JUSTICE FOR CHILDREN AND YOUTH

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Via electronic submission

Commentary to the Ministry of Health and Long-Term Care

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Regarding the Proposed Amendments to Ontario Regulation 201/96 made under the *Ontario Drug Benefit Act*

Introduction

Thank you for the opportunity to provide comments on this important regulatory change. We applaud the government for pursuing the objective of "*focusing benefits on those who need them most*" and continuing to recognize that children and youth are a vulnerable group that needs coverage through OHIP+ to access prescription drugs.

We ask the government to maintain the current OHIP+ for all children and youth under 25 years of age as the change in regime proposed will create economic disparities between families across Ontario, cause financial hardships, result in delays and barriers to treatment and will not save the province money.

In the alternative, we ask that the government provide second payer coverage through OHIP+ for children and youth who have access to a private plan to bring all children and youth to the same level of full coverage.

About Justice for Children and Youth (JFCY)

JFCY is a non-profit specialty legal aid clinic that provides legal services to children and youth under the age of 18 years in Ontario and to homeless youth up to the age of 25 years through our Street Youth Legal Services program. Our services include legal representation for young people in diverse areas of the law and in various systems, including criminal justice, education, social services, child protection, health and mental health. Most of our clients have multiple legal concerns, and come to us with complex personal and social backgrounds. Our comments, case studies and recommendations are based on our unique perspective and extensive experience providing legal services for children and youth across Ontario.

Commentary

Children and youth are particularly vulnerable with respect to their healthcare needs as any delay or barriers in receiving timely treatment can cause poorer health outcomes.[i]

We have framed our commentary around four co-related concerns:

a) Private plans do not provide full coverage
b) Cost barriers and administrative delays
c) Access to the private plan
d) Overall cost savings are illusionary

a) Private plans do not provide full coverage

The proposed change creates a stark distinction between children and youth with access to a private plan and those without a private plan; and fails to address the significant costs that families with access to private plans will incur. The Canadian Medical Association has reported that these changes will not provide better coverage of medications and will hit the middle class the hardest.[ii]

The impact is that those with private plans will have to cover many out-of-pocket expenses before any drugs are even prescribed; specifically, in the form of co-payments and premiums for the plans themselves.[iii] These front-end costs can be significant, especially for lower income families, as many private plans have co-payment costs to the employee; and a further additional and often exorbitant cost to "bump up" to the level of 100% prescription drug coverage.

On top of these costs, the proposed change is overly broad in that it excludes public coverage or top-up for other out-of-pocket private plan expenses such as deductibles (which can be in the hundreds of dollars) and for prescription drugs that are not covered by the private plan.

Studies show that Canadians will skip doses or reduce dosages, delay refilling prescriptions or not fill prescriptions at all to reduce their drug costs – a phenomenon known as cost-related nonadherence; and that when out-of-pocket costs are $25-50 or even less, it can prevent someone from filling out a prescription.[iv] Plus as a result of the out-of-pocket costs under the private plan system, some families will be forced to make the hard choice between paying for much needed drugs, or for other basic necessities such as food, heating and housing.[v] This is of utmost concern as children and youth rely on their adult care-givers to provide for and assist them.

Also of concern is the full exclusion of those with private plans to OHIP+ coverage even when prescription drug entitlements under a private plan have been exhausted. As described in the next section, an alternative such as the Trillium Drug Program does not resolve the barriers and may fail to meet the needs of a child or youth with a vulnerable health status.

b) Cost barriers and administrative delays

The proposed change to OHIP+ will negatively impact the health of children and youth through the creation of cost associated barriers and administrative delays; and does not meet the Province's goal of "*focusing benefits on those who need them most"*. It is the vulnerable children and youth of Ontario, in all stages of their developmental growth, that have benefitted the most through the current OHIP+ program that provides 100% cost coverage for prescription drugs.

In addition to the cost associated barriers mentioned above, there will be further significant barriers for children and youth with higher prescription drug costs related to chronic, serious or sudden onset of healthcare needs. Prescription drugs can prevent and cure illnesses, and lessens other demands on the healthcare system by reducing the need for additional health practitioner visits and emergency care admissions.

Statistics Canada reports that the most frequently used medication and/or most expensive drug classes for children and youth are for attention deficit and hyperactivity disorder, depression, asthma and contraception.[vi] These are a few of the common needs of children and youth that may go unmet under the proposed amendments.

Families with private plans will have to turn to the Trillium Drug Program for any significant out-of-pocket costs. This requirement fails to recognize the potentially serious and life threatening impact of the administrative barriers and delays of this program which includes completing a complicated application every year, document gathering, proof of income that includes any income from children in college or university, processing delays, and having the extra finances to be able to pay the deductibles.[vii] This creates barriers to access medications that can prevent or cure a serious illness or disease, in particular where treatment must begin immediately to ensure a positive outcome.[viii] These are hardships that no parent or guardian would want their child to go through.

> Case study:
> Simon is 14 and was just diagnosed with cancer. Simon's mom works part time and has no health plan, and Simon's dad just started his job at the factory in town which has a health plan that covers 80% of prescription drug costs. However, only some of the drugs required to treat Simon's cancer is covered under his dad's plan and the more expensive ones are not. The doctors believe Simon would respond well to the cancer treatment if he starts immediately. Simon's parents struggle for over two weeks to complete Trillium Drug Program application and were told they may have to wait another four to six weeks for a decision. Meanwhile, the family is devastated as Simon's health continues to deteriorate.

As stated above, some families with private plans with many out-of-pocket costs will be forced to make the hard choice of paying for much needed drugs or other essential

household needs.[ix] The access and use of prescription drugs for children and youth should be based on medical needs; needs that, if unmet, can lead to lifelong health consequences.[x] It is essential that that health policies facilitate rather than deter optimal medical management by removing financial barriers.[xi]

c) Access to the private plan

In addition to the administration and cost barriers, the existing OHIP+ that provides full drug coverage for all children and youth addresses the social and/or psychological barrier of being embarrassed and/or protecting oneself from the stigma attached to needing medications for sensitive healthcare issues; for example, mental health related mood disorders, gynecological and reproductive needs;[xii] and it also protects youth over 16 who have been kicked out or forced to leave home due to abuse.

A program that does not require a young person to ask for money from their caregiver for prescription drugs means that treatment for sensitive healthcare issues can be sought out and that the medications prescribed can be easily accessed, while protecting a young person's right to privacy and reducing the stress or embarrassment of having to share this private information. Privacy protection might also be required if the young person has a fear of reprisal and/or punishment by a caregiver who does not support the young person's needs or does not believe that the young person is having health issues. Although some of these medication needs may be short-lived, some may have far-reaching consequences; the difference between having a private plan and the full OHIP+ coverage may mean the difference in preventing long-term health problems.

Similarly, in circumstances where a young person finds themselves homeless and has been listed on a caregiver's private plan, full coverage under the current OHIP+ means that there won't be any interruption or delay in accessing prescription drugs. Being kicked out or leaving home due to abuse does not usually allow time for a young person to plan and discuss their departure; if anything, it is usually an abrupt event that leads to a series of traumatic changes. It will be the responsibility of the caregiver to remove the young person from the private plan, and without removal, the young person may be unable to continue their medications or access drugs for new healthcare needs. Of concern is that may also result in the young person returning home to a dangerous situation if the medication needs are serious. Even if the young person has the capacity to seek out legal and social service supports, delays to remedy such problems can still take weeks or months.

> Case study:
> Andrew is 16 years old and was diagnosed with type 2 diabetes at a young age. He is listed under his parent's insurance but had to leave home due to abuse and is staying with a friend. Under the current OHIP+ program, Andrew would continue to get his refill for diabetes related medications; however, under the proposed OHIP+ regime, he would be told that he is under his parent's private plan (which covers 70% of the drug cost) and will not be given his refill unless he pays the remaining

balance. As a result, Andrew starts rationing his remaining medication. He is afraid to return home and does not have money to pay for the refill. He experiences blood sugar fluctuations at school and passes out during one of his classes. He explains his rationing strategy to the hospital staff when they take his blood tests; and they tell him he should just return home even if he does not feel safe. Andrew continues to hoard his medication upon his release and is hospitalized again soon after.

d) Overall cost savings are illusionary

There will be no budgetary benefit to Ontario by eliminating prescription drug coverage to all children and youth who have access to a private plan; and will not save the province money.[xiii] In fact, there will be increased costs from additional physician visits, hospitalizations and emergency care needs; as well as costs associated with exacerbated social vulnerability and mental health issues, and long-term harm to the health and well-being of children and youth.[xiv] This will also impose a new level of inequity for middle class families in the form of premiums, deductibles, copayments & coinsurance costs related to having a private plan; costs which are ever increasing.[xv]

Recommendations

Maintain the current OHIP+ for all children and youth under 25.

In the alternative, ensure a seamless system is created where OHIP+ is second payer to cover the prescription drug costs for children and youth under 25 who have access to a private plan.

Thank you for your consideration of our comments.

Justice for Children and Youth

[i] Government of Canada. (2018). *Towards Implementation of National Pharmacare: Discussion Paper, at p 14.* Retrieved from: https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/implementation-national-pharmacare/discussion-paper.html

[ii] Collier R, CMAJ (2018). Decisions by new Ontario government worry science and health care communities. *Canadian Medical Association Journal, 190*(30), E917-E918.

[iii] Government of Canada. (2018) at p 4, 6 and 14.

[iv] Law MR, Cheng L, Kolhatkar A, et al. (2018), The Consequences of patient charges for prescription drugs in Canada: a cross-sectional survey, *Canadian Medical Association Journal, Open*, 6(1), E63-E70. DOI:10.9778/cmajo.2080008, at E63 and E66; and Government of Canada. (2018) at p 14.

[v] Daniels C, Ungar WJ, McNeill T, & Seyed M. (2003). Children in Need of Pharmacare: Medication Funding Requests at the Toronto Hospital for Sick Children. *Canadian Journal of Public Health, 94*(2), 121-6, at 121-122; and Law MR, Cheng L, Kolhatkar A, et al. (2018) at E67.

[vi] Rotermann, Sanmartin, Hennessy and Arthur. (2014). Prescription medication use by Canadians aged 6-79. Stats Can. 25 (6), pg. 3-9.

[vii] Daniels C, Ungar WJ, McNeill T, & Seyed M. (2003) at p 123.

[viii] Daniels C, Ungar WJ, McNeill T, & Seyed M. (2003) at p 122-123.

[ix] Daniels C, Ungar WJ, McNeill T, & Seyed M. (2003) at p 122.

[x] Government of Canada (2018) at p 4, 5 and 8.

[xi] Daniels C, Ungar WJ, McNeill T, & Seyed M. (2003) at p 125.

[xii] Rotermann, Sanmartin, Hennessy and Arthur. (2014) at p 6.

[xiii] Collier R, CMAJ (2018). Decisions by new Ontario government worry science and health care communities. *Canadian Medical Association Journal, 190*(30), E917-E918.

[xiv] Law MR, Cheng L, Kolhatkar A, et al. (2018) at E66 and E67, and Government of Canada. (2018) at p 5.

[xv] Government of Canada. (2018) at p 4 and 6.