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Submission to the Ministry of Health and Long-Term Care Regarding the Proposed Amendments to the OHIP+ Program under *Ontario Drug Benefit Act* Ontario Regulation 201/96

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About the HIV & AIDS Legal Clinic Ontario

The HIV & AIDS Legal Clinic Ontario (HALCO), founded in 1995, is a community legal clinic serving the legal needs of low-income people in Ontario who are living with HIV. It is the only such organization in Canada. The clinic is governed by a board of directors, the majority of whom must be persons living with HIV. In addition to providing direct legal services in relation to various areas of law, including health, privacy, and human rights, HALCO staff engage in public legal education, community development and law reform activities. HALCO staff routinely provide legal services in relation to matters of private and public drug coverage.

Importance of Drug Coverage for People Living with and Affected by HIV

In Canada at the end of 2016, there were an estimated 63,110 people living with HIV, with an estimated 6-22% not yet diagnosed. Of youth who had been diagnosed, 81% were on HIV treatment. Of youth on treatment, an estimated 91% have achieved suppressed viral loads.[i]

More than 40% of people living with HIV in Canada reside in Ontario.[ii]

In 2016, in Ontario, 24.8% of new HIV diagnoses occurred among children and youth under the age of 25.[iii]

HIV treatment is the key to improving and maintaining the health of youth living with the virus and a linchpin in efforts to prevent transmission and control AIDS as a public health threat. Advancements in HIV treatment, including the introduction of highly active antiretroviral therapy (HAART) in the mid-1990s, have meant that (i) HIV has transformed into a chronic, manageable medical condition and (ii) the risk of transmission of HIV is greatly reduced or eliminated for youth being effectively treated[iv]. While this means that many people can live near-normal life spans with HIV as a chronic manageable illnesses (and without the risk of transmitting HIV), there are important caveats related to treatment access.

An interruption in treatment can be deadly. An interruption can result in a rebound of the virus, with a consequent reduction in health as well as the development of resistance to HIV medications that can result in reduced treatment options. Early treatment is vital as a delay in initiating treatment can result in negative health consequences.[v]

In addition, HIV medication is also prescribed to HIV negative individuals as a prophylaxis against infection, both as a pre-exposure prophylaxis (PrEP) and as a post-exposure prophylaxis (PEP).[vi]

HIV-related medications are costly. The price of a month's supply of daily HIV medications can run into thousands of dollars – rendering it unaffordable for most Ontarians. As a result, the most significant barrier to treatment access in Ontario is cost. Without universal public coverage, people living with HIV have to rely on a flawed patchwork of public programs and private insurance policies for coverage.

Given the vulnerability of youth[vii], the introduction of OHIP+ was a welcome buffer against barriers to HIV-related medication access, decreasing the risk of delayed antiretroviral therapy initiation for youth newly diagnosed and of treatment interruption for youth already living with HIV, and, increasing the protection of youth who are HIV negative and who use treatment as prophylaxis. While we recognize that youth who are not "captured by" a private insurance plan will maintain access to full drug cost coverage under OHIP+, we are deeply concerned that the Regulation change as it is drafted creates overly-expansive exclusions from coverage for any who are in any way captured under a private insurance plan, which will result in barriers to access to anti-retroviral treatment. Such barriers will increase the risk of:

a) negative individual health outcomes;
b) public health consequences [viii]; and
c) increases in public health care spending and other economic losses (e.g., workplace productivity)[ix].

We also recognize that these changes will impact treatment access and lead to negative health outcomes for HIV positive youth with other chronic illnesses managed with drug treatment.

Regulation Change under the Ontario Drug Benefit Act Will Result in Coverage Gaps

On June 30, 2018 Christine Elliott, Minister of Health and Long Term Care issued a statement about the government's intention "to fix the OHIP+ program by focussing benefits on those who do not have existing prescription drug benefits."[x] It further stated that "those who are covered by private plans would bill those plans first, with the government covering all remaining eligible costs of prescriptions."[xi] We recognize that the proposed changes to OHIP+ are intended to decrease public spending by shifting the province's role to that of "second payer" where there is private insurance drug coverage. However, the recently released draft Regulatory amendment to the *Ontario Drug Benefit Act* (the "Draft"), included below, will fall far short of covering the remaining costs of prescriptions outside of prescription drug coverage

under private plans. The Draft exclusions are overbroad and will terminate coverage for some youth living with HIV without adequate alternative private or public coverage, resulting in barriers to access to HIV-related medications.

ONTARIO REGULATION made under the ONTARIO DRUG BENEFIT ACT Amending O. Reg. 201/96 (GENERAL)

1. (1) Paragraph 3.1 of subsection 2 (1) of Ontario Regulation 201/96 is revoked and the following substituted:

3.1 Persons who are under 25 years of age and who do not have a private plan.

(2) Section 2 of the Regulation is amended by adding the following subsections:

(2.1) For the purposes of paragraph 3.1 of subsection (1),

"private plan" means an employer, group or individual plan, program or account, however described, **that could provide coverage** for, including the provision of funding that could be used to pay for, any drug product, **regardless of the following**:

1. Whether the drug product that could be eligible for coverage under the private plan is a drug product that has been prescribed for the person who has the plan and which the person is asking to be dispensed.
2. Whether the person who has the private plan or any other person **is required to pay a premium, co-payment, deductible or other expense**.
3. Whether the person who has the private plan **has exhausted their entitlement under the plan**.

(2.2) For the purposes of paragraph 3.1 of subsection (1), a person is considered to have a private plan **if they are in any way captured by the plan**, including, without being limited to, being captured as a named insured, an unnamed insured or an additional insured.

2. Subsection 20.1 (1.1) of the Regulation is revoked and the following substituted:

(1.1) Despite subsection (1), the maximum co-payment that the operator of a pharmacy or a physician may charge a person in respect of supplying a listed drug product for an eligible person who is under 25 years of age is $0, unless the person is an eligible person described in subsection 3 (1).

[emphasis added]

Specifically, the Draft operates to terminate OHIP+ for youth who "have a private plan." Moreover, the expansive definition of "private plan" under subsection (2.1) and of "have a private plan" under subsection (2.2) will leave some youth, including youth with no meaningful access to a plan and youth with access but no or only limited coverage for their prescribed medication, facing significant financial and other barriers to treatment.

In our work with clients, we have observed that such financial and administrative barriers are the primary reasons individuals avoid filling their HIV-related prescriptions. Lack of access or avoidance can lead to delayed antiretroviral therapy initiation for youth newly diagnosed, treatment interruption for youth already living with HIV, and decreased protection of youth who are HIV negative and who use treatment as prophylaxis. As a result, forcing youth off of OHIP+ restricts access to HIV-related medications thereby increasing the risks noted above. The specific areas of concern under the Draft are discussed in further detail in the following sections:

A. Youth "Captured by a Plan" Will Lose Full Drug Coverage

The expansive definition of "private plan" will result in the termination of OHIP+ even for youth whose drugs are not covered or who have illusory access to a plan, and consequently will restrict access to HIV-related medications. This is deeply concerning as, even if a drug is covered, the scope of coverage is often far from adequate due to deductibles, co-payments and caps present in insurance policies. In short, full coverage of drug costs under private insurance plans is rare, and based on the high cost of HIV-related medications, such features of insurance policies (as well as the requirement in some policies to pay, upfront, the full cost of medications) act as significant barriers to accessing treatment.

Similarly, administrative requirements for enrollment in a family private insurance plan and resultant time delays may result in a coverage gap. A youth could be terminated from OHIP+ without active private insurance coverage because the expansive definition of "have a private plan" under subsections (2.1) and (2.2) to include plans which "could" provide coverage and to youth "in any way captured" by a plan even before becoming enrolled in a family member's private insurance plan. In some cases, family members may be able to access optional dependent coverage but the youth has little or no control over whether, how or when the changes are made.

This may lead to delayed antiretroviral therapy initiation for youth newly diagnosed, treatment interruption for youth already living with HIV, and decreased protection of youth who are HIV negative and who use treatment as prophylaxis.

B. Trillium Drug Program Is An Inadequate Substitute for OHIP+

It is true that people in Ontario who have high drug costs relative to household income have access to the Trillium Drug Program (TDP). However, TDP is imperfect, and we have seen many people fall through the cracks.

Contrary to the government's statement about maintaining complete coverage, forcing youth to access TDP where there is a delay or shortfall in the scope of private insurance coverage will restrict access to HIV medications because TDP, unlike OHIP+, always requires payment of a deductible. Even a person with no net income is required to pay an annual TDP deductible.[xii] [xiii] Moreover, the TDP deductible is calculated on the basis of *household* income, which must include the income of family members, if the youth live with or are financially dependent on them, even in part.[xiv] This could lead to high out-of-pocket deductible amounts under TDP coverage.[xv]

Further, unlike OHIP+, there are significant administrative requirements[xvi] for TDP enrollment and resultant time delays that may result in a coverage gap.

This may lead to delayed antiretroviral therapy initiation for youth newly diagnosed, treatment interruption for youth already living with HIV, and decreased protection of youth who are HIV negative and who use treatment as prophylaxis. In fact, Canadian research on public prescription drug plan coverage "have shown that cost-sharing arrangements for antiretrovirals result in substantial numbers of patients who are unable to afford their medications and consequently, nonadherence."[xvii]

C. HIV and Privacy

HIV is a highly stigmatized condition that gives rise to complex privacy concerns for people living with or at risk of HIV. Even if the private plan covers HIV-related medications at 100% or there are no cost issues in relation to TDP, the stripping of OHIP+ gives rise to serious privacy-related barriers to access to HIV-related medication for youth.

A 2012 nation-wide study[xviii] of Canadian attitudes toward people living with HIV found that:

- **69%** believe that people would not be willing to tell others they have HIV/AIDS because of the stigma
- **55%** believe that people living with HIV/AIDS can experience difficulty obtaining housing, health care and employment because of the stigma
- **27%** feel uncomfortable wearing a sweater once worn by a person living with HIV/AIDS
- **25%** feel uncomfortable shopping at a small neighbourhood grocery store owned by someone living with HIV/AIDS.

HIV stigmatization is often associated with moral blame for those living with or at risk of HIV, and youth accessing HIV-related medications may forego treatment rather than risk having their family members learn of their HIV-status or the circumstances that lead to their need for the medication. Frankly, in some situations it would be wise for youth to keep such information from other household members as disclosure may result in rejection or worse. For some youth, such disclosure may also result in the unwanted sharing of information about sexual activity or sexual orientation, which may result in rejection or worse.

In essence, the loss of OHIP+ forces youth living with HIV to disclose their HIV status to family members in order to access medications under private plans or the TDP. This is highly unacceptable, and places youth at risk of isolation, violence, homelessness, and potentially worse, while also restricting access to HIV-related medications, which may lead to delayed antiretroviral therapy initiation for youth newly diagnosed, treatment interruption for youth already living with HIV, and decreased protection of youth who are HIV negative and who use treatment as prophylaxis.

Recommended Action to Reduce Negative Impacts

Forcing youth off of OHIP+ restricts access to HIV-related medications thereby increasing the risks noted above.

Therefore, we urge the Ontario government to maintain the OHIP+ program as it currently operates, so that all youth under 25 continue to have full coverage of medications.

In the alternative, we ask that you exclude HIV-related medications from the changes under the Draft.

We also urge you to amend the Draft to:

- **allow youth captured by private insurance coverage to maintain full OHIP+ coverage until enrolled so that there is seamless coverage; and**
- **allow youth with private insurance coverage to maintain OHIP+ as second payer, rather than relying on TDP so that there is comprehensive coverage.**

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[i] See Figure 6 in the Public Health Agency of Canada (PHAC) Report *Summary: Estimates of HIV incidence, prevalence and Canada's progress on meeting the 90-90-90 HIV targets, 2016*, Centre for Communicable diseases and Infection Control, Public Health Agency of Canada (PHAC), 2017: https://www.canada.ca/en/public-health/services/publications/diseases-conditions/summary-estimates-hiv-incidence-prevalence-canadas-progress-90-90-90.html.

[ii] *HIV/AIDS epi Updates: National HIV Prevalence and Incidence Estimates for 2011*, Centre for Communicable diseases and Infection Control, PHAC, 2014, Table 3: https://www.catie.ca/ga-pdf.php?file=sites/default/files/64-02-1226-EPI_chapter1_EN05-web_0.pdf.

[iii] *Percent of new HIV diagnoses by age and sex, Ontario, 2016*, the Ontario HIV Epidemiology and Surveillance Initiative, Table 1: http://www.ohesi.ca/new-hiv-diagnoses-by-age/.

[iv] Supported by various sources including: Canadian consensus statement on HIV and its transmission in the context of criminal law Can J Infect Dis Med Microbiol 2014: http://www.cfenet.ubc.ca/sites/default/files/uploads/news/releases/Statement%20(May%202-14).pdf at p. 4; *Your Guide to HIV Treatment*, CATIE 2017: https://www.catie.ca/sites/default/files/Your%20Guide%20to%20HIV%20Treatment_EN_web_march2017.pdf, at p. 9; Information *For health professionals: HIV and AIDS*, Government of Canada: https://www.canada.ca/en/public-health/services/diseases/hiv-aids/health-professionals-hiv-aids.html; Information about *Treatment of HIV and AIDS*, Government of Canada: https://www.canada.ca/en/public-health/services/diseases/hiv-aids/treatment-hiv-aids.html.

[v] *Canadian Guidelines on Sexually Transmitted Infections 2016 Updates Summary*, PHAC, 2017: https://www.canada.ca/content/dam/phac-aspc/migration/phac-aspc/std-mts/sti-its/assets/pdf/updates-summary-eng.pdf, see section "Early Initiation of antiretroviral therapy (ART)" at p.5. See also "British Columbia researchers study HIV treatment interruptions and their consequences", CATIE News, July 18, 2017: https://www.catie.ca/en/catienews/2017-07-18/british-columbia-researchers-study-hiv-treatment-interruptions-and-their-conseq.

[vi] *Canadian Guidelines on Sexually Transmitted Infections 2016 Updates Summary*, PHAC, 2017, per note v, at p.5.

[vii] Youth diagnosed with HIV at under 25 years old have the highest associated life years lost (32-45 life years lost) than all other ages at infection, see Table 3 in *The Economic Cost of HIV/AIDS in Canada*, Canadian AIDS Society, 2011: http://www.cdnaids.ca/wp-content/uploads/Economic-Cost-of-HIV-AIDS-in-Canada.pdf.

[viii] Because viral suppression has the dual effect of improved health outcomes for people living with HIV, and reducing and even eliminating the risk of onward transmission, treatment is central to a global public health strategy. In fact, Canada has endorsed The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization global health sector strategy that includes global targets to generate momentum towards the elimination of AIDS as a public health threat, "including the specific set of 90-90-90 targets that by 2020, 90% of all people living with HIV know their status, 90% of those diagnosed receive antiretroviral treatment, and 90% of those on treatment achieve viral suppression." PHAC Report *Summary: Estimates of HIV incidence, prevalence and Canada's progress on meeting the 90-90-90 HIV targets, 2016* as per note i.

[ix] For a discussion of the economic cost of HIV, see *The Economic Cost of HIV/AIDS in Canada*, Canadian AIDS Society, 2011: http://www.cdnaids.ca/wp-content/uploads/Economic-Cost-of-HIV-AIDS-in-Canada.pdf. Table 1 sets the dollar estimate of the Net Present Value of the Lifetime Economic Loss Attributed to All Those Who Tested Positive in 2008 including health care costs, lost productivity and quality of life of $1,300,000 per person. Table 4 estimates that health costs increase with treatment delays.

[x] Ministry of Health and Long-Term Care Statement: *Ford Government Making OHIP+ More Cost-Effective*, June 30, 2018: https://news.ontario.ca/mohltc/en/2018/06/ford-government-making-ohip-more-cost-effective.html.

[xi] As above, per note x.

[xii] A single person with net income of $0 to $6,500 in a year pays an annual deductible of $350. See the deductible table in *A Guide to Understanding the Trillium Drug Program* (TDP): https://www.ontario.ca/page/get-help-high-prescription-drug-costs.

[xiii] Ontario's TDP results in higher out of pocket costs for HIV medications than public drug coverage programs in other provinces: "For example, in Nova Scotia, for both case scenarios, there is no premium and no deductible, but there are 4 copayments of $11.25 for each 90-day prescription totalling $45 annually. While there is also no premium in Ontario, the man with an income of $39,000 would be required to pay an annual deductible of $1,344 (3.4% of $39,000) plus 4 copayments of $2 for each of his prescriptions, resulting in $1,352 paid out-of-pocket.", *Public prescription drug plan coverage for antiretrovirals and the potential cost to people living with HIV in Canada: a descriptive study*, CMAJ Open, 2018: http://cmajopen.ca/content/6/4/E551.full, at p. E552.

[xiv] In fact, even reliance on a family member's private health insurance coverage itself may be a basis for characterizing the youth as financially dependent.

[xv] For example, a family of three with a combined net income of $80,000 would be responsible for $3,039 annual deductible before accessing public drug coverage under TDP; a family of four or more with the same combined net income would pay marginally lower deductible of $2,989 annually. A family of three with a combined net income of $100,000 would be responsible for $3,939 annual deductible before accessing public drug coverage under TDP; a family of four or more with the same combined net income would pay marginally lower deductible of $3,889 annually. See the deductible table in *A Guide to Understanding the Trillium Drug Program* (TDP) as per note xii.

[xvi] For example, if a household is not already enrolled for TDP, they will have to provide financial information from the tax returns of every member of the household as well as private insurance policy information. While it is possible to enroll without a tax return, providing alternative proof of income (e.g., pay stubs from all household members) can be more administratively complex. An applicant is also required to provide signatures from each member of the household. If a youth is financially independent, the youth is required to obtain signed statements from family members attesting to financial independence.

[xvii] *Public prescription drug plan coverage for antiretrovirals and the potential cost to people living with HIV in Canada: a descriptive study*, as per note xiii, at p. E559.

[xviii] *2012 HIV/AIDS Attitudinal Tracking Survey*, PHAC: https://www.catie.ca/ga-pdf.php?file=sites/default/files/2012-HIV-AIDS-attitudinal-tracking-survey-final-report.pdf, at p. x.