in the Workplace:** In addition to fears about being discriminated against, people living with HIV report experiencing actual discrimination in the workplace based on their HIV status and related issues. Key issues include:

- **Being Fired:** People living with HIV may be fired from their jobs after disclosing their HIV status.

*“They talked to me and they told me it was causing conflict with the other workers, and blah blah blah. I said, ‘What kind of conflict?’ ‘Well you’re HIV, they’re afraid.’ In the 80s it was not as well known as today. But then I was, I talked to him and I said, ‘What about my work?’ And he said ‘Your work is super.’ But I said ‘What’s the problem then?’ And we talked for about an hour and a half, and then I said ‘OK then.’”*

*“When my partner got sick and I was going through my financial mess, I had expended so much energy looking after him and making sure that his family was fine, I forgot a lot about me. And what happened is, I ended up turning to the bottle for my solace. And I started drinking quite heavily, which I did for a year, year and a half, and in that time my employer had known that I was gay but now I was HIV and I was also dealing with an addiction problem. I had a very powerful position with the company for a lot of years and helped build it to a fairly large company, but when it came to the fact that I had any needs at that time, I was pretty much let go. I was basically booted out, asked to leave kindly, with two weeks severance pay. So I know that there was a lot of, I probably faced a lot of discrimination....I think they were almost thankful that I had a bit of a drinking problem, I had a good drinking problem actually, because it gave them some ammunition, and they never did have to look at the HIV.”*

*“Through peer support I’ve had a couple of matches, where they’ve indicated that they were dealing in a food environment and with their [HIV] status they were removed from those types of environments, and there again, it wasn’t so passive, but there was definitely a ‘We don’t want your services’”*

*“I’ve heard a few stories about people who have released their information about HIV status and they got dismissed, but on different grounds.”*

*“Well, you may not be able to dismiss someone on the grounds of HIV, they sure as hell will find another way to let you go. They’ll do a review of your work..., your productivity.”*

*“They’ll either talk to you and say you’re out, or they will make enough trouble for you to quit.”*

*“They hide that though. If they find out that you’re HIV or whatever, then they’ll have a different excuse [to fire you].”*

- **Being Laid off:** People living with HIV may be laid off from their jobs after disclosing their HIV status.

*“It’s just like when the employer found out [your HIV status] he’d send you on time off and then say sorry, we don’t have any work right now, don’t bother coming back right now. They don’t say, ‘you have HIV we don’t want you there.’ Nobody is that silly. Even the last job I was on, they knew I was taking all kinds of pills, and as far as I disclosed to them it was diabetes, but they probably didn’t want some pill popper [working for them]...I think the fact that you’re taking all those pills makes them wonder...I’m sure as far as direct discrimination there really isn’t anything there. I ask for a record of employment and they say shortage of work, but they hired two new guys.”*

*“I had a situation where I was working in computer software support position, and it tended to be fairly seasonal, where the peak period was January to April, you know the ramp up period being through the fall, and the summer was the extremely slow period. So, the number of staff in the support positions rose and fell based on that. Now, one particular year, in the summer they were going to keep on four people, and they found budgetarily that they couldn’t have all four all summer, so they laid off two for one month, and then two for the other month. And this was at the point where I was just going to start, start back on, antiviral meds. And I’m sort of the guy where if there’s a bad reaction to be had, I’ll have it. So, at the point where my employer was laying off the other two for the month, and it was just at the point where I was starting the meds, and I really didn’t know whether I was going to have a bad reaction or not, so I felt as a courtesy that I had to explain to my boss that I was starting on, I didn’t say they were HIV meds, I didn’t disclose that, but I wasn’t closeted at work, either, so I think two and two. As it turned out, I didn’t have a bad reaction till several months later, but through that month, I didn’t have any kind of a reaction. It was my turn to be laid off the next month, but at the point where I was to come back to work after being laid off for the month, on the day I arrived back it was like, your services are no longer required...So, I have the feeling that there was a bit of fear on their part that if I had a reaction down the road that I wouldn’t be able to do the job.”*

*“Does that raise the question of, a person in a temporary position or a rotating position is more at risk for that type of abuse?”*

### **Responses of Service Providers:**

**Discrimination in the Workplace:** Service providers report that the people who use their services report experiencing actual discrimination in the workplace. Key issues included:

- **Problems Being Hired:** Service providers report that people living with HIV/AIDS may not be given a job due to their HIV status, and that employers are apprehensive about hiring people with any disability. For example, once an employer finds out that someone has a disability they will ask questions about whether the person can do the job or about whether they have a claim in to the workers compensation board.
- **Being Fired/ asked to resign:** Service providers report that some people living with HIV have been either fired or asked to resign from their jobs after disclosing their HIV status in the workplace. Service providers also report that people may be dismissed from their jobs due to issues with drug use (e.g. employer may see track marks on someone’s arms or see them hanging around downtown with people who are known to be involved with drugs and dismiss the person on this basis, even though the person does not use drugs in the workplace). Service providers also report that people may be dismissed from their jobs due to sexual orientation.
- **Discriminatory Treatment:** Service providers report that transgendered people may be discriminated against in the workplace due to concerns about which bathroom they should use. According to the service providers, this may be related to the assumption that because they are transgendered they may also be living with HIV.

### **Workplace Policy and Accommodation:**

According to the Alberta *Human Rights, Citizenship and Multiculturalism Act*, employers in Alberta have what is known as a “duty to accommodate” people living with disabilities. This means that employers must take reasonable steps to support people with disabilities with whatever they need to do their jobs (e.g. time off when they are too sick to work, lighter work duties if they are unable to do heavy lifting). Employees are not required to disclose their HIV status in order to get accommodation, but they do need to request accommodation and can be required to provide supporting documentation from their doctor. Despite the right to accommodation, the fear of disclosing one’s HIV status to one’s employer can pose a huge barrier to asking for accommodation in the workplace.

**Responses of People Living with HIV/AIDS:** The following examples illustrate how people living with HIV/AIDS are dealing with this barrier to accessing their accommodation rights:

- **Lying about HIV status:** People may lie about their HIV status and claim to have a different disease (e.g. diabetes, cancer) in order to explain being sick, needing to take time off or having to take medications.

*“Well first of all the beeper would go off while the boss was there. ‘Oh shit my pills!’ ‘Oh, what are you taking pills for?’ ‘Experimental diabetes medications.’”*

*“Well, I found that having HIV you learn to lie better.”*

*“When I was going through KS [Kaposi’s Sarcoma], I had to come with every lie under the sun to get a day off, because I had chemo and I was changing doctors and he wanted to change me from chemo to radiation, and I was like, ok, I have to remember how I’ve worded all of this, who did I tell what to who. And it was just trying to keep everything straight, after a while I just said ah, to hell with it.”*

- **Lying about why they need time off:** People may make up other excuses to request time off when they are really dealing with HIV related issues.

*“I find that hard too, like when you do get a full time job, again it’s, you either, you’ve got to weigh out the doctors or the job. Because you have to go to the doctors, and blood work, and follow up so I mean that’s nothing to do with discriminatory, but in a way it is. So you end up lying to the, you say you’re out at the dentist.”*

- **Using Own Time:** People may use their lunch hours or vacation time instead of asking for time off to see a doctor.

*“I’ve been fortunate that I’ve had employers in my work environment that if you have to run off and do something you can just go and do it and come back. I would certainly adjust my lunch hours and take extra long lunch hours, without asking for that accommodation. And now I’m fortunate that I’m in a situation that I can come and go as I please, so I don’t have to check with my boss, you know. I do remember though way back struggling to get blood work. Like it was a, God, I’ve got to do my blood, that’s 2, 2 ½ hours. I would just take a half-day vacation. That’s how I dealt with it. So I sacrificed my free time for my health.”*

- **Overcompensating:** People may come to work when they are sick to avoid asking for time off.

*“I’m always at work. When I’m sick I go to work. I have colleagues that have a little sniffle or a slight headache, and take three days off. I never do that, and yet, I live in this constant fear of disclosure, and the moment that disclosure happens,*

*that glass ceiling, when my career comes to a grinding halt. And yet, my work is exemplary.”*

- **Quitting Work:** People may go so far as to actually quit their jobs to avoid disclosing.

*“I was having a lot of problems with my liver, some days I’d feel like getting out of bed, other days I wouldn’t feel like getting out of bed. And I had to come up with some lame excuse to call in sick, and once I got there I felt shitty already, so then I had to give up my position, because I was going through the jaundice and the yellowing of the eyes. And I didn’t want that to be known, or a big question behind that so I came up with another excuse that I was going through chemo on my leg...[If I had disclosed] I would have been [discriminated against]...I got treated really different after I told them I was going through chemo on my leg, he says, take as much time as you need, and everything else, and I’m thinking, if I go one step forward and disclose, I’m setting myself up for a whole different can of worms.”*

- **Disclosing one’s HIV Status to get Accommodation:** Some people feel they have to disclose their HIV status in order to get the amount of time off they need, then they worry that they will be fired because they need too much time off.

*“That’s part of the reason I had to disclose in my last job that I was positive, was because I was needing all this time. And I just said here we go, I can’t lie about this because it’s too small of an office, there’s three people...That’s one thing that always kind of concerned me at some points, was to me it was like always a bit of a risk of having to disclose something, or the risk of, whether it’s discrimination or just plain being fired because you need too much time off all the time. And you’re kind of caught between a rock and a hard place, and the fact is, you know, you’ve got to do this to keep your health well enough so that you can keep working, but the same time, you’re also wondering if you’re pushing your envelope with your employer by saying I need to take off for half an hour here, an hour there.”*

- **Making Discrete Inquiries:** It is difficult to find out workplace policies on HIV or on workplace accommodation without disclosing one’s status or making other people suspicious.

*“I’m not out about my HIV at work, and I’ve even tried to make some discrete inquiries about what our corporate policies are about AIDS in the workplace. As far as I know, there are none. Which also leads me to believe there are no policies about duty to accommodate either. But even in the asking about those things, it’s revealing, right? You risk exposing yourself just by asking. Well, why would you ask about that unless you had HIV, right? So it’s pretty hard to get information about it unless you’re in human resources yourself. ‘It’s for a friend’?”*

**Responses of Service Providers:** Service providers report that people living with HIV have difficulties getting accommodation in the workplace. Key issues included:

- **Letters to Support Accommodation:** Service providers are sometimes required to write letters on behalf of their service users requesting accommodation in the workplace. It is difficult for service providers to know how much you can ask an employer to do to accommodate a person without risking that the employer will fire the person. It is also difficult to state how some things can be accommodated [e.g. how do accommodate someone with diarrhea or someone who is fatigued?] Service providers report that in writing these letters it is important for service providers to avoid disclosing the person's HIV status, but to communicate that the person has a medical problem and that their activities need to be limited on that basis.
- **Quitting Work:** Service providers report that people may actually quit their jobs to avoid disclosing their HIV status. [e.g. a service user who had a heavy lifting job wanted to change his job duties to be less intense, but he felt that he could not word his request for accommodation in a way that would not disclose his HIV status so he quit his job because he was afraid his HIV status would be disclosed]

## Housing:

Issues related to human rights and housing were discussed by people living with HIV/AIDS during the focus groups and by service providers during the interviews. Key issues included disclosure of HIV status in housing, discrimination in housing and issues with subsidized housing/ shelters:

### Disclosure in Housing:

#### **Responses of People Living with HIV/AIDS:**

**Disclosure in Housing:** Due to the stigma attached to having a positive HIV status, people living with HIV have significant concerns regarding the risks associated with disclosing their HIV status to landlords/ when accessing housing. Key issues included:

- **Reluctance to Disclose in Housing:** There is a general reluctance to disclose HIV status in housing.

*“Well, there again, you don't say Hi, I'm [so and so], I'm broke, I make no money, I'm on assistance, I have HIV...please rent me a room!”*

- **Perceived Attitudes of Landlords Towards HIV:** Many people living with HIV believe that a landlord would discriminate against them if they were to disclose their HIV status:

*“If you go to rent a place, you go to that landlord and say hey, by the way, I’ve got HIV, do you think they are going to give you the place? Come on! Most landlords wouldn’t on that basis.”*

- **Disclosure to Roomates:** In situations where people share accommodations it is very difficult to maintain their privacy and avoid disclosing their HIV status, particularly if they are taking medications.

*“You’d buddy up with somebody [share a room] and [taking your medications] would be really hard to keep from him, really hard. Especially when you wouldn’t go drinking with him. On your pills the smart thing is to not drink. I mean, why are you on the pills in the first place? To get better. Why drink and make it worse. And that’s the dead give away right there.”*

### **Responses of Service Providers:**

**Disclosure in Housing:** According to service providers, people living with HIV have significant concerns regarding the risks associated with disclosing their HIV status to landlords/ when accessing housing. Key issues included:

- **Non-Disclosure:** Service providers report that most people do not disclose their HIV status to landlords or housing workers.
- **Institutional Disclosure:** In situations where people live in institutional settings (e.g. group homes), service providers report that institutional codes are not always followed and confidentiality of HIV status can be a problem. In such settings service providers may lack an understanding of confidentiality and universal precautions (i.e. that if you use universal precautions you do not need to know who is living with HIV because universal precautions protect you from HIV transmission).
- **Halfway Houses/ Transitional Housing:** Staff and the people who live in these settings may create a hostile/ poisonous living environment for people from diverse sexual orientations. [e.g. one gay man lived at a halfway house where the staff and residents made gay jokes and he felt that he could not disclose his sexual orientation in that environment because he felt the staff would not support him, and as a result he did not feel safe living there].

### **Discrimination in Housing:**

#### **Responses of People Living with HIV/AIDS:**

**Discrimination in Housing:** In addition to a reluctance to disclose their HIV status, people living with HIV report experiencing actual discrimination in housing. While some of the reported incidents of discrimination are directly related to HIV status, many others are related to issues of sexual orientation and source of income (which are also protected

grounds for discrimination under the *Alberta Human Rights, Citizenship and Multiculturalism Act*). Key issues include:

### **Applying for Housing:**

- **Refusal to Rent:** Landlords refuse to rent to people on the basis of sexual orientation or source of income.

*“We went looking around for a place to stay and [we] were rejected a place to stay because we don’t have a job, but yet, we have assured income, both [of us]...It’s crazy, and I think that is discrimination. Because I’ve got an assured income, which is sometimes better than a job, because you can get fired from a job, right?”*

*“There’s another thing that happened too, I think it happened in 95 or 96, me and [my partner], we applied for a one bedroom, and they were giving [us] a hassle about having a one bedroom, two guys in a one bedroom! That landlord almost took a fit. You cant have two guys in a one bedroom. I said hey, we’ve been together for two years. He outright said to me, two guys renting a one bedroom? We cant do that!”*

*“But every time [my friends] went and said they were together they wouldn’t let them in because they were two guys...So on the one hand, you try going together and they won’t let you in because you’re two guys, but if you do it individually they say your income is not high enough. So on the one hand, they’re kicking you in the teeth, on the other hand, they’re kicking you in the ass, either way, you’re out the door.”*

*“I’m living [in transitional housing], which, it was just temporary. But now, I didn’t think it was that hard to find an apartment! Everybody wants you to work. There’s one place... that had a room. I phoned, the first thing she asked me is, do you have a job? No.”*

- **Unreasonable Deposits:** Landlords sometimes ask for first and last month’s rent, and a damage deposit. Requiring damage deposits creates a real barrier for people trying to get housing on a limited income.

*“My friend and I were looking at a place, and they want first and last months rent plus damage deposit. Something like \$2600 dollars to move into a \$900 apartment. Kind of ridiculous.”*

*“The landlords here, they have, we had that before in Montreal, the damage deposits, and the people thought it was discriminating for people, so they went to court, we fought, and now there is no more damage deposits down there. It’s you pay your rent, period. And that’s discrimination of one kind. Why should I pay my*

*month plus another month? That's discriminating, that's saying you guys on AISH, welfare or whatever, ha, I will get you."*

### **While Living in Housing:**

- **Harassed by Landlords:** People may be harassed by their landlords due to their HIV status.

*"I also know of people that were harassed by their landlords due to their [HIV] status...people that were dealing with their HIV status and were worried about being booted on the street because they didn't know their legal rights, their human rights. They were terrified that their landlord was going to boot them on to the streets."*

- **Shared Accommodations:** If roommates discover a person's HIV status they may not want to continue to share accommodations.

*"The boss comes over to me and says 'Have you got something to tell me?' and I said, 'I guess I do, I've got HIV.' 'Well, why didn't you tell me?' I said, 'well I didn't know that it was really important.' 'And you're sharing a shack with a guy!' The guy I'm sharing a shack with is a huderite, running away from the colony, like just plain scared, terrified, seeing red. And he's looking at me, and I can tell he's just like he doesn't even want to share the shack with me anymore. And it wasn't very long, a few days later, and I'm going home on time off, and I'm not called back. 'No, we don't have work, we're sending everybody home, there's no work at all.' So that was the last time that I specifically told an employer."*

*"Well, my landlord disclosed my stuff by going into my room because I was renting a room in a condo and all of a sudden she turned against me. I knew she was in my room. I was gone for a month and a half or more. And I come back and I know darn well she was in my room. I took my pills with me up north, but even when I was back and had my pills, I mean, I shouldn't have to hide my meds because someone might come in my room and see it. And why else would she start acting strange and wanting me out, like there are a lot of unknowns in there but I also assume that she knows because, you know, like, you can't stop the landlady from going in your room. The only thing you can do if you rent a room in a condo is phone the police. If you figure she's been in your room you can't go to landlord and tenant, because you don't have a separate entrance, because you're in their house. So they figure they can go in whenever, and that's the situation that I've been in."*

- **Costs of Housing:** Due to the limited income many people receive through disability benefits, it is difficult to afford rent and to also afford to eat nutritiously and maintain their health.

*“So in other words, if we’re paying all of this money for rent, how do we afford to eat nutritiously and everything?”*

### **Subsidized Housing:**

- **Barriers to Getting Subsidized Housing:** It is difficult to afford an apartment on disability income and waiting lists for subsidized housing are long.

*“So if you don’t meet that formula, 30% of your income, you don’t qualify to live anywhere. Basically, the only place you qualify to live is subsidized housing. So every other place, you can’t get in the door...It took me two years of living on the street to finally get a place.”*

- **Quality of Subsidized Housing:** The quality of subsidized housing available to single men is an issue.

*“It’s like this. So you have to go through Calgary Housing and wait for a transfer, so you’re just a sitting duck, waiting for a transfer. I can’t afford \$700 a month on AISH... With Calgary housing, if you’re a single male, where do they place you? At the York... Another men’s shelter. Like, I don’t want to go stay where people, you don’t know who is going to break into your apartment, you know, its like...it should be, if I want an apartment, I should have the right to have an apartment like anybody else, not just in one place because I’m a man, I should be able to go wherever.”*

*“But I got another very important point to, is that applying for Calgary housing or whatever, right, is also, they’ll, like you said, they’ll stick you in the York, or they’ll give you a bachelor suite. You ask for a one bedroom, you’ve got to fight like a, and they still won’t give you a one bedroom. They’ll give you a bachelor suite and that’s all they’ll give you. You can’t get a one bedroom, which is, its stupid, its crazy.”*

### **Staying in Shelters:**

- **Barriers to Taking Medications:** Shelters may not allow people to bring their medications into the shelter with them.

*“You know what? [The shelter], they won’t let you take your meds in...No, you have to leave the building, and when you leave the building, they put the sign up, “we’re full.” That’s what they’ve done to me every time. Like when I was using, I’d go there because I knew I wasn’t going to get in [the other shelter]...And you put [the medications] behind the counter, and then your beeper goes off, so I’ve got to take my meds. Well, you can’t take your meds in here, you have to leave. You have to take everything, you have to leave your bed, and then they put the sign up saying ‘we’re full’, because they don’t want you coming back in after*

*you've been on your meds, they're afraid your going to lose it in there or something....yeah, you lost your bed, you have to sit outside and wait forever."*

### **Responses of Service Providers:**

**Discrimination in Housing:** According to service providers, people living with HIV/AIDS experience significant discrimination in housing. Key issues included:

#### **Applying for Housing:**

- **Refusal to Rent:** Service providers report that landlords refuse to rent to people on the basis of HIV status, race, source of income (AISH, SFI) and to women fleeing domestic violence and women who have children.
- **Problems with Rent Reports:** Service providers report that when people who are on "welfare" get a new place to live they must have the landlord fill out a rent report. The landlord then becomes aware that the person is on social assistance and the landlords sometimes collect the damage deposit and then refuse to rent the apartment to the person. According to the service providers, AISH is better because people do not require a rent report which makes its recipients more invisible and enables them to say they are on "disability benefits" without disclosing which benefit they receive.

#### **While Living in Housing:**

- **Harassed by Landlords:** Service providers report that people may be harassed by landlords based on their HIV status or other reasons [e.g. one woman's landlord refused to fix anything in the apartment so she was forced to leave].
- **Eviction:** Service providers report that people have been evicted due to their HIV status.
- **Physical Accessibility:** Service providers report that people living with HIV may have special needs when they get sick (e.g. need access to an elevator). These accommodations may not always be available when people need them.

#### **Subsidized Housing:**

- **Barriers to Getting Subsidized Housing:** Service providers report that general access to public housing is "horrendous." The Calgary Health Region has been subsidizing housing for some clients in cases where people are "unwilling or unable to protect themselves or others from HIV" because housing is often key to changing behaviour.

**Staying in Shelters:**

- **Women's Shelters:** Service providers report that some communities do not want women's shelters located in them because they fear that they may bring violence into their community.

**Services:**

Issues related to human rights and accessing services were discussed by people living with HIV/AIDS during the focus groups and by service providers during the interviews. Key issues included disclosure of HIV status in accessing services and discrimination in accessing services:

**Disclosure in Services:****Responses of People Living with HIV/AIDS:**

**Disclosure in Services:** Due to the stigma attached to having a positive HIV status, people living with HIV have significant concerns regarding the risks associated with disclosing their HIV status when accessing services. Key issues included:

- **Confusion about disclosure:** In some cases, people are unsure about whether they legally must disclose their HIV status when accessing services.

*"I'm in a quandary as to whether you're supposed to [disclose to the dentist] or not. As [Lyle] said, it's probably on the questionnaire that you fill out."*

- **Disclosure to ensure health:** Although people do not have to disclose their HIV status to health service providers, some believe it is in the best interests of their health to do so.

*"I'm not sure there is an obligation to [disclose], but it just made sense to me at the time to do that just in terms of my overall health picture."*

- **Signs demanding disclosure:** In many medical clinics there are signs on the back of examination room doors asking people living with HIV to disclose their status to the doctor. People are concerned that they will be refused treatment if they disclose.

*"So I went in [to the clinic] and they took me to the room to wait, but when they close the door there's a sign, if you know that you are HIV or something else, notify the doctor. So I looked at that and I said, what is this? If I tell the doctor I'm HIV that means I'm not going to be treated? Or, you know, it's like, it doesn't catch by touching."*

- **Maintaining Confidentiality:** In health care settings, people are concerned about violations of confidentiality.

*“I’ve heard, on more than one occasion, from more than one person, that someone who is positive and admitted to [hospital], that, shall we say, the grape vine spreads very quickly and all the staff of the hospital knows in very short order that the patient in room such and such is HIV positive.”*

- **Health Care Cards:** Although clinics use codes to preserve the confidentiality of patients, people must show their Alberta Health Care Cards in order to receive services. This may compromise a person’s confidentiality.

*“Go get you blood work done. ‘Show us your health card.’ There’s my confidentiality gone...Right then and there. You get the forms, and the forms don’t have your name, your number, they kind of, you know, it’s partially your name, a little bit of lead towards it and then some numbers, and then you go get your blood work done, we need your health care. ‘Ahhh, no!’”*

- **Clinic Numbers:** Clinic numbers are supposed to be confidential, but these numbers are required on blood work forms. This may compromise a person’s confidentiality.

*“If you go down for blood work, they’ve got your name and your clinic number on your forms, but your clinic number is not supposed to be divulged to anybody, but yet, it’s on your bloodwork forms. So, I don’t understand why they put it on your forms. I mean sure, it only goes to the people in the labs, but to me, it’s always seemed off that it was on there. And they don’t tell us where they’re sending our blood to, like they send it to Ottawa and all kinds of places for DNA testing, so you don’t find out who all has access to it.”*

### **Responses of Service Providers:**

**Disclosure in Services:** Service providers report that people living with HIV have significant concerns regarding the risks associated with disclosing their HIV status when accessing services. Key issues include:

- **Fear of disclosure:** Service providers report that people living with HIV may be so afraid that their HIV status will be accidentally disclosed while they access services (e.g. someone they know may see them go into the HIV clinic) that they may not access any HIV related services at all. In one case, a health care provider transferred the care of a service user to the HIV/AIDS clinic, but due to a fear of disclosure, the service user never actually accessed any services at the HIV/AIDS clinic and as a result they “fell through the cracks”. In some cases, the fear of disclosure leads people from Edmonton to access their HIV related health services

in Calgary or vice versa. Similarly, some people living HIV prefer to access services through the STD clinic rather than going to the HIV/AIDS Clinic.

- **Maintaining Confidentiality in Health Care Settings:** Service providers report that confidentiality in health care settings is often violated. For example, client files may be faxed containing information that does not need to be shared, files may be left open so that people walking by can see them, doctors may disclose a person's HIV status unnecessarily (e.g. to the partner or family of a person who has been newly diagnosed), a person's HIV status may be put in their chart and their chart may be left in the open, a person may be asked for information about their blood work in an open area in front of other people with no respect for confidentiality, (in the past) biohazard signs were used to indicate HIV status and HIV status was written up on boards where everyone could see it. According to the services providers, although HIV status should be disclosed on a "need to know" basis (e.g. when a woman is delivering a baby and it is relevant to the care of the baby), at the hospital, health care providers always want to know the person's HIV status. Service providers have also been told that cleaning staff at hospitals need to know a person's HIV status, but state that this is unnecessary because cleaners use universal precautions. Some service providers advocate on behalf of clients to let health care workers know that what they are doing is not appropriate and to offer training regarding confidentiality.
- **Confidentiality and the Police:** Service providers report that the police want to know the HIV status of the people who access services through the service providers. According to service providers, in some cases a person living with HIV may disclose their HIV status to the police so that the police will not hurt them, but then that information may be put in the police computer system and confidentiality becomes an issue. In one case, a woman was in the police data base as HIV positive but she was actually HIV negative. After she spat at a police officer the police wanted to test her for HIV. In some case the police want to tell johns and their wives the HIV status of sex trade workers and although the information they collect is governed by privacy legislation they worry that the john's wife could sue them if they do not disclose that information to her.
- **Perception that fear of disclosure is bigger than actual risk:** Service providers report the perception that the fear people living with HIV have regarding disclosure/ breaches of confidentiality is out of proportion with the actual occurrence of such breaches.
- **Strategies to Maintain Confidentiality:** One service provider suggested that, as a service provider, one way to ensure that you do not breach someone's confidentiality is to hold three way conversations when speaking to third parties in order to avoid going beyond the scope of the what service user is comfortable sharing.

- **Confidentiality and Schools:** Service providers report that schools may not respect the confidentiality of their students. In one case a school sent confidential information regarding a child's HIV status to another school.

### **Discrimination in Accessing Services:**

#### **Responses of People Living with HIV/AIDS:**

**Discrimination in Accessing Services:** In addition to fears about being discriminated against, people living with HIV report experiencing actual discrimination in accessing services. Key issues include:

**Doctors Refusing and Abandoning Care:** Many people have been refused as new patients or refused treatment by their long term doctors.

*"[The doctor] just said, 'I'm not going to treat you,...I don't treat you people.'"*

*"I've been looking for two years for a GP and there's not one that will take an HIV patient. As soon as they know you're HIV they say 'sorry, we're not taking any patients.'"*

*"My doctor of 25 years fired me because I was a junkie. I didn't even get a chance to tell him I was HIV positive because I didn't know at the time. But there were bruises, he was treating me for compensation for a wrist injury and I got bruises all over my arms. And he's like, 'What are you mainlining?' 'Coke' 'Would you find yourself another doctor. Here's the AADAC number. Don't come back here.' But that's discrimination because I was a junkie, not because I was, I didn't even know my [HIV] status then"*

*"I was prepped, already in the surgery suite, and they said oh, this other doctor has to do it. And I had to wait another 6 days until I contacted the other doctor because he's apparently the GI specialist that handles all the HIV patients so they figured it would be better if he did it because he'd know what he was looking at I guess."*

*"He came right out and said it to me, one of the doctors [who refused me service], he said 'I've never dealt with this, the HIV part of it.' And I said, 'You're a doctor!' I mean, 'Didn't you go to school?'"*

**Dentists Refusing and Abandoning Care:** Many people have been refused as new patients or refused treatment by their long term dentists.

*"Certain dentists in the city will say 'yeah', others will kind of go, 'well, you know, we're kind of full.'"*

*“So when I went to see the dentist, when I went in and filled out the forms, I said on my form that I was positive, and when I got to the suite where they were going to work on me, the hygienist, she came in and had a look at my chart, and then she left the room. Shortly afterwards, the dentist came back without the hygienist and said that she was ‘uncomfortable’ working on me. He said, ‘we’ve never had an AIDS patient before.’”*

*“I just had one [dentist] where she said that we don’t do anyone who is HIV, so we’ll send you to one that will.”*

*“Well, I mean, at the time I was diagnosed, there was only one dentist in the entire city that was accepting, that was openly accepting HIV+ people, and he’s moved on to the foothills hospital and has a large clinic there now. You know, and it’s not an issue there. I don’t know how much of an issue it is at others.”*

**Receiving Different Care Due to HIV Status:** Often HIV status is seen as a person’s primary diagnosis and their other health concerns may not be given the amount of attention or treatment they require.

*“I did have a friend who came down with a non-HIV related cancer, and basically got a line from a cancer surgeon along the lines of, ‘you’ve got HIV, you’re going to die anyway’...they treat as far as chemo or radiation or whatever, but as far as an operation to remove the tumor, no.”*

*“I had to go for hernia surgery, when I first was meeting the surgeon I was really nervous to put on the form my [HIV] status. It wasn’t a life threatening thing, it was just a discomfort and so on and so forth. And when I was in there with the surgeon, very professional, was nondiscriminatory in the sense that I think there was a little bit of education having to happen there, but you know, book the appointment, and so on. It turned out to be a pleasant experience and so on and so forth. There were some other issues there that are not HIV related, and they were dismissed. Which was rather odd, which were to me, they took precedence over status, because they were more critical to well being versus the status at that time...And that was very interesting that there was a dismissal of, to me, very important issues. Not the HIV. Because the status right now, all of us here are working, we’re healthy, we walk around, we go and we socialize, you know, we’re able to get up and do things, so we’re contributing members to society.”*

*“Not a GP, but a specialist at the... hospital. Yeah, it was a mix up, That’s when I broke my shoulder, and there was a mix up that morning. The receptionist put me through to the other doctor, so, ‘Oh, well we do some more X rays and we’ll operate.’ Go and get the X rays, they come back with the X rays and he’s going ‘Oh yeah, we’re going to have an operation and we’ll fix this.’ Id already been seeing the other doctor for about a month at that point in time, but I went, ‘How come the other doctor didn’t want to operate? Do you know Im HIV +?’ ‘Oh!*

*Wait and see the other doctor.' That was his reaction. He hadn't read the file through the whole way... so when I asked my own doctor how come you're not operating he says 'I can't guarantee you will get any better, your shoulder will either heal that way and I can operate but it won't make it any better, I can't guarantee it.' So that's why he wasn't going with the operation, but because I was HIV+ he wasn't thinking so much about an operation. And it was just, the discrimination was just 'no!' to me that's the only thing I've ever had."*

**Extra Universal Precautions:** Although health services providers are required to use universal precautions, they sometimes use extra, unnecessary and stigmatizing precautions when working with people living with HIV.

*"When I went for my liver biopsy, it's kind of funny, cause I was laying there and I'm telling the doctor, you know, I don't just have Hep, I have HIV . And the nurse, she's like, to the doctor, 'Did you want to wear two pairs of gloves?' and the doctor was like, 'Leave the room' type thing. But the nurse was a little bit freaked out because I said that."*

*"When I went for a hearing aid just three months ago, I didn't know where to go, but I seen this ad on TV. So I went there and there was a guy just before me that was being looked at and everything. When you have the form to fill out , if you have a disease you have to put it on. And here I am watching him testing the other guy. So after [the nurse] reads the form, she calls [the doctor] in the back and was telling him that I was HIV blah blah blah. So, when it was time to treat me, gloves on, everything, and I said, what's he doing? So I looked at him and said see you later. I went to another place, and it was no problem. But, that's because the public is uninformed...He wasn't wearing gloves for the other guy, and that's what pissed me off, and that's why I said bye-bye."*

*"You can certainly tell the people in the hospital who have been around it before and are comfortable , and the ones that are just totally uncomfortable. And so you'll have someone whose been there and dealing with it who are just open hands and very aware, you know, that there's no danger of transmission through skin, that they're doing something that there's not going to be anything. And the other person putting on the face mask and the gloves and the gowns."*

**HIV Testing/ Pre and Post Test Counseling:** Although doctors are required to provide adequate pre and post test counseling for people being tested for HIV/AIDS, often this counseling is inadequate, and discriminatory.

*"I'm arranging for my permanent residence here in Canada. And you know, as part of the process you have to take medical exams...I remember when they called me from the general physician's and they asked me to go there because he needed to talk to me...And I don't want to exaggerate, the first thing that the doctor said was, 'You know what, you lied to me. You were lying.' And I'm like 'Excuse me?"*

*What do you mean?’ [and he said] ‘Yes, because you are gay and you have AIDS!’”*

*“I still hear horror stories of people being told in emerge with no one there. That’s downright frightening. Is there not a responsibility of hospitals and of just institutions to provide [pre and post test counseling]?”*

*“I went to the hospital for something totally different...and they did blood work on that, they thought maybe it was, it’s so rare that thing, they thought maybe it was really advanced stages of AIDS. So they test for that, and that’s when I found out I was positive...Yeah, they said ‘Good news and bad news.’ That’s how they told me....Actually, the nurse said, ‘You’ve got something that’s going to kill you.’ That’s how she put it, and she said ‘You’re going to have to change your lifestyle, and you’ve got something that’s going to kill you.’ And then I needed a smoke so bad, and you know the old [hospital], across the street was a 7-11. I took the bottle thing, with the hook on it, I walked right with the gown, and went to buy cigarettes. And they thought, it was right after they told me, they thought I went to snuff it. They thought I was going to kill myself. Cause I disappeared. When I came back they were happy.”*

**Consent to be tested:** Hospitals now require patients to sign forms stating that if a worker experiences a needle stick or exposure they must consent to HIV testing. There is some concern about what kind of pre and post test counseling would be accompany this testing.

*Ray: “Since we’re talking about the hospitals, how many people have noted that if you’re getting any kind of a procedure done in the hospital now there’s a consent form that you sign that says basically if the health care worker dealing with you gets a needle stick or any thing like that, that you must consent to having an HIV test?”*

*Donald: “But what about the person who is unconscious? They certainly can’t have them sign, they’re just going to do the test. Do they have them sign after and is there counseling and awareness then? Is that a defined procedure?”*

### **Responses of Service Providers:**

**Discrimination in Accessing Services:** Service providers report that people living with HIV experience discrimination when accessing services. Key issues include:

**Doctors refusing and abandoning care:** Service providers report that it is difficult to find a family doctor at all, but especially difficult to find a family doctor who is willing to take patients living with HIV, a doctor who understands HIV or a doctor who is “gay friendly.” Some service providers have lists of doctors who are willing to serve people living with HIV and so they refer their service users to those doctors. Some service providers counsel people not to tell the receptionist at the General

Practitioners office about their HIV status until after they have been accepted as a patient because if people disclose the receptionist is likely to say that they are not accepting patients. Also, people who are generally disenfranchised have less access to General Practitioners and may have no health number so are limited in the services they can access. One service provider accompanied a person living with HIV to their appointment with the GP, and when they GP found out the person's HIV status their attitude changed and the GP stated that they "didn't have time" to provide the person with service. One service provider stated that the doctor at the HIV clinic is now willing to act as a family doctor, but if it were not for her many people would not have a family doctor at all.

### **Dentists Refusing and Abandoning Care:**

- Service providers report that many people living with HIV are refused care by dentists.
- Service providers report that there is only one dentist in Calgary registered on the list of dentists willing to serve people living with HIV.
- Service providers report that many service users do not have any problems getting dental care because the service providers refer them all to the dental clinic at the Foothills Hospital where the one dentist on the list works.
- Service providers report that it is difficult to get to the Foothills Hospital, it is hard to get parking there and that it is stigmatizing to receive dental care there, partly because people may be asked questions about why they go there for their dental care rather than to a regular dentist. This can also risk disclosing the person's HIV status.
- Service providers report that people sometimes have a dentist for ten years but once the person is diagnosed with HIV the dentist will refuse to treat them, which is known as "abandonment of care."
- Service providers report that in some cases people have shown up at the dental clinic with a crown in their hand because another dentist had refused to cement the crown in after the person disclosed their HIV status to them. In a case like this "the science goes out the window" because once the tooth is cut and prepared, the impression is taken and the crown is made, the cementing of the tooth "is no big deal". According to service providers, dentists use universal precautions, so the discrimination is not based on the science of situations, it is based on the social issues.
- Service providers report that they hear stories about people being refused care or having their long term dentists abandon their care, but once people find a dentist who is willing to serve them they usually do not lodge a complaint because they are just happy to access the service they need.
- Service providers report that fear of being refused care can lead people living with HIV not to disclose their HIV status to their dentist because they have a tooth ache and they do not want to risk the refusal of care.
- Service providers report that a dentist made a child living with HIV wait until the end of the day for his appointment so that the child could be the last patient of the day due to his HIV status.

- Service providers report that dentists may discriminate based on sexual orientation, fear of contagion, dentists and staff being afraid of becoming infected with HIV by the patient, fear of cross contamination, not being confident about sterilization techniques and being worried that another patient may become infected with HIV.
- Service providers report that dentists often tell patients that they “don’t have the right kind of equipment in this office to treat you” and instead refer them to the Foothills clinic. However, there is actually no “special equipment” required to treat people living with HIV.
- Service providers report that dentists say “It’s not that I’m uncomfortable with seeing “those people”, it’s my hygienist.”
- Service providers report that dentist say “You have a medical condition that I don’t know how to treat, you need to go somewhere they are more comfortable treating this condition.” However, according to service providers, the Alberta Dental Association and College does not accept this as a good enough reason to refuse care. According to service providers, this is a “double edged sword” because there are in fact some oral manifestations of HIV that you need know how to deal with and identify when working with people living with HIV, but if dentists are afraid of people taking legal action against them for refusing their care in the long run that could compromise the quality of care people receive because most dentists do not receive specialized training regarding these oral manifestations. Service providers suggest that ideally people living with HIV could go to a regular dentists for basic care (cleanings and fillings) and to the specialized HIV dental clinic every 6 months to look for oral manifestations. This is currently the model of care many people living with HIV are using, but their regular dentists may not be aware of it.
- Service providers report that dentists living with HIV also encounter problems. A staff member at one dentist’s clinic took out an ad in the paper advertising the dentist’s HIV status, and another dentist was dropped by his liability insurance company.
- One dentist proudly told a service provider that he had found out that his patient was gay and had kicked the patient out of his practice.
- People living with HIV who live outside of Calgary must travel, at the own expense, to Calgary to access dental service.

**Receiving different care due to Injection Drug Use:** Service providers report that in cases where a person living with HIV is prescribed morphine for pain control, they may choose to inject it because the pain medications are inadequate (e.g. when using twelve hour slow release morphine people experience a window of pain between doses for about two hours). When the doctor sees the person’s track marks they may cut them off the pain medication because they are afraid they are feeding the person’s addiction. The result is that someone who needs pain medication is denied adequate medication. [note: it would be better if people were given oral fast acting morphine to fill this window, rather than having to inject the morphine, because the wax and filler in the morphine can cause vein problems]. Service providers also report that injection

drug users are often labeled “non-compliant” in taking their medications due to their drug use and disorganized lives. While in some cases people are non-compliant, in other cases people are stable enough (e.g. some people who use morphine) to be taking HIV medications compliantly. The result is that some people who are stable enough to receive HIV treatment are denied this treatment due to injection drug use. One service provider reported that health care providers may assume that “drug seeking” is the only reason that people who use injection drugs seek health care, therefore when people attempt to access hospital/ emergency services they may not be cared for properly. This service provider felt that although people do sometimes drug seek in the emergency room, it is usually too long a wait and it is easier to “turn a trick.” One service provider reported a case in which a man who was HIV positive was also a former “morphine addict”. Due to this former addiction, in the end stages of his life he required very high doses of pain medication. The service provider reported that it was difficult to find a doctor who was willing to prescribe this medication and summed up the situation as being “a question of dignity versus drug addiction, which is more important?” In contrast, another service provider stated that it was difficult to know what constitutes discrimination in cases where someone is drunk or stoned and trying to access services or when they are in fact drug seeking and selling drugs on the street. According to this service provider, people living with HIV need a good family doctor to prescribe pain medications because hospitals will discriminate against them.

**Communicable Disease Control:** Service providers report that after being contacted through contact tracing people are sometimes afraid to go to the Communicable Disease Control office because they are afraid their employer may see them and they fear they might be fired (especially when they work for the City or Calgary Transit who share physical space with the CDC). In order to preserve people’s confidentiality, the CDC can meet people in the third party location or talk to people over the phone on a secure line. The CDC also does outreach with people on the street and will go to people’s homes to provide services.

**HIV Clinics:** Service providers report that HIV clinics have limited hours (no early morning or evening access). According to service providers, if people’s lives fit the schedule of medical clinic then they get health care. But if a person can’t change their life to fit clinic hours they don’t get care [e.g. if someone’s job is not flexible, and they can’t get time off work to visit the doctor during clinic hours, they can’t access care/treatment]. Service providers also report that there are no HIV services available outside of Calgary and Edmonton which means that people from other cities/towns/rural areas must travel to these centers at their own expense to receive treatment or to do blood work.

**Receiving different care due to being an Aboriginal person:** Service providers report that health care providers may assume that Aboriginal people have addictions and will not prescribe pain medications for them.

**Hospitals:** Service providers report that rather than just using universal precautions, hospital staff may test people they suspect to be at risk for HIV in order to avoid putting “staff at risk”. In the past, people living with HIV were put in quarantine in hospitals and staff would refuse to feed them and instead would put people on an IV. According to service providers, people living with HIV report being discriminated by hospital staff who will not come when they ring the buzzer or who ask women intrusive questions about how they became infected with HIV. One woman living with HIV was scheduled for a surgery at 6 am and was not operated on until 6 pm because they wanted to “sterilize well” after her, despite the fact that they should be sterilizing well after everyone. According to service providers, doctors and nurses have little education about HIV and are not well educated about caring for people living with HIV. One service provider reported a breach of confidentiality wherein a patient was diagnosed with HIV at one hospital and within a day his HIV status had become known “through the grapevine” by his wife who worked at another hospital. The investigation into this breach of confidentiality led no where due to the “code of silence” adopted by the hospital staff. However, according to one service provider, when you call admitting at the hospital and tell them someone has HIV it may be easier to get them in to access services in a sort of “reverse discrimination”.

#### **HIV/AIDS Testing:**

- Service providers express concern over hospitals requiring patients to sign forms stating that if someone “comes in contact with blood” that they must consent to HIV testing. Service providers are concerned about how “informed” this consent process was, they questioned whether these forms were necessary since most people would agree to be tested in the event of an exposure and they are concerned that “comes in contact with blood” is a broad description and the consent could be used improperly to test people in circumstances that did not constitute true exposures.
- Service providers also express concern that Alberta uses an “opt out” pre-natal HIV testing system because under this system women may not receive adequate pre test counseling before they are tested. Many people report that they have been tested for HIV but were never given pre test counseling, especially when they were tested pre-natally.
- Service Providers report that doctor’s need education regarding pre and post test counseling because often people who engage in major risk activities are not tested for HIV until they are showing symptoms of AIDS defining opportunistic infections and even after people are tested doctors fail to ask what their risk factor for HIV was. According to one service provider doctors do not think asking about sex is their concern and out of negligence or a need to be educated they fail to ask these questions.
- Service providers report that in rural areas, people are reluctant to be tested for HIV or other STDs due to concerns about their confidentiality with their small communities.

- Service providers report that most people that use anonymous testing are health care providers who are fearful that there will be job implications if they test positive for HIV.
- Service providers report that people going through immigration medical exams may not be counseled about HIV or the implications of a positive test result.
- Service providers report that if they are not pregnant, even women who are presenting with AIDS may not be tested for HIV. Doctors should be aware that when people have STDs or yeast infections that should be a trigger to test them for HIV. Doctors need to look at people's behaviours, not just their appearance.
- Service providers report that many people report that they have been tested for HIV but were never given pre test counseling, especially when they were tested pre-natally.
- Service providers report that new technologies around HIV drug resistance testing (i.e. genotype and phenotype testing on strains of HIV) may be used to track transmission and could lead to targeting certain groups (e.g. barring immigration from certain countries because we do not want to introduce a new strain of HIV into our country).
- Service providers report that when people do not receive proper pre and post test counseling, they are not given information about the Criminal Code and their legal responsibility which can put people living with HIV and others at risk .One service provider suggested that defense lawyers should consider whether or not this counseling was done adequately.
- Service providers report that one person was told by their doctor that if they "prayed hard maybe their HIV would go away."
- Service providers report that one doctor was not educated about HIV, and diagnosed a person, told them they had AIDS and they did not have long to live, but did not realize that the person had really just seroconverted.
- Service providers report that the "post test counseling" one person received consisted of the doctor telling the person they were HIV positive and giving them the phone number for the HIV clinic.

### **Other General Concerns in Services:**

#### **Responses of People Living with HIV/AIDS:**

### **Other General Concerns in Services:**

- Ambulance Service: One person had a bad drug interaction and called an ambulance. When the ambulance came the ambulance attendant commented to the person's friend that he was getting "another free ride to the hospital".
- Police: People report concerns over whether or not the police can access your health information.
- Medications: People report concerns over list of medications covered by the province. This list is limited and doesn't include a lot of medications people living

with HIV require. Also, if someone's primary diagnosis is HIV, they may not qualify for other medications (e.g. cancer meds).

- Transit Policy: People report concerns with transit police. One person reported being harassed and discriminated against by them.
- Medial: People report concerns regarding the publication of personal information.

*"They did put my picture and my name in the paper with a phone number to contact if I was seen...because the health board was looking for me because I had HIV."*

- Mothers: People report concerns regarding the way mothers living with HIV are viewed and the implication that has for their children.

*"So I spent my whole maternity time in the hospital, but when I had the baby they took it, and then they said that I might as well give the baby up for adoption, I'm going to die in five years anyway. And I said no, I want to make sure she's going to be ok, because we didn't know if she was going to be healthy or not, and they have to do a mandatory of three tests which concludes like 6 months into her life, and then I went to visit her every, like 3 times a week I had to go there to visit her, and they kept on putting me down, putting me down, 'Your not going to live long enough to see her go to school, to get her in her first grade, we got a family that's healthy, that's going to be able to take care of her.' So that way, I lost a child because of discrimination and I seriously believe that."*

### **Responses of Service Providers:**

#### **Other General Concerns in Services:**

- Service providers report that people with higher socioeconomic status have greater access to information about clinical trials and opportunities to participate in them.
- Service providers report that people who have been treated negatively when accessing health services say they can access medications faster on the street, or they will only access services specifically targeted at their population (e.g. Safeworks) because the staff are aware of the diverse needs of the service users, or people avoid accessing medical services at all because they want to avoid having another negative experience.
- Service providers report that a man attended a church service and people were friendly towards him, but after he disclosed his HIV status the next week no one would talk to him.
- Service providers report that it is difficult for service organizations to control their volunteers and ensure their volunteers maintain the confidentiality of their service users.
- Service providers report that people who are prescribed morphine for pain management may be harassed by the police if they see drug paraphernalia in their homes, if they see track marks, or if the person purchases morphine beyond what they are prescribed.

- Service providers report that qualifying for Alberta Health can be difficult because some people are transient, they cannot afford to pay for it, they don't have a T4 so they cannot get a subsidy and they are afraid of getting a bill, they lose their card and they are afraid of getting a bill, and if a person admits to making money in the sex trade they may not qualify for a subsidy.
- Service providers report that there are issues regarding the informed consent people give when participating in drug trials.
- Service providers report that if people have a right to the best health care possible, then they should have access to creative service delivery like directly observed therapy (DOT) for HAART which supports people who use injection drugs to take HIV medications by keeping the medications on site, having people drop in to take them and providing people with specific food to maximize their diet.
- Service providers report that health services do not actively pursue treating people who use drugs, but these same people need to have multiple visits before they make changes in their lives, which means that if service providers do not follow up with them after their first visit they may not get care.
- Service providers report that programs may not be funded/ supported when they work with certain populations (e.g. men who have sex with men)
- Service providers report that in one case of assault, the police refused to investigate because of the sexual orientation of the person assaulted. The service provider had to advocate for the service user in order to get the situation investigated.
- Service providers report that people with physical/mental disabilities may not be seen as "worth the effort" to provide appropriate services (e.g. educational upgrades).
- Service providers report that people living with HIV who have mental health issues may not be able to access mental health services because their primary diagnosis is HIV.
- Service providers report that addiction services require that people are not actively using in order to access their services, but if a person is sober then they may not need that service.
- Service providers report that youth who go to clinics to access the morning after pill or due to casual sex encounters are often not offered HIV testing.
- Service providers report that a hepatitis C positive woman was kicked out of a swimming pool.
- Service providers report that corrections would like to know who is HIV positive so that they can lock them in their own cell and so that staff can protect themselves rather than using universal precautions.
- Service providers report that corrections guards put people who ask for condoms in segregation, they may assume the person is HIV positive or refuse to give out the condoms at all.

**Issues for Children living with HIV:**

- Service providers report that a school for special needs children refused to take an HIV positive child due to that child's HIV status. According to the school, they "didn't know how to keep [the child] safe."

- Service providers report that a day care refused a child living with HIV service.
- Service providers report that an in home care giver wore gloves when working with an HIV positive child, despite the fact that other care givers never wore gloves to do the same tasks.
- Service providers report that an eye doctor said a child living with HIV must wait until the end of the day so the child could be the last patient due to the child's HIV status.
- Service providers report that there are no support services available for foster parents who are fostering HIV positive children.
- Service providers report that a dentist made a child living with HIV wait until the end of the day for his appointment so that the child could be the last patient of the day due to his HIV status.

#### **Public Health System:**

- Service providers report that it is better to give an isolation order through public health than to go through criminal system and put someone in jail where they could potentially infect others.
- Service providers report that there is no advocate or appeals process built into the public health act.
- Service providers report that women in other health regions have been told that they have violated the public health act by getting pregnant. This has made women fearful to access services and has risked losing them to care which would have a negative impact on their babies.

### **Immigration/ Travel:**

#### **Responses of People Living with HIV/AIDS:**

Issues related to human rights and immigration were discussed by people living with HIV/AIDS during the focus groups. Key issues include inadequate pre and post test counseling for immigration medical exams, discrimination in immigration and barriers to international travel. Only one focus group participant had recently immigrated to Canada.

- **Inadequate Pre Test Counseling:** People applying to immigrate may not be aware they are undergoing testing for HIV during their medical exam due to inadequate pre test counseling.

*“They just took your blood and that was all. Actually, they don't, you know, that's something that I find very bad, they don't really let you know anything. They give you a manual, and its just like 10 pages you have to read, thank god I understand a little bit of English, because they don't even give you, they don't ask if you need a translation. Nothing at all. It was like, this is the kit you have to follow, bring the papers, and good luck. And they don't even specify what kind of medical tests you need, they just send you to the doctor and he doesn't even tell you anything.”*

- **Test Results not Communicated:** Once immigration applicants undergo medical exams, they may not be informed of the results of those exams.

*“Like a month ago they asked me to get tests for hepatitis. And I don’t know if I have it or not because they will never let me know, because they send the results to immigration, they don’t give you any kind of results to you, and if I am hepatitis or not, I will never know it, unless they talk to me again and let me know that way.”*

- **Inadequate Post Test Counseling/ Discrimination:** People applying to immigrate may not receive proper post test counseling when they test positive for HIV. The way they are informed of their status can also take a highly discriminatory form:

*“I’m arranging for my permanent residence here in Canada. And you know, as part of the process you have to take medical exams...I remember when they called me from the general physician’s and they asked me to go there because he needed to talk to me...And I don’t want to exaggerate, the first thing that the doctor said was, ‘You know what, you lied to me. You were lying.’ And I’m like ‘Excuse me? What do you mean?’ [and he said] ‘Yes, because you are gay and you have AIDS!’”*

- **Barriers to Travel:** People living with HIV are prohibited from entering the United States. Customs may use HIV medications to identify that people are HIV positive and, based on this, people may be barred from the US for life.

*Rick: “That’s the law of the states, if you’re HIV+ and you come from another country, they will not let you into the country.”*

*Stan: “Not even if you wear a condom at the border?”*

*“To be honest with you, I’m absolutely terrified to even attempt it [crossing the US border].”*

*“I would love to go to the states for a visit, but if they catch you with your drugs, so then that means you have to go off of your drugs.”*

*“Remember that time me and you went [to the US], and they turned us back when they found our drugs...and they said don’t ever try to get into the States.”*

*“I was going for my dual citizenship, and I stopped right when it said test for HIV, and I knew I wouldn’t get it...My dad’s American, so I was going for my dual because the company I was working for wanted to set up an office in Texas, and wanted me to work down there.”*

## **Responses of Service Providers:**

Issues related to human rights and immigration were discussed by service providers during the interviews. Key issues included fear of disclosure, barriers to accessing services and barriers in immigration system. None of the service providers interviewed worked in organizations specifically serving immigrant/ ethnocultural communities, but many had clients who belonged to these communities.

### **Fear of Disclosure:**

- Service providers report that members of small refugee/immigrant/ethnocultural communities often live in fear that someone in the community will find out their HIV status. People may bring the social stigma around HIV from their home countries, and fear being ostracized if their HIV status is found out. People living with HIV do experience discrimination within their communities.
- Service providers report that women from ethnocultural communities who use interpreters are worried their medical info won't be kept confidential.
- Service providers report that it is difficult to have a relationship with someone in a small ethnocultural community. People fear that if they disclose their HIV status to someone that person may tell other people and the whole community will find out.

### **Barriers to Accessing Services:**

- Service providers report that immigrants from some ethnocultural communities don't access traditional services very willingly (i.e. don't come to AIDS Calgary very often, don't feel comfortable, have concerns about confidentiality).
- Service providers report that local AIDS Service Organizations need to make services as accessible as possible, reach out to ethnocultural communities and provide totally confidential service.
- Service providers report that the immigration process is slow and during this process people may have no official immigration status and often have no access to services (e.g. health services).
- Service providers report that people who are federally sponsored refugees are sponsored in terms of getting a drivers license, ID, and a place to stay, but they don't get a medical assessment. They are often not tested for HIV and therefore do not get access to the services they need.
- Service providers report that there are language barriers to accessing services.
- Service providers report that people don't know how Canadian systems work and this poses a barrier to accessing services/ testing. [e.g., a pregnant woman who didn't speak English had syphilis, but she didn't know that we had a treatment to cure it. She was also HIV positive but didn't know it. If she had known about her

HIV status earlier, she may have made different decisions regarding her pregnancy.]

- Service providers report that refugees/ immigrants may come from countries where the government is the enemy and people in authority are dealt with with suspicion, and this may discourage people from asking questions/accessing services.

### **Barriers in Immigration System:**

- Service providers report that there are barriers to getting a visa for a spouse living with HIV in another country so that they can join their partner in Canada. Spouses may be denied immigration into Canada due to HIV status.
- Service providers report that visitors to Canada may be tested for HIV. [e.g. a man wanted to bring his mother to Canada from Nigeria for his wedding but there was a huge delay because she had to be tested for HIV].

### **Insurance:**

#### **Responses of People Living with HIV/AIDS:**

Issues related to human rights and insurance were discussed by people living with HIV/AIDS during the focus groups. Key issues include refusal to insure, confusion regarding insurance coverage and gaps in ability to be insured.

- **Refusal to Insure:** Insurance companies can legally refuse to provide insurance to people living with HIV.

*“Well, you can be denied health insurance on the basis of HIV...That’s discrimination isn’t it?”*

*“Another discrimination they have in Alberta, actually, its in Canada, is insurance companies are not allowed to insure anyone who is HIV or anyone with a preexisting medical condition, so your medical status is based as preexisting conditions. So, if you’re going to go get your very first HIV test, before you do that, you go get your house insurance, car insurance, your employment disability insurance, your insurance that if you can’t work they’ll pay for your car payments. Because if you don’t do that prior to your test, you’re screwed because you won’t get nothing, but if you do it before, you can buy life insurance, car insurance, any insurance you want, before you get that first test. So, people should know, are you going to get yourself tested for HIV, if you are, you have to do all this first, because you cannot go get life insurance after you find out. Because once they find out when you got your diagnosis back, its null and void.”*

- **Confusion Regarding Insurance Coverage:** Due to having a “preexisting condition,” people living with HIV are concerned that their workplace insurance plans may not provide coverage in the event of their illness.

*“I do get health insurance through my employer, and I don’t think that was actually, I don’t remember filling out forms for them. It’s a group plan so in that case they’re not so concerned about the individual. And even the same with life insurance coverage through your company, up to a certain limit, I think its 20 thousand dollars or something worth of coverage, you don’t have to fill out forms and such. But I wonder if you tried to collect on that, or if my partner tried to collect on that after I died, and they found out that I had died of HIV, would they void the insurance anyway. I don’t know.”*

*“Ok, you have to join a company’s insurance program but if you have a preexisting condition, you’re now exempt, even though you have to pay for it. A lot of companies do that where you have to, after a certain period of time, you have to go on this, because part of that program is you get some dental or whatever, basic dental, but in the life insurance or whatever if you have a preexisting condition its null and void. Which is fine when you’re healthy, but once you start to get sick, does the preexisting come into place for long term and short term disability, how does it affect that?”*

- **Insurance Gap:** People are not sure where they can get insurance. People may not be able to access certain kinds of insurance (e.g. mortgage insurance).

*“Are there federally or provincially funded insurance companies that people like us can get insurance from, that would be able to fund insurance for people with illnesses like ours?”*

*“Something that I came across as far as discrimination for myself, it happened several years ago, I purchased a house back in the early 90s before I was positive, and at that time I got life insurance for myself on the house that I had bought. And a few years down the road afterwards, my partner contracted, I contracted HIV and when I went to rewrite my mortgage because of a financial mess I found myself in, because of my partner getting sick and ending up in a hospice and things like that, I was left with a financial debt load, I had to do some restructuring. And I’d found out that because I had to disclose that I was HIV positive at that time, that they weren’t going to give me any life insurance whatsoever, and they were going to cut me right from that, which kind of was a bit of a, took me back a bit. I’m not too sure how it worked in their policy, but I did get a letter back stating that they would cover the percentage of what I had on the house prior to disclosing that I had HIV or contracting HIV but anything after that, no. So lets say I had a \$100,000 mortgage, and lets say I paid it down to \$50,000 and then I was topping it up to another \$100,000 when I restructured, they would cover the lower 50, but not the upper 50 that I was going to be having to refinance, and that was their policy.”*

*“If you buy a car there’s a disability section in the insurance that if you get sick, they pay the car payments. That portion, if they know you have this before you get the insurance, your not covered under that.”*

### **Responses of Service Providers:**

Issues related to human rights and insurance were discussed by service providers during the interviews. Key issues include:

- **Fear of Disclosure:** Service providers report that some people who have STDs will pay for their medications out of pocket instead of going through their insurance in order to avoid the possibility that their employer will find out that they have an STD.
- **Filling in Forms:** Service providers report that when employers have group insurance plans there is some pressure on employees to fill out forms asking about their HIV status, but that, due to their HIV status, the employees know that they will not qualify for the insurance. There is some confusion about whether or not people should fill out these forms, and whether this could affect their employment. One service provider suggested that an employee just tell the insurance company that his doctor said he would not qualify for the insurance and that he should not fill out the forms.
- **Getting Job Conditional on Qualifying for Insurance:** Service providers report that passing a group life insurance medical exam is a condition for some employment. In one case a service provider reported that a man did not pass his medical due to his preexisting condition (HIV) and he lost his job because his employment was conditional based on qualifying for the insurance.
- **Human Resource Gatekeepers:** Service providers observe that within the workplace human resource gatekeepers (e.g. secretaries) hold information about long and short-term disability programs. In order to get this information, employees must request the forms and the fact that they requested these forms can become known within the office. In order to avoid this, employees can request forms directly from the union or insurance company. However, people worry that once filled out, these forms may not be sent directly from the doctor to the insurance company. Instead, forms may be sent through human resource so they can “sign off” on them, and, as a result, sensitive health information can be very difficult to keep confidential.

## Income Support:

### Responses of People Living with HIV/AIDS:

Issues related to human rights and income support were discussed by people living with HIV/AIDS during the focus groups. Key issues included problems with application for and administration of benefits, inadequate benefit levels, inflexible benefit programs and return to work issues.

- **Ineligibility/ Appeals:** People living with HIV may be denied AISH [Assured Income for the Severely Handicapped] benefits and required to appeal their applications.

*“I was having my interview with my AISH intake worker, and he says to me, he says ‘Well everything looks in order’, because I was going on the permanent disability, and he says you have all the qualifications, and he says “Yes, one of the qualifications is that you are terminally ill’, and he says and ‘Yes, you know that HIV will claim your life.’ And I sat there and I started to cry, and he says, ‘Well you should know that by now, you should be used to that by now.’...But that’s an interesting thing. It’s all very silly. The whole thing is very silly with AISH, I was denied...Because, I think they make everybody appeal, as part of the thing...Yeah, you have to appeal. And then other people said you have to appeal, they don’t usually give it to you on the first go.”*

- **Slow Application Process:** The administration of AISH is extremely slow. This slow administration can pose a barrier to people moving from province to province.

*“I moved here and I fought for 8 months before I got AISH, and they had all my files from Montreal here, all the proof, the doctors, I had to go through all that all over again. Are we in the same country, or did I skip a country here or something?”*

- **Payments Stopped during Review of Benefits:** When AISH income benefits are reviewed a person’s payments may be stopped and they may be left without an income.

*“I remember years ago when they decided to review my AISH and pension at the same time, so they stopped paying me both of them to do the reviews. It took them 8 months, so for 8 months I never got a cheque from nobody. I couldn’t even qualify for basic welfare because I was already in the AISH system. But I wasn’t receiving a cheque. So it took them 8 months to review my AISH and pension at the same time. Sure, they paid me at the end of the year, 4-5 thousand dollars. But I mean, for 8 or 9 months, I was not getting a nickel from nowhere. The only thing that kept me going was that I was volunteering at the soup kitchen so I got food and everything, but I wasn’t getting any money.”*

- **Limited Quality of Life:** AISH benefits are inadequate.

*“There’s no quality of life on AISH. They give you the barest bones to live on. After rent, bills, groceries are paid for, there’s not a hell of a lot of money left over to do anything with.”*

- **Lack of Flexibility in Programs:** The AISH system is not flexible enough to accommodate the episodic nature of HIV (i.e. the ups and downs in health status experienced by people).

*“I don’t know if its unfair, but [AISH is] certainly an inflexible system in terms of accommodating the realities of HIV. Because with HIV, the truth is, one day you’re feeling fine, and you’re capable of doing an 8 hour day. And the next day you crash, it’s a whole roller coaster, and there may be days on end where you’re not well enough to work. And AISH doesn’t accommodate that, you’re either a sick person or a healthy person, and if you’re a healthy person you don’t qualify for AISH. So there’s no gray area, there’s no middle ground for AISH. Because even if you could qualify for partial support or something and still get the health benefits and the optical plan and all that stuff that most of us otherwise don’t have access to, that would be a real boon to people with HIV.”*

- **HIV seen as Physical not Psychological:** Income support programs may assess whether you are physically able to return to work, but ignore whether you are psychologically prepared to return to work.

*“The very systems don’t recognize it, the psychological aspect of it is just as debilitating, sometimes more, than the actual physical manifestations.”*

- **Barriers to Returning to Work:** Low limits on income exemptions, the fear of losing access to medical benefits and policy restrictions for collecting long term disability benefits may all pose a barrier for people to return to work.

*“This has been brought up time and time and time again...where they say It’s pointless for us to go try to find a job because we get dinged so much money if we’re working say 20 hours, and then all of a sudden we can only make \$200 dollars extra a month, then they start taking 75 cents on the dollar. That’s not really an incentive for us to go back to work.”*

*“My pension’s within 20 bucks of my AISH limit, so if I go back to work, that’s it. For six months, increase my pension by 20 bucks, I would no longer qualify for AISH and I would have to live on my pension which would mean I would have no medical coverage. I would have to pay for all my meds and everything else, so for me, there’s no advantage to going back to work. I may make extra money for 6 months, but at the end of those 6 months, you’re going to be stuck on \$900 bucks*

*a month, but you'll have no home care, you'll have to pay for your own meds, the whole 9 yards."*

*"For a lot of the larger companies, like I worked for a...company, what happens when you go back to work they have to start the benefits all over again. So that, I worked for that company for 12 years, but if I go back to work now, they start my benefits all over again. So, like all they have to do really is to find another reason to get rid of me and I'm stuck with nothing."*

### **Responses of Service Providers:**

Issues related to human rights and income support were discussed by service providers during the interviews. Key issues include:

- **Slow Application Process:** Service providers report that the administration of AISH is extremely slow, it can take up to 14 months to go through the application process.
- **Transgendered issues:** Service providers report that transgendered people face many barriers to employment due to being transgendered but they are viewed as "able bodied" and as a result have difficulty accessing income supports.
- **Issues for People Who Inject drug users:** Service providers report that people who inject drugs do not qualify easily for income supports. They also report that because other people living with HIV are able to take medications and maintain employment, income benefit programs expect people who inject drugs should be able to do the same.
- **Limited Quality of Life:** Service providers report that AISH benefit levels are inadequate, alternative therapies are not covered by AISH, people must advocate to maintain benefits and people may be forced into uncomfortable living arrangements (i.e. staying in an abusive relationship) because they cannot afford to live on their own and they believe a roommate would be afraid of contracting HIV.
- **Barriers to Returning to Work:** Service providers report that people are reluctant to return to work because they do not want to lose their disability benefits. According to service providers, when people return to work their AISH file remains open for a year, but after that time passes it is a long wait to get back on the benefits. Likewise, while people are on AISH their medications are covered but if they return to work they worry that their medications will not be covered by their new employer and/or have concerns about their privacy. According to service providers, systems need to be more flexible to accommodate people working part time.

- **Bridging Gaps:** Service providers report that they can advocate (by writing letters) on behalf of service users to help people get temporary support between the end of their employment and the start of their disability benefits.

## **Aboriginal Issues:**

**Responses of People Living with HIV:** Aboriginal issues were not discussed during the focus groups with people living with HIV.

### **Responses of Service Providers:**

- Service providers report that aboriginal people who are HIV positive experience double discrimination.
- Service providers report that it is difficult to maintain confidentiality within aboriginal communities because “everybody knows everything.”
- Service providers report that aboriginal people may be asked to leave their community based on their HIV status, which can lead to losing their support system and their extended family. Likewise, their families may be marginalized within the community.
- Service providers report that health care providers may assume that aboriginal people have addictions and may not give them pain medications.
- Service providers report that two spirited people may be discriminated against, and if they are also HIV positive they may be not be accepted in the aboriginal or gay communities.
- Service providers report that aboriginal youth will not access health care or buy condoms on the reserve.
- Service providers report that transportation from reserves is a barrier to testing
- Service providers report that aboriginal people must sign a consent form to release their medical information in order to be reimbursed by Health Canada for their prescription costs. This is a barrier for people who cannot afford to pay for medications up front and is a violation of treaty rights that say the government will pay for their medical costs.
- Service providers report that in employment discrimination is subtle because aboriginal people just do not get hired.
- Service providers report that the racism experienced by aboriginal people when accessing health services makes people reluctant to access health services which has a negative impact on their health.

## **Taking Action on Discrimination:**

### **People Living with HIV/AIDS:**

Issues related to human rights and the challenges of dealing with human rights issues were discussed by people living with HIV/AIDS during the focus groups. The key issues discussed centred on the large number of barriers and challenges people have faced in trying to deal with human rights issues. These issues included:

- **Keeping Quiet:** Even when people are aware of their rights, they may choose not to take any action when they are discriminated against because they believe it may make the situation worse.

*Researcher: "Do you feel pretty confident in most situations that you know what your rights are?"*

*Lenny: "Yeah, I did, but you just shut up about it and don't talk about it, and if you do, it's going to bite you."*

- **Keeping Quiet, Going Elsewhere:** A combination of issues, like believing a complaint will not make a difference, not wanting to cause trouble, and being able to access services elsewhere, can pose a barrier to lodging an official complaint.

*"I got diagnosed with colitis, about two years ago, and the gastrologist was good and he sent me to a follow up doctor, just a GP, and he was... just an asshole. I can't remember what he said, but he just said 'I'm not going to treat you.' And I said, 'I was recommended, this other doctor recommended you' And this and that. But yeah, I slammed the door and walked out. I was pretty mad. But it was definite discrimination. Not without, saying outright but I knew, 'I don't treat you people'...My doctor at [the HIV clinic] wanted me to call some panel or something that looks after that, just to file a complaint, but I never did...She said it probably wouldn't make and difference, but she said if enough people complained about that, if he's had other problems with patients before, they probably would do something. I don't know. I don't like to cause trouble right, just find another doctor."*

- **Writing Letters, Getting Referrals:** Even when people choose to file a complaint, the process may not be effective or successful.

*"Anyway, I never did get [dental] care that day. This was a long time ago, so I don't remember all the details. But I do remember writing a number of letters to the hygienist association, the Alberta dental association, but I didn't get much response from any of it. Eventually I was referred, I think through AIDS Calgary, to [another dentist]."*

- **Feeling Empowered:** Due to the introduction of antiretroviral treatment, the length and quality of life for people living with HIV has been dramatically improved. This has had an impact on how people view human rights issues:

*"If I can interject, that the face of HIV has changed so much in the last 15 to 20 years, that like you said, the individual that was diagnosed back in 85, it was an automatic death sentence, and there was so much stigma around that that it seemed like you had so little time, why fight for anything. But now, it's a lot different. People are more empowered. I even feel more empowered myself today"*

*that I would fight more in a position, if I was being challenged as far as my status or whatever, through work, where I wouldn't before."*

- **Not knowing rights:** People may be unsure about whether something is really against the law.

*"I think people not knowing their rights puts them at risk. They allow themselves to be vulnerable and exploited. So if people know their rights they're probably going to be in a position where they are going to challenge and say 'no, I don't have to', or 'I'm more aware, I'm choosing not to.' They suddenly have options and they discover how to deal with a situation, turn it around, or just survive it in a better fashion."*

- **Not Thinking in terms of Rights:** People may not think about their human rights or the options they have to complain.

*"I probably have never really thought about the fact that I have human rights issues, that I have been discriminated against, and that I have just kind of choked it back and that's kind of the way life is, and not really realized that no, I don't have to take that, there is resources, I don't have to put up with that bullshit."*

- **Discrimination is Subtle:** When discrimination is indirect it may not seem like it is really discrimination.

*"It's just like when the employer found out [your HIV status] he'd send you on time off and then say sorry, we don't have any work right now, don't bother coming back right now. They don't say, 'you have HIV we don't want you there.' Nobody is that silly. Even the last job I was on, they knew I was taking all kinds of pills, and as far as I disclosed to them it was diabetes, but they probably didn't want some pill popper [working for them]...I think the fact that you're taking all those pills makes them wonder...I'm sure as far as direct discrimination there really isn't anything there. I ask for a record of employment and they say shortage of work, but they hired two new guys."*

- **Fear:** People are afraid of standing up for themselves because they may lose even more or be discriminated against further.

*"I think that one of the biggest challenges you face though...is that [people living with HIV] are so fear based that they're not even going to stand up for their rights because 'I don't want to lose what I have. I may lose something, but if I stand up for my rights, I'm going to lose even more.'"*

*"The barrier for me is exposing myself to risk. The risk of discrimination. The risk of rejection. We've all experienced so much of that in our*

*lives...When you go to challenge something you just risk further rejection.”*

- **Lack of Energy:** People may have no energy left to invest in a complaints process.

*“Not to mention the energy it takes, and a lot of us are compromised that way, about our available resources to undertake that kind of challenge. You know, to lodge a full blown human rights complaint takes an amazing amount of energy for well people, let alone for people facing HIV.”*

- **Burden of Proof:** People are concerned they may not be able to “prove” that they were discriminated against.

*“But do you have to have something in writing to back you up? If they say, ‘we won’t rent to you because...’ [you should] say ‘can I have that in writing please’, because it’s your word against them.”*

- **Hindsight:** People may not realize something is discrimination while it is actually happening, they may only realize that afterwards.

*“I think that’s most often the case, you don’t realize the discrimination while it’s happening, its not until well after the fact when you can reflect on it that it’s like, wait a minute!”*

- **Being used to Discrimination:** People may be so used to discrimination it seems like just a regular part of life, they may feel numb about discrimination.

*“I think for me, discrimination is something I am so bloody used to, its so much a part of my being on the planet, that I’m almost numb about the whole topic. It’s just been what I’ve walked with my whole life, so that fact that I was HIV positive, I was already so laden with discrimination that it’s like, oh, big deal. I’m quite numb about the whole issue”*

- **Self Esteem:** Having low self esteem/ internalized stigma can be a barrier to addressing discrimination.

*“Once you’re defeated by the family, by the friends, it makes you weaker when it comes to fighting for your rights as far as employment or out on the street. Because when it’s so close to home that you don’t have value, that you’re an abomination and all these things, it weakens the soul as far as being able to deal with the outside issues”.*

- **Believing Complaint will not be Effective:** People may believe that employers landlords etc. will be able to “get around” a lawsuit.

*“An employer can get rid of you, they can get around a discrimination lawsuit and everything, they just say well, they figure out something, it would never hold up.”*

- **Invisibility:** The culture of secretiveness and invisibility around HIV and sexual orientation can be a barrier to standing up for one’s rights.

*“I guess in some ways, we’re invisible. I mean, as gay men we’re an invisible minority right? So, its not like we’re black for example, and we can sort of present that face to the world and present our case on that basis. I mean, so much of it is secretive, there’s a culture of secretiveness around HIV, you know, that in itself is a barrier too.”*

- **Dehumanization:** People may not feel like they have human rights.

*“Do I even consider myself a human being, let alone human rights?”*

- **Legislation:** Sexual orientation is not listed in Alberta’s human rights legislation so the combination of being gay and HIV positive marginalizes people even more.

*“And if you look on the internet on the human rights of Alberta, you don’t see this on human rights, sexual orientation, all the others are there, but not sexual orientation, its not on there.”*

- **Fear of Police:** People may fear the police and believe that if they try to lodge a complaint with them (e.g. if they are being harassed by a member of the public) that the police will not take them seriously and that they could make things worse.

*“I’d be nervous about the risk factor, there’s a lot of fear, I don’t know if I would stand up to a cop like that. In a situation like that, I don’t know what powers they have.”*

### **Responses of Service Providers:**

Issues related to human rights and the challenges of dealing with human rights issues were discussed with service providers during the interviews. The key issues included:

- **Public Attitudes:** Service providers report that members of the general public do not know how HIV is transmitted and think it can be transmitted by kissing, touching or sharing drinking glasses. This can pose a challenge to ensuring that people are not discriminated against.
- **Lack of Knowledge about Rights:** Service providers report that they are sometimes unsure of what is legal and what is not, they do not understand the principles, the legislation, “the whole way of thinking” and “the rights-based approach.” Likewise, when issues presented do not fit into race/colour, service

providers are unsure of what to do. According to service providers, sometimes both service users and service providers may fail to identify that something is a human rights issue.

- **Lack of knowledge about resources available:** Service providers report that they do not know where to refer people, or who to call to find out, or how long it will take for people to get back to you, or what the first step of the process would be so that they could describe it to their service users (e.g. what happens when you arrive at the front desk of the Alberta Human Rights Commission?)
- **Family Issues:** Service providers report that it is difficult for people to feel confident in making a complaint when they are worried about embarrassing their family and that people may feel that if their family does not accept them (e.g. due to being HIV positive and/or gay) why would an employer be accepting?
- **Being used to Discrimination:** Service providers report that some people have been discriminated against for so long they “think it’s normal.”
- **Being involved in illegal activities:** Service providers report that when people are engaged in illegal behaviours (i.e. drug use) they may feel like they lose their rights due to their choice to participate in illegal activities.
- **Feeling Powerless:** Service providers report that people may feel powerless to deal with discrimination and they may prefer to avoid confrontation.
- **Reluctance:** Service providers report that people may be reluctant to go to the human rights commission because they do not want to “enter the system”, they think it will be “too much hassle”, or they believe they will be told “you are HIV positive and you have no rights.”
- **Internalized Stigma:** Service providers report that internalized stigma can be a barrier to filing a complaint. In one case, service providers provided 3-4 months of counseling to a service user to convince the person that they were a worthwhile individual, that their sexual orientation and behaviours did not justify the discrimination they had experienced and that it was ok to stand up for themselves before the person was ready to take the first steps to stand up for themselves.
- **Hate Crimes:** Service providers report that, in the case of people who experience hate crimes, people may not report these crimes because they are not “out” about their sexual orientation, they fear being victimized further by the police and they may be embarrassed about the circumstances under which they were assaulted (e.g. if they were assaulted by someone they met through the internet).
- **Human Rights Issues not a Priority:** Service providers report that when people are first diagnosed with HIV they may be more focused on their emotional health than on dealing with human rights issues they encounter.

- **Access to Lawyers:** Service providers report that people may not have the resources to pay for a lawyer, that they might feel intimidated by the legal aid process and that they might not qualify for legal aid (sometimes due to their illegal income being too high to qualify).
- **Language Barriers:** Service providers report that there may be a language barrier to getting assistance or filing a complaint.
- **Limited Knowledge of Human Rights Commission:** Service providers reported that once a person files a complaint with the Human Rights Commission, the Commission may be lacking the knowledge they need to carry out settlements. For example, the Commission ordered an employer to do an in-service on HIV for their employees but the Commission did not tell the employer who to contact to carry out the in-service. Instead, the company asked the person who had filed a complaint against them, who was discriminated against, to provide that information.
- **Not Complaining:** Service providers report that in some cases people do not want to “kick up a stink,” but they do want things to be done right in the future.
- **Complaining:** Service providers report that some people do file complaints. For example, service providers report that one person who worked for airline had to fight in court to keep their job (the airline claimed that due to their HIV status they would not be able to help passengers in an emergency).
- **Notes on the Dental Complaints Process:** If people complain there is an investigation (like a trial) by a peer committee connected to the dental association. The committee decides if restitution must be made (e.g. redo work, pay damages). The process gives people their “day in court”, educates the dentist and the dentists are responsible for paying for the process which gives them an incentive to avoid going before the committee.

## **RECOMMENDATIONS**

The following is a list of information and/or services requested by research participants.

### **People living with HIV/AIDS:**

#### **Human Rights Information:**

- Basic human rights information, relevant to laws in Alberta/ Canada
- Accessible human rights information (e.g. website, chat rooms, pamphlets in hospitals/ health clinics, articles in Calgary Herald).

- Specific human rights information regarding accessing health services, the rights of people who inject drugs, and rights-based information for newcomers to Canada.
- Information for potential discriminators (e.g. employers, landlords, general practitioners etc.) about the rights of people living with HIV.
- Posters about HIV and human rights, including a big logo, could be put up in bars.
- A summary report HIV and human rights in the community (based on Equality Project research).

### **Human Rights Services:**

- Train the trainer workshops to educate people living with HIV about human rights.
- A human rights worker at AIDS Calgary.
- Training for doctors and dentists regarding how to work with people who are living with HIV .
- AIDS in the workplace program to provide information to employers
- An advocate available at the hospital.
- An advocate who could approach discriminators and/or gather information from potential discriminators (e.g. an advocate could request a company's HIV/AIDS workplace policy on behalf of an employee without that employee having to come forward to make the request and risk disclosing their HIV status).
- A phone number potential discriminators can call to get more information about HIV and human rights.

### **General Information/Services**

- 1-800 number to call for HIV transmission information to reassure people, inform them about universal precautions etc.
- Education for youth about the gay community.
- Education for youth to build self-esteem.

### **Service Providers:**

#### **Human Rights Information:**

- Basic human rights information, relevant to laws in Alberta/Canada (esp. protected areas and grounds for discrimination).
- Accessible human rights information (i.e. using simple language, confidential, accessible through website, glossary of human rights terms, brochures, pamphlets, fact sheets, posters, videos, one good brochure that points people towards more information, links to Equality Project materials/services from other HIV websites).
- Real life examples of human rights violations.
- Information on immigration and human rights, with language translations.
- Information on disclosure and HIV. Who needs to know your HIV status?
- Information on what to do when you are discriminated against, basic steps to follow, detailed information about complaints processes available and the

- implications of filing a complaint (e.g. do you have to disclose your HIV status?), strategies for service providers to assist people in addressing human rights issues.
- Empowerment resources, encouraging people to stand up for rights, highlighting success stories, encouraging people to be proactive in protecting themselves from discrimination.
  - Information on using a rights based approach to address discrimination and to provide frontline services (including examples of traditional programs that have a rights-based component).
  - Pamphlets from the Alberta Human Rights Commission.
  - Information and education for potential discriminators (e.g. health professionals employers, caregivers, dentists, other service providers).
  - Comprehensive list of relevant human rights services, referral information, and contact information for key contact people to help avoid getting the run around (e.g. name and phone number of someone at the Alberta Human Rights Commission that is knowledgeable about HIV/AIDS).
  - Bill of rights for people living with HIV (there is already one for battered women).
  - Information about tenant rights and responsibilities (e.g. in case of eviction, what is tenant's responsibility and what is discrimination?).
  - Hot topics list, Info updates (like Epi updates), things to watch for regarding doing advocacy
  - Package on workplace issues, including insurance and rights in employment.
  - Materials that use an education approach with employers, rather than an adversarial approach.
  - Information on legal resources (e.g. legal aid, what kinds of cases they will take, contact information for lawyers who will work on refugee claims for an affordable rate).
  - Basic information on hate crimes.
  - Better integration of Canadian Legal Network's resources into our programming.

### Services:

- Workshops/ Training regarding human rights and complaints processes for service providers and people living with HIV/AIDS.
- One-on-one assistance for people experiencing discrimination (i.e. safe, comfortable place to talk).
- Outreach services to reach employers, landlords, housing corporations etc. in order to be proactive rather than always reacting to discrimination once it happens (suggestion: do information sessions for dentists at dental association meetings)
- Advocate at the hospital, advocacy services for people who are facing public health orders, an ombudsman who could be a liaison between individuals and the Alberta Human Rights Commission.
- In-service with the Alberta Human Rights Commission regarding human rights.
- Phone line to assist people experiencing discrimination and for service providers to call to see if something is a human rights issue.

- Legal advice/ services.
- Training component regarding HIV and human rights integrated into curriculum for social worker/ nurses.
- Group of frontline professionals at different agencies who know the steps of the human rights complaints process (i.e. people do not like to go through intermediaries, better if they can get services without going somewhere else).

**General Information/Services:**

- Education in Aboriginal community to help support people living with HIV and reduce the stigma (prevent people from feeling they must leave their communities).
- General information for the public and employers regarding HIV transmission.
- Education for funders about the importance of advocacy.
- Information to encourage gay community to feel comfortable going to the gay and lesbian community liaison officer with Calgary Police Services.

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<sup>1</sup> *Alberta Human Rights, Citizenship and Multiculturalism Act*  
<http://www.qp.gov.ab.ca/Documents/acts/H14.CFM> Note: The *Act* does not specifically list HIV/AIDS as a disability, but the *Act* has been interpreted to include HIV/AIDS under its definition of disability.

<sup>2</sup> Buffalo Trail Regional Division No. 28 Policy and Operation Manual, Personal/Sexual Harassment [www.btrd.ab.ca/documents/policies/GBEA.PDF](http://www.btrd.ab.ca/documents/policies/GBEA.PDF)