Court File No. T-1301-09

FEDERAL COURT

BETWEEN:

Nell Toussaint

Applicant

and

Attorney General of Canada and Minister of Health

Respondents

APPLICATION UNDER section 18.1 of the *Federal Courts Act*, R.S.C. 1985, c. F-7

Affidavit of Ilene Hyman

I, Ilene Hyman, Ph.D., of the City of Toronto, Province of Ontario, professor of Public Health, make oath and say:

1. I hold the degrees of B. Sc. (Physical Therapy), M.H.S.c. (Community Health and Epidemiology) and Ph.D. (Public Health). My primary affiliation is with the Dalla Lana School of Public Health Sciences at the University of Toronto. I am also a research affiliate of CERIS – The Ontario Metropolis Centre. For the past 20 years, my research focus has been on health and health access issues faced by immigrant and marginalized populations in Canada. I have written several policy reports on immigration and health for municipal, provincial and federal health departments and I do research consulting in this area. Attached hereto and marked as exhibit "A" is a copy of my curriculum vitae.

2. A major area of concern for immigrants without status is their lack of access to social and health services. People without status are not entitled to provincial health insurance in Canada. Most immigrants without status have to pay out of pocket for medical services received, and this is a tremendous burden for this group who are already experiencing financial insecurity.

3. In Ontario, some funding is provided to community health centres to provide limited health services to this population. In Toronto, the Toronto Central Local Health Integration Network (LHIN) funds Community Health Centres (CHC) to deliver primary healthcare to the uninsured. While uninsured is a broad category, it generally includes members of the military/RCMP, permanent residents in their first 3 months in Canada, federal penitentiary inmates, those who have lost their OHIP card (people who are homeless, have mental illnesses etc.) and some precarious status migrants (Elgersma, 2008). As such, this funding both facilitates and limits points of access. While some uninsured patients can receive care through these avenues, many do not because of eligibility restrictions and lack of resources. For example, Community Health Centres receive some funding for uninsured patients but this is often not enough for what some see as an increasing precarious migrant population: "To date, CHCs have been provided with funds by the Ministry of Health and Long-Term Care to pay for services for non-insured clients, but the funds are not enough, can be exhausted with several high-needs

patients, and rely on the goodwill of hospitals to actually provide care" (Gardner, 2008). Thus even among those who receive care, that care may not be sufficient.

4. Lack of access to specialized care and a lack of continuity of care are other serious issues for immigrants without status. At present the system does not permit access to specialized care in a systematic way. The *ad hoc* nature of service makes it difficult to make referrals or provide additional care, because subsequent health professionals or even other staff members might not agree to serve a given client. As a result, health services may not be consistent or reliable. This may lead to "run around" for uninsured people trying to access services (Access Alliance, 2005). The situation also places a heavy burden on front-line service providers – one study found that "they spend a considerable amount of time trying to negotiate for services to be made accessible to individuals, to ensure that paperwork is up to date and correct, and to try to protect [clients] from direct bills or from the threats of the collecting agencies" (Elgersma, 2008).

5. There are many organizational barriers to providing access to health care for immigrants without status and these have been described in a brief submitted to the Precarious Status Research Group at CERIS (Villegas et al., 2009). Among organizational challenges faced by publicly funded institutions when they work with immigrants without status are inconsistencies in the policy and legislative directives that frame the rights of immigrants without status between provincial and federal departments and across provincial government institutions. However

even when policy directives exist in terms of providing services for immigrants without status, these policies are often subject to considerable variation of interpretation and discretionary decision-making on the part of local institutions and frontline staff. In my opinion, such inconsistencies can put immigrant families without status at increased health risk, and can undermine the effectiveness of public institutions. Immigrants without status may distrust service providers and avoid institutional situations in which questions about their status may arise. This puts additional pressure on the capacity of public institutions to work effectively with immigrants without status.

6. Service providers in Toronto have reported that many agencies (health and otherwise) do not have an official policy about working with immigrants without status (Berinstein, 2006). While some frontline workers in different sites of health care delivery have developed informal networks of access in order to provide some health care to immigrants without status, these are not "sustainable" mechanisms of access. Some doctors in hospitals may have clauses in their contracts that bind them to treat a certain number of uninsured clients. However, this is not a consistent practice. Physicians treating non-OHIP patients may also be able to set their fees without regulation from the government, and hospitals have been known to use collection agencies for those unable to pay. Health care workers often tell patients to come directly to their office rather than presenting at the front desk, or process patients without keeping records of it (Rousseau et al., 2008).

7. According to Villegas et al (2009), access barriers for immigrants without status lead to the individualization and invisibilization of health care. When individuals are dealt with on a case by case basis often systemic barriers are not addressed. It also does not protect immigrants without status, when seeking care, from fees including those for service delivery and laboratory work. While some service providers and advocates are becoming more active in visibilizing the problems faced by immigrants without status when receiving care (Community Health Centres of Greater Toronto, 2008; Women's College Hospital's Collaborative Task Force on Uninsured and Undocumented Clients, 2008), and include immigration status as a factor that affects health and wellbeing, there is a tension between such promotion and the actual availability of services. Hospitals and clinics are financially stretched, may have long waiting lists, and may be unable to accept new clients or referrals. Thus, patients may have to go from clinic to clinic (or hospital to hospital) before they receive care. In addition to this, there is a decrease in the number of doctors who specialize in general medicine or family practice, while more established doctors are overworked and unable to accept new patients.

8. In addition to access barriers directly associated with lack of status, my research has identified other access barriers – informational, financial, linguistic, cultural and systemic (Hyman, 2001) and these barriers are especially prominent for immigrants without status. Some examples are provided below.

- Informational – These refer to a lack of knowledge about services – both settlement and otherwise.

- Financial – Poverty affects the ability of immigrants to live well, secure necessary health services, and participate in/access municipal and community programs. The high cost of private health insurance puts this option out of reach for the large majority of immigrants without status. Barriers to government services such as welfare and housing and health services represent a major obstacle for immigrants without status (Oxman-Martinez et al., 2005). Caulford & Vali (2006) described the effect of not having health insurance on immigrants and refugees (including claimants) using Scarborough Clinic data; the majority of attendees were female and had experienced deficiencies in prenatal care. Lack of access to health care except what is provided through community health centres (where available) results in huge medical bills that families are paying off for many years and more often delaying seeking treatment for anything but the most serious conditions (Simich, 2007).

- Language - The largest single access barrier to government and community services is language. Language barriers may be increased for immigrants without status who may have had less opportunity to learn an official language. In the area of health, language barriers have been associated with increased risk of hospital readmission, drug complications, lower rates of optimal pain medication and less

access to mental health services. There is some evidence that language barriers may also be related to less adequate management of chronic diseases such as diabetes and asthma (Hyman, in press).

- Cultural – Perceptions of cultural incompatibility are barriers to necessary serves and also limit immigrants' social integration. In the area of health, treatment decisions flow directly from health beliefs. Cultural barriers include lack of knowledge of services, lack of culturally appropriate services, racism and fears of becoming involved with the Canadian legal system as a result of experience with repressive regimes in the country of origin. Several reports have highlighted the need for policies and programs to ensure staff training in culturally sensitive practice methods, including the use of culturally consistent ideology.

- Systemic - Systemic barriers refer to existing formal and informal structures and processes that maintain the status quo, and act as a barrier to access and effective participation of marginalized groups. A useful definition of institutional racism was provided by the Stephen Lawrence inquiry, i.e., "the collective failure of an organization to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. This can be seen or detected in processes, attitudes, and behaviour that amount to discrimination through unwitting prejudice, ignorance, thoughtlessness, and racist stereotyping which disadvantages people in ethnic minority groups". Systemic barriers likely contribute to all of the barriers described above. Immigrants and service

providers testify that immigrants without status avoid health and social services out of fear of deportation (Simich, 2007). Several researchers noted the "run around" that uninsured people typically experience when trying to access services. In some cases, individuals experienced long waiting lists, racism or offensive treatment, rude staff members, or were denied service altogether. Frustration over these factors combined with a lack of information in general about services led to eventually giving up and not receiving the much needed care.

9. Two types of health consequences for immigrants without status were noted in the literature. The first concerns their lack of access to health services and the second concerns their lack of legal status.

10. Health Consequences related to Lack of Access: According to Health Canada, access to health care is considered to be a significant determinant of population health in Canada. Immigrant families waiting through the three-month eligibility period may delay seeking medical care for financial reasons, and the non-status population may be reluctant to present themselves for medical care for fear of jeopardizing their position in Canada. Delayed care, in turn, can have serious health implications, ranging from complications in pregnancy, to more severe health needs (for instance, a ruptured appendix) to even death (Rousseau et al., 2008). Research shows that parents' immigration status affects the whole family. Parents' without status fear of discovery may prevent them from inquiring into

potential health benefits for Canadian-born children and may prevent them from presenting their children for care (ter Kuile et al., 2007; Bernhard, 2007). Accordingly, the incidence and extent of problems in accessing health care may be underestimated.

11. Health Consequences related to Lack of Status: Immigrants may be at particular high risk for negative health and mental health consequences, and that the precarious nature of their lives may exacerbate existing health issues. The impact of living without valid status or access to the process whereby status can be acquired creates physical, emotional and psychological threats to health, and ability of families and children to adapt and integrate into Canadian society. According to the Canadian Council for Refugees, the long waits without status create anguish, including extended family separation, limited access to education and employment, and lack of access to credit or loans, which seriously affects parent and children's emotional and mental integrity. The arbitrariness, the delays over several years, the uncertainty, and the constant fear and stress and the separation of family members results in feelings of hopelessness, lack of control, and mental and physical stress (Simich, 2006). Women are particularly vulnerable for a variety of reasons (responsibility for children, more financially dependent on spouses, more likely to be victims of abuse and violence). They are more likely to work as cleaners, caregivers, or factory workers in unsteady low paying jobs, to lack resources, savings and English language skills, and to have unmet health care needs (Simich 2007b). In interviews women were more likely to show emotional

distress and to reveal traumatic experiences than men. Most of the studies articulated that all study participants entered Canada legally and attempted to follow correct immigration procedures. Even those legitimately awaiting immigration decisions were fearful of being deported. Present and future uncertainty took a great toll on their health. All came for reasons of personal security to escape rape, violence, police harassment, political threats violence against self and family members and life-threatening situations (Simich, 2006). Most reported emotional suffering from chronic stress, depression and family separation.

12. As previously discussed, uninsured immigrants who access medical services have to pay out of pocket, which may be very costly. Research and media reports indicate that costs for hospitalization are often in the tens of thousands of dollars, creating a barrier to medical care and a significant additional financial burden. The debt affects not only immigrants themselves, but also their families overseas, who, for instance, may not be able to reunite under the live-in caregiver program, or who may not receive remittances, because of the health care debts. Vulnerability to the risk of unaffordable medical expenses separates established Canadian citizens and permanent residents from newcomers and others who are uninsured.

13. There has been limited research on issues related to immigration and settlement for people with disabilities. Among the prominent issues faced by racialized

people with disabilities are difficulties accessing appropriate services. In my opinion, these issues are compounded in the case of immigrants without status because financial insecurity is coupled with the lack of access to required services. These findings are consistent with the notion of 'multiple minority groups' introduced by Barile (2000) to describe the double, triple or more layers of oppression experienced as a result of varying minority statuses. Thus, the health and social consequences associated with immigrants' lack of status are intensified when one considers their intersections with disability, racialized status, income insecurity and gender that contribute to marginalization and social exclusion.

Full citations for the above in-text citations are set out below:

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Sworn before me at the City of)
Toronto, in the Province of Ontario)
this 25th day of August, 2009)

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Ilene Hyman

Andrew C. Dekany, a commissioner for oaths