

# IN **MY** EXPERIENCE...

**Clients, advocates  
and government  
workers talk about  
HIV and provincial  
disability assistance**

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### **About the Canadian AIDS Society**

The Canadian AIDS Society (CAS) is a national coalition of over 125 community-based AIDS organizations across Canada. We are dedicated to strengthening the response to HIV/AIDS across all sectors of society, and to enriching the lives of people and communities living with HIV/AIDS.

We advocate on behalf of people and communities affected by HIV/AIDS, facilitate the development of programs, services and resources for our member groups, and provide a national framework for community-based participation in Canada's response to HIV and AIDS.

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## Executive Summary

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### The Problem

Poverty has become epidemic in the HIV community, and it is clear that some people living with HIV/AIDS (PLWHIV/AIDS) are more vulnerable to poverty than others. While the bulk of these problems lie in the policies themselves, many of the barriers that PLWHIV/AIDS face are found in how these policies are implemented. This represents the gap between how policy is written, and how it is administered in practice.

### The Impact

Flaws in the policy structure and in the administration of provincial disability assistance programs have left clients without the resources for nutritious food, safe housing, warm clothing, health services, and access to community support systems.

Reducing and preventing poverty among Canada's most marginalized and vulnerable persons will increase the physical, mental and social health of individuals, and can help reduce factors associated with new HIV infections. Addressing poverty as part of the continuum of care and illness prevention is especially important for people living with, and vulnerable to, HIV.

As a social determinant of health, living in poverty is a key factor causing Canadians to be vulnerable to HIV infection.

People diagnosed with HIV face many barriers when attempting to gain, maintain, or establish economic security.

PLWHIV/AIDS who experience poverty or economic insecurity are at risk of having their disease progress quickly, and of having a lower quality of life.

### The Project

Through discussion groups, in-person interviews and phone-based interviews, the Canadian AIDS Society was able to speak to over 74 provincial disability assistance clients, advocates in the community (most of whom volunteered or worked with an AIDS service organization) and individuals who worked in provincial disability programs (government workers) from across the provinces and territories. These stories shed light on the complexities involved in administering provincial assistance programs, and underline the "real life" barriers that traditional policy analysis has difficulty capturing.

### The Solution

Reform is needed not only for many of the policies themselves, but for the approach that is used to implement policies and manage client files as well. The goal of reform is to ensure that the needs of PLWHIV/AIDS are met, ensuring that they can continue to be as healthy as possible and maintain their independence.

While an effective reform process will combine changes to policy and program implementation, many of the solutions suggested in this report can be implemented in the short-term, with immediate results, and with no changes to legislation.

This report identifies *seven goals* and accompanying *indicators of success* for provincial governments that will improve how they administer disability assistance programs.

Goal One: Information about provincial disability assistance benefits is transparent and easily accessed by clients, advocates and government workers.

Goal Two: Provincial Disability Programs Reflect the Changing Nature of HIV Disease Management

Goal Three: Provincial Assistance Programs Communicate Effectively with All Clients

Goal Four: Clients are able to access safe and clean housing, and the nutrition, clothing, health and social supports that they need.

Goal Five: Multiple Jurisdictions, Departments and Programs Align their Goals

Goal Six: Unemployed Clients Experience the Right to Privacy, Independence and Self-Determination

Goal Seven: Strong Communication and Partnerships Between the Voluntary Sector and Provincial Governments

## Introduction: The Case For Program Reform

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Flaws in the policy structure and in the administration of provincial disability assistance programs have left clients without the resources for nutritious food, safe housing, warm clothing, health services, and access to community support systems. However, reform is needed not only for many of the policies themselves, but for the approach that is used to implement policies and manage client files as well. The goal of reform is to ensure that the needs of people living with HIV/AIDS (PLWHIV/AIDS) are met, ensuring that they can continue to be as healthy as possible and maintain their independence.

Effective reforms to provincial disability assistance should have two outcomes. The first is an assistance program that enables clients to enter, or re-enter, the workforce without jeopardising their health and risking a premature return to income support. This responds to the needs of clients who experience HIV as an episodic illness, which is characterized by having periods of good health followed by unpredictable periods of illness. The long-term impact of this policy reform is evident – fewer long-term disability assistance clients and a more active, healthy labour force.

This report, however, addresses the reforms needed to achieve the second outcome: **an assistance program that enables clients who cannot work to meet nutrition, shelter, social and health related needs necessary for long-term health and independence.** This is in response to the needs of clients who experience multiple disabilities in addition to HIV (such as Hepatitis C, drug dependencies and mental health issues) and multiple vulnerabilities (such as homelessness, street involvement, illiteracy, and/or surviving violence). The long-term impact of this program reform is a healthier population of persons with disabilities, and a more effective approach to the social, behavioural and mental health issues often associated with multiple vulnerabilities.

This consultation demonstrates that a good deal of the problems experienced by clients is not found in the policies themselves, but in how the program is implemented. These problems are rooted in stigma, discrimination, and a lack of understanding/recognition of the issues that persons with multiple vulnerabilities and multiple disabilities face.

Unlike traditional policy recommendations that require legislative changes, many of the recommendations in this document outline steps that provincial governments can take to improve services without changing legislation. While an effective reform process will combine changes to policy and program implementation, many of the solutions suggested in this report can be implemented in the short-term, with immediate results.

The Context: The Changing Social and Economic Environment of HIV

New treatment options in the 1990s have helped to extend the lives of people living with HIV, to the extent that returning to, or remaining at, work became a viable option for thousands of PLWHIV/AIDS in Canada. However, the situation was not perfect. The side effects of treatments and the progression of HIV disease made it clear that the illness had become an episodic disability. This recognition sparked a movement to respond to this new understanding of the disease, by promoting retraining and part-time and flexible employment models. The HIV/AIDS movement has built new partnerships with wage replacement programs (such as private long-term disability insurance, Canada Pension Plan -

Disability or Québec Pension Plan), and has engaged other sectors (such as rehabilitation and human resource management) in exciting projects on HIV and employment. While we are still far away from having a workforce that is prepared to completely accommodate and integrate people living with HIV/AIDS, we have already made some advancement.

Unfortunately, as more individuals with multiple disabilities and multiple vulnerabilities become infected, there is a shift in the distribution of HIV in Canada. Many of these individuals have had little or no attachment to the workforce, and have a range of social and health challenges that must be overcome before gainful employment becomes a viable option. Having not worked sufficient time to qualify for any wage-replacement programs, many of these clients will likely be on a provincial disability assistance program permanently, or at least for many years. We know through communications with local AIDS Service Organizations (ASOs) that these clients are living in poverty, are experiencing heightened stigma and discrimination, and are not meeting the most basic needs of food and shelter. Nor are they accessing the mental health, social support or health care programs required to improve and maintain good health, independence and meaningful social inclusion.

#### The Problem: Policy versus Practice

Poverty has become epidemic in the HIV community, and it is clear that some PLWHIV/AIDS are more vulnerable to poverty than others. While the bulk of these problems lie in the policies themselves, many of the barriers that PLWHIV/AIDS face are found in how these policies are implemented. This represents the gap between how policy is written, and how it is administered in practice. Some of this has been documented in recent reports on policy and legislation and wage replacement programs<sup>1</sup>. However, until now, the missing piece was an understanding of the social and economic forces driving this gap.

#### The Impact: Poverty is a Health Issue

Reducing and preventing poverty among Canada's most marginalized and vulnerable persons will increase the physical, mental and social health of individuals, and can help reduce factors associated with new HIV infections. Addressing poverty as part of the continuum of care and illness prevention is especially important for people living with, and vulnerable to, HIV.

As a social determinant of health, living in poverty is a key factor causing Canadians to be vulnerable to HIV infection.

People diagnosed with HIV face many barriers when attempting to gain, maintain, or establish economic security.

PLWHIV/AIDS who experience poverty or economic insecurity are at risk of having their disease progress quickly, and of having a lower quality of life.<sup>2</sup>

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<sup>1</sup> Support for Survival: Barriers to income security for people living with HIV/AIDS and directions for reform. Canadian HIV/AIDS Legal Network. Toronto: 2006 [www.aidslaw.ca](http://www.aidslaw.ca)

Anderson, Joan and Glen Brown. HIV and Disability Insurance in Canada: An Environmental Scan. Canadian Working Group on HIV and Rehabilitation. Toronto: 2005 [www.hivandrehab.ca](http://www.hivandrehab.ca)

<sup>2</sup> Chapman, Ainsley. HIV and Poverty Information Sheet Series. Canadian AIDS Society. Ottawa: 2004 [www.hivandpoverty.ca](http://www.hivandpoverty.ca)

## How did the Canadian AIDS Society Document this Issue?

### Bringing “Voice and Experience” to these Issues

By capturing the voices of the individuals at the heart of these policy discussions, the Canadian AIDS Society (CAS) is bringing a new dimension to the national dialogue. These stories shed light on the complexities involved in administering provincial assistance programs, and underline the “real life” barriers that traditional policy analysis has difficulty capturing.

### Interviewing Clients, Advocates and Government Workers

Through discussion groups, in-person interviews and phone-based interviews, we were able to speak to over 74 provincial disability assistance clients, advocates in the community (most of whom volunteered or worked with an AIDS Service Organization) and individuals who worked in provincial disability programs (government workers) from across the provinces and territories. The overwhelming interest in the project and response to our requests illustrated how much people want, and need to talk about these issues.

When summarising the consultation, this report refers to the following groups:

**Clients:** Individuals who are living with HIV and who are clients of a public income support program.

**Advocates:** Individuals who advocate with or on behalf of a disability assistance client. Some of these individuals are employed or volunteer with an AIDS Service Organization, or community-based organizations addressing other disabilities. Some are family or friends that have advocated with disability assistance clients.

**Government Workers:** Individuals who administer or develop policy for a provincial disability assistance program.

### Limitations of this Consultation

This consultation process included a wide range of individuals and experiences, taking care to include: women; men; youth; parents; active and former substance users; active and former sex workers; clients who have experienced recent periods of incarceration; clients who are healthy and who are sick; clients from various ethnocultural and aboriginal communities, clients who have recently immigrated to Canada as well as immigrants who have been in Canada for many years; urban and rural communities; English and French-speaking clients (in the language of their choice); unemployed clients (some who want to return to work and some who do not); and clients who have had negative and positive experiences with government workers. Advocates and government workers who spoke to us include individuals new to working with clients on disability assistance, individuals who have been in this field for many years, with legal training, social work training, and no training at all. It also includes government workers who spoke freely on behalf of their department, as well as government workers who spoke anonymously.

This consultation represents only the voices of the persons to whom we spoke. These voices cannot be used to generalize or to speak on behalf of other individuals, on behalf of any community organization, or on behalf of a government department/program. They can be used to identify trends, as the experiences that were reported were very similar from community to community. To preserve confidentiality of all participants, this report does not name a program, province or region.

### Recommendations for Improving Programs

The goal of this report is to explore the gap between policy and practice, and to provide direction for action and program reform. This report highlights how issues such as communication, client management systems, and stigma and discrimination can drastically impact how a policy is implemented. More importantly, it documents the impact that this has on the life of a disability assistance client. Using this information, the Canadian AIDS Society was able to identify key strategies for program and policy development around provincial disability assistance.

## How Can You Use this Document?

The document is divided into four sections. Sections one, two and three organise the consultation feedback into general themes, while the fourth looks to the future and presents new models to deliver disability assistance.

### **Section 1: Why is there unequal access to provincial disability assistance?**

An overview of the barriers in accessing provincial disability assistance;

### **Section 2: Why is provincial assistance inadequate for client needs?**

An assessment of the adequacy of benefits and its impact on clients;

### **Section 3: Why is the administration of provincial benefits inconsistent and ineffective?**

A review of the key challenges in administering a disability assistance program.

### **Section 4: Seven goals for provincial governments**

A response by the Canadian AIDS Society, that discusses the issues, and provides our recommendations to reform provincial disability assistance.

## Identify Actions, Issues and Recommendations for your Community

Some of these issues are not applicable everywhere (i.e. rural versus urban issues); however, most of these issues were raised at least once in every community that was consulted.

Whether you work in the government or you are a community advocate, this document can be used to reflect on the provincial disability assistance program in your community, while asking the following questions:

- Are any of these issues a surprise? Or were we already aware that they existed?
- Have I/we tried to address these issues before? What worked? What didn't? Is there something that has not yet been tried?
- Where do I/we fit into this?

This consultation is an overview and not the final word on these issues. We encourage researchers and governments to use this as a starting point for further investigation. The Canadian AIDS Society extends an offer of support to anyone interested in pursuing research on an issue raised through this consultation. We are available to answer questions about our methodology, and about the results of this consultation; in addition, we can offer feedback on any local initiative.



## Section One: Why is there Unequal Access to Provincial Disability Assistance?

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Some of the barriers to accessing provincial disability programs, or to accessing specific benefits are linked to the written policies and legislation of each provincial disability assistance program. Some are related to how the more ambiguous policies are interpreted or understood by a government worker or department as a whole. This section explores some of the different barriers that disability assistance clients, community advocates and government workers face when trying to assess what benefits are available, and how clients can access them.

### Key Points Raised in Section One

- There is a lack of understanding of which benefits clients should be accessing, and why some clients access them while others do not.
- Information about provincial disability assistance programs is not accessible.
- Intake and eligibility assessments are not capturing all of the necessary information that is required to determine eligibility.
- Despite experiencing the debilitating effects of HIV disease, many people living with HIV/AIDS struggle to gain and/or maintain eligibility for provincial disability assistance.
- A lack of awareness of the full benefits that are offered by each program is reported to be not only a problem among clients and advocates but among many government workers themselves.
- Because provincial assistance programs are designed to have other local government programs and community services “fill in the gaps” with programs such as homecare, childcare, medication coverage and rehabilitative supports, figuring out who offers what is challenging and overwhelming to many clients, advocates and government workers.
- Clients in all communities expressed a strong need to have a single point of contact.
- Many participants expressed frustration with the lack of time that is available for clients in many communities.
- The autonomy of government workers over the benefits that they can provide can both help and hinder clients.
- There is a strong sense of frustration among clients who feel that provincial assistance programs set them up for failure, and then punishes them accordingly, particularly when they attempt to be honest and upfront about their situation.
- Among many clients, protections to prevent fraud and the enforcement of eligibility policies create a constant fear of investigation. They are also inconsistently enforced, and discourage independence and resourcefulness.
- Clients and advocates feel that disability assistance programs discourage opportunities to receive honorariums and other community-based cash supports.
- Many clients and advocates expressed frustration at the level of surveillance that clients experience on disability assistance programs, and described the constant stress that they feel because of it.
- With the exception of two provinces, respondents were not able to identify any formal means of providing feedback or evaluation on the effectiveness of the income support programs.

## Transparent Eligibility

In all communities, the number one issue that was raised by participants was the lack of understanding which benefits clients should be accessing, and why some clients access them while others do not. This lack of transparency when determining eligibility is observed by clients and advocates from the first intake, and extends throughout the time that clients stay on the program. In one community, advocates reported that while the application process is extremely rigorous, if a client was able to bring in all of the documents and “jump through all of the hoops”, then they could be assured that they would receive what they are entitled. In most cases, however, clients and advocates believed that the policies were not consistently enforced and that factors such as individual negotiating skills and discrimination influenced how much a client would receive.

*If you move here, I think it really depends on your worker, how much you get. They say “oh there’s a set amount”, I don’t believe that. Because you talk to other people, and they get this amount or that – all different amounts! ...It just depends on your worker. – A client*

### Lack of Accessible Information About Provincial Disability Programs

There was a sense among most clients and advocates that information about provincial disability assistance programs is not accessible. Many felt that the onus is on AIDS Service Organizations (ASOs) and other disability organizations to promote provincial programs and to make this information accessible, rather than on the program itself to make its policies known. Examples that were given of helpful tools to improve this included: plain-language policy manuals that are available online, and a proactive communications strategy to promote all the benefits that are available to people with disabilities and HIV. Increased access to transparent and easy to understand policies is an important step in reducing the pressure on ASOs and other disability/community groups. A few larger ASOs in urban centres are able to dedicate human resources to learn policies, build relationships with government workers and provide one-on-one support to clients. Most communities, however, do not have these resources and struggle to understand the language and details of policies themselves. Advocates from other disability groups such as lupus and cancer emphasized that their clients and members have even fewer advocates to support them. Many clients from other disability groups have spent years not knowing that provincial disability assistance programs exist at all.

*I think social services should have a presentation of what they can provide, you know? That way it gives the clients a much better understanding of what they can get from them. Because it’s a learning process as you go, and then some people say... ‘how come I didn’t get that?’ Or if you’ve been in the program such a long time and you didn’t get the furniture grant that you can get, but didn’t know about it...and then explain to them, it’s only a one-time thing too. – An advocate*

*The whole system seems to be shrouded in secrecy. They won’t tell you what you need to know. It’s always ‘oh maybe I’ll run it by my supervisor’ – you’re always waiting – A client*

In one community, the department governing the disability assistance program mailed the local ASO the full policy manual, enabling the advocates to look up what their members are entitled to. For the advocate who spoke to us in that community, the fact that everyone was looking at the same information made the process more transparent, and easier for everyone involved.

*[Having the policy manual] makes it a lot easier, and it's like they have the same and we have the same, and I can just tell the clients too that this is what you can get. – An advocate*

#### Intake and Eligibility Assessments

Intake and eligibility assessments are not capturing all of the necessary information that is required to determine eligibility. Some of the government workers expressed frustration that they can only determine what a client is eligible for with the information that is given to them. If a client does not disclose their HIV status or other health issue, the government worker cannot properly assess them. These workers reported that in cases where the full benefits were not given when they should have been, it is because the client did not provide all of the information about their situation. In most cases, when the information was discovered, the benefit was provided immediately.

Most advocates understood that government workers face time constraints because of high caseloads. Many also noted that government workers administering provincial disability assistance are civil servants, and are usually not trained as social workers. Because of this, there is the perception that many lack the specialized interpersonal skills that are needed to acquire all of the clients' relevant personal information. This is particularly true when working with clients that have multiple vulnerabilities that make communicating about personal, health and financial situations difficult. However, these advocates also believed that it is the role and responsibility of an income support program to have trained staff, and to implement an overall policy structure that fosters trust, enforces confidentiality, and is proactive about offering benefits equally to all clients.

One government worker felt frustrated by the confines of her position. Her role is to approve applications for disability assistance based solely on medical evidence. While she understands the need to take factors into account such as someone's socioeconomic status, literacy level, the local labour market and psychosocial aspects of HIV, she is required by the program to interpret only the biological progression of the disease, its symptoms, and treatment side effects.

#### Eligibility and HIV Disease

Despite experiencing the debilitating effects of HIV disease, many people living with HIV/AIDS struggle to gain and/or maintain eligibility for provincial disability assistance. For many of the clients and advocates that spoke to us, there is a sense that it is more difficult for persons living with HIV to qualify for provincial disability assistance than it has been in the past, or in comparison to persons with other chronic illnesses. Many clients told us that they were "lucky" because they have received assistance for many years, and believed that their peers were having a much harder time meeting eligibility criteria. They attributed this to a greater public awareness of the effectiveness of HIV treatment in extending the life of individuals. These clients were very concerned, however, that while clinically this is true,

there is a lack of understanding among government workers of the seriousness of treatment side-effects, the psychosocial impact of living with HIV and the complexity of living with multiple disabilities such as mental health issues and substance use. Some suggested that one way to improve this would be to address rigid definitions of disability and eligibility criteria. Others suggested that more training for government workers on the current realities of HIV is needed.

Most advocates and government workers suggested that increased training and support to government workers would improve communication with clients and consequently, make the process to determine eligibility faster and more efficient. However, advocates were concerned that under current funding conditions, they did not have the time to provide this training. Many of the government workers that CAS spoke to were interested in more skills building, but given their high caseloads, did not know how or when they could incorporate this training.

#### Government Workers who Know the Policies

A lack of awareness of the full benefits that are offered by each program is reported to be not only a problem among clients and advocates, but among many government workers as well. One former government worker explained that even though she worked in one of the departments responsible for extended health benefits, she did not know all of the benefits that were available. When her adult child became sick with HIV and became a disability assistance client, she would frequently pay for his nutritional supplements and palliative care items because the monthly disability assistance allowance could not handle these costs. It was much later that she found out that there was a policy that approved these expenses.

*Before I worked in the department, I would literally drain my pockets from buying [my child] stuff, and I just went and mentioned how much I was putting in out of my pocket, and my supervisor said 'well you don't have to, get [your child] to get a letter from his doctor.' – An advocate*

#### Interaction and Coordination with Other Programs

Because provincial assistance programs are designed to have other local government programs and community services “fill in the gaps” with programs such as homecare, childcare, medication coverage and rehabilitative supports, figuring out who offers what is challenging and overwhelming to many clients, advocates and government workers. There is a sense among clients and advocates that this coordination is not very effective, as many reported not knowing about or were unable to access other services for months or years.

Many clients who are able to tap into local service programs such as homecare and other supports through social assistance are frustrated by not being able to choose their provider. The ability to choose a care-provider is particularly important for people living with HIV/AIDS because of the intimacy of caregiving and the stigma and discrimination that is unfortunately present in many care-giving sectors. Some clients have faced stigma and discrimination from their care providers, but do not see a way to address the situation.

*Home Care – they come by every two weeks, and the last time the lady, she hadn't even come in the house, she had gloves on, well I don't know what my neighbours are going to think. And also when she got in, she put on an apron and put a mask on and I was really like – you know I'm not dying. – A client*

In other communities, there is a lack of awareness of local community resources among government workers, or if there is awareness, they are not adequately promoted to clients.

*We have meals on wheels, and that service should have been mentioned to him prior to him getting as sick as he was. I thought they were only for the elderly who couldn't make their own meals, I didn't realise the service was there for anybody who's unhealthy. – An advocate*

In one interview with the Canadian AIDS Society, the government worker showed us a list of all of the food banks and soup kitchens in the area that clients were referred to. However, the government worker was not permitted to distribute the list or provide us with a copy, because it could result in an increased strain on food banks by clients outside of each food bank's district.

#### Policies around Client Management

While every province has its own approach to managing case files, whether it is a single government worker for a group of clients, or a team of workers for each individual, clients in all communities expressed a strong need to have a single point of contact. Clients desire a single person who knows their situation, with whom they can build a relationship and whom they trust.

*Client 1: "It seems like they change workers, every few weeks"*

*Client 2: "Like they change shampoo"*

*Client 1: "You don't really get to know anybody"*

*Client 2: "I think they make it that way so they won't get too attached"*

*Client 3: "Yeah, they're not social workers"*

*Client 2: "Social worker, I mean there's no social in the worker any longer"*

#### Time to Spend with Clients

Many participants expressed frustration with the lack of time that is available for clients in many communities. It did not allow for relationship and trust-building between government workers and clients, or for time to thoroughly examine a client's unique situation.

*Having a discussion in half an hour – not everything's going to come out. Part of the appointment is determining financial eligibility. – A government worker*

#### Autonomous Decision Making

The autonomy of government workers over the benefits that they are able to provide can both help and hinder clients. While autonomous decision-making is, in part, what leads to

different benefits to different clients, some clients and advocates expressed frustration that government workers could not or would not find a way around a particular policy. It is believed that a government worker who had knowledge of a client's unique circumstances should be able to use his or her discretion around when to apply a particular policy.

For example, the Canadian AIDS Society heard a number of stories where policies were interpreted to the letter, and were applied without consideration to a larger social and economic context. Sometimes this is because of a policy that does not have much room for interpretation, and sometimes it is because of the willingness of an individual government worker to make a situation fit. Either way, many decisions do not reflect the larger social and economic contexts. For example, a refugee escaping genocide was not able to sell his house before he left his home country. When he told this to his government worker, he was given the minimum amount of monthly income because according to the policy, he was considered to be a homeowner, even though he had no access to his assets.

#### Policies around External Income and Supports

There is a strong sense of frustration among clients that the program sets them up for failure, and then punishes them accordingly, particularly when they attempt to be honest and upfront about their situation.

*People on welfare should have the right to dream. When you're not allowed to do this or do that, you're going to be prone to take from others and do atrocities. We need to be creative and constantly develop their outcomes. – An advocate/mental health worker*

*I've learned the hard way not to be honest with them, because whenever you try to, it's almost a recipe for disaster to try to actually deal with them as another conscientious, caring human being – A client*

#### Undeclared Income and "Fraud"

Protections to prevent fraud and enforce eligibility policies create a constant fear of investigation among clients, since they are inconsistently enforced, and discourage independence and resourcefulness. A number of advocates and government workers explained that when clients are targeted for fraud or get caught up in a problem because a policy was violated, it is often based on a misunderstanding. However, many advocates explained that the way disability assistance programs are set up, it is almost impossible to survive without violating some of the policies, and acknowledged that both intentional and unintentional fraud happens frequently.

*There are always some mechanisms [to prevent and catch fraud], but the government spends money on people who don't deserve it. Maybe there would be more money for others. But we're governed by people who commit fraud all the time – the government is an example. Sometimes the only difference between [the government] and my clients, is that my clients get caught. – A government worker*

*[The disability program] has a program that teaches you how to cheat and then they penalize you for cheating. – A client*

*So the only way to operate – I've become very cynical-...accessing the...underground economy to me is the only way to survive. Because if I do it above board, if I'm completely honest, I'd be shooting myself in the foot...My honesty won't help me. My honesty will set me back further...it drives people to do things that they might not ordinarily do. – A client*

*The only other person who is able to commit fraud, possibly comes from workers who have given extra milk tickets to the HIV positive mom... – An advocate*

*They asked me if I was away for more than a month in the last five years...I forgot and said no, can they find out that I did? I took care of my partner who was sick, and I took care of him until he died. – A client*

A number of participants believed that, while in some cases having unreported income and support is necessary to survive, it is also important for clients to take responsibility for their actions when they know it violates a policy.

*When it's someone who knows exactly what they were doing, usually we will just explain to them 'look, you know what you had to do, and you didn't do it. Now you've got to take responsibility.' – An advocate*

One government worker discussed his approach to clients who violate a policy or condition of the program. He explained that it is important to recognise that each situation is unique, and something may seem clear and reasonable to one person, is not for someone else. A policy is a policy, but there can be more at work than someone just not meeting a condition of the program.

*People may appeal something that all they had to do was a simple step to get the ball rolling the challenge may be to get them to do that...the biggest challenge is when you know there's something they can do to better their situation but they're reluctant to do it, or they don't really know. Some people can't comprehend certain things, you can tell them 50 times, but they need to be told again. – A government worker*

#### Honorariums and Health Funds

Clients and advocates feel that disability assistance programs discourage opportunities to receive honorariums and other community-based cash supports. Many advocates expressed frustration that when they provide occasional cash to clients, this money may be deducted from an individual's cheque if it is reported (depending on the program's wage-exemption policy), or it puts the client at risk of violating program policy if it is not declared.

Examples of cash supplements include an honorarium to clients for serving on a governing board, for volunteering in an AIDS Service Organization (ASO), for participating in a research project, even cash for emergencies, and support for complementary and alternative

health care not covered by the program. The frustration stems from the fact that this money has usually been fundraised privately to acknowledge outstanding contribution to the community and to improve the quality of life for persons living with HIV/AIDS. While wage-exemption policies allow clients to earn extra money without having it deducted, the earnings of a client that is actively involved in an ASO or in other community initiatives can easily exceed the monthly wage exemption, particularly if the exemption is very low. It also limits what funding a client can access from her local ASO for complementary health supports. In one community, a government worker actually approached the local ASO to find out if they were providing any kind of cash supplements that were not being declared by her clients.

Some ASOs find alternative ways of providing supports, such as providing a gift certificate in lieu of cash. While for many this is a viable alternative that allows them to side-step the issue of declaring income, others believed that it is one more step towards limiting the autonomy, independence and discretion that clients have around how they want to spend their money. These advocates emphasised that the deeper someone is in poverty, the fewer choices he or she has.

#### Surveillance

Many clients and advocates expressed frustration at the level of surveillance that clients experience on disability assistance programs, and described the constant stress that they feel because of it. Clients and advocates reported the feeling of always being watched, of having to report all of their activities (particularly when it comes to volunteering and being active in the community), and of always being vigilant about maintaining their eligibility and not violating policies. People living in poverty not only lose the range of choices they have in deciding how to spend their money, but dependence on a public program reduces the amount of privacy that they experience.

## Feedback About the Program

With the exception of two provinces, respondents were not able to identify any formal means of providing feedback or evaluating the effectiveness of the income support programs. When specific problems arose, an advocate or client would most often phone a government worker, or a supervisor if necessary. For individual problems, this was cited as the most effective way of resolving them, especially if the government worker and the advocate have a relationship. Advocates who have relationships with the government workers in their community have much more success resolving problems.

*I've actually gone to welfare rights before to complain, and nothing has ever been done, you know. They'll talk to you but once you leave the door, you don't hear any more about it. It's just another person with a complaint, and you got a hundred million complaints a day – that's how they see it I'm sure. You know some complaints are big, some are little, I guess they evaluate what's more important or whatever, I don't know how they go about it, but I find you don't get very far that way. – A client*

*Interviewer: What opportunities are there for you to give feedback about the programs? Has anybody ever approached you to ask you to give feedback?*

*Participant: No. Can you give feedback over the phone? Is there a way?*

*Interviewer: I don't know. That's why we're asking people, to find out.*

*The rules are changing around you, and you have no voice. If the department of social services makes arbitrary changes, they don't ask you how it's going to affect you, they just cut your cheque. They don't look at how that affects people in their daily lives. – A client*

In one province where a review of the program had been conducted by the provincial government, it was felt that the process took a very long time, and that there was little in the way of changes (positive or negative). In another province, when asked about opportunities to give feedback, some of the clients we spoke to began to recollect a message that was included with their most recent cheque:

*Believe it or not, I got a little thing in my check, Thursday, and it say something about – I didn't read it all, it's home on the fridge, but something about trying to reduce poverty, and if we had any questions, concerns or comments, there's a contact number. – A client*

Many clients expressed interest in providing feedback about the program, but some were very sceptical about the effectiveness of a review/feedback process.

*No, I don't know if would do any good. I certainly would fill out questionnaires and do what I'm doing today if it would do any good. – A client*

One advocate emphasised that for clients who have problems with reading and writing, expressing their opinions or providing comments on how to improve a program is far removed from their reality.



## Section Two: Why is Provincial Assistance Inadequate for Client Needs?

The disability assistance clients that the Canadian AIDS Society spoke to experienced high levels of poverty, and reported a large number of problems when trying to meet their needs. Most expressed frustration, anger, fatigue and sadness when discussing their financial situation, and could not see any way out of the poverty and financial constraints that they were experiencing. Housing uses up most of the financial resources that are available to clients, forcing them to dip into budgets meant for nutrition, phone, and utilities.

*Nobody really cares about what my needs are or how I'm doing. And the system was not designed to meet my needs, the system was designed to just keep me alive – keep me from starving to death and looking like a failure to the government, you know, an embarrassment to the government, they're giving me enough to keep me alive, but it's an existence, and not a living – A client*

*There's a feeling sometimes among sick clients that they're almost better off in the hospital, because at least there, their needs are taken care of and it doesn't cost them anything... and to them it's almost like a perfect world, compared to their normal life, which is living in a rooming house with a total expendable income of like \$75 a month. – An advocate*

### Key Points Raised in Section Two:

- Clients receive mixed messages and gaps in service from a range of government jurisdictions, departments, and programs.
- A lack of adequate housing and subsequent access to transportation were problems that were reported most frequently.
- Individuals who are not yet connected to community resource, particularly among those in the refugee and immigrant population from endemic countries, were identified by some advocates as the clients that experience the most problems with housing.
- Weak rental control on non-subsidised housing, a lack of subsidised housing units, policies constraining housing independence, housing abuse by landlords, and the lack of travel supports are some of the key housing issues that were reported.
- A lack of resources for utilities, phone, nutrition, childcare, and clothing are problems for many clients.
- Clients and advocates report problems accessing many medications, health professionals, and specialists, including eye and dental care.
- Participation in exercise and leisure activities are difficult for clients because of the lack of resources.
- While some clients with family networks access financial and housing support from family, many clients become dependent on personal relationships or rely on black market income to meet basic needs.

## Mixed Messages Between Jurisdictions, Departments and Programs

Because disability assistance requires access to a range of health and social supports, clients interact with and receive messages from a range of government jurisdictions, departments, and programs. Unfortunately, many of these messages are contradictory, and interaction is wrought with problems. While most of the clients that we spoke to were only on a provincial disability assistance program, some of the clients had a combination of income support from provincial disability assistance and CPP(D)/QPP. For these clients, once they qualified for CPP(D) or QPP, there was little required in terms of paperwork and speaking to government workers to maintain eligibility. In comparison, the amount of contact that is required with government workers, the number of forms that are required, medical documents that need to be collected or forwarded to maintain ongoing eligibility is exponentially higher for provincial assistance programs.

Advocates also commented that there is a gap between the messages about health being promoted by federal and provincial health ministries, and what is actually accessible by clients living on provincial disability assistance. While the federal government has expressed an interest in addressing the social determinants of health and promoting a population health framework, the disability assistance programs for clients are a long way from meeting the basic requirements of safe housing, nutritious food, accessible health care, and social inclusion.

*It's basically a form of systemic discrimination...because on the one hand, you have the provincial agency that has so much allocated funds in which they have to give out...but be conscious of their monetary situation. On the other hand, you have Health Canada saying that they just upped it by two or more food groups...the necessities that are required for an individual to provide and maintain a healthy lifestyle...you put that in...conjunction with a disease in which where there are other nutrients which are required...the reality is it's systemic discrimination. Promoting on the one hand, but denying on the other. – A client*

*Interviewer: Does the program meet your needs?*

*Client 1: Well, I guess it puts a roof over our heads.*

*Client 2: The program meets my needs for the time being. I live at home. If I didn't live at home, I'd be fucked. But I think – I'm very grateful that there's things paid for.*

*Client 3: Yeah, I am too. Or we're just so damn conditioned now, we're just grateful for anything that we get. And I think that's what the system promotes, they condition you.*

Many clients and advocates expressed how being on the program negatively impacts a client's self-image. For example, in addition to having a frustrating application process and inadequate amounts, the programs are structured in a way that risks making clients feel badly about themselves.

*Sometimes I would rather panhandle, because I would make more money panhandling and bumming, selling drugs, or anything... because it's so, so degrading to a person. Because of the little amount of money that they give you. You feel like a bum already, you know, so why not be one? Because once you get locked on, you really do lose your ambition in life, because you don't have the money to do anything... there is no point in doing anything with your life. Because you're stuck. - A client*

*Sometimes they look at you like, like you're nothing, like you don't mean anything because well, 'it's your fault that you got this and so why should we care?' You know they don't come up and say that, but you know that by the way they act and talk. - A client*

## Housing and Transportation Issues

In all of the communities that CAS consulted, clients, advocates and government workers frequently reported a lack of adequate housing and subsequent access to transportation. For all provinces, there is not enough money in the allowance to cover the cost of rent, and many have to use some or most of their food allowance. The number one challenge with this is that frequently when social assistance rates are increased, landlords of buildings with many assistance clients will increase the rent accordingly, leaving individual clients and families without any improvement in their economic situation.

### Homelessness and the Shelter System

When clients move between provinces or are released from prison and are not able to secure a place to stay in advance, they are often forced to rely on the shelter system (where shelters exist). There were a range of problems raised by clients and advocates about the shelter system and the lack of resources to support clients experiencing temporary homelessness.

- Homophobia: Some communities with high homophobia levels reported that violence made shelters dangerous for men who are known or perceived to be gay.
- Lack of shelter for women: Many smaller communities did not have a formal shelter for women; in cases where women needed emergency housing, they were provided extremely low-quality and dangerous lodging.
- Lice and communicable infections: Some of the larger communities reported epidemics of lice, scabies, tuberculosis and communicable infections that put clients living with HIV at a high risk of new or aggravated health problems.
- Clients recently released from prison: One advocate explained that for many men who leave the prison system and are waiting for their assistance to be reinstated, the shelter system is too close in structure to what they experienced while incarcerated. Many of these men choose to spend the night outdoors.
- Age: Many youth who do not have family support but do not qualify for financial assistance because of their age, have a particularly difficult time making ends meet. Many are dependent on the shelter system, on the street, or become part of the "hidden homeless" by couch surfing (moving constantly between the homes of friends and/or acquaintances).

## Connecting to Community Resources

Individuals who are not yet connected to community resources, particularly among those in the refugee and immigrant population from endemic countries, were identified by some advocates as the clients that experience the most problems with housing. Without family and friends, compounded with experiencing additional language and cultural barriers, they face a wider range of challenges when they attempt to seek housing and other supports. One advocate in an urban centre suggested that once clients are hooked into a community resource and have access to advocacy and support services, there was an increased likelihood of accessing adequate housing.

## Weak Rental Control

Some advocates suggested that a lack of government control over rental rates, as well as a lack of accountability and control over landlords and low-income housing owners limits how much non-subsidised, safe, low-income housing is available in a community.

## Subsidised Housing

Waiting lists for subsidized housing in all of the communities that we spoke to are very long, particularly for single men. Many clients felt that entry into the subsidized housing system was through luck. In some communities, there is a perception that if you know someone in the housing department, you can get yourself bumped up the list. One advocate mentioned that many of her clients are reluctant to even consider subsidized housing because of their reputation of being a “ghetto”. For ethnocultural communities, subsidized housing is often not close to their family, friends and social network, putting them at increased risk of isolation.

## Exchanging Labour for Housing

Some clients made arrangements with family or friends to exchange labour around the house (such as cleaning and snow shovelling) or covering household expenses (such as heat or groceries) in exchange for a room. Often, clients who do this are careful not to report the extent of their home relationship to a government worker (because they are concerned that their housing allowance would be reduced), increasing the stress and feeling of being watched.

## Independence

Clients moving out of a home that they shared with individuals such as a family member, a parent, or an abusive spouse have difficulty seeking support for moving expenses and furniture, particularly for beds. It also seems to be discouraged by workers in some communities. One client told CAS that a government worker actually phoned his mother to find out why he was leaving, and complained to her, asking if it was really necessary for him to leave.

## Sharing Accommodations

In some communities, clients are in a range of shared accommodations, with anywhere from one roommate, to many people in a rooming house with a single shared bathroom. Many women with children share a home with one or more family members. While within some programs this is a financially beneficial arrangement, many clients and advocates expressed a

number of health concerns. For example, a client that shares a home with children is at risk of the many colds and flu that children bring home. Sharing a bathroom while experiencing side effects such as vomiting and diarrhea is also problematic, particularly in shelters and rooming houses.

One woman who was living with her daughter and grandchildren told us that the children had been frequently getting sick, which she attributed to the fact that their subsidized housing had inadequate heat. The client was told to get a journal and record the number of times the children got sick while they were on a waiting list to transfer between units.

A number of advocates explained that immigrants or refugees escaping violence and genocide face an additional set of social barriers based around fear and distrust of others. One client who came to Canada from a country with violence and genocide, felt very isolated during the weeks and months after arriving. This was due in part because she knew few people in her community, and due in part because the violence that she experienced in her home country had made her reluctant to connect with others. Shared accommodations, as a way to save money, was not a realistic or acceptable option for her.

Many people share accommodations with other low-income individuals. One challenge that clients face in this situation is the risk that a roommate cannot make their portion of the rent. One client told us that periodically he must cover some of the rent when one or more of his roommates do not have enough, putting additional strain on his limited monthly allowance.

While some programs encourage shared accommodations, other programs discourage it by penalizing recipients. This appeared to happen most often when two clients receiving assistance try to share accommodations. Clients in these communities expressed a fear of being investigated by a government worker trying to determine if a friend or roommate is actually an intimate partner. With the increase in same-sex rights, both same-sex and opposite-sex relationships are now scrutinized. According to many clients and advocates, there is confusion among some government workers around the difference between maximizing resources, and taking financial responsibility for another person. For example, one client had moved in with his aging parents to provide them with physical and emotional support. According to his worker's interpretation of the assistance program, his parents should be financially responsible for him even though he was providing them with unpaid caregiving. He was eventually forced to find employment to cover his living costs since his parents could not.

Some communities have had success with having a housing unit with multiple apartments designated for people living with HIV, while others emphasized that the discrimination in their community makes this approach too challenging to attempt. These communities have been working towards securing apartments that are spread throughout the area.

For clients who are trying to reduce their exposure to substance use, rooming houses in some communities are very difficult because of the high rates of active substance use among residents.

*We have a lot of people who are living in rooming houses, which isn't always the best place, because unfortunately, in those places there's a lot of drugs, there's a lot of prostitution, there's a lot of unhealthy stuff that goes on there. Some of our clients don't mind being there because that's their world...but some of the other people who don't want to be involved in that, they have to be involved and it's just because they don't have anywhere else to go. – An advocate*

## Neighbourhood and Housing Safety

Because the housing budget from income support programs does not meet local housing market demands, clients on assistance are often locked into a sector of the housing market where abuse and exploitation of tenants is high. Many clients experience abuse from their landlords. A number of advocates explained that many landlords of low-income properties know how to “work the system” and take advantage of vulnerable clients. Clients who are most vulnerable are those that are in and out of hospitals, prisons, and/or who are transient. Many have had their rent and damage deposits stolen, and their belongings sold, given away or destroyed.

While these practices violate provincial and municipal laws and safety codes, the lack of money, time and knowledge of tenants' rights make recourse difficult, if not impossible. These landlords know that vulnerable clients are less likely to report these incidents, and are often not trusted or believed if they do. One government worker expressed much frustration at the local housing situation, and her inability to help her clients. In this community, much of the housing that her clients could afford was managed by known slumlords that were able to use her clients to abuse the income support system. One government worker told us that his frustration with the lack of recourse for his clients drove him to anonymously phone and confront a known slumlord.

In other communities where similar events occurred, advocates were forced to use extreme measures to get basic repairs made to local rooming and low-income housing. A couple of communities told us that phone calls, letters and in-person complaints by tenants and by advocates on behalf of tenants to the landlord were ineffective. Advocates phoned the fire department to report safety violations on a building, forcing the owner to upgrade the building to meet basic safety codes.

## Institutionalization

For some people who spend time in the prison system or who are hospitalized, they not only lose their apartment but are also at risk of losing their belongings. In cases where landlords do not accept collect calls or a client is delayed in contacting the landlord, clients have had their belongings stolen, sold or thrown away because the landlord believed that the tenant skipped out on rent or is not coming back. Some clients who were hospitalized also mentioned similar situations.

However, there were situations where government workers were able to support these individuals. For example, one client explained that during a sudden illness, he contacted his government worker to tell his landlord that he was going to spend a number of months in palliative care. In this case, his worker offered to pay for his belongings to be moved and stored during this period. This was an extremely positive and supportive policy that was implemented by a caring and compassionate government worker.

*A good example is, we have a guy in the hospital who's very sick, and can't get to social assistance, and it means one of us running to social assistance to get the forms he needs to have, and while he's in the hospital he doesn't have an address so he can't get his cheque, so it means he basically bends the rules a bit. It seems that [provincial disability assistance] is almost encouraging [clients] to bend the rules a little bit sometimes. – An advocate*

## Travel and Transportation

In urban communities, affordable and safe housing is often away from the downtown core, forcing clients to spend much time and money traveling to medical appointments. In rural communities, the primary issue that was reported was transportation to appointments and specialists in other regions, communities, or even provinces. In many circumstances, there are resources that are available to cover the cost of low-cost travel (bus) and an overnight stay if necessary. However, some clients reported only receiving partial payments, or limits to the number of times they can qualify for additional travel funds.

*I remember having to go to [redacted] to the clinic, and I called in for transportation and of course they're supposed to cover the cost of food...the worker said 'well, we pay for your food everyday anyway, pack a lunch'...but ten hours on the road – you don't want to eat a soggy sandwich right?...Even to get off and get a cup of coffee or something. – A client*

*And with the price of gas today, you know, I can't afford to be going around, I can't afford to move the car. – A client*

Among programs where local travel is not provided or is restrictive, travel is a challenge for clients. This is a key barrier to participating in community events in rural areas.

*Because of course you know...even the ability to feel useful, to be a part of something, so the ability to get on the bus and come to the [local ASO] and volunteer everyday, you know, it helps. But if you live in [redacted], [redacted], or wherever, you don't have the funds to jump on the bus everyday and come in and try to have a healthy lunch, which we do try to provide for them, but not all the time. – An advocate*

In one rural community, clients can access taxi coupons for travel to and from a designated site for health treatment. Injection drug users began using their coupons to travel to a local AIDS Service Organization to receive new syringes - the only location where needles can be accessed since needle exchange was not recognised as an official or legal program in the community. The government program stopped issuing taxi coupons to the individuals who were not on record as being HIV positive because, according to the program, the ASO is not a designated health site for persons that are not living with HIV.

In some cases, it is not simply a matter of requiring a bus, but full assistance for activities such as grocery shopping or going to the bank. When clients are ill, these are activities that become very difficult, if not impossible.

*There's a gap between when people are so sick that they can't go out and grocery shop for themselves...but aren't sick enough to go into the hospital. There's a real gap there, and if they don't have support from family or friends or people around them, then they're on their own. – An advocate*

For some clients, living in a downtown centre where there is access to health resources and community supports also means having less access to the bulk and discount stores. One client mentioned that friends (also on an income assistance program) earned extra money by driving up to the bulk stores on the day when assistance cheques are issued, and charging assistance clients money to drive them back into town with their groceries.

*One drug I was on costs \$110 a month at Shoppers, and \$80 at Wal-mart...but it's hard though here, and in most cities, I mean [those stores] are not in the centre of the city...you need a car, unless you have half a day or so to spend on the bus, or somebody to catch a ride with. – A client*

*They can't go out and do their own grocery shopping, they can't go out and bargain hunt for things... – An advocate*

In some cases, where taxis are covered for medical treatment, delays in administering a request for travel resulted in missed appointments. This is frustrating for health professionals who have a policy of charging for missed appointments.

#### Telephone and Utilities

A lack of money to pay for basic phone service is a problem for a lot of clients. When clients are ill or at risk of an emergency or sudden illness, this is very dangerous, especially for clients in rural communities. It also makes it difficult to communicate with their government worker and to maintain regular communication with their local AIDS Service Organization. In some communities, temporary telephone coverage is available only for clients that are enrolled in a return-to-work program, however most clients on a disability assistance program reported a lack of phone access to be a large barrier. To cover the cost of basic phone service, many clients cut back on already inadequate food and housing expenses, while others use non-legal sources of income to cover the cost of their phone.

*They should try and set up a program for people who have HIV/AIDS so they do have an access, at least with the people that have kids...so at least my child can at least pick up the phone and dial 911, instead of running down the street by herself, looking for help for me. – A client*

*Participant 1: ...they don't care if you have a phone or not. Here we're all –*

*Participant 2: Rural.*

*Participant 2: Yeah, and living with HIV – if anything happened, how the heck am I going to get help to me?*

The increasing cost of both gas and electric heat is adding pressure to the already stretched budgets of clients. For some clients, moving enables them to find housing that better fits their price range, however hook-up costs for utilities add to the price. In regions where winters are very harsh and long, heating becomes a serious issue. This issue was reported to be very serious in northern communities.

*I'll probably have to sell my place because I won't have enough to heat it or anything..the heat and telephone alone. – A client*

### Missing Rent

Some clients told us that mental health issues, periods of depression or an addiction problem makes it very difficult to stick to their budget and ensure that their rent is paid. One client discussed this with his government worker after a period of not paying his rent. Together they developed a plan where the government worker spoke to the landlord, and made arrangements for the disability program to cover the cost of the missed rent to prevent eviction, and the client would pay back these funds over a period of a few months.

*It's like with the issue of me not paying my rent. [my worker] said 'I've been with you for three years, you've never had a problem paying your rent, I can understand once' she said 'I'm not going to punish you or anything like that'...she's one of the best workers there. – A client*

## Other Needs

There was a wide range of additional needs that were identified by clients, advocates and government workers.

### Food

Clients living on assistance are not getting the food and nutrition that they need. Because many clients are using their food allowance to pay for their rent, there is not enough money to buy food.

*I often tell people, "You know, if you got some of your food here, you could afford to go to a movie." - An advocate*

One advocate explained that in the Aboriginal community in her region, large families or multiple families receiving income assistance frequently share a home. Unfortunately, the lack of income for food often leads to conflict in the home. Clients and advocates who spoke about the experience of immigrants and refugees explained that it is a very hard adjustment simply learning how to cook with the ingredients that are available in Canada. One client who had recently immigrated to Canada told us that she hopes that when she learns how to use Canadian ingredients, she will be able to stretch her food allowance. In the meantime, she cannot make her budget stretch to the end of the month.

Many clients mentioned the low-nutritional content or quality of the food at food banks, and in many cases gave us examples of finding mould on bread and being given rotting

vegetables. Healthy food like fresh vegetables, fruit, meat and dairy is expensive, and is not always available at food banks. In rural communities, food banks do not exist at all, or are out of reach of the clients that we spoke to.

*Client 1: Well, don't go to the food bank here, all you get is sugar donuts. And a couple of tea bags.*

*Client 2: Are you serious? See, there's none out our way.*

Some clients had strong personal feelings against using a food bank because of the social stigma that they felt, and preferred to find food or money for food from other places. Others are afraid of using up resources that they felt should be used by others. One client had to be encouraged by an advocate to use the food bank, because he felt that he would be using up resources that were meant for people who were “more needy” than him.

For other clients, food banks are a critical community service. In some communities, being HIV positive can qualify them for food programs targeting people living with HIV. Some of these are based out of a local ASO, while others are programs in the community. The emphasis of these food banks is on high protein diets required by many people living with HIV.

*Friends of mine in Montreal and Toronto gave me a hard time when I told them – ‘you should be ashamed’.- I'm not taking food away from anybody, I'm not taking food out of anybody's mouth, and it's a big help. Because it's just about anything other than perishables...but it helps. I'd probably pay \$100 or more for stuff like that. – A client*

One service provider was concerned that if people who were in need were not using the local food bank, the problem would become even more hidden, and the need for food would continue to be underestimated.

*I mean, we'd all like to be able to pick healthy choices, but the fact of the matter is...they're eating Kraft Dinner every night. They're not even eating Kraft Dinner; they're eating like, Sobey's brand macaroni and cheese. Kraft Dinner would be a luxury for them. - An advocate*

*It's really hard to work around the food bank with allergies. – A client*

For those who rely on coupons and comparison shopping to maximize their food budget, it becomes a time-consuming process of collecting flyers, clipping coupons, and travelling from store to store to get the best bargain. Buying in bulk or accessing lower-priced stores out of walking distance requires finding a ride or taking multiple trips. For those without bus passes, this must all be done by walking, paying the added expense of bus fare or paying others with cars to drive them.

Many communities are concerned about the quality of the local water supply, and its impact on the immune systems of people living with HIV. However, bottled water and subsidies for bottled water are rarely available.

*Water too, water should be paid for because the water you get in [redacted] is not as clean as everybody thinks it is, but yeah, that is one thing that would help their immune system much better too. - An advocate*

### Clothes

Clients are not able to buy the clothes that they need. Clients rely on used clothing stores like the Salvation Army, but when it comes to proper footwear and warm coats, it becomes very challenging. Buying items like shoes or a winter jacket means planning and budgeting months ahead of time. Many clients just do not have the “extra” money that they need to save for this kind of purchase. This is particularly challenging for immigrants and refugees from warmer regions. These clients are not prepared with the boots, jackets and warm clothing that are necessary for the Canadian climate and have to purchase all of these items. One client told us that she was overwhelmed at how expensive these items are, and felt frustrated at not knowing where to go to find them at a lower-cost.

### Medication

In many communities that spoke to us, access to HIV medication for clients on disability assistance generally, does not seem to be a problem. However, there are some exceptions. For example, one advocate explained that many clients who have had problems getting their HIV medications covered by the province were people who were living on a reserve and had been given misinformation about the application process. There were many examples of clients having problems replacing lost or stolen medication. In one situation, a client was told by the hospital that his medication could not be filled on the weekend, but accessed his medication within hours of having a family member call a personal connection in the pharmacy department.

The key medications that were reported as being difficult to access because of the financial burden were over-the-counter medications treat nausea and diarrhea, colds and flu, and lower dose painkillers. Many clients reported paying for these from their monthly allowance.

*So, I'm paying \$10 a month out of my pocket for Gravol because welfare won't cover it...Gravol you can buy over the counter, that's why it's not on the list [of medications covered by the disability program]. - A client*

Some ASOs are able to provide a “Health Fund” to clients to cover the cost of additional medications, medicinal marijuana, vitamins, or any other complementary and alternative health product of their choice. A number of clients indicated that this monthly resource is usually spent on basic food and groceries, and not on therapies to enhance their health.

### Doctors and Health Care

All clients and advocates spoke very positively about their HIV specialists. The challenge, however, is that clients living in rural areas often have a very difficult time accessing the specialists that are located in urban centres or who only make scheduled visits to rural areas. While most clients explained that disability assistance does provide some resources to cover

their travel, it is very minimal and barely covers the cost of food. In some cases, travel by bus to the specialist could take a full day.

When it comes to other specialists, mental health/psychiatric supports, general practitioners and emergency care, there is a serious lack of resources in most communities. Clients and advocates across Canada emphasised the lack of physicians taking on new patients, and very long waiting lists for other specialists. A number of clients suggested that the only reason they were able to access a general practitioner or specialist care is because they had health professionals in their circle of friends or family, which enabled them to move up the waiting list or provide referrals. There were also many stories of substance users being treated very poorly or being turned away for treatment.

#### Dental

A lack of access to preventative dental care was a concern among clients and their advocates. Some participants mentioned that there was (limited) coverage for emergency care, but yearly preventative care and maintenance was cited as a problem. In one case, the AIDS Service Organization had done fundraising to cover both the preventative and emergency dental costs of their clients. Because these resources are from private fundraising, they are unpredictable and depend on the success of fundraising initiatives.

*I think they should have preventative measures like that, as far as their dental...because a lot of [clients living with HIV] had a very difficult time, because I know my son...he's always had his teeth, and because of his illness, he had no bone, so when he had that, then it really made me aware of the problem that this could cause...I think the dentist needs to be done yearly. – An advocate*

#### Glasses and Eye Care

A few participants expressed frustration that clients did not have the resources to cover the cost of glasses, or the program did not have enough flexibility to meet the needs of clients.

*So, you know, if my kids sit on my glasses, or takes them and bends them, I'm out glasses for a year you know and – because I've asked [the disability assistance program] if they'll cover my – and they won't. – A client*

#### Rehabilitative Supports

Most of the clients and advocates that we spoke with were not concerned about access to supports such as canes, wheelchairs, etc. Most clients said they were not needed at this point in their illness, and most advocates suggested that when clients did need these resources, they were readily available from other local services, such as through the hospital or Red Cross. None of the advocates reported any problems when attempting to access them, although a few of the advocates were not very clear on how these programs operated or what they fully offered. One advocate suggested that by the time his clients required physical supports they were already in a hospice and had full-time or almost full-time care and support.

In one rural community a client was very concerned about a lack of access to a scooter. This client lived on a hill, and found it difficult to become active in his community. Among those

who did indicate that they accessed a physiotherapist, long wait-times (over a year) were a problem.

#### Exercise

A few clients and advocates identified exercise as a daily need. In one community, clients can get their physician to write them a prescription for exercise (particularly in the winter months) that allows them to get coverage for a gym membership.

*...I used to go to exercise class, which is really good for me. \*crying\* It's tough you know. So for twice a week, because I'm on low income, it's \$18 a month, so it's really wonderful, but at \$18 I can't even afford it. But I really love it, because it's not only physical but mental...if only social services ... could give us a little something for the one's of us who would like to have exercise, you know? - A client*

#### Daily Living and Leisure

It is very difficult for clients to get involved in recreation and social activities, and daily living often involves a lot of frustration and struggle. One client was not able to enrol her child in local music program because she could not guarantee that she would be healthy enough to walk her to the class, particularly in the winter. She wished that someone could come to her house to take her daughter when she wasn't able.

Some clients explained how frustrated they were with how little they have, what little they can do in terms of social events (like going to a movie) and how this makes daily life very hard. One service provider explained that while his organization offered workshops on managing your money, he felt that many clients were already quite expert at it. Some people raised the issue of volunteering as a source of support for daily living. In one case, volunteering provided a client with training and courses and gave him purpose to his day. However, this client also explained that his financial and home arrangements are much more secure and comfortable than many of the clients he works with.

*A lot of our clients living on social assistance, they learn to survive, but it's a really small life, and it can be a very discouraging life, because you don't ever see getting out of it. - A client living with HIV/service provider*

*I was used to having everything, whatever I wanted and my income was a lot higher and I could do whatever I wanted to and I had a good job. I don't go to movies now; I don't go to clubs. There is actually nothing that I really get involved in except for these [Annual General Meetings] and stuff. - A client*

*I used to be part of a women's group that actually travelled around, and women met together who were positive...but that was a long time ago, and now that I have a daughter, of course trying to find something that I can do and still be with her. - A client*

*I often tell people, “You know, if you got some of your food here, you could afford to go to a movie.” - An advocate*

## Supporting Family Overseas

What is particularly challenging for many clients that are refugees or immigrants is that they send money to their children and family in their home country. While the disability assistance programs are not meant to accommodate this expense, it is a reality among these clients. Many of them are cutting back on their own food and housing budget to create extra income to send home to their families. Consequently, they are experiencing even more challenges accessing adequate housing and nutrition.

## Childcare

When we spoke to parents or to advocates working with parents, it was clear that a lack of childcare resources is a serious concern. There is a feeling that parents cannot access the childcare that they need to participate in workshops, volunteer, and participate meaningfully in their community. All of these parents expressed a need for childcare for a few hours, a few times a week, to allow them to sleep, take care of their own illness, and participate in community activities and programs offered by local community agencies and ASOs.

*I'm with my daughter 24/7. I don't have anyone to watch her. And I don't have the money to pay anyone to watch her...[the disability assistance program] expects you, even if you're sick at home, to watch them yourself. - A client*

*What I find is that if I get sick, right, and I have a bad day, there is really no respite for a person, because what they want to do is if you phone your worker and say 'listen, I've got a couple bad days there' what they want to do is...to take your kid and keep them for three months. - A client*

These parents are also facing the challenge of meeting their child's health needs (particularly if the child is living with HIV), the challenge of meeting the family's basic needs on an insufficient income, and the stigma that their children experience because of the presence of HIV in the family. Many parents expressed frustration that their children would also experience discrimination because of the poverty that they experienced.

*They don't understand, kids, you know, that we're poor...and to be able to try and treat my daughter once and a while, and I just can't do it, and so she goes without and she wonders why?  
- A client*

## Other Ways of Meeting Needs

Clients, government workers and advocates were asked about other sources of income or support clients used to get their needs met.

## Financial Support from Families

Many clients are able to make their income stretch to meet their needs. However, for many of the clients that we spoke with, much of this was due to family support. Clients that reported more comfortable living often had support from family because of living arrangements that they have made (such as exchanging labour or childcare for having a portion of their rent covered), or because a family member purchased groceries, paid a bill, etc.

*So I don't know what the cost is to my brothers and sisters, I mean, they all kind of contribute, so it enables me to have the luxury about thinking longer and harder about going back to work. – A client*

## Black market/"Under the Table"

When clients cannot meet their needs on assistance, some turn to other sources of income - such as selling drugs (particularly if they have a past history of drug-selling), sex work, or under the table work in jobs such as housecleaning - and not reporting this income.

*You have to pretty much lie to your workers, clean house under the table, sell drugs, get money from your family and not tell about it, is the only way to get by. You just can't do it with what they give you. – A client living with HIV*

## Personal Relationships

A number of clients and advocates indicated that having a personal relationship with someone that had resources (housing, income, etc.) could help you meet your needs. While most of these relationships are based on trust, intimacy and friendship, one advocate suggested that in her experience, many of the female parents in her community went out of their way to seek or maintain a relationship as a way of finding relief from being a single parent. For many of these parents, the financial support and childcare relief that they receive can outweigh the need to avoid or leave an unhealthy relationship.



## Section Three: Why is the Administration of Provincial Benefits Inconsistent and Ineffective?

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Understanding the complexities of how programs are administered is a significant missing piece in understanding why our provincial disability programs are not working for disability assistance clients living with HIV/AIDS. Based on conversations with disability assistance clients, community advocates and government workers themselves, it is clear there is a range of factors at work.

### Key Points Raised in Section Three

- There are varied perspectives among clients, advocates and government workers around whether the use of drugs, alcohol, smoking and gambling should affect benefits.
- Decisions around eligibility do not always reflect medical evidence.
- There is a lot of fear around disclosing HIV status to government workers, particularly in rural and remote communities.
- Disability assistance policies and the way in which they are implemented often demonstrate stigma towards people who require financial assistance.
- There is a need for more training and support for government workers concerning HIV, poverty, stigma and discrimination, mental health issues and substance use.
- There is a lack of human resources to offer training, and a lack of time to receive training.
- Clients with mental health issues report high levels of problems when communicating and interacting with their government workers.
- Strategies to manage client files are problematic, and frequently result in lost documentation, burdensome paperwork, and inappropriate language used in correspondence.
- Clients, advocates and government workers are concerned that caseloads among government staff are too high, resulting in high levels of burnout and turnover among government workers.
- Communication and relationships between clients and government workers are made more difficult because many clients experience fear, a distrust of authority, and/or are reluctant to ask for support.
- Clients have had the most success with workers who listen, who have compassion and empathy, who spend time with clients, who are accessible and forthcoming with information, and who know the policies.
- Advocates that are able to build relationships with government workers have high success rates in resolving problems on behalf of their clients.

## Stigma and Discrimination

Unfortunately, stigma and discrimination is present to some degree in all communities that we spoke to. The stories that were told speak to the need for more training and education for government workers, not just around HIV, but around other vulnerabilities such as substance use, mental health issues, and barriers related to being an immigrant or refugee.

### Drugs, Alcohol, Smoking, and Gambling

There are different points of view towards how drugs, alcohol, smoking and gambling affect what resources a client can access, and whether or not these choices *should* affect what they access at all.

For example, many clients, government workers and advocates suggested that clients who do *not* drink, do drugs or gamble, should be offered more respect, more opportunities for support, and more resources than those who are involved in those activities. Some people felt that clients who “wasted” their support on substance use or gambling were examples of how many clients choose not to work with the system. They suggested that clients spending their money on these activities, and on other items like cigarettes, should take responsibility for their problem behaviour and how they spend their money. There is a feeling that there is no point trying to help someone who does not want to help herself, and that financial support would be better spent on clients who can better maximize their resources. In one case, a client suggested that money for rent and food should be more controlled by the government so parents cannot spend money that is meant for their children on these activities.

Others felt that this was an example of how clients that are most marginalized, most discriminated against, and in most need of support and resources are made even more vulnerable. They suggested that it does not matter what clients spend their money on or why. Fundamentally, caring for others means being non-judgemental and working with clients “where they’re at”, even if it means giving them money that they will probably use for drugs instead of food. One service provider gave us an example of how, on a personal level, he gets frustrated when clients buy cigarettes instead of healthier options that he would choose. In his professional role, he works to acknowledge his personal judgements, tries to understand where they are coming from, and tries to empathise with their situation. In this case, he empathises with people whose “only escape or luxury” is a pack of cigarettes. As an advocate, he told us that this is key to building a trusting relationship with a client, so that they feel comfortable approaching him for support knowing that they are not being judged.

There are a number of factors at work on this issue. Some of this discrimination is grounded in a lack of awareness and understanding of problematic substance use or gambling as an illness. This was widely reported across the communities that were consulted. One advocate explained that this situation could be very complex for advocates and government workers. For many people responsible for administering financial support, there is a struggle between trying to support individuals that are marginalized, while remaining accountable to the individuals behind the funding. She felt that most of the money that is going towards supporting marginalized communities could be traced back to donors with “middle-class values” who have corresponding expectations towards how donations are spent.

## “Invalid” Medical Evidence

It appears that some government workers do not always defer to the medical evidence when determining eligibility. A number of examples were given where it seems that the appropriate forms and medical evidence were provided, however, the assessor or caseworker decided independently that a client was not in need.

*So it felt like she was trying to say that I was just trying to get disability when I didn't need it...I would have went for it twenty years ago [when I was diagnosed] if I was the type of person that didn't want to work, right, because twenty years ago it was easy to get, which it's not now. – A client*

## Inappropriate Questions

One advocate expressed frustration that some government workers ask questions that are not relevant to an assessment, which reflect personal judgments and assumptions about the client in front of them. Evidence of a *current* medical problem should be provided by a physician or other health professional (as approved by the local program), and should never include information about the point of infection. Some activists attributed this to a lack of knowledge and training in HIV issues among government workers.

*...I think you're looked on a little bit differently if you access government services, if you already [qualify for a private long term disability plan], they look at that different...because I guess they look at me as a gay loser...or as someone who hasn't contributed that much, you know, and probably never will, because he won't have a family. You know? I don't know what they're thinking: I don't know where they're coming from. When they're sitting up on a panel, judging me...and allotting whether I'm going to eat next week or not. And that's what they're doing – they've got all this control, and I'm a sick man, I need help, I need resources. This is, I live in Canada, I mean, don't we have a charter of rights and freedoms? What was Trudeau all about? – A client*

## Fear of Disclosure

A number of ASO workers and clients discussed the fear of disclosing to government workers. Whether individuals have actually experienced it first hand or not, the fear of being discriminated against is real, and the consequences are serious. For clients in smaller communities, the fear is often based on having the government worker disclose to others in the community.

A number of individuals knew that this information should be legally protected, but questioned whether or not government workers respected it. In some cases, simply being in the building or waiting room to talk to a government worker risks disclosure. In others, submitting receipts for HIV medication or even discussing medication coverage in a government office risks disclosure. While some clients trust their individual worker with confidential information, there is the fear that other workers, administrators, receptionists and office staff do not recognize, respect or understand non-disclosure.

Some activists mentioned that clients do not always tell the government worker about their status, and try to qualify based on other factors. Some government workers were concerned that by not disclosing, their clients were not qualifying for all that they could. In other

communities, advocates felt differently. They felt that disclosure should not be necessary and that a physician should be able to provide the necessary evidence that would qualify someone for a program, without disclosing the full health condition. The premise of this approach is that it is the immediate medical condition that is relevant, and not the diagnosis. All that should be required to qualify is a certified statement from a physician that indicates that a client or potential client cannot meet the requirements of gainful employment. Once it is determined by a medical professional that gainful employment cannot be met because of an individual's illness or disability, the actual diagnosis and personal medical information is not relevant.

### Stigma Towards People on Assistance

Unfortunately, there are government workers who are judgmental of clients simply because they are on social assistance. While many people suggested that this was built into the policies governing the social assistance programs, not all government workers communicate this – it seems to be on a very individual level, and it feels to clients as if it's random and unpredictable. Some clients and advocates mentioned that individuals with a family history of being on social assistance face additional roadblocks from government workers.

*I was told in [redacted] that the government owns me. And I was really upset about that. I said nobody owns me, and the [government worker] said yes, we do, we own you. You know? ...but that's the way they see it, once you're on assistance, they own us, they can tell us what to do, where to go, you know, that's not how you treat a human being. – A client*

*Like my first social worker, just wonderful, and now I have this other worker, she's a [redacted]. And I can't talk to her, and when I do talk to her, I end up crying...I'm thinking of getting a different [government case worker]. I don't know, because I'm afraid that I might get a worse one. – A client*

Some of the stigma that clients feel is simply from being on assistance and having to ask for help to meet basic needs. This was most often the case among clients who use, or who have considered using, food banks and soup kitchens, even when they are hosted out of the local AIDS Service Organization.

*Some people won't access [our food bank] because it stigmatizes their status and then they have to go and ask for food from somebody else, and it makes them feel less than human. – An advocate*

One advocate emphasized how being on the program puts clients at risk of stigma from all directions. For example, a client risks stigma, discrimination and privacy violations by disclosing their HIV status to their government worker, and in turn, risks the stigma associated with disclosing to their physician that they are on welfare.

### Stigma Based on HIV

Unfortunately, there were many stories about government workers who demonstrated inappropriate behaviour or even abusive comments targeting the fact that clients are living

with HIV. In one example, a government worker that advised a client, an active volunteer tutor with children, to stay away from kids because of his health condition.

*I think a lot of the time that stigma is still there, that you're looked down upon because you're HIV positive, so you must be a junkie or a prostitute, or you're just not good enough...it's there in the hospitals too, it's not just in these programs. People should know better by now, I guess is what I'm saying, but they don't. – A client*

*PLWHIVs are already rejected by society, and the agents aren't helping. – An advocate*

Other examples reflect more subtle behaviour, for example, not using the same pen, shaking hands, or body language such as moving further away from clients.

*I don't think they know they're doing it, but it hurts anyway. – A client*

#### Mental Health Issues

A number of clients and advocates indicated that there was stigma and discrimination specifically towards clients living with mental health problems. This stigma makes interacting with government workers more challenging. It also makes accessing housing for some people difficult.

### Managing Client Files

While each province and program has its own approach to case management, and each approach has its own successes and challenges, there are some observations and recommendations that were made that can apply everywhere. The following is a summary of the comments made by activists, clients and workers themselves.

#### Repetition

Frequently, the same question or the same document is requested of a client more than once. This seems to happen most often when there is a “team” approach to managing cases (more than one person is responsible for a case file), or when there are multiple steps (i.e. a phone interview, followed by a personal interview). Not only is this frustrating to the client, but if a client is fearful, he or she may see it as a trap to catch them in a lie. Many details and key pieces of information are also lost in the process.

*Clients are shifted from caseworker to case worker, they have to repeat their whole story over again, and the anecdotal stuff isn't recorded.- An advocate*

#### Managing Documentation

In many of the communities that CAS consulted, there was a problem with the disability assistance department losing documentation. Clients and advocates found that submitting documentation through fax or mail did not guarantee that it would be received. In some

cases, even when documentation was submitted in person, if it was not entered into the “system” properly or quickly, form letters would be automatically generated that threatened to cut the client off. While often the individual problem is resolved and decisions are reversed, advocates are concerned about the impact it has on clients.

*But like, because they got burnt so much, they don't want to be burnt anymore. – An advocate*

There was a lot of frustration among clients and advocates over ongoing paperwork requirements. For clients who experience mental health issues, literacy problems, or have problems keeping track of documents, maintaining forms that require multiple signatures or repeated signatures for each medical appointment can be extremely challenging. Departments keeping track of client travel to medical appointments often use this strategy. Not only is it frustrating for clients, but it is also time-consuming for community organizations and health professionals who need to fill out the paperwork or support the client.

*It's a pain to carry that form with us. Our meds make us forget. It's another process we shouldn't have to do. We should be able to say “we have two appointments per month, at \$10 an appointment” and just get the doctor to sign the form once...I'm losing money because of the process, but I don't want to go through the whole process of submitting the paperwork, and maybe them losing it, and following up with them, and being on hold for two hours. – A client*

*In fact, it is the people who needed it the most (the most isolated) who suffered because of this change, and all that to save what? \$10? While we take the time for social workers, doctors... Imagine having a thousand clients! – An advocate*

*It's a police state. – An advocate*

## Recording Information

Some advocates supported clients by making photocopies of any correspondence, prescriptions, letters, forms and faxes that the client brought to the advocate, providing the client with a copy, and keeping a copy in the client's file. Some advocates mentioned that they send documentation electronically where possible, and simultaneously by fax and mail to increase the likelihood of it reaching its destination, while recording that it was sent as evidence if needed. In some cases, clients requested that when they submitted documentation in person, the recipient stamps the document as received, and provides the client with a photocopy of the stamped document. While these steps do not guarantee that the document will be received, the client will have the evidence needed that he or she fulfilled her obligations.

## Collecting Medical Information

One government worker expressed frustration with the amount of time that it can take to collect and receive the necessary medical information and laboratory results. If a client has multiple health professionals or has moved from another province, collecting all of this

information can extend an already long assessment process. Occasionally, local labs will not send someone's file at all.

Advocates emphasized that how a health professional completes a form can significantly affect how much a client receives. Factors such as the lack of access to health professionals, the lack of time available to spend with clients on paperwork, and most importantly, the lack of awareness among many doctors on the importance of these forms are example of factors that can affect how much in benefits that a client receives. One advocate expressed frustration that local health professionals do not understand the greater social impact that the symptoms and treatment have on individuals. It is a challenge to get them to complete the forms indicating all the different ways that the diagnosis, the symptoms and treatment side effects negatively impact on an individual's life. This is particularly true when it comes to clients who have only recently been diagnosed and are coming to terms with the illness, and clients who are marginalized by multiple vulnerabilities. There is not enough acknowledgement of the need for a full package of services, not just medical treatment and an adequate income. Clients that accessed health professionals who understood this often had an easier time qualifying for the maximum amount.

#### Accessing Workers and Client Caseloads

Many people are concerned about the caseload of government workers. A high caseload limits the training opportunities for government workers, reduces the amount of time that can be spent with clients, both in person and on the phone, and makes it difficult to return phone calls promptly. When calls are screened or redirected by a central answering service or receptionist, many clients complained of long waiting times on hold. Many clients also found that they were routed through two or more persons, and had to repeat themselves multiple times before their question could be answered. Clients who did not have phones and/or answering machines or who were in prison found it exceptionally difficult to reach their caseworker, since the caseworker was rarely available to answer a direct call. When the caseworker was ready to return the call, the client could no longer be reached at that number, or there was no way to leave a message.

*I think [the disability assistance program] has too many clients and not enough workers, that they can't handle the workload themselves. Whereas Welfare, they respond in a timely manner and don't lose paperwork. They let you know what services they provide. - A client*

Some programs use a "team" approach, arguing that it enables more than one caseworker to be able to access a client file and process information. Many communities also complained of high turnover, with a single client being assigned two or three caseworkers within a single year. Clients told us that the most productive and positive relationships were built with a single caseworker that got to know their history, their personality, their needs and their challenges.

*And when they do get on, the first thing I tell them is...transfer your file to [the HIV/AIDS financial worker], because he knows a lot more than the other one, and knows what a client who is positive will get financially - or should anyway. - An advocate*

*We have a HIV/AIDS financial worker that works specifically for the clients. And having that good relationship with him really helps too, because if there was a client that was here and had gone missing for some time...they'll call me and we'll figure out where this person is. – An advocate*

## Letters and Updates to Clients

Many clients reported felt that the letters that were sent to them used language that they perceived as very threatening, emphasizing the consequences of non-compliance. In some cases, the letters were generated automatically, or by someone other than the clients' caseworker. Often it did not clearly explain in plain language what was requested. Clients responded very positively towards letters that was signed by their caseworker or by the person responsible for the decision in question, particularly when they included a phone number where they could be contacted directly.

In one community, advocates found it frustrating because the disability assistance program relied on an electronic system to manage information. The biggest frustration was when clients submit a form to their government worker in good time, but the worker was not able to enter that information on time and a letter was automatically generated and sent to the client. The worker can override this and correct the error, however, the client still receives a notice that may tell them incorrect information about their benefits. This leads to stress and fosters distrust.

## Training and Support for Government Workers

### Burnout and Government Worker Turnover

Some advocates are very concerned with government workers experiencing stress and “burnout”. This makes it difficult for government workers to be effective with clients, and corresponding turnover creates a lack of continuity for clients.

*The primary challenge is the burnout among caseworkers in income programs, turnover is high. There's only two people that I can think of in the whole province who have been there for more than a few years. – An advocate*

*A lot of the caseworkers I'm sure are completely burnt out and completely overloaded with work...I guess they're there to deal with an issue and move on, but just checking in [with clients] to make sure they're ok, and how they're doing and how are things. – An advocate*

*As a caseworker, you want to do the best you can, but with the time limitations...and the scope of our program, you can't really be that advocate for all 150 people on your caseload. You have to realize you have limitations because you'll burn yourself out on this job. – A government worker*

## Knowledge of HIV

Many misunderstandings and problems arise when a government worker knows little about HIV. Just as many Canadians lack knowledge of HIV biology and transmission, many government workers have fears based on misinformation about the disease. While many workers have a basic knowledge of HIV, there still seems to be a lack of understanding of the psychosocial impact of living with the disease. Some workers are unclear about the episodic nature of the illness, and do not understand why a client needs support when they appear to be healthy. It is also difficult for some workers to understand that many HIV symptoms and medication side effects are hidden.

## Government Worker Training

Many ASOs have offered training and one-on-one support to government workers, or suggested that they would be interested in doing this, resources permitting. Many government workers said they would also be interested in training, but mentioned that they didn't have much time with their caseload. What training they had received concerning HIV and various illnesses was usually very brief.

*Every [government worker] is different...my old one knew more about HIV because she went and saw one of the [HIV information] seminars. – A client*

*We had an HIV/AIDS financial worker come to our women's retreat, and I thought that was really great, she took the initiative to know what HIV and AIDS was, and by doing that she had more information to what happens to a person who's HIV positive and the changes that they go through – that was a success. – An advocate*

*The first one that we had, she was excellent, and that was a good thing too with her, she came to meetings here, and we all heard, other staff, like things that are happening at our agency that could benefit her as a financial worker. – An advocate*

*Because there's been a lot of changes around HIV, especially around medication, and that confidentiality issue, stuff like that...I would like to set up for different organizations to come in and to listen around treatment, you know, you can't expect a [person who is not] very healthy to do [treatment education]. – A client*

*All workers should be trained, thoroughly. Not just HIV 101, but how they live with the stigma. – An advocate*

*I don't think [government workers] have the capacity to deal with people or be patient. Maybe they don't have the training or the resources, I'm not sure why, but they can't deal with people on an individual level...anyone who's visibly homeless, who stinks, those clients really fit into that category, and have problems accessing anything, particularly [REDACTED]. – An advocate*

*Part of our training say, if we notice that there's one office that we notice a lot of our clients are having problems with, we may approach them and offer up some awareness training about working with prisoners. They don't usually take us up, but we offer it. – An advocate*

Some clients that had positive experiences with their government workers indicated that they were asked about HIV disease, treatment, side effects, etc., because their workers wanted to learn more.

*...every time that I come back from [the HIV clinic], if I have any appointments, I go in to see her again, she asks 'how was your appointment' How are your side effects and all that' She wants to be informed. And then I tell her about the new drugs, and she says 'how are the side effects?' – she wants to be educated a little more. – A client*

One government worker acknowledged that there are gaps in their provincial disability program, but felt that workers are in a challenging position because they are expected to be everything to all people. He explained that they do try to provide training to their staff.

*We try to do workshops on mental health issues for the intake staff, helping them to be able to identify behaviours...we try to provide tools for intake specialists...an assessment tool, to assess initial behaviours. Not tools to be able to deal with the problem, we don't have time to be personal counsellors, but try to give workshops to be able to know the resources. – A government worker*

*We're having the workers from the shelters come and present to us. Our workers aren't all aware of what services [the local shelter] provides. They didn't know they provide laundry. – A government worker*

One advocate expressed frustration at having invested a lot of time and resources into training government workers (including housing, disability assistance workers, directors, managers, etc.), but felt that it did not result in a measurable change in how her clients were treated. One of the problems that this worker saw with this approach is that by making the training mandatory for government workers, most of the participants were not interested in learning anything about the disease or about the social issues associated with it.

*Only 5% bought what we were selling and looked at the situations differently. – An advocate*

## Working with Specific Populations

Working with clients living with HIV often means working with a number of other experiences and factors that impact on their needs. A number of advocates and government workers mentioned that some individuals have more problems accessing the program or working with a caseworker than others. These include:

- Clients with mental health problems;
- Clients who struggle with interpersonal skills, anger management, and a lack of trust towards other people;
- Clients who are active substance users;
- Clients who do not speak English or who speak English as a second language;
- Clients who are refugees and immigrants from endemic countries; and
- Clients who have recently been in prison.

These clients were reported to be more likely than others to be caught up in misunderstandings and require an advocate to intervene. It also seems that these clients tend to be “flagged” by workers as difficult to work with. In some communities, the program “flags” the case file if the client has a history of violence or is threatening to the worker, or is potentially violent or threatening. In one of the communities, clients flagged as having a violent or unpredictable past moved to an administrative building in another location, where interviews and meetings are conducted behind Plexiglas.

*[Clients frequently in and out of prison] – their ability to solve problems is not high. They have low self-esteem. They're not seen very well by others, including doctors. - A government worker*

One successful approach to managing clients who seem to be more challenging to work with has been to assign a worker with expertise in a particular field or area. For example, in one community, a government worker was hired to work only with men who have been released from prison. In another, a single worker, who is familiar with HIV, serves all clients living with HIV. The overall feedback among clients, advocates and government workers is that this was a positive strategy for their community, and led to a better understanding of clients and their needs. Some advocates expressed concern that this strategy risks labelling clients, and can overlook the fact that clients with multiple disabilities (such as HIV, substance use and mental health issues) may not benefit from being assigned to a specialized worker. This is of particular concern around disclosure, when clients of a worker “known” for her HIV positive caseload are at risk of being identified simply by showing up for an appointment. An advocate expressed concern that one of their government workers is an important ally for same-sex rights and has an excellent reputation among her clients that are gay. In contrast, she was identified as treating substance users very poorly, so having someone specialise in HIV does not guarantee that they are able to support clients with multiple vulnerabilities.

## Language and Cultural Barriers

Many clients from other countries experience a wide range of problems centred on the lack of adequate language and culturally-sensitive resources. While advocates working with these

communities are able to provide some translation and interpretations services, they can only work with the clients that they are connected with, and a lack of resources restricts what they are able to provide. For example, they do not have the resources to provide a translator or advocate to accompany every client, for every meeting with their government worker. There is also a big cultural adjustment that must be made, particularly among clients who come from countries where corruption and abuse within the government is rampant, or there is a strong lack of trust towards governments in general.

*Someone who has English as a second language isn't able to ask for the same things. – An advocate*

*Women who have English as a second language – there are a lot of barriers there, a lack of cultural sensitivity. Most of the women who have problems are women of colour. – An advocate*

*Talking to a worker, I'm not sure if they're really helping me or something, it's like, anyone in customs, they have the power to stop your benefits, you tell them the wrong information. I think you need someone you really can trust and someone who's on our side, who's understanding. Otherwise I like to keep distance. – A client*

While English literacy is a problem when filling out forms (or in the case of Francophone communities, French literacy), there is often a lack of sensitivity towards the ongoing challenges that it can pose. For example, one client told us of a time when he received a one-time gift of \$100. While trying to report it on his monthly update form, he reported it as regular income. As a result, he received a call telling him his cheque would be cut back by that amount. In another case, the client explained that when she first applied for disability assistance, she signed all of the required legal documents, although not having been able to read anything on them.

While many clients in Canada were frustrated with the threatening and/or complicated language of the forms and letters, clients with low levels of literacy find the process particularly threatening.

In some of the helpful situations, the government workers and health professionals that were involved in processing an application with someone who was new to Canada explained clearly, and emphasized how, the client's HIV status would be kept confidential. In this particular case, she was able to keep her HIV status a secret from everyone other than her doctor and government worker.

## **Communication and the Client-Worker Relationship**

Many of the issues that were raised centred on miscommunication between clients and government workers.

## Client Perceptions of Government Workers

Many clients spoke positively about their government workers and provided many examples of how they received compassion and help. However, most clients and advocates described at least one government worker in their recent past with which they had a very negative experience.

Among those who did provide negative examples of their interaction with their government workers, many provided opinions on the motivation behind why a government worker denies benefits. Some felt that often government workers want to find ways to help, but are bound by the need to save or stretch the money that is allocated to their department. One government worker confirmed this, expressing his frustration at the lack of resources that are available for his clientele through him, and through community-based programs. Others felt that the motivations behind some government workers are grounded in stigma and discrimination based on culture, substance use, ethnicity and gender, as well as attitudes towards people living with HIV/AIDS and people who live in poverty. In many communities, advocates and clients reported that the reluctance of government workers to provide benefits made it seem as if they were handing out their own personal money.

*I don't think the government is against us, I think they want to work in tandem with us, it's a matter of telling them exactly what they need, and trying to be realistic about it. HIV is such a strange disease right now. – A client*

*Welfare don't give you nothing unless you ask. They come from a different world. If they need it, they have family members with money. In the Aboriginal community, if you ask for help, you're putting a strain on families. – An advocate*

The reasons behind why some benefits are granted and others are not, and why some client-worker relationships are positive and others are not, are varied and complex.

Communication was the number one issue that was raised by clients, AIDS Service Organizations and people working for government-based social assistance programs. Most of the problems that arose between government workers and clients were easily and quickly resolved when the issue was clarified and both sides were able to understand each other. Usually this involved having someone from a local organization make a phone call or attend a meeting, and figure out what each party was trying to communicate. Until everything had been cleared up, however, many clients were left with the impression that the government worker was being impatient and invasive. Similarly, the caseworkers were left with the impression that the client was being uncooperative and was withholding information.

While policies governing a program must be followed by both caseworker and client, there are many ways to build a positive relationship and maximize the benefits. There were many examples of government workers who took initiative to understand the policies and procedures, and figured out ways to implement them in a forthcoming, transparent and respectful way. While some workers found ways of “bending” the rules in order to get clients what they needed, there were many ways of simply interacting and communicating with clients that have a very positive impact on the individuals who access the program.

In some cases, a negative relationship begins before a client even walks through the door or makes the first phone call to apply for disability assistance. Many clients are very uncomfortable about the fact that they need social assistance, are upset that they are now dependent on someone else to meet their basic needs, and struggle with social stigma towards being on a disability assistance program.

*I think it's demeaning for most people that go in [to the disability assistance office]. It's not a good feeling, you get there and you know what kind of reaction and treatment you're going to get, when you get walking in those doors, so obviously your defences are up, because you feel like, you're – I don't know, I feel like I'm a tax burden when I walk into that office, you know what I mean? – A client*

*But like a lot of [government workers], before we got sick, we had jobs and we paid into it. So we are entitled to what little we get from them, and we should be grateful for it, but it's still not enough to live on. But like they're doing their best to try to compromise with everyone, but they're not doing their best with us. – A client*

Across all clients, there is clearly a need to feel that they have been respected, that they have been treated with fairness and without judgment, that they have had a voice, and that their needs have been acknowledged. One government worker expressed it this way:

*Good service means that [clients] are satisfied, their question has been addressed, and we have listened to them. The answer may not always be yes, but the outcome should still be that they have been validated and their concerns have been taken seriously. – A government worker*

## Interviewing Clients and Applicants

For people who are familiar with bureaucratic and government processes, an interview to determine eligibility or to update a file may be an inconvenience, but for many others, it can be a frightening, intimidating and even a threatening process. These are some of the feelings that clients frequently have when they talk to a government benefits worker during an intake interview or eligibility assessment:

### Fear or Distrust of Authority

Many individuals see government workers as authority figures, particularly when they have the capacity to determine how much income someone can access. This was flagged as a large problem among people who have spent time in prison, and who are used to seeing people such as doctors, nurses, and social workers as authority figures. It was also raised as an issue for some clients who have come to Canada from other countries and who are used to more controlling governments, or who are afraid of being deported. If clients do not feel safe providing personal information, they may not provide what the worker needs to process the application or to determine that someone is eligible for a benefit.

*They ask a whole list of stuff and ask questions about things from a long time ago. And they ask for things for no reason, like my birth certificate – I wasn't born in Canada. Maybe I take things too seriously. You just don't want anything to happen. – A client*

*People who are in [prison] for a long time, like ten-fifteen years, just doing anything outside is really hard...when you've been institutionalized that way, everyone looks like an authority figure to you, anyone who has the authority to say yes or no to you...it can be not [just] some simple application process, but a very intense experience for people because of what they went through inside. – An advocate*

One advocate emphasized that for people who have experienced violence or abuse, experiencing aggressiveness or intimidation from a government worker is a much more acute, humiliating and dangerous experience.

*They have been traumatised and they are frightened. Aggressiveness doesn't have the same meaning for us as it does for them. – An advocate*

#### Reluctance to Ask for Support

Many clients do not ask for additional support because they might not know what to ask, or assume that the government worker has provided all of the information that they need. Without knowing that they can ask questions or understand that there may be more resources that they were not told about, clients might not be proactive, make requests, or challenge a decision.

*My son was always very quiet, so he would never ask the worker if they would pay extra for that, he would think that would just come out of his money...so he would never really fight for a thing – Mother of a HIV positive client*

*Others may come here and not disclose anything to us because they're not comfortable doing so. It's not until we get calls from community agencies that other things start to come out. – A government worker*

Many advocates and clients expressed how important it is for workers to ask questions and probe when necessary.

*...when [a client] does relay some information and they didn't bring it far enough, maybe the worker can come back and say what did you mean by that? How does that affect you? What is your opinion on that? – Mother of a HIV positive client*

#### Relevance of the Information

Many clients don't understand why a question has been asked, or why a particular document must be provided. Without that understanding, they often do not answer with the information that is required, which can be interpreted as non-cooperative. Clients who had

workers who explained each form to them, told them why they needed the information and asked if they had any questions felt much more comfortable providing what was needed.

It was also reported that some government workers ask questions that are not relevant to an assessment, and violate someone's privacy. The most frequently reported problem is when workers ask clients *how* they were infected with HIV. An individual's medical and social history is rarely relevant, if ever, when determining someone's eligibility. Evidence of a *current* disability should be provided by a physician or other health professional (as approved by the local program), and should never include information about the point of infection. Some activists attribute this to a lack of knowledge and training in HIV issues among government workers.

Some government workers feel frustrated with clients who do not follow through with their obligations. One government worker explained the process that he uses with clients, emphasizing that he is very proactive in making sure that clients know exactly what is expected of them. He illustrated the many different opportunities that he gives them to discuss different issues and to reschedule appointments before there are any consequences.

*I'm very clear about what you need to do. Many people don't take responsibility for their actions. They need to be independent. I'm not their mother; I'm their caseworker. – A government worker*

#### Misunderstanding the Question

Often clients don't understand the question the way it has been asked, so they do not provide the information that is needed. Clients who have little or no knowledge of English seem to encounter this frequently. Community-based translation services are used when they are available, but because of the issue of confidentiality (both ethically and legally), doing an intake through a third party is challenging. A few respondents suggested that racism compounded the language barrier.

One advocate suggested that it would be easier if the local government worker would come down to the ASO in person and meet with both the client and the translator. That way the government worker would be assured that the information is actually coming from the client himself or herself.

*It's also hard when [the government workers] call here and an advocate is trying to translate, but they can't see that the client is actually here. You know, it would be easier if they could send someone here. If there was one worker who can link local ASOs, to have a contact person. – An advocate*

### The Skills of a "Good Government Worker"

We asked what skills, qualities and attributes a government worker who works with clients should have. Some people viewed this as a "wish list" and were frustrated with some of their local workers. However, most of the communities that we spoke with had at least one

worker who was identified as being kind, caring, and respectful, and exceptionally good at their job. Here is what people said:

#### Someone who has Patience and Takes Time with Clients

Everyone that we spoke to emphasized that this is a very stressful time for clients. Not only are they worried that they might not get benefits when they apply, or that their benefits might be cut off if something goes wrong, they're also worried about their health, their medication, their children or their pets, their landlord/rent/mortgage, and a long list of other issues. Respondents expressed a need for workers who are patient and who do not easily frustrate.

*She's good enough that many times when people are kind of caught in a predicament or a bit of a weakness or something like that, or just get off guard and will say something that they didn't mean it to come out, and she will say 'you know what, I'm just going to pretend I didn't hear that'...because she knows it's going to have a huge impact on someone's life if she has to do something about it. – An advocate*

It is also extremely helpful when government workers take the time to spend with clients in order to fully understand a client's situation.

*Someone who's willing to talk to you, someone willing to lead you in the right direction for help. Willing to go over your budget. – A client*

#### Someone who Listens

Often, clients just need someone to listen to them. A number of activists mentioned that that for some people, this is the first time they have accessed any kind of support or services in their community. Workers who are active listeners can identify when someone needs additional social or emotional supports and can refer them to their local community-based service organizations.

*Someone who is culturally sensitive, who recognizes that people are not less intelligent because they have accents. – An advocate*

Many of the activists mentioned that clients don't always understand that a government worker is rarely trained as a social worker, nor do they play a social worker's role. However, it is possible to actively listen to a client without engaging in counselling.

#### Someone who has Compassion and Empathy, Someone who Cares

Clients are able to tell quickly whether their worker is simply processing a file or whether they have a genuine concern about the welfare of their clients. Program workers who had a positive impact asked clients how they were doing when they spoke to them, periodically called to find out if they needed anything, and volunteered a range of resources and referrals in their community.

*It is a very emotional time to figure out how you're going to get by now that you have this terminal illness. – An advocate*

*Sadly for us, I think that's wishful thinking because we're never going to see that, every time I turn around – the only time I hear from social assistance is when they're, when they want something – A client*

*There's no compassion, no empathy, no recognition of the circumstance that people are having to face. They're just there to – they're gatekeepers to the very small amount of money. – A client*

*Someone who's empathetic, and not sympathetic. – An advocate*

*Someone who actually looks you in the eye when they're talking to you, that's really important. – A client*

*I think that if we didn't have [REDACTED], then [our clients] would be much worse off than they are. She's really caring, and she's told me before that [her supervisors] asked her if she could split up her positive clients and let other people handle them and she won't...to her they're not just numbers and cases, they're people, and I think she feels their pain and she works as hard as she can. – An advocate*

One advocate explained that it is difficult working with some clients, particularly ex-offenders, who are used to experiencing stigma and marginalization. To these clients, government workers are just strangers, enforcing bad policies. It takes a long time to gain the trust of clients and to develop a positive relationship.

*If you don't have any compassion, at least show some respect. – An advocate*

*They shouldn't be considered as responsible for their condition. – An advocate*

Someone Who is Accessible and Available

Each province has its own approach to case management. Some provinces assign a single worker to a number of clients, while others assign a team of three or four workers per client. Some government workers have clients that have little in common with each other, while others specialize in clients who share a common experience, such as a recent period of incarceration or HIV. Regardless of how the program is structured, most respondents explained how important it is to be able to reach someone with answers quickly and easily. Workers who could be reached through a direct line (rather than being routed by a receptionist), or returned calls within twenty-four hours had a very positive impact on clients. When clients spend a long time on hold, or have to wait a number of days or even weeks before their calls are returned, expressed a lot of frustration.

*Right now, even if I did have a social worker, which I don't, I can't call that person and speak to them. The phone system is such that they don't take calls directly, you have to call and leave a message on the message manager, and they get back to you within a couple of days, so there's nobody that you can reach in the event that you have urgent circumstances, or things that require immediate attention, everything takes a long time, there are lots of times that I can think of. – A client*

*I think they could do a lot better, and the sad part is that social workers have such a workload that they don't get time to sit down with the clients and seriously get to know these people, and see what their skills are, and point them in the right direction, you know. Instead they just push them out the door, get going I have another client, you know? – A client*

It was important to many clients that they are on a first-name basis with their worker.

*When I call, it's first name basis. I say it's me or whatever, and I am good this week, or I need something...I don't really even know what she looks like. It's kinda funny that way, because I don't really know who she is. It's just a person on the phone who is always 'hi, how are you?'. – A client*

In cases where client files are transferred between workers, clients and advocates expressed the need for good communication about the transfer process to clients. Many clients and advocates expressed frustration about when a file has been transferred between government workers and only a letter is provided.

Someone Who is Proactive and Forthcoming with Information

Many clients are unsure of what they may be eligible for, and because of cultural reasons, shyness, fear, language barriers, or lack of awareness, do not ask their workers about specific programs or supports. Workers who volunteer information about a program without being asked were described as being the most helpful and having the most positive impact on clients. Having to research all the different components of the program and learning or understanding how to ask for it puts a lot of stress onto the client, and also means that benefits are not being distributed and accessed equally. Not all local AIDS Service Organizations have the time or experience to do research about what is available and under what circumstances.

*Client 1: [When I moved out of my parents' place]...I didn't get a bed, I didn't get a table to eat off, I didn't get nothing, and I didn't even ask for a bed for myself, I ask for one for my son, and I was flat out told no.*

*Client 2: But you're supposed to be entitled to one? Why didn't you get it?*

*Client 1: ...maybe because of all the paperwork and the crap that I would have had to go through...they told me I wasn't [eligible], but if I had kept hounding them I probably would have got it, but I was so stressed out...*

In some cases, clients weren't aware of basic resources such as a toll free number that they could use to contact a government worker instead of dialling long distance.

*It was a while before they gave me a toll free number I could use. I didn't know, I was calling all that time – and you're looking at \$60-70 a month for the phone bill, and I didn't know there was a 1-800 number. – A client*

Some clients had government workers who were able to identify a need and were proactive in responding to it. For example, when one client was hospitalized and at risk of losing his apartment, his government worker phoned his landlord and helped make arrangements to move his belongings into storage for the duration of his care.

*She suggested that she could put some more money on my cheque [and] when I go to the doctor [get him] to write down on a piece of paper that I would be going to the doctor for the next year quite a bit and give it to her to put on my cheque, instead of me calling her and asking her for it every month. – A client*

*[My worker] makes sure I know about things... 'Did you know you could get a letter from your doctor to pay for the gas mileage of going to your doctor?' I wouldn't have known that if he hadn't had said it. I wouldn't have asked for it. I guess just being honest and helpful. –A client*

Some government workers were helpful by explaining the different parts of forms, explaining how to fill them out or how to get a physician to fill them out, and explaining how this process will help the client access something that benefits them.

Someone who Knows the Policies

In a few cases, clients were aware of what the program could offer, having heard from friends, advocates or from the program's website and asked for an item directly. The worker initially denied the benefit until the client used the policy itself to demonstrate that he qualified.

A number of clients and advocates identified government workers who were able to figure out ways to make a situation fit within the policies. This requires a detailed knowledge of the policies, knowledge of the unique situation, and a creative and flexible approach to the issue.

*We have one that we work with who will work for us. She will do anything that she can. If it doesn't fit into the criteria, she will work on it and...make it fit the criteria...it's not going to be 'no no no', it's going to be 'well, it doesn't fit this way, but maybe we can adjust it to another program'. – An advocate*

Good Relationships with Advocates

A few advocates mentioned that having their own positive relationship with government workers promoted good communication and provided better support to their mutual clients. While all of the advocates that spoke to us emphasized that their role is to support clients and to intervene only when asked, many indicated that they play, or have the potential to play, an important role in the process. In communities where advocates were very close to

government workers, the government workers seemed to spend more time participating in training opportunities and learning about the issues facing PLWHIV/AIDS. Close relationships also enabled some government workers and advocates to locate vulnerable clients who had gone missing from the community.

*...And having really good communication with the financial worker too, between myself, the client and social services, that's a great success, there's trust built then. – An advocate*

*In the fall, a couple of things come up for individuals, and [I] just call [redacted] and say 'certain individuals are having problems with this' and it's like 'well I'll deal with it' and so that kind of helped foster [our relationship] as well, because she knows me and she knows that it's not going to go any further...after I'm off the phone, the conversation never happened. – An advocate*

Having a strong relationship between advocates and government workers was also seen as important in building trust between clients and government workers. For example, one advocate explained that being able to accompany clients to a meeting with their worker enabled the clients feel less fearful, helped them understand what was being said, and to feel confident that they were not going to have money unjustly cut from their monthly payments. Other advocates were able to bring in government workers to provide information and workshops directly to the clients of the ASO.

*Once they get to know me, we have a frank and open discussion...trying to have my voice heard on behalf of others is a challenge. I don't know what it is, whether they're threatened, whether I'm questioning their job, or whatever, but once they know I'm the person around there – they get to know me as a person and I get to know them as a person. – An advocate*

*A lot of times we like to go directly to the worker so that we don't go over their head. I feel very free in calling them if I sense something wrong. It depends on the approach, if you go in mad, they get defensive. –An advocate*

In one community, a positive relationship that the local advocates had with one government worker enabled them to access a large amount of information about government processes and programs quickly and easily. This relationship bridged a gap in communication not only around income programs, but around social services and treatment issues as well.

One government worker felt frustrated that an overload of clients means that there is little or no time to follow up when a referral is made to a partner organization.

*We lose track of it once the referral's assigned...it's hard to facilitate that two-way communication when you have a caseload of 150. One person may be involved with four different agencies, you can provide resources, talk to the participant, but unless...you're actively dealing with an issue that's jumping out, there may not be that contact between you and that agency you referred them to. – A government worker*



## Section Four: Seven Goals for Provincial Governments

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The Canadian AIDS Society (CAS) spent twenty-seven months speaking to a range of communities and individuals. Given how many different issues were raised, and how many conflicting points of view we encountered, we feel that we captured the thoughts and ideas of a very broad spectrum of people. After listening to what others had to say, we want to share our own thoughts and reflections.

What are some of the underlying messages behind these comments? What trends do they represent? What implications do they have? More importantly, what solutions are there? And what outcomes would we want to see from these reforms?

### Twelve Years Later – How Far Have We Come?

One of the questions we asked ourselves, is, what has changed since a similar consultation was conducted by CAS in 1994? The short answer – very little. What has changed is that the number of people living with HIV in Canada is estimated to have risen from approximately 33,000 in 1994 to 56,000 in 2006. The socio-economic dimensions of the illness have also become much more complex. But the barriers that are driving people living with HIV/AIDS on provincial disability assistance into poverty have remained exactly the same, and according to some of the individuals who spoke to us, they have become even worse.

The 1994 consultation broke down into three categories the barriers that PLWHIV/AIDS faced when attempting to access benefits: Accessibility, Adequacy and Administration.

*PLWHIV/AIDS have problems accessing the full array of available benefits. Current benefit programs are inadequate to meet the basic needs of PLWHIV/AIDS, and PLWHIV/AIDS have difficulty making their needs understood by the administrators of social assistance programmes. – Excerpt from “Provincial Income Security Programmes”, Canadian AIDS Society, 1994*

Unfortunately, an analysis of the consultation undertaken for this project reveals the same barriers. Moreover, many of the advocates, disability assistance clients and government workers we spoke with believe that in 2006 it is *more difficult* to access benefits than it was in earlier years.

Based on this consultation, the Canadian AIDS Society has identified seven goals that provincial governments can work towards, which will have a significant positive impact on the lives, and health, of its disability assistance clients. Accompanying each goal are *indicators of success* that can be used to focus reforms, and be used in short-term and long-term evaluation strategies.

## **Goal One: Information about provincial disability assistance benefits is transparent and easily accessed by clients, advocates and government workers.**

### Marginalization Leads to Further Marginalization

Not all clients are accessing the same information about policies and programs. The unfortunate irony is that the clients who already experience social and economic marginalization, and who are supposed to find relief and support through these initiatives, are being pushed even further to the social and economic margins of society just by being on the program. Clients who have the communication skills, the social capital and the ability to research information about the provincial program seem to be better able identify and negotiate the maximum benefits from their disability program. Clients without these resources and who face additional social and economic barriers access fewer benefits, and have to fight harder to access and maintain the ones they are receiving. All of this is done while attempting to stretch fewer resources further and trying to address their additional health concerns.

### Indicators of Success

- Front-line government workers responsible for administering social assistance programs are provided with ongoing training concerning social assistance legislation and policy.
- Complete collections of legislation and policy are made publicly available online and, where requested, in paper.
- Policy documents are made available in plain language to clients.
- A proactive communications strategy promotes this information online and throughout the community.
- A specialized strategy targets rural and remote communities where current and potentially new clients cannot access the Internet and/or community services.
- Promotional resources and information about programs are distributed to health clinics and hospitals, to increase awareness of the program among current and new clients that are not connected to community-based organizations.
- Specialized outreach efforts to target those clients who are less likely to be able to understand policies because of low-literacy, mental health issues, or language barriers.
- Government workers are pro-active during intakes and assessments, ensuring that the full range of benefits is offered to all clients.

## **Goal Two: Provincial disability programs reflect the changing nature of HIV disease management**

### Understanding HIV Biology and Disease Management

It became clear from clients and advocates that the knowledge of HIV disease and treatment, as well as the understanding of the psychosocial impact of the illness, varies between workers in each community, and within each local office. On one end of the knowledge continuum, clients reported interacting with government workers that were afraid of sharing pens or of shaking hands, indicating that there is a serious lack of basic

information on HIV and HIV transmission. Around the mid-range of this continuum, clients reported government workers that understood the biology and physiology of the disease, but had no understanding of the psychosocial impact of living with the illness. On the other end of the continuum, clients reported having government workers that used the face-to-face meetings to ask questions about the illness, and were willing seek a better understanding of what their clients were experiencing. It was clear that government workers who had this knowledge or who sought this knowledge were seen by clients and advocates in a more positive light, and led to positive working relationships. Many of the government workers that we spoke to who understood the physical and psychosocial aspects of the disease felt frustrated with the limitations of their job. They mentioned examples such as the clinical markers that they are required to use to determine eligibility, and the limitations they face when implementing clearly outlined (if inefficient) policy. It is challenging for the HIV/AIDS movement to advocate for policies and implementation practices that reflect a holistic approach to HIV disease management, when many government workers are missing even the most basic information about HIV transmission.

#### Indicators of Success

- Policy-level and front-line government workers are provided with ongoing training concerning current trends in HIV disease management; HIV and vulnerability and the experience of living in poverty.
- Eligibility assessments take into consideration the psychosocial impact of living with HIV.
- Government workers are connected to local AIDS Service Organizations and receive regular information, newsletters and other opportunities for ongoing learning and partnerships with the HIV community.

### **Goal Three: Provincial assistance programs communicate effectively with all clients**

#### Understanding Multiple Disabilities and Multiple Vulnerabilities

A strong message from the 2006 consultation is that many clients experience a combination of disabilities that may include Hepatitis C, dependency on a substance, and mental health issues in addition to HIV. There is also the recognition that many clients experience multiple factors that increase their social and economic marginalization, including illiteracy, a lack of understanding of the language that is prominent in the community, a history of poverty in their family, street-involvement, homelessness and under-housing, a history of violence (against them and/or towards others), active substance use, issues around social interaction and communication, mental health issues, and factors associated with gender (such as parenthood) and ethnicity (particularly among aboriginals, immigrants and refugees).

Clients with multiple disabilities and/or multiple vulnerabilities require a diverse and coordinated program that responds to their needs. Program policies and government workers need to acknowledge that these clients require a wider range of supports, and more coordination between government and community agencies. Most importantly, the approach to communication and file management needs to be particularly flexible and sensitive to the unique physical, social and economic barriers that such people face. There is an immediate and urgent need for training on these issues. A strategy to increase the effectiveness of communication, understanding and awareness of the issues faced by vulnerable clients will

require more than an annual information session. It will require ongoing skill building and support.

#### Clarifying the Role of Government Workers in Client Care

In every community that the Canadian AIDS Society consulted, there was a lack of clarity and consistency around what role government workers *currently* play, as well as what role they *should* play in, client care. On one end of the continuum, the government worker's role is to administer a financial program and apply policy accordingly. On the other end of the continuum, this role is more that of an active member in the continuum of care and support for clients. Many of the challenges that are found in the government worker-client relationship are based on the range of expectations along this continuum. The service that is being expected of government workers by many clients and to some degree, advocates, is much different than what is being delivered.

The primary challenge in understanding this dynamic is the variableness involved when a government worker interacts with a client. Each community and local government office has a diverse range of government workers, each one bringing his or her own approach to interacting with clients and implementing policy. Some workers manage their client files "by the book", to ensure that all paperwork has been filed properly and according to policy, with little personal interaction. Other government workers in the same office play a more social role, phoning their clients to find out how they are, or including more personal interaction through active listening and generally communicating more empathy. The rest are somewhere in between.

The relationships between clients and government workers that are described as being more personal, that involve active listening, and more one-on-one contact seem to leave clients feeling better about being on social assistance, and more assured that their needs were being met. In contrast, clients who have government workers that they perceive to be more interested in properly implementing a policy expressed anger, frustration and sadness. Many felt that they were being treated in a stigmatizing and discriminatory manner. For many clients, simply having a more personal relationship and feeling as though they are being respected, listened to, and treated with care would make a significant difference in their relationship with their worker, in their self-image as a disability assistance client, and their overall mental health. The challenge is in trying to achieve more personalized relationships that reflect empathy, caring and understanding, while acknowledging that the role of a government worker is to administer a financial program and not to provide mental health support. This is an important point, because in addition to needing an increase in respect from their government workers, clients are clearly expressing a need for more personal and social support.

#### Indicators of Success

- Government workers are offered professional development opportunities to better understand their clients.
- Government workers are offered training in communication and active listening.
- Government workers are offered ongoing support when administering services to clients with multiple vulnerabilities.

- Written communication with clients is in plain, non-threatening language.
- Written communication explains, in detail, what is required or requested from a client, why it is required or being requested, or why a decision has been made, and includes specific contact information so that clients know whom (and how) to contact for clarification.

**Goal Four: Clients are able to access safe and clean housing, and the nutrition, clothing, health and social supports that they need.**

It is clear from these consultations that clients are facing too many barriers that are preventing them from accessing safe and clean housing, nutrition, warm clothing for the Canadian climate, basic health care, social and mental health support. For those who are able to access additional cash benefits for nutritional supplements, this is often used towards covering basic housing expenses. Significant changes need to be made to provincial disability support programs if clients are to reduce their individual poverty and improve their health.

Although clients on disability assistance programs access some health care benefits, there is a serious gap in social and mental health supports. The clients that seem to have the most difficulty interacting with government workers and/or accessing the financial supports that they need, also seem to be lacking the social and mental supports that they need. Some of the reasons cited for this gap included a lack of these types of programs in many communities and a lack of effective programs targeting individuals with multiple disabilities and vulnerabilities.

Indicators of Success

- Affordable housing is increased in both urban and rural communities.
- The safety of affordable housing in both urban and rural communities is increased.
- The opportunities for emergency funds, monthly utilities such as phone, and resources to facilitate moving (including furniture and utility connection fees) are increased.
- Clients are able to access preventative eye and dental care.
- Clients are able to access the mental health and social supports that they need.
- Calculations used to determine basic living allowances are adjusted to reflect current recommendations in Canada's Food Guide to Healthy Living
- Financial support to food banks and domestic food security initiatives are adjusted to reflect current recommendations in Canada's Food Guide to Healthy Living
- Clients are able to access the physical activity that they need to meet the recommendations outlined in Canada's Physical Activity Guide to Healthy Living.

**Goal Five: Multiple jurisdictions, departments and programs align their goals**

Addressing the social determinants of health requires a response from multiple levels of government, multiple departments, and multiple programs. The nature of this framework emphasises that health and economic issues are intertwined. Poverty prevention and

reduction is a key strategy in improving population health. The practical application of this approach is to ensure that various programs and departments are not only aware of what other jurisdictions and policies are doing, but that they can integrate those visions and goals into their own initiatives.

An excellent example of this need for integration occurs around the subjects of nutrition and food security. Health Canada promotes Canada's Food Guide to Healthy Living, which outlines a recommended daily caloric intake and suggests how those calories should be distributed across the different food groups. It is clear from this consultation that even with the help of food banks (if they exist in the community), clients cannot access even the basic necessary food to get through the day. A comprehensive, unified strategy to promote health and reduce poverty would involve provincially administered disability assistance that reflects the messages about healthy eating that are being promoted by provincial and federal health departments.

A second example of this need for the integration of policies occurs with housing. Provincial and municipal housing programs and rent policies directly impact the amount of money that disability assistance pays in housing costs for its clients. When the market is such that there is a lack of affordable housing, and landlords or rooming house owners have found ways to take advantage of clients receiving assistance, the high cost of rent is not just felt by clients, but by the assistance program as well. Simply increasing the amount of money for the cost of clients' housing can result in a corresponding increase in rent among building owners. What is needed is more support for local housing initiatives that respond to the unique social, economic and housing environment in each community. A number of communities have already conducted economic analyses of the cost for low-income housing. More resources need to be made for these analyses, and government programs need to find ways of ensuring that these initiatives are resourced and followed through.

A last example of the need for policy integration is in the relationship between provincial health and provincial disability assistance. Many disability assistance regulations put a strain onto health professionals as well as clients, requiring extensive written documentation and support. In some communities, there seems to be an increase in the number of times that clients see their health care worker just to get the documentation required to establish their eligibility for, and entitlement to, benefits. In some communities, the documentation that health care professionals must complete if their clients are to be eligible to receive assistance is overlooked or not given the weight that it deserves by assessors and adjudicators. Conversely, in other communities, there is undue pressure on health care professionals to complete forms in a particular way, which can be a deciding factor in how much financial support a client receives. Some health care professionals do not understand the costs of the treatments that they prescribe or recommend, or do not know that their clients are on fixed budgets demonstrated by the fact that many have prescribed medications or other types of health care that is not covered under the provincial disability assistance plan.

#### Indicators of Success

- Disability assistance food budgets are adjusted to reflect current recommendations in Canada's Food Guide to Healthy Living.
- Support to food banks and food security initiatives are adjusted to reflect current recommendations in Canada's Food Guide to Healthy Living.

- Methods are identified that will allow provincial disability assistance to support physical activity for clients, in accordance to Canada's Physical Activity Guide to Healthy Living.

## **Goal Six: Unemployed clients experience the right to privacy, independence and self-determination**

### Loss of Privacy

Because the process to determine eligibility for a disability assistance program is based on a combination of financial need and medical need, the amount of information that is collected on each client can be extensive, and invasive. Financial records and medical conditions are scrutinized and can be questioned during the application phase, and can be a condition of ongoing eligibility. Simply being a client of a program results in an ongoing loss of privacy.

### Fraud

There were a number of comments suggesting that mechanisms to prevent or reduce fraud were a necessary tool to maximize the limited resources that are available. They are (in theory) designed to ensure that those who most need support access the programs. However, there are a number of problems with this approach to managing a disability assistance program. Clients are left feeling harassed, invaded, and treated as if they are intentionally trying to steal from the program. Rather than ensuring the fair and equitable distribution of resources, strict policies are playing into stereotypes about who is "defrauding" the system and what constitutes fraud. Some clients are targeted and held accountable for violating policies while others (usually the most marginalised and vulnerable) are not.

### Loss of Independence

As the amount of money that is available for housing decreases, so does the amount of control that a client has over where to live. By being restricted to neighbourhoods that they can afford, clients are no longer able to choose to be close to their friends, family and cultural community, their community supports and ASOs, the school for their children, or the social and leisure activities that they enjoy. They do not have control over the safety of their neighbourhood, access to public transportation or wheelchair accessible homes and sidewalks. Many clients are vulnerable to abusive landlords and can only access housing that violates safety codes. Without access to trained legal advocates, there is little that can be done to fight illegal practices by unscrupulous or negligent landlords. Social assistance policies exert a great deal of control over a person's decision to live alone, move out, or move in with a family member, friend or stranger.

This lack of control extends into the choice of stores where someone can buy groceries, the food that can be purchased (or accessed through a food bank), and the clothes that can be bought. Clients lose the choice to take the bus instead of walk, and by default, whether or not they visit their friends, family, or access community resources. When clients qualify for programs such as dental coverage or rehabilitative care, much of the time they do not have a choice around who provides that care, where they can access it, and when they can access it. Clients that experience vulnerabilities such as mental health issues and substance use risk additional controls because of the stigma towards their inability to make 'responsible'

financial choices. Clients are no longer able to make the choices that many individuals and families enjoy and protect.

#### Indicators of Success

- Funding for disability assistance programs are increased to enable more funds to be distributed with fewer restrictions.
- Clients receive enough income and access enough resources and services to meet their needs.
- Financial assessments are reviewed, with client participation, and adjusted to increase the economic privacy of clients.
- Medical assessments are reviewed, with participation from clients and a range of healthcare experts, to prioritize evidence demonstrating a clients' inability to participate in gainful employment, rather than on HIV diagnosis and clinical markers.
- Clients accessing social and medical services are provided with information on who to contact and steps to take when clients experience discrimination from their assigned caregivers.

### **Goal Seven: Strong communication and partnerships between the voluntary sector and provincial governments**

The 1994 report emphasised the need for strong partnerships between the government programs and community-based organizations such as ASOs.

*...partnership development between the traditional and community-based service sectors is critical to ensure better coordination of services and a more appropriate division of responsibility between the volunteer sector and government. – Excerpt from “Provincial Income Security Programmes”, Canadian AIDS Society, 1994*

It appears that little progress has been made in this area. Each community that we spoke with had at least one good personal relationship between an advocate and a government worker that enhanced the exchange of information between the sectors. However, this is largely informal and dependent on the effort of individuals to initiate and maintain this relationship, and consequently, is at risk with each staff turnover.

#### Indicators of Success

- Government workers have a caseload that is balanced with partnership-building activities and ongoing communication with local community organizations
- AIDS Service Organizations have the resources they need to offer partnership-building activities and ongoing communication with front-line government workers.

## Summary of Goals and Indicators of Success

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**Goal One: Information about provincial disability assistance benefits is transparent and easily accessed by clients, advocates and government workers.**

Indicators of Success:

- Front-line government workers responsible for administering social assistance programs are provided with ongoing training concerning social assistance legislation and policy.
- Complete collections of legislation and policy are made publicly available online and, where requested, in paper.
- Policy documents are made available in plain language to clients.
- A proactive communications strategy promotes this information online and throughout the community.
- A specialized strategy targets rural and remote communities where current and potentially new clients cannot access the Internet and/or community services.
- Promotional resources and information about programs are distributed to health clinics and hospitals, to increase awareness of the program among current and new clients that are not connected to community-based organizations.
- Specialized outreach efforts target those clients who are less likely to be able to understand policies because of low-literacy, mental health issues, or language barriers.
- Front-line government workers are pro-active during intakes and assessments, ensuring that the full range of benefits is offered to all clients.

**Goal Two: Provincial disability programs reflect the changing nature of HIV disease management**

Indicators of Success:

- Policy-level and front-line government workers are provided with ongoing training concerning current trends in HIV disease management.
- Eligibility assessments take into consideration the psychosocial impact of living with HIV.
- Government workers are connected to local AIDS Service Organizations and receive regular information, newsletters and other opportunities for ongoing learning and partnerships with the HIV community.

**Goal Three: Provincial assistance programs communicate effectively with all clients**

Indicators of Success:

- Government workers are offered professional development opportunities to better understand their clients.
- Government workers are offered training in communication and active listening.
- Government workers are offered ongoing support when administering services to clients with multiple vulnerabilities.
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- Clients are able to access preventative eye and dental care.
- Clients are able to access the mental health and social supports that they need.

**Goal Five: Multiple jurisdictions, departments and programs align their goals**

Indicators of Success:

- Calculations used to determine basic living allowances are adjusted to reflect current recommendations in Canada's Food Guide to Healthy Living
- Financial support to food banks and domestic food security initiatives are adjusted to reflect current recommendations in Canada's Food Guide to Healthy Living
- Clients are able to access the physical activity that they need to meet the recommendations outlined in Canada's Physical Activity Guide to Healthy Living.

**Goal Six: Unemployed clients experience the right to privacy, independence and self-determination**

Indicators of Success

- Funding for disability assistance programs are increased to enable more funds to be distributed with fewer restrictions.
- Clients receive enough income and access enough resources and services to meet their needs.
- Financial assessment procedures are reviewed, with client participation, and adjusted to increase the economic privacy of clients.
- Medical assessments are reviewed, with participation from clients and a range of healthcare experts, to prioritize evidence demonstrating a clients' inability to participate in gainful employment, rather than on HIV diagnosis and clinical markers.
- Clients accessing social and medical services are provided with information on who to contact and steps to take when clients experience discrimination from their assigned caregivers.

**Goal Seven: Strong communication and partnerships between the voluntary sector and provincial governments**

Indicators of Success

- Government workers have a caseload that is balanced with partnership-building activities and ongoing communication with local community organizations
- AIDS Service Organizations have the resources they need to offer partnership-building activities and ongoing communication with front-line government workers.



## Other resources on HIV and Poverty published by the Canadian AIDS Society.

ALL DOCUMENTS ARE AVAILABLE FOR DOWNLOAD FROM <WWW.HIVANDPOVERTY.CA>

### Toolkits

#### **Online Compendium of Provincial Income Support Programs**

A plain-language, online, searchable database. It can be used by individual people living with HIV/AIDS who want an overview of how their benefits will change if they move, and by smaller or rural AIDS Service Organizations that do not have the human resources to research their own provincial programs.

#### **The Canadian AIDS Society Guide to Income Advocacy**

A toolkit of resources that individuals and AIDS Service Organizations can use to fight poverty and to advocate for increased income and disability supports. It addresses housing, income, health, food, and more!

#### **Resource Directory - Income Support Programs and Services in Canada**

A directory of community-based income support programs and services in Canada. Search by region, type of service, organization and language.

#### **Benefits Counseling Train the Trainer Manual**

A "Train the Trainer" manual that outlines how to create and offer a skills -building workshop on benefits counselling. It contains detailed directions and tools on how to choose, invite and train participants, as well as skills -building for staff and volunteers interested in counselling clients on income support benefits.

#### **HIV is Still at Work: Is Your HIV Workplace Policy Up to Date? The Canadian AIDS Society Guide to an HIV Friendly Workplace**

This site contains a pamphlet with basic info that can be handed out to employers and employees, and as a series of pages explaining the rights of a person living with HIV/AIDS and the rights of an employer in the workplace. It also contains a guide to building your own HIV in the Workplace Policy.

### Background Information and Research

#### **Position Statement - HIV and Poverty (2004)**

This is the official position that the Board of Directors have approved for the Canadian AIDS Society. It outlines CAS's philosophy and approach to HIV and poverty issues in Canada.

#### **HIV and Poverty - Information Sheets (2004)**

A series of information sheets outlining the relationship between HIV and Poverty in Canada. This is an excellent tool to support funding proposals, training new staff and volunteers, and in developing an awareness of how to look at poverty issues in your community.

#### **Supporting Clients with Income Needs: A Survey of CAS Members (2004)**

A survey exploring the ability of CAS members to provide programs responding to the income needs of people living with HIV.

#### **Prioritising Income in HIV Research (2004)**

A survey of HIV researchers on the collection of income data.

### Policy Related Documents

#### **HIV and Disability Policy: Evaluating the Disability Tax Credit and Medical Expense Tax Credit (2004)**

The Canadian AIDS Society prepared a brief for the Technical Advisory Committee on Tax Measures for Persons with Disabilities.

#### **HIV as an Episodic Illness: Revising the CPP(D) Program (2003)**

In partnership with the Canadian Working Group on HIV and Rehabilitation, the Canadian AIDS Society prepared a brief for the House of Commons Sub-Committee on the Status of Persons with Disabilities, during their review of the CPP(D) program. It contains a list of recommendations for the Sub-Committee to consider.