

# Children Living with HIV: Reshaping Law and Policy in Québec to Preserve and Promote Their Rights

Angela Campbell\*

## Introduction

In 1999, 97 cases of AIDS among children and adolescents under the age of fifteen were reported in Québec.<sup>1</sup> On its face, this apparently low figure may suggest that this issue does not deserve much attention from the medical and legal communities in the province. The rate of pediatric AIDS seems particularly minimal when it is compared to the number of adults in Québec living with the illness, which in 1999 totalled 5,458.<sup>2</sup> In light of this contrast, it is understood why medical research and the academic discourse on HIV and AIDS have concentrated primarily on adult populations, while children have been considered only peripherally. Nevertheless, although children may suffer from HIV at a less alarming rate than persons of full age, the repercussions of this illness are just as significant for children as they are for adults. While many of the effects of HIV are shared by adult and pediatric HIV patients alike, others are particular to children. Thus, to fully understand the implications of HIV in childhood, the specific impacts of this illness on the lives of children must be considered.

Accomplishing this objective will require all professionals who deal with HIV-related issues to push children to the forefront of their concerns. Jurists are among those who must undertake this task, given that the law is often called into play when topics linked to HIV arise. Yet, despite this, legislators and legal academics in Canada and Québec have paid very little attention to the distinct legal questions that surface in the context of pediatric HIV. The goal of this paper is to address these issues and investigate the particular ways in which law and policy impact the lives of HIV-positive children.

---

\*Angela Campbell is a Law Clerk at the Supreme Court of Canada 2000-2001 and recently completed her LL.M at Harvard University.

<sup>1</sup>Information about the AIDS rates among different population groups in Québec was received from Les enfants de Béthanie, an organization that works with children affected by HIV and AIDS in the Montreal community. This organization received its statistical information from the December 1999 report of Le Centre québécois de coordination sur le sida.

In considering the statistics related to pediatric AIDS or HIV in Québec, the reader must bear in mind that they reflect only those cases that are known and have been reported. In many instances, a child and her family may not even be aware that she has HIV. Furthermore, even if there is knowledge of this illness, a family may be reluctant to reveal this information, fearing the harmful social consequences that may befall a child who is HIV-positive.

<sup>2</sup>Les enfants de Béthanie, *ibid.* In this context, “adults” include all persons over the age of 19.

In Québec, the necessity of this analysis and discourse is underscored by the fact that the numbers presented above may not accurately indicate just how pressing the issue of pediatric HIV has become. Although 97 children were reported to be infected with AIDS in 1999, it is estimated that the number persons under age 15 with HIV is actually 4 or 5 times greater than this.<sup>3</sup> The rate of HIV and AIDS among children in Québec also appears to be slowly increasing, given that between 1998 and 1999, four additional cases of AIDS diagnoses in children were reported.<sup>4</sup> Moreover, from a geographical perspective, Québec appears to have the most serious problem of pediatric AIDS. While 97 cases of the illness were reported in 1999 for Québec alone, Health Canada reported that 196 children aged 0 to 14 years old were living with AIDS throughout all of Canada in that same year.<sup>5</sup>

These figures indicate that studies concerning children with HIV in Québec are not only relevant, but they are also necessary to ensure that the rights, needs and interests of such children are protected and preserved. Initially, it may appear that the law's role in this domain will be marginal in comparison with that of other disciplines. If asked to consider how the lives of HIV-positive children can be improved, our thoughts may turn immediately to physicians and biomedical researchers whose work may allow these children to live longer and healthier lives. We may also consider social workers as intimately connected to children with HIV. For a variety of reasons that are explored below,<sup>6</sup> a disproportionate number of these children may end up in foster care or protective custody, providing social workers with a critical role in ensuring that they receive the protection, care and support required by their state of health.

Although law may have a less obvious relationship with pediatric HIV than medicine or social work, the legal community also has the potential to make a significant contribution to the lives of HIV-infected children. In particular, the law may promote some of the interests and values that children with HIV consider most critical. For the law to be meaningful for HIV-positive children and youth, it must consider and reflect the issues that are of foremost importance to them. For the purposes of this paper, an article that compiled short essays and artistic works by children with HIV was considered to determine some of the concerns that are most

---

<sup>3</sup>Telephone interview with Le Centre maternelle et infantile sur le SIDA, an organization working with HIV-infected children and mothers in Montreal (8 April 1999).

<sup>4</sup>Information regarding 1999 rates of pediatric AIDS in Québec was obtained by documentation provided by Les enfants de Béthanie, *supra* note 1. Information regarding 1998 rates of pediatric AIDS in the province was received from the website of Le Ministère de la Santé et les Services sociaux du Québec, online: <<http://www.msss.gouv.qc.ca/fr/statisti/indisp/niveau5/vih.htm>> (date accessed: 3 March 1999).

<sup>5</sup>Health Canada, *Actualités en épidémiologie sur le VIH/sida* (Ottawa: Actualités du Bureau du VIH/sida et de la tuberculose Laboratoire de lutte contre la maladie, 2000). I am again indebted to Les enfants de Béthanie for its assistance in providing me with information from this report.

<sup>6</sup>See discussion, *infra* notes 47-48.

significant to them.<sup>7</sup> This article referred to works completed by 24 HIV-infected children and adolescents and 8 non-infected siblings. These children ranged from 5 to 17 years of age, and all were from the United States. Although their stories and pictures differed depending on their distinct situations, two common themes threaded the ideas they put forward. First, these children expressed their hope for a cure for HIV, or at least, for quality medical care that would strive to prolong their lives and preserve their health. Second, many of them conveyed a desire to be treated with equality and dignity, and a hope that having HIV would not interfere with their ability to socialize and interact with their peers.<sup>8,9</sup>

This paper strives to determine whether these two interests that seem to be critical in the eyes of HIV-positive children bear the status of “rights” that are recognized and enforceable in Québec. Although various provisions in the U.N. Convention unequivocally afford all children rights that would cover the concerns articulated by these children with HIV, law and policy in Québec is less clear in this regard. As such, this paper assesses whether current legal standards in the province meet the requirements imposed on states by the U.N. Convention. Where law and policy fail to adequately address the rights, needs and interests of children living with HIV, improvements will be suggested through a series of specific recommendations addressed to the Québec government. While the analysis undertaken here focuses on Québec, it should not be considered as bearing relevance only in this setting. Despite variations in social and legislative circumstances in different provinces, the discussion presented in this paper is

---

<sup>7</sup>See L. Wiener *et al.*, “Children Speaking with Children and Families about HIV Infection” in P.A. Pizzo & C.M. Wilfert, eds., *Pediatric AIDS: The Challenge of HIV Infection in Infants, Children, and Adolescents*, 2<sup>d</sup> ed. (Baltimore: Williams & Wilkins, 1994) 937. Other useful mechanisms that may be employed to ensure that legislation and policy reflects concerns voiced by children include interviews or discussions with children and surveys in schools or community service programs.

<sup>8</sup>Although the children considered in this study were not from Québec, their artistic and written expressions represent one of the scarce resources available for accessing the voice of HIV-positive children, and thereby learning about how they understand and experience their illness. Moreover, the fact that common themes linked their stories and drawings is telling, and suggests the importance that HIV-positive children attach to quality medical services and to freedom from discrimination. For these reasons, the reflections of these children guide the discussion that takes place in the present paper.

<sup>9</sup>Another concern expressed by children with HIV is that their illness may threaten the integrity of their family. The state’s obligation to respect family unity and privacy insofar as possible is established at articles 2, 5, 9, and 16 of the *United Nations Convention on the Rights of the Child*, 20 November 1989, GA Res. 45/25 UNGA Doc. A/RES/44/25 (1989) [hereinafter “U.N. Convention”]. Although this issue is less obvious at first glance, it does arise in this context given that family members’ children with HIV also may be infected with the illness. As such, parents of children with HIV often die or become too ill to care for their children, causing a disproportionate number children with HIV to end up in foster care. See. S. Oletto *et al.*, “Paediatric AIDS: A New Child Abuse” (1994) 400 *Acta Paedrica Suppl.* 99. Therefore, an analysis of the way in which the law interacts with the HIV-infected child in the context of her family also is imperative. Although the scope of this work does not permit a complete assessment of this topic, it is considered to some degree below, where the rights of foster children to participate in medical research are considered. See discussion, *infra* notes 47-51.

framed in a manner that attempts to ensure its relevance and applicability throughout Canada.

Part I of this paper considers the right of children to medical services in the province. The issues raised in this section will be considered in light of article 24 of the U.N. Convention which obliges states to ensure that children enjoy the "highest attainable standard of health". The focus of Part I will be on the need for the inclusion of children in medical research concerning HIV. The law in Québec regulating the participation of minors in experimental treatment requires refinement so that children who might otherwise be excluded, most notably those in foster care and protective custody, may enroll in medical research and enjoy the benefits of this. At the same time, this law must be carefully crafted to protect minors from the potential risks that they may face as research subjects. These risks, and the safeguards required to protect children from their materialization, are explored within this discussion.

Part II of this paper deals with the rights of privacy, dignity and equal treatment for children, and is intended to address a child's fear that having HIV will prevent her from associating freely with her peers. Given that the most frequent locus of child-socialization is the school setting, Part II will focus on the rights of children with HIV to attend and participate in academic and extra-curricular activities in daycares and schools. In this section, relevant legislative provisions and jurisprudence will be considered to discern whether the exclusion of an HIV-positive child from a school or daycare can be legally upheld. This analysis will be guided by various provisions of the U.N. Convention which confer rights to protection from discrimination (article 2); freedom of association (article 15); education, social integration and individual development for children with disabilities (article 22); equal opportunity in the context of education (article 28); and equal opportunity in the context of cultural, artistic, recreational and leisure activity (article 31). To ensure maximum protection of these rights for HIV-positive children, a broad understanding of the "duty to accommodate" is required. Thus, specific measures aimed at ensuring that children are permitted to enter and remain in daycares and classrooms, and that their rights are protected once in these social institutions, will be developed as recommendations for the Québec government.

As such, this work endeavours to encourage jurists to consider and discuss whether the principles established in the U.N. Convention are adequately upheld with respect to children living with HIV in Québec. Where the standards in the U.N. Convention have not been met, immediate legislative reform is required. The recommendations presented in both parts of this paper are intended to serve as a starting point for such reform that will ensure greater protection for the rights, need and interests of HIV-positive children in the province.

## Part I: Right to the “Highest Attainable Standard of Health”

### “I Often Wonder...

I wonder why they can't find a cure for HIV. If they can't find a cure then I can get real sick and get AIDS. I wonder what that would be like. I think that would be hard. I might get real, real sick and die. That would be scary. The hardest part about dying would be missing my family. But I would see them in heaven one day and I know they would love me forever.”

-Rachael, age 8<sup>10</sup>

As reflected in this passage, a concern of primary importance to children with HIV is that a cure for their illness will not be discovered. Initially it may appear that the law's ability to address this issue is quite limited, given that it cannot afford children the “right” to a cure, nor impose on the medical community an “obligation” to find one. Nevertheless, the law still can play a critical role for children by guaranteeing them access to the best standard of care that currently is available. This right is specifically conferred by article 24 of the U.N. Convention which provides that children have the right to “the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.”<sup>11</sup>

While this provision affords all children an unequivocal right to the best standard of medical care, specific considerations emerge when it is considered with reference to HIV-infected children. Where HIV is at issue, the terms “access”, “health” and “highest attainable standard” have particular implications that may not arise in other contexts. As such, specific definitions for these terms must be formulated so that the application of article 24 of the U.N. Convention will account for the distinct health care concerns of HIV-positive children. In particular, the meaning of the “highest attainable standard” of health must be given careful consideration in this context, as it will likely require the enrollment of children in biomedical research. Yet, given the potential harm that children may face as research subjects, the risks of their participation must be assessed. As such, provincial law and policy must cautiously weigh the benefits of enrolling HIV-positive children in medical research against the possible risks of this to ensure that a child's participation in an experiment is consistent with her rights, needs and best interests.

---

<sup>10</sup>Quoted in L. Wiener *et al.*, *supra* note 7 at 947.

<sup>11</sup>This right also is recognized for all individuals by the *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, 993 U.N.T.S. 3, art. 12.

### (A) The Meaning of "Access"

Although obstacles to accessing health care traditionally have been thought of in economic terms, several authors have noted that other serious impediments also may exist for children with HIV. Wise notes that the ability to attain health care for HIV-positive children is contingent not only on financial access, but also on logistical access (which includes the transportation of children and parents to health facilities, the safety of such travel, and the provision of child care for siblings of children with HIV), cultural access (which may require the services of a translator, and sensitivity training to understand how HIV may be perceived by different cultural groups) and integrated access (which will require the co-ordination of health and social service programs and case management).<sup>12</sup>

In addition to the obstacles identified by Wise, discriminatory beliefs and practices within the medical community also may bar access to health care for children with HIV. Given the expertise and experience of medical professionals, one would not expect them to refuse treatment to HIV-infected patients purely on the basis of their illness. Nevertheless, a 1992 survey of internal and family medicine residencies in Canada, France and the U.S. reported that 13% of Canadian residents questioned had worked with surgeons who had refused care to at least one patient with HIV.<sup>13</sup> Furthermore, 14% of Canadian residents surveyed indicated that they would not treat persons with AIDS if they had the choice.<sup>14</sup> Although this research was undertaken some time ago, a more recent study on the treatment of patients with HIV by Canadian dentists reveals that discrimination against individuals with this illness persists within the medical community. This research indicates that, while 32% of dentists who participated in the study knowingly and willingly treated HIV-infected patients over the previous year, another 16% stated that they would refuse to treat individuals with HIV.<sup>15</sup>

The bias against treating AIDS and HIV patients reflected in these statistics is evident in the case of *P M et Commission des droits de la personne du Québec v. Dr G.*<sup>16</sup> In this case, a dentist in private practice refused treatment to patients with HIV, stating that he had adopted a policy of denying services to carriers of the infection. Before the Québec Human Rights Tribunal, Dr. G.'s actions were found

---

<sup>12</sup>P. Wise, "Expanding Access to Health Care for Infants, Children, and Adolescents" in Pizzo & Wilfert, *supra* note 7 at 75. For a discussion on the particular challenges of accessing medical care faced by minority communities, see R. Tuckson, "Health Care Perceptions and Needs of America's Poor" in Pizzo & Wilfert, *supra* note 7 at 63.

<sup>13</sup>Compared to 39% and 8% of American and French residents respectively. M.F. Shapiro *et al.*, "Residents' Experiences in, and Attitudes Toward the Care of Persons with AIDS in Canada, France and the United States" (1992) 268 JAMA 510.

<sup>14</sup>Compared to 23% and 4% of American and French residents surveyed, *ibid.*

<sup>15</sup>G.M. McCarthy *et al.*, "Factors Associated with Refusal to Treat HIV-infected Patients: The Results of a National Survey of Dentists in Canada" (1999) 89 Am. J. Pub. Health 541.

<sup>16</sup>[1995] R.J.Q. 1601 [hereinafter *Dr. G.*].

to violate article 10 of the *Québec Charter of Rights and Freedoms*<sup>17</sup> which prohibits discrimination on the basis of a “handicap”. This judgment clearly establishes that health care providers in Québec may not legally refuse to treat patients with AIDS or HIV, including those who are children, solely on the basis of their illness.<sup>18</sup>

The foregoing discussion illustrates how potential discrimination must be considered as an additional factor that may obstruct access to medical care for HIV-positive children. Thus, before we can be certain that the state has upheld its obligation under article 24 of the U.N. Convention, children must be guaranteed that having HIV cannot be a legitimate basis for refusing health services. In light of article 10 of the Québec Charter and the ruling in *Dr. G.*, it is clear that such refusal is not justified in law. Yet, this principle also must be made clear in codes of professional and ethical conduct for the medical profession, as well as in hospital guidelines and policy statements throughout the province.

## **(B) The Meaning of “Health”**

In addition to ensuring that access to health care for HIV-infected children is not barred by discrimination or any other factor, the application of article 24 of the U.N. Convention requires a thorough evaluation of the meaning of “health” in this specific context. The health care needs of children with HIV are distinct from those

---

<sup>17</sup>R.S.Q. c-12 [hereinafter “Québec Charter”].

<sup>18</sup>Note that this case was decided under the Québec Charter because it involved a “private actor,” that is, a dentist providing private services. However, a refusal to treat patients with HIV within the public sector also will likely be considered as an illegal act of discrimination. In this context, the action could be considered “state action,” particularly if the decision was made in adherence with a hospital policy. In such a case, the policy and decision would be subject to scrutiny under the *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c.11 [hereinafter “Canadian Charter”]. Although the analysis of a case like *Dr. G.* under the Canadian Charter would be somewhat different, the application of the equality provision in section 15(1) likely would lead to the same result.

The test for determining whether a violation of the equality rights guaranteed by section 15(1) has occurred in the context of disability was established in the Supreme Court’s decision in *Eldridge v. British Columbia (Attorney General)*, [1997] 3 S.C.R. 624 [hereinafter *Eldridge*]. Pursuant to this decision, the provision of medical services by hospitals constitutes an expression of government policy regarding the delivery of social programs to the public. In carrying out the objectives of providing access to these services, the legislature is not entitled to evade its duty to comply with the equality provision established by section 15(1) of the Canadian Charter. If a hospital policy or the conduct of hospital staff results in discrimination—whether it be direct or adverse effect—a *prima facie* violation of section 15(1) exists. Such a violation can be saved under section 1 of the Canadian Charter only where the government has made reasonable accommodations to ensure that disadvantaged groups benefit equally from its services, or where it has accommodated disadvantaged individuals or groups to the point of “undue hardship”. Although *Eldridge* dealt with discrimination on the basis of disability, Canadian courts have held that HIV-positive status does amount to a “disability” within the rubric of section 15(1) of the Canadian Charter. See *infra*, note 57. Potential arguments based on the equality provisions of the Québec and Canadian Charters are explored in further depth below. See discussion, *infra* notes 58-63.

of other children who are healthy or who suffer from other types of illnesses. HIV-positive children require significant medical attention for their physical health. However, their illness also may incur an overwhelming emotional and psychological impact. This is primarily due to two factors. First, the virus is one for which there is no known cure. As such, a child old enough to understand that she is infected with HIV will also learn that she will likely die once she has developed full-blown AIDS.<sup>19</sup>

Although HIV is not the only illness that carries such emotional impacts, the social stigma attached to HIV-positive status renders the psycho-social consequences of this disease quite distinct. A child diagnosed with HIV will learn that she is different from those around her given the significant way in which her life and social interactions may change after her diagnosis. Moreover, the way in which families and communities deal with HIV may cause children to perceive it as a shameful or morally reprehensible illness. This likely will be the case where a child is instructed not to disclose the fact that she is HIV-positive. For these reasons, children with HIV may experience severe psychological and emotional repercussions that deserve consideration in assessing how the disease affects their overall well-being.<sup>20</sup> As such, the multi-faceted health issues that arise in the context of pediatric HIV must be recognized, and each distinct aspect of a child's health care needs must receive adequate attention and treatment.<sup>21</sup>

Taking these factors into consideration, it is clear that any meaningful discussion of article 24 of the U.N. Convention in the context of children with AIDS or HIV requires a specific understanding of affording "access to health care". "Access" to care must entail a guarantee that children will not be discriminated against or refused treatment by health care providers. Furthermore, "health" in this context includes not only a physical dimension, but also an emotional and psychological element. Incorporating these ideas into the application of article 24 of the U.N. Convention to children with HIV will ensure that their right to health care accounts for the particular characteristics of their illness.

---

<sup>19</sup>Once diagnosed with AIDS, mortality rate of children is high. Approximately 57% survive for at least one year after their diagnosis, however infants and children with HIV are particularly susceptible to certain infections that are a primary cause of their early mortality. See A. English, "The HIV-AIDS Epidemic and the Child Welfare System: Protecting the Rights of Infants, Young Children, and Adolescents" (1992) 77 Iowa L. Rev. 1509 at 1522.

<sup>20</sup>See T. Campbell, "A Review of the Psychological Effects of Vertically Acquired HIV-Infection in Infants and Children" (1999) 20 Brit. J. Health Psychology 1; J.F. Havens *et al.*, "Mental Health Issues in HIV-Affected Women and Children" (1996) 8 Int. Rev. Psychiatry 217; and J.A. Adnopolz *et al.*, "Psychiatric Aspects of HIV Infection and AIDS on the Family" (1994) 3 Child & Adolescent Psychiatric Clinics of North America 543.

<sup>21</sup>J. Gittler & S. Rennert, "HIV Infection Among Women and Children and Antidiscrimination Laws: An Overview" (1992) 77 Iowa L. Rev. 1313.

### **(C) The Meaning of the “Highest Attainable Standard” of Health**

Pursuant to article 24 of the U.N. Convention, states are obliged to ensure that children enjoy the “highest attainable standard” of health. As such, this provision confers a right not only to care that will preserve the child’s general state of health, but rather, to the best standard of care that is available or feasible. While this appears to promote the interests of sick children, understanding what is meant by the “highest attainable standard” of health care with reference to HIV is not an easy task. This difficulty results from the fact that HIV treatment is limited, and a cure for it has not yet been developed. Moreover, biomedical research regarding HIV is ongoing, resulting in a continuously advancing level of understanding about this illness within the medical community. Thus, what is considered the “highest attainable standard” of care for HIV patients may shift quite rapidly.

For children to be guaranteed the most advanced care, they must be at the forefront of medical research related to HIV where the most innovative treatments can be made available to them. However, the inclusion of children in biomedical research has generated considerable debate among lawyers and bioethicists. From this discourse, it is clear that there are advantages to be gained for all pediatric HIV patients from the participation of children in medical research. At the same time, there are serious legal and ethical issues raised by the inclusion of a vulnerable population, such as children, in clinical trials.<sup>22</sup> The remainder of Part I of this paper will be devoted to considering whether the law in Québec properly promotes the participation of HIV-positive children in medical research, while at the same time including safeguards to protect them against the potential risks that they may encounter as research subjects.

#### **i) The Benefits and Risks of Child Participation Medical Research Related to HIV**

In North America, medical researchers who have conducted clinical trials on AIDS and HIV have concentrated on finding treatments primarily for adult patients.<sup>23</sup> The specific characteristics of pediatric HIV have not, however, received much medical or scientific attention. As a result, nearly all drugs approved for

---

<sup>22</sup>“Clinical trial” has been described as research that evaluates interventions, usually by comparing two or more approaches. In general, it involves medical research undertaken in a clinical setting where the outcomes of different treatments for patients can be contrasted. See: Medical Research Council of Canada, Natural Sciences and Engineering Council of Canada, Social Sciences and Humanities Council of Canada, *Tri-Council Policy Statement. Ethical Conduct for Research Involving Humans* (Ottawa: Public Works and Government Services Canada, 1998) [hereinafter *Tri-Council Policy Statement*] section 7.

<sup>23</sup>See C. Levine, “Children in HIV/AIDS Clinical Trials: Still Vulnerable after All These Years” (1991) 19 *Law, Medicine & Health Care* 231; and B. McNutt, “The Under-Enrollment of HIV-infected Foster Children in Clinical Trials and Protocols and the Need for Corrective State Action” (1994) 20 *Am. J. Law & Med.* 231.

distribution to HIV patients have been tested only on adults. Although most physicians are warned that this medication should not be used to treat children, some pediatricians have, due to a lack of choice, administered these drugs to children by extrapolating from research carried out exclusively on adults.<sup>24</sup>

However, treating children with this medication fails to account for the considerable physiological differences between adults and children with HIV. For example, although adults with HIV remain asymptomatic for an average of ten years after contracting the illness, HIV-infected children develop symptoms more rapidly. Almost fifty percent of children who contract HIV perinatally become symptomatic in the first year of life. By the end of the second year, almost seventy per cent have HIV symptoms, and by their third year, almost all infected children are symptomatic.<sup>25</sup> These distinctions impose an ethical and legal obligation on researchers to investigate the types of treatment that will be effective for the pediatric form of HIV.<sup>26</sup> Without such research, the right to the "highest attainable standard" of health conferred by article 24 of the U.N. Convention will not be guaranteed for HIV-positive children.

Promoting biomedical research that considers the specific features of HIV in children also is consistent with article 27 of the *Universal Declaration of Human Rights*<sup>27</sup> and article 15(1)(c) of the *International Covenant on Economic, Social and Cultural Rights*.<sup>28</sup> These provisions establish the right to benefit from scientific progress and research as a fundamental human right. For this right to be extended to HIV-infected children, research projects that focus on pediatric HIV must be devised. These studies will allow for the development of treatments sensitive to the particular affects of HIV in children. As a result, the risk of unforeseen medical complications to children eventually prescribed such medication will be greatly reduced.<sup>29</sup>

---

<sup>24</sup>Levine. *ibid.* .

<sup>25</sup>McNutt, *supra* note 23 at 235-36.

<sup>26</sup>This requirement is even more imperative when one considers the possibility of death or disability that may result from treating children with medication that has been tested on adults only. For example, physicians previously treated newborns with an antibiotic, chloramphenicol, for years before research revealed that many newborns suffered from "gray-baby syndrome," causing them to die because their enzyme systems were unable to metabolize accumulations of this drug. Also, physicians administered an antibacterial drug, sulfisoxazole, to newborns before research indicated that this drug caused cerebral palsy in infants. See: The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *Research Involving Children: Report and Recommendations* (1977) at 24, cited in McNutt, *supra* note 23 at notes 26-28.

<sup>27</sup>December 10, 1948, GA Res. 217A, 3 U.N. GAOR Pt. I, UN Doc. A/810 (1948).

<sup>28</sup>December 16, 1966, 993 U.N.T.S. 3.

<sup>29</sup>Although children stand to benefit from biomedical research that focuses on how pharmacotherapy treatments would affect them in particular, it would be difficult to devise policies or regulations that would *require* clinical researchers to carry out child-specific studies. At the same time, it is possible for state agencies to *encourage* such research by securing generous funding for a larger number of protocols that concentrate on children, yet which also adhere to the strictest scientific, ethical and legal standards.

Participation in clinical trials also has important advantages for individual children with HIV who act as research subjects. The most obvious benefit is that enrollment in a clinical trial may, if the experimental treatment proves effective, increase their longevity and improve their health.<sup>30</sup> Various studies involving children with HIV also have demonstrated that the administration of certain drugs tested in clinical trials improve the physical growth, as well as the cognitive and motor development of these children.<sup>31</sup> Furthermore, a child who participates in a clinical trial will have access to the most advanced treatment before other children with HIV. Unlike many other HIV-infected children, those enrolled in research investigations also undergo frequent medical examinations during which physicians and researchers who specialize in HIV can detect complications and illness early on, and thereby provide appropriate treatment.<sup>32</sup>

In light of these factors, it is clear that children may derive individual and collective advantages from their participation in HIV-related biomedical research. Yet, before it can be determined that children with HIV should be entitled to act as research subjects, an examination of the potential risks that may be occasioned by their participation in clinical trials must be assessed. Although children have a right to benefit from medical research and enjoy the highest attainable standard of health, article 3 of the U.N. Convention also provides that all decisions and actions concerning children must be taken in their best interests. Many different aspects of this right could be jeopardized through the enrollment of children in research that is inadequately monitored and regulated.

Participation in a clinical trial may result in a series of consequences which many children and their families will consider as too harmful to justify their enrollment as subjects. Experimentation frequently requires prolonged stays in hospitals where children often must receive painful and uncomfortable treatments. The emotional disturbances created by these circumstances are heightened by the fact that they take place in unfamiliar environments, and become even more acute when trials are conducted at hospitals in different regions or cities and require the relocation of pediatric subjects.<sup>33</sup> As a result, they will be separated from their family and friends, and may be prevented from participating in the activities which

---

<sup>30</sup>For example, in research that studied the effects of zidovudine (AZT), didanosine (ddI) and intravenous immunoglobulin (IVIG) on pediatric HIV patients, the rate of bacterial infections among the children who participated as research subjects had decreased. In particular, these drugs were shown to reduce infections such as meningitis, osteomyelitis, pneumonia and internal-organ abscess. See McNutt, *supra* note 23 at 233.

<sup>31</sup>*Ibid.*

<sup>32</sup>*Ibid.* at 233-34.

<sup>33</sup>The risks and harms associated with the enrollment of children in medical research is considered in a report prepared by Canada's National Council on Bioethics in Human Research. See Consent Panel Task Force of the National Council on Bioethics in Human Research (NCBHR) *Report on Research Involving Children* (Ottawa: National Council on Bioethics in Human Research, 1992, revised 1993, reprinted 1997) at 28-31.

shape their identity as “children,” such as going to school, socializing with their siblings and peers, and partaking in family and holiday celebrations at home. In addition, enrolling a child in clinical research may threaten her autonomy rights, given that she may lack the legal capacity to consent independently to participation as a research subject. Thus, in light of the harms that may arise to children who act as research subjects, special legislative mechanisms are required to ensure that their participation in medical research is consistent with article 3 of the U.N. Convention, which requires all decisions made in regard to children to be commensurate with their best interests.<sup>34</sup>

A review of Québec law and policy concerning the participation of minors in medical research is required to ascertain whether the rights of HIV-positive children are adequately protected and promoted in the province. Ideally, Québec’s legislative structure would carefully balance the need for protection, with the objective of encouraging the enrollment of minors in clinical trials so that they can enjoy the benefits of scientific progress. In other words, the law would protect children from participating in research that would be harmful and contrary to their best interests, while at the same time, promote their right to health by encouraging the development of research protocols aimed at examining and treating pediatric illness. Where current legislation does not meet this standard, alternatives for its improvement will be sought by making reference to the Tri-Council Policy Statement<sup>35</sup> which has developed guidelines for the involvement of children in medical experimentation.

---

<sup>34</sup>The reality of the risk to vulnerable groups who participate in medical research is apparent in the aftermath of the Tuskegee study. The objective of this research was to study the effects of untreated syphilis in poor, black men living in rural Alabama. So that the long-term effects of their illness could be monitored, the researchers did not offer these individuals treatment nor inform them about their disease. The men were not treated even after penicillin became available. Instead, the research investigators continued to study them for forty years. As a result, between 29 and 100 men died of complications caused by untreated syphilis, and others suffered serious health conditions that may have led to their death. See English, *supra* note 19 at 385.

The Tuskegee experiment reveals the abhorrent repercussions that may result from unmonitored research that seeks to study a vulnerable social group. Thus, while research generally requires legislative and ethical regulation, special protective mechanisms are required where the subjects include individuals whose social and economic clout is limited. Children are perhaps the paradigm of this category, given that they often are prevented from deciding and speaking on their own behalf. As such, Québec law and policy must be carefully structured to ensure that the participation of children in medical experimentation occurs only where this is in the best interests of the children who will act as research subjects.

<sup>35</sup>*Supra* note 22.

## ii) Evaluating Québec Law Concerning the Participation of Children in Medical Research

In Québec, the law concerning the right of children to act as research subjects recently has been amended.<sup>36</sup> Under the revised version of article 21 of the *Civil Code of Québec* (hereinafter “C.C.Q.”), a set of specific criteria must be met before a minor may participate in an “experiment.” Article 21 of the C.C.Q. states that a minor may not be submitted to medical experimentation if this will involve a serious risk to her health, or if she understands the nature and consequences of participation in the research and objects to being a subject. In addition, the minor (or the group under study in which she is a member) must benefit from participation in the experiment, the research must be approved and monitored by an ethics committee formed or designated by the Minister of Health and Social Services, and finally, the child's parents or tutor also must consent to her enrollment as a research subject.

Article 21 of the C.C.Q. is consistent with the position adopted in the Tri-Council Policy Statement. Although article 5.3 of the Tri-Council Policy Statement provides that minors shall not be automatically excluded from research, their inclusion is subject to the requirements stated at articles 2.6 to 2.8. The latter provisions ensure that minors and other persons incompetent to consent to participation for themselves may not be enrolled as research subjects without the consent of an authorized third party. Moreover, if the child understands the nature and consequences of the research, the researcher must ascertain her wishes concerning her participation as a subject, and any expression of dissent will preclude her enrollment.

The Tri-Council Policy Statement and article 21 of the C.C.Q. encompass several important principles. The first of these is a respect for the integrity, inviolability and physical well-being of the minor person, which is reflected in the requirement that participation as a research subject benefit the child. In addition, there is a recognition of autonomy for children, as both article 21 of the C.C.Q. and article 2.6 of the Tri-Council Policy Statement afford children of all ages the right to refuse experimental treatment, provided that they understand its nature and consequences. Finally, these provisions also incorporate the principle that a child's decision-making autonomy can be limited for her protection. The requirement of consent from parents, tutors or other “authorized persons” responds to concerns about children succumbing to potential pressure by adults, such as scientific investigators carrying out research, who may seek to enroll a child in a clinical trial even if this is not in her best interests.<sup>37</sup>

---

<sup>36</sup>An Act to amend article 21 of the Civil Code and Other Legislative Provisions, S.Q. 1998, c.32, s.1 (17 June 1998).

<sup>37</sup>C. Bernard & B.M. Knoppers, “Legal Aspects of Research Involving Children in Canada” in B.M. Knoppers, ed., *Canadian Child Health Law: Health Rights and Risks of Children* (Toronto: Thompson Educational, 1992) at 287.

Yet, although article 21 of the C.C.Q. incorporates many important safeguards to prevent children from participating in research that presents an unacceptable level of risk and/or harm, the protection that it confers is not unequivocal. In its fourth paragraph, article 21 of the C.C.Q. states, “[c]are considered by the ethics committee to be innovative care required by the state of health of the person concerned does not constitute an experiment.” This stipulation suggests that certain cases exist in which a medical intervention that may look like research in fact should be considered “innovative care.” In these circumstances, the process of obtaining consent for administering this intervention to a child would not be regulated by article 21 of the C.C.Q., and the protections encompassed by this provision would be inapplicable.

On one hand, it is arguable that paragraph 4 does not detract significantly from the safeguards that are otherwise conferred by article 21 of the C.C.Q. Ultimately, it is up to the “ethics committee,” and *not* a person’s health care provider or a clinical investigator, to determine whether an intervention should be considered “innovative care” rather than an experiment. Yet, on the other hand, the meaning of “innovative care” within the context of article 21 of the C.C.Q. has never been clarified, and much uncertainty exists within the medical, legal and bioethics communities regarding the definition of this term.<sup>38</sup> As such, the spectrum of medical interventions that may fall within this rubric, and thus may be exempt from the heightened scrutiny mandated by article 21 of the C.C.Q., is potentially quite broad.

A hypothetical example may help to illustrate the types of situations in which the distinction between “research” and “innovative care” may become blurred. Suppose that all conventional therapies have failed for treating a child with HIV. It now is certain that, without any additional medical interventions, she will die. A member of the medical team who has been working with the child is aware of a drug treatment that has been tested on adult subjects, and has proved effective in treating their HIV symptoms. This medication, however, has never been tested on pediatric populations. If the health care provider proposes this drug therapy to the child and her parents, should it be characterized as “research” or “treatment”?

As King describes, the primary distinction between these terms in the context of medical experimentation lies in the underlying intent of a physician.<sup>39</sup> According to the *Belmont Report*,<sup>40</sup> medical “practice” is defined as “interventions...designed

---

<sup>38</sup>Interview with Professor Kathleen Glass, McGill Biomedical Ethics Unit, Clinical Ethicist of the Montreal Children’s Hospital (11 May 2000). I am very grateful to Professor Glass for her instructive comments regarding article 21 of C.C.Q., and the involvement of children in clinical research.

<sup>39</sup>N.M.P. King, “Experimental Treatment: Oxymoron or Aspiration?” (1995) 25:4 *Hastings Center Rep.* 6 at 9.

<sup>40</sup>The *Belmont Report* was created by a National Commission in the U.S. that was charged with defining research for the purposes of protecting human subjects. See National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report: Ethical principles*

solely to enhance the well-being of an individual patient...and that have a reasonable expectation of success.” In contrast, “research” is defined as “an activity designed to test a hypothesis, permit conclusions to be drawn, and thereby to develop or contribute to generalizable knowledge.”

In the hypothetical presented above, the proposed pharmacotherapy was recommended with the sole intention of enhancing the patient’s state of health. However, its potential for success is uncertain. As such, it falls outside the strict definition of medical “practice” formulated in the *Belmont Report*. At the same time, the intervention does not appear to be “research” either, since it is not designed to test a hypothesis and thereby advance scientific learning in a particular area. Moreover, given that it offers the child a last hope for surviving her illness, the intervention may be considered necessary for her state of health.<sup>41</sup> As such, it may well be characterized as “innovative care,” and thus fall outside the realm of “experimentation” regulated by article 21 of the C.C.Q.

Although very little attention has been given to the meaning of “innovative care” in Québec, certain American authors have written about this concept. While distinguished from “research” in the *Belmont Report*, some writers have argued that “innovative therapies” must be conducted and reviewed with the same degree of care and scrutiny as medical research.<sup>42</sup> This argument is quite compelling. Interventions that may be characterized as “innovative care” in fact may carry significant risks and harmful consequences for patients, particularly if they have not been tested nor proven effective in the population concerned. In this way, the care proposed is not significantly different from enrolling subjects in clinical research trials. Protecting the rights and interests of patients thus mandates that the intervention be subject to the same degree of scientific and ethical review as would any other research protocol involving human subjects.

In most cases, the distinction between “treatment” and “research” will be clear. However, the example described above reveals how it might become confused as a result of paragraph 4 of article 21 of the C.C.Q. In situations where a medical intervention bears features of both “innovative care” and

---

*and guidelines for the protection of human subjects research*, DHEW Pub. No. (OS) 78-0012 (Washington, D.C.: U.S. Government Printing Office, 1978).

<sup>41</sup>The line between “research” and “treatment” is particularly difficult to draw in cases where interventions aim to treat or cure seriously debilitating and life-threatening illnesses for which there exists no standard effective therapy. As King describes, the confusion between “research” and “treatment” has significantly impacted the development of drug treatments for HIV, and on the conduct of clinical trials for many types of cancers and other illnesses. More specifically, access to experimentation often is considered as a “last chance cure” in these contexts, and is more likely to be considered “treatment,” given the ultimate objective of benefiting the patient and the absence of alternate treatment options. See King, *supra* note 39 at 10.

<sup>42</sup>As King describes, this argument was put forward by Robert Levine in the preliminary papers prepared for the National Commission that ultimately produced the *Belmont Report*. See King, *ibid.* at 9.

“experimentation,” it becomes difficult to ascertain the appropriate requirements for obtaining consent. If the intervention is considered to be “experimentation” or “research,” the measures stipulated at article 21 of the C.C.Q. must be followed. However, if it is characterized as “innovative care” or “treatment,” then article 14 C.C.Q. (which is described below) will apply.

As mentioned, the cases in which this ambiguity will arise will be rare. Nevertheless, the theoretical complexity surrounding the distinction between “research,” “innovative care,” and “treatment” deserve attention, particularly given its importance for the rights and interests of children. Thus, Québec’s legislature must be encouraged to articulate more precise requirements for administering medical interventions to a child that are experimental in nature, yet which also may be characterized as innovative care that is required by her state of health. However, it would be unsatisfactory to simply select the current version of either articles 14 or 21 C.C.Q. as establishing the appropriate consent requirement for such procedures, since neither is entirely consistent with the normative principles embodied in international human rights law. An analysis of articles 14 and 21 of the C.C.Q. reveals the need for a provision that is more closely tailored to the rights and interests of sick children, and which upholds the standards established in the U.N. Convention.

Article 14 of the C.C.Q. provides a minor who is 14-years old or over with a clear right to consent to treatment required by her state of health. However, this provision is deficient in two regards. First, it precludes children under the age of 14 from having any input in decisions made concerning their health, even if they have a full understanding of the nature and effects of their illness and of the necessary treatment. This may violate article 12 of the U.N. Convention which affords a child capable of forming her own views the right to express these views freely in matters affecting her, and to have them considered in accordance with her age and maturity. Article 14 of the C.C.Q. also may be inconsistent with article 34 of the C.C.Q. which gives *all* children the right to be heard in cases affecting their interests, whenever their age and power of discernment would permit this.

A second challenge to article 14 of the C.C.Q. lies in the fact that, although it extends the right to *consent* to medical care to minors over the age of 14, it does not specifically confer a right to *refuse* this treatment. In cases involving persons of full age, Canadian courts have recognized and upheld the right of refusal as the corollary to the right to consent to medical care.<sup>43</sup> However, decisions affecting children have not been consistent on this point. For example, in *Walker v. Region 2 Hospital Corp.*,<sup>44</sup> the New Brunswick Court of Appeal held that a mature minor who may consent to care also has the right to refuse treatment. Similarly, in

---

<sup>43</sup>See *Nancy B. v. Hotel Dieu de Québec*, [1992] R.J.Q. 689 (Que. Sup. Ct.); and *Malette v. Shulman* (1990), 72 O.R. (2d) 417 (Ont. C.A.).

<sup>44</sup>(1994), 4 R.F.L. (4<sup>th</sup>) 321 (N.B. C.A.).

*Children's Aid Society of Metropolitan Toronto v. K.*,<sup>45</sup> a child was permitted to refuse care that medical professionals considered necessary to her state of health. Although the child in this case did not meet the legal definition of a "mature minor," the court found that a failure to respect her wishes would violate her rights of equality and security of the person protected by the Canadian Charter. In contrast, the Québec Superior Court has held that the right to refuse care required by a child's state of health cannot naturally be inferred from her right to consent to such care.<sup>46</sup> In light of this jurisprudence, it appears that a child's autonomy may be further limited as a result of the uncertainty concerning whether her right to consent to care under article 14 of the C.C.Q. also implies a right to refuse treatment.

In many respects, article 21 of the C.C.Q. provides a more assertive recognition and articulation of the rights of children with respect to health care than does article 14 of the C.C.Q. Insofar as the autonomy rights of children are concerned, article 21 of the C.C.Q. gives *all* minors a voice regarding their participation in experimentation, as it explicitly states that their objection to such participation will bar their involvement in the research. Furthermore, as mentioned above, this provision also is designed to advance the specific rights of children that may be threatened in the research setting. In particular, article 21 of the C.C.Q. ensures that the child will be enrolled in a research protocol only where she stands to benefit from this, that the research project is ethically valid and that the child is not placed under undue pressure to participate. As such, article 21 of the C.C.Q. appears to be the appropriate provision for assessing the rights and interests related to the enrollment of HIV-infected children in clinical trials, even when this may yield a therapeutic benefit.

Yet, despite the merits of article 21 of the C.C.Q., this provision is not without its difficulties. Its primary challenge lies in the ambiguity created by its fourth paragraph, which exempts "innovative care" considered necessary for a child's state of health, from the more exacting consent requirements encompassed in this provision. As discussed above, this stipulation creates uncertainty regarding the characterization of medical interventions that look experimental, yet which also may have a direct therapeutic benefit for a child. This ambiguity has important repercussions, given that, if the intervention is characterized as "treatment," it will be subject to the less rigid consent requirements found at article 14 of the C.C.Q. In this way, the law may fail to adequately safeguard the rights and interests of the child concerned.

Thus, some work is required to render Québec law more consistent with the principles established in the U.N. Convention. In particular, article 21 of the C.C.Q. requires amendment to ensure that *all* medical interventions that deviate from

---

<sup>45</sup>(1985), 48 R.F.L. (2d) 164 (Ont. Prov. Ct.).

<sup>46</sup>See *Protection de la jeunesse - 884*, [1998] R.J.Q. 816 (Que. Sup. Ct.).

standard medical practice must remain characterized as “experimentation,” even where they also might be considered “innovative care.” As such, all therapies, including those designed and intended to benefit a pediatric or incompetent patient directly, must be characterized as “research” and thus remain subject to the consent requirements laid out in article 21 of the C.C.Q.

In addition to clarifying the ambiguity surrounding the distinctions between “treatment,” “experimentation,” and “innovative care,” a second revision to article 21 of the C.C.Q. must revisit its requirement for consent from a child’s parent or tutor before she may be enrolled in a clinical trial. Requiring consent from a third party for a minor’s participation in research is not inherently objectionable. Although it may restrict the liberty and autonomy of a child who may be competent to consent to medical care (that is, under article 14 C.C.Q.), it is a reasonable requirement given the potential risk to vulnerable persons who partake in medical research. The difficulty, however, stems from the requirement that this third party consent be issued by a parent or tutor.

For children in the custody of biological or adopted parents or a legal guardian, it is quite simple to discern where parental authority lies. However, where a child has been removed from the custody of her parents and is in the care of a child protection agency or foster parents, this becomes a much more complex issue. In such cases, if parents are unwilling or unable to consent to their child’s enrollment as a research subject, and no tutor has been appointed, children in protective custody may be excluded from biomedical research. As such, specific concerns about access to health care for these children must be addressed. This analysis will illustrate how article 21 of the C.C.Q. must be amended to enable all children in Québec with HIV to meet the legislative requirements necessary for their participation in medical research.

**(a) Ensuring the inclusion of HIV-positive children in protective custody and foster care as participants in clinical trials**

In 1990, the Center for Disease Control in the United States conducted a survey which indicated that forty-two percent of HIV-infected children lived with foster families, non-parental relatives or persons other than their relatives.<sup>47</sup> Although this figure is not determinative of the percentage of Canadian children with HIV in foster care, it indicates that a disproportionate number of such children may end up in protective custody or foster care. This may be explained by the fact that many parents of HIV-infected children also suffer from this illness and thus may be too ill to care for a sick child, or worse, they may have died because of an illness related to HIV. In addition, many parents with HIV may have contracted the

---

<sup>47</sup>D. Weimer, “Beyond *Parens Patriae*: Assuring Timely, Informed, Compassionate Decision-making for HIV-Positive Children in Foster Care” (1991) 46 Univ. Miami L. Rev. 379 at 380.

illness through the use of contaminated needles to inject drugs, or from being the sexual partner of an intravenous drug user. Parents thus may lose custody of their children if a drug addiction has caused their child to be neglected or abandoned.<sup>48</sup>

Given that such a high number of children with HIV ultimately may end up in foster care, their enrollment in clinical trials is necessary to ensure that the benefits of participation are equitably distributed among all children with this illness. Under section 5.1 of the Tri-Council Policy Statement, researchers may not select their subjects on the basis of irrelevant factors such as age, sex, or ethnicity. These Canadian guidelines thus encourage researchers to adopt a policy of inclusion with respect to the recruitment of potential research subjects.

Implementing this policy in the context of HIV-related research requires a recognition of the correlation between HIV and marginalized social and economic status.<sup>49</sup> Any study on children with HIV must make a deliberate effort to include participants with diverse family structures, cultural affiliations and levels of wealth. As such, research must be designed to ensure that children in foster care or protective custody are given the opportunity to participate in clinical trials. However, before this goal can be realized, two obstacles must be overcome. First, social services and health care agencies must coordinate their resources to facilitate the enrollment of HIV-positive children in clinical trials.<sup>50</sup> If such children are hospitalized, their illness will be known to health care workers and thus, they may be enrolled in a trial more quickly. However, if children live with foster parents or in a group home, then a clear link between health care providers and social workers is necessary so that they will come to the attention of medical professionals and can be given the opportunity to participate in medical research.

Children in foster care and protective custody also may be barred from participating in clinical trials by current provincial legislation. As discussed earlier, article 21 of the C.C.Q. appears to establish the law concerning the right of minors to participate in medical research. Pursuant to this provision, a minor's enrollment in a clinical trial requires the consent of the person having parental authority. When a child is in protective custody, her biological parent(s) may still retain legal custody. However, in these circumstances, parental consent frequently will be difficult or impossible to obtain, given that agencies often lose contact with parents after a child is placed in foster care. Moreover, children may be placed in the care

---

<sup>48</sup>McNutt, *supra* note 23 at 237.

<sup>49</sup>On the relationship between AIDS and poverty, see e.g., P. Shine, "AIDS and Poverty Law, Inaction, Indifference and Ignorance" (1994) 10 J. Law & Social Policy 155.

<sup>50</sup>The need for integrated services for children with HIV has been recognized by Wise, *supra* note 12 at 981ff. In Canada, Bala has recognized that effective child protection and care depends on the coordination of services provided by child protection agencies with other agencies and professionals, particularly in the sectors of law enforcement, education and health care. See N. Bala, "An Introduction to Child Protection Problems" in Bala, Hornick & Vogl, eds., *Canadian Child Welfare Law* (Toronto: Thompson Educational, 1991) at 1.

of social services because their parents are ill, or involved in criminal or drug activity. In such cases, they may be difficult to access, or unresponsive to agencies' attempts to contact them.<sup>51</sup>

These issues call for an amendment to article 21 of the C.C.Q. that promotes a more equitable distribution of the benefits gained from participation in medical research among all HIV-positive children. This amendment must reflect the principle that good medical research requires a representative population of subjects. Thus, given the high percentage of children with HIV likely to be in foster care or protective custody, this group must be included in any study that purports to research pediatric HIV.

A source that may guide the amendment of article 21 of the C.C.Q. is article 2.6 of the Tri-Council Policy Statement. Under this provision, a child may participate in research if an "authorized person" gives her consent. Because "authorized persons" are not restricted to individuals having parental authority, the Policy Statement suggests that any person with a meaningful connection to the child, and who acts in her best interests, should be entitled to consent on her behalf. Accepting this notion, foster parents or social workers may consent to a child's enrollment in a clinical trial if this serves to promote her rights, needs and best interests. An amendment to article 21 of the C.C.Q. that adopts this approach will extend the benefits of participation in research to all HIV-infected children, including those in foster care or protective custody.

Although the Québec Government must be urged to undertake these legislative reforms quickly, it also should be cautioned about the potential risks of enrolling HIV-infected children in clinical trials. Measures must be taken to ensure that research in which children participate is safe and in their best interests. Moreover, if a child is in foster care or protective custody, she may be even more vulnerable than other children with HIV because she may not have anyone to advocate or make decisions on her behalf. To reconcile this difficulty, the legislative amendments must indicate that the "authorized person" who consents for the child also must assume responsibility for this decision. This will place a clear onus on the authorized person to make choices that are in accordance with the child's best interests, and will safeguard against treating children who are particularly vulnerable as the "guinea pigs" of child-specific research.

If these proposed amendments are adopted, article 21 of the C.C.Q. will become a more comprehensive provision that considers the specific issues that may arise when it is applied to minors with HIV. It will ensure that all children, irrespective of their family situations, will have an equal opportunity to enroll in clinical trials and enjoy the advantages of such participation. At the same time, it

---

<sup>51</sup>See Weimer, *supra* note 47 at 384-85.

will include protective mechanisms to ensure that the autonomy and physical integrity of children retain paramount importance, and further, that the consent given by authorized persons will be entirely motivated by and consistent with the rights, needs and best interests of children.

#### **(D) Summary of Recommendations to the Québec Government**

In light of the rapid growth in the number of children living with HIV in Québec, legislative reforms which ensure that provincial law and policy are commensurate with article 24 of the U.N. Convention must be undertaken as soon as possible. So that all children with HIV in Québec are afforded “the highest attainable standard of health,” it is recommended that the Government of Québec:

- Develop a comprehensive definition of “access” to health care which incorporates measures to deal with specific issues that arise for children with HIV. The meaning of “access” must be broadened to ensure that a child cannot be barred from acquiring necessary medical care because of her social or economic situation, nor because of the discriminatory beliefs and practices of health care professionals. Québec law and policy must clearly reflect that these grounds do not justify the refusal to treat a pediatric HIV patient. This principle must be made clear in legislative codes of professional conduct, as well as in hospital guidelines throughout the province.
- Develop a comprehensive definition of “health” which recognizes the physical, emotional and psychological ramifications of HIV on the lives of children. As such, the “health care” needs of children with AIDS or HIV will be met only when all of these aspects receive proper medical attention.
- Recognize that, for children with HIV, receiving the “highest attainable standard” of health requires that they be a prominent concern within biomedical research. As such, scientific investigators must be encouraged to pursue pediatric HIV studies. Law and policy must not tolerate the medical treatment of children through the extrapolation of results from research carried out exclusively on adults, as this fails to consider children’s best interests.
- Promote the participation of children in medical research by clarifying the law that articulates the consent requirement for their enrollment in clinical trials. More specifically, article 21 of the C.C.Q. must state explicitly that all medical interventions that are experimental in nature and that deviate from standard clinical practice fall within the rubric of “research,” which is governed by this codal provision.
- Ensure that children in foster care or protective custody enjoy equal access to participation in medical research. This objective can be accomplished by amending article 21 of the C.C.Q. to replace the requirement for consent by

a parent or tutor with a stipulation that would permit an “authorized person” to consent to a child’s enrollment in a research trial. The “authorized person” should not be required to have parental authority; she may be anyone that has a meaningful relationship with the child *and* who acts in her best interests.

However, because children in foster care and protective custody represent a vulnerable social group, the legislation also must protect them against the potential harm that they may face as research subjects. Law and policy thus must oblige the authorized person who consents for the child to assume legal responsibility for this decision. This will help ensure that consent to a child’s participation in medical research will be given only where this accords with her rights, needs and interests.

## **Part II: Right to Dignity and Equality in the Context of Education**

### “The Pros and Cons of Telling Other People My Diagnosis

Sometimes I want to tell people about my virus, but then I think about the Pro’s and Con’s. Some Pro’s that I think about are that I wouldn’t have to hide anything or lie anymore. I feel bad about lying, but then again, I can’t tell anyone...

But then there’s always the Con’s. People could just forget about the facts and just get away from me. They could tell their parents, but then the parents would maybe want to get me out of the school, but from my point of view, they have nothing to worry about. Another Con could be that the people I tell and that I trust to keep it a secret could tell someone else and then they would tell everyone else so then everyone would get away from me. Even if I tell them and they know the facts, they just wouldn’t understand. Then there are always the people who won’t believe me or the facts.”

- Jamie, age 10.<sup>52</sup>

For children living with HIV, a right considered as important as access to quality health and medical care is the right to be treated with dignity and equality. As this passage illustrates, HIV-infected children need reassurance that their illness will not cause them to be stigmatized or ostracized by their communities. To achieve this objective, the right to personal development through interaction and socialization with their peers must be recognized for all children, including those with HIV. Several provisions of the U.N. Convention uphold these rights for children.

Article 2 of the U.N. Convention requires states to ensure that children are protected from discrimination of any kind, including discrimination on the basis of disability. Furthermore, article 15 obliges states to recognize the child’s freedom

---

<sup>52</sup>Quoted in Wiener *et al.*, *supra* note 7 at 950-51.

of association. Although the second paragraph of article 15 states that freedom of association may be limited where necessary for the protection of public health, as will be discussed below, children with AIDS or HIV may not be legitimately barred from interacting with their peers on this basis.<sup>53</sup>

The two primary contexts in which children have the opportunity to socialize with their peers include recreational or community activity, and daycares or schools. The U.N. Convention recognizes that all children have the right to full participation and integration in both of these settings. Article 31 recognizes the child's right to play and leisure, and further, requires states to provide equal opportunities to children for cultural, artistic, recreational and leisure activity. With respect to schools and daycares, article 28 establishes the child's right to education on the basis of equal opportunity. Pursuant to article 22, children with mental or physical disabilities also have the right to education and to the "fullest possible social integration and individual development".

In North America, discussions in legal circles concerning the social integration and inclusion of children with HIV have focused primarily on the school setting.<sup>54</sup> This discourse has been concerned primarily with questions concerning whether such children should be educated in ordinary daycares or primary school classrooms, and further, what accommodations can and should be undertaken to ensure their full participation in these institutions. However, because this debate has been undertaken mainly by scholars in the U.S., it has concentrated on the rights of HIV-positive children under American law.

Part II of this paper aims to consider how the rights of such children play out in schools and daycares in Québec and Canada. In particular, it will consider whether the articles of the U.N. Convention listed above are adequately upheld under the legislative structure in Québec. The first section will discuss an actual incident of a child's exclusion from a Québec daycare because she had HIV, and will consider the rights and interests advocated by both sides of the debate which emerged over her story. Because this case was never litigated, it is difficult to ascertain which of the competing interests would have been more compelling before a court or human rights tribunal. Thus, the second section seeks to determine how the law of Québec and Canada would have applied in this case, and whether it offers sufficient protection for the rights of children with HIV. The final section of Part

---

<sup>53</sup>As discussed below, the risk of HIV transmission in a classroom or daycare is negligible, and thus is not a legitimate ground for the exclusion of HIV-positive children. See discussion, *infra* notes 63-64.

<sup>54</sup>See L. Hammet, "Protecting Children with AIDS Against Arbitrary Exclusion from School" (1986) 74 Calif. L. Rev. 1373; L.N. Brockman, "Enforcing the Right to a Public Education for Children Afflicted with AIDS" (1987) 36 Emory L.J. 603; M.M. Murphy, "Special Education for Children with HIV Infection: Standards and Strategies for Admission to the Classroom" (1990) 19 J. L. & Educ. 345; L.J. Sotto, "Undoing a Lesson of Fear in the Classroom: The Legal Recourse of Aids-Linked Children." (1986) 136 Univ. Penn. L. Rev. 193; and W.F. Foster *et al.*, "HIV/AIDS and School Boards: A Policy Approach" (1990) 30 J. Social Science & Med. 267.

It will consider what accommodations are both reasonable and necessary for schools and daycares in Québec to undertake to ensure the integration of children with HIV to the fullest extent possible. Through the development of a clear policy that obliges schools and daycares to undertake such accommodations, the Government of Québec will have taken an important step towards fulfilling its obligations to children under the U.N. Convention.

### **(A) Garderie Les Petits Lutins: A Story of Exclusion**

Although there has never been a litigated case involving the exclusion of a child with HIV from a school or daycare in any Canadian province, the story of Jessica Dos Santos illustrates the potential for such a situation to arise. On February 7, 1994, two-year old Jessica Dos Santos was expelled from Garderie Les Petits Lutins, her Côte St-Paul daycare centre, because she was HIV-positive. Although Jessica's illness had not been disclosed to the daycare, the daycare's director eventually learned that the medication she was given every six hours was AZT, an anti-viral treatment used to combat HIV infection. Once this was discovered, Jessica was asked not to return to her daycare.<sup>55</sup>

The daycare attributed its decision to the concerns of other parents who reacted strongly against the admission of a HIV-positive child into the daycare. Once this story became public, the daycare's board of directors invited a panel of health-care experts to address these parents and explain that the risk of transmission in a daycare or school is nearly negligible. Yet, even after this information session was held, most parents remained skeptical and voted against allowing Jessica's return.<sup>56</sup>

Although Jessica Dos Santos' case never went before a court or the Québec Human Rights Tribunal, it indicates the potential for an infringement on the rights of a child who is HIV-positive. This story also illustrates the issues and tensions at play in these cases. On one hand are the rights of the child: Jessica's right to receive the same daycare services as those provided to other children and to learn and play with her peers. On the other hand are the concerns of the parents in her community, in particular, their responsibility for ensuring the health and security of their own children. Yet, because this case was never litigated, these competing interests were never framed in terms of defined legal rights or obligations. Stories about Jessica's exclusion from La Garderie Les Petits Lutins did not explore how law and policy

---

<sup>55</sup>J. Bitchburn, "Girl with HIV is no Risk to Others in Daycare: Experts" *The [Montreal] Gazette* (11 February 1994) A3.

<sup>56</sup>A. Derfel, "Daycare Parents Wary of HIV-Positive Child" *The [Montreal] Gazette* (17 February 1994) A3.

in the province would have applied to her case.<sup>57</sup> Yet this discussion is necessary to determine whether her exclusion was justified, and whether any other child in Québec may be legitimately removed from her daycare or classroom on the basis of having HIV.

## **(B) Is Exclusion Justified? Law and Policy in Québec**

### **i) The Canadian and Québec Charters**

The starting premise for assessing the legitimacy of excluding a child with HIV from an educational institution must be the Canadian and Québec Charters which establish the fundamental rights and liberties of all persons.<sup>58</sup> Pursuant to the principles articulated in these documents, there is a presumption that any child with AIDS or HIV has the right to be educated in an integrated classroom or daycare. This presumption derives primarily from the right to equal protection and benefit of the law under section 15(1) of the Canadian Charter, and under article 10 of the Québec Charter which guarantees freedom from “wrongful discrimination”. The courts have established that differential and prejudicial treatment on the basis of HIV constitutes discrimination on the grounds of disability, and is thus contrary to both the Canadian and Québec Charters.<sup>59</sup>

Rights of personal dignity and privacy also are at stake where a child with HIV is threatened with exclusion from a school or daycare. These rights are protected by articles 4 and 5 of the Québec Charter, and by sections 7 and 8 of the Canadian

---

<sup>57</sup>Although some limited discussion about the law, particularly the Québec Charter, appeared in some articles about Jessica Dos Santos, this was cursory, and, in at least one instance, incorrect. In one article, an individual identified as a “government official” was quoted as stating that discrimination on the basis HIV-status is not prohibited under the Québec Charter. See: Bitchburn, *supra* note 55. However, this comment runs counter to the jurisprudence, both in Québec and in the rest of Canada, concerning persons with HIV. These cases have consistently held that HIV is included within the meaning of “handicap” under article 10 of the Québec Charter and “disability” under section 15(1) of the Canadian Charter. Thus any discrimination on the basis of HIV is illegal. See: *Dr. G.*, *supra* note 16; *Brown v. British Columbia (Minister of Health)*, (1990) 66 D.L.R. (4<sup>th</sup>) 444 [hereinafter *Brown*]; and *Wakeford v. Canada*, (1998) 166 D.L.R. (4<sup>th</sup>) 131 [hereinafter *Wakeford*].

<sup>58</sup>In this section, the rights of children with HIV are considered with reference to both the Canadian and Québec Charters. A decision to exclude an HIV-infected child from a daycare could be governed by the Québec Charter or by the Canadian Charter. If the daycare is private, the former will apply, yet if the latter is state-subsidized, then the decision may be characterized as “state action,” which is subject to scrutiny under the Canadian Charter. The same logic applies to school decisions and policies that purport to isolate or exclude a child with HIV. Unless the school is completely private, its actions will be subject to the standards established by the Canadian Charter. However, even if a school receives no state funding, its curriculum is set—at least in part—by government requirements. As such, private schools may remain subject to challenge under the Canadian Charter.

<sup>59</sup>For analysis of HIV-based discrimination under section 15(1) of the Canadian Charter, see: *Wakeford*, *supra* note 57; and *Brown*, *supra* note 57. This analysis under article 10 of the Québec Charter is undertaken in *Dr. G.*, *supra* note 16. Note also that in Québec, freedom from discriminatory exclusion from schools is buttressed by article 40 of the Québec Charter which provides a right to free and public education.

Charter.<sup>60</sup> As the story of Jessica Dos Santos reflects, a child's removal from a school or daycare can be so controversial that it may become the subject of widespread public debate. In such cases, the rights of children to keep information about their illness private will be undermined. As such, a complete protection of the rights of HIV-infected children requires that, unless a child and her family decide otherwise, information about her illness must remain confidential.<sup>61</sup>

Given that the rights of equality, privacy and dignity are upheld in constitutional and quasi-constitutional documents, they provide strong support and protection for children with HIV in educational institutions. However, these rights are not absolute. Under section 1 of the Canadian Charter, the state's infringement on an individual's fundamental rights is legitimate if it can be justified in a free and democratic society. Similarly, article 52 of the Québec Charter creates a notwithstanding clause that allows legislation to derogate from the provincial Charter. In addition, a violation of equality rights article 10 of the Québec Charter may be upheld if it is shown that reasonable accommodations were made to provide equal treatment, or that such accommodations would have imposed an undue burden.<sup>62</sup>

However, any restriction on an individual's rights and freedoms must be narrowly interpreted. In the context of children with HIV, any limitation on access to schools or daycares is unjustifiable under both the Canadian and Québec Charters. All of the research on this topic to date indicates that such restrictions are not necessary for the protection of children with HIV, nor for others in the school

---

<sup>60</sup>Section 7 of the Canadian Charter protects the right to life, liberty and security of the person, while section 8 guarantees freedom from unreasonable search and seizure. The Supreme Court has ruled that rights conferred by section 7 include the freedom from physical restraint (see *Re B.C. Motor Vehicle Act*, [1985] 2 S.C.R. 486 [hereinafter *B.C. Motor Vehicle*]), and a right to physical health and safety (see *R. v. Morgentaler (No. 2)*, [1988] 1 S.C.R. 30). Section 7 also provides that the right to life, liberty and security of the person cannot be deprived except in accordance with the principles of fundamental justice. According to the Supreme Court's decision in *B.C. Motor Vehicle*, this stipulation protects an individual's procedural as well as substantive rights. See P.W. Hogg, *Constitutional Law of Canada*, 3rd ed. (Toronto: Carswell, 1992) at 1033. Although the right to privacy is not an explicit constitutional guarantee, Canadian courts have found that it is protected by sections 7 and 8 of the Canadian Charter. See M. Marshall and B. von Tigerstrom, "Confidentiality and Disclosure of Health Information" in J. Downie and T. Caulfield, eds., *Canadian Health Law and Policy* (Toronto: Butterworths, 1999) 143 at 147-52.

For example, the Supreme Court of Canada's decision in *McInerney v. MacDonald*, [1992] 2 S.C.R. 138 recognized a link between health information, which is highly personal in nature, and an individual's autonomy and integrity. Similarly, in *R. v. O'Connor*, [1995] 4 S.C.R. 411, L'Heureux-Dubé J. held that individual privacy is an "essential component" of a person's liberty. Academics also have argued that privacy may be viewed as an integral part of the right to security of the person which is protected by section 7 of the Canadian Charter. See Foster *et al.*, *supra* note 54 at 271.

<sup>61</sup>Measures required to protect the privacy rights of children with HIV are considered below. See *infra* notes 73-78 and accompanying text.

<sup>62</sup>*Dr. G.*, *supra* note 16 at 1621-22.

community.<sup>63</sup> Moreover, as will be shown below, accommodations that encourage the full inclusion of HIV-infected children in regular classrooms and daycares can, in most cases, be implemented without imposing an undue hardship on the institution.<sup>64</sup>

## ii) Jurisprudence Instructive to Québec Courts

As mentioned above, Canadian courts have yet to be faced with the issue of the rights of HIV-infected children in schools and daycares. However, the Supreme Court of Canada and the Québec Court of Appeal have had occasion to consider the rights of disabled children to receive instruction in integrated classrooms.<sup>65</sup> These decisions should be considered to determine how influential they should be in a case similar to that of Jessica Dos Santos'. In both *Eaton* and *Chauveau*, the children's equality rights were asserted to challenge their school boards' decisions to place them in special education classes. In *Eaton*, the Supreme Court discussed the issue in light of section 15(1) of the Canadian Charter, whereas the Québec Court of Appeal in *Chauveau* considered the matter under articles 10 and 40 of the Québec Charter.

In each case, it was held that the child's right to equality had not been infringed. The focus of the Supreme Court as well as the Québec Court of Appeal was on substantive, rather than formal equality. As such, the courts questioned whether the differential treatment in the particular case could be beneficial to the child. In both decisions, this question was answered affirmatively, and it was held that placing the child in a conventional, integrated classroom would be disadvantageous. Therefore, separate education that tended to the child's special needs was considered as promoting a genuine and substantive notion of equality.

Although *Eaton* and *Chauveau* seem to seriously limit the rights of disabled children to participate in the integrated classroom setting, the particular facts of these cases must be recalled. In both decisions, evidence presented at first instance indicated that special education would better accommodate the intellectual and psychological needs of the child. As such, the holdings in these cases would not extend to a situation where there is no clear evidence that integrated education will be harmful to a child. The rulings in *Eaton* and *Chauveau* state that separate special education for children with disabilities is legally sustainable only where this is clearly mandated by their intellectual and psychological needs.

---

<sup>63</sup>In North America, there have been no reported cases of HIV-transmission through contact in a classroom or daycare setting. See Foster *et al.*, *supra* note 54 at 267.

<sup>64</sup>See discussion, *infra* notes 69-81.

<sup>65</sup>See *Eaton v. Brant County Board of Education*, [1997] 1 S.C.R. 241 [hereinafter *Eaton*]; and *Commission Scholaire Regionale Chauveau v. Commission des Droits de la Personne du Québec*, [1994] R.J.Q. 1199 (Que. C.A.) [hereinafter *Chauveau*].

Having HIV thus is not, in and of itself, grounds for the legitimate exclusion or separation of a schoolchild, since the illness does not normally impair one's learning capacity. Given that the child's removal is likely to be psychologically and intellectually harmful, any claim that special education is required to further the child's right to substantive equality would be unfounded. In light of these factors, it seems that in most cases, the exclusion of children with HIV from schools or daycares will be inconsistent with the Canadian and Québec Charters, and will not be supported by the Canadian jurisprudence concerning the rights of disabled children in schools.

The illegality of removing HIV-positive children from integrated classrooms is supported by the American decisions that have considered this precise topic. These cases reveal a commitment to ensuring the inclusion of children with HIV and AIDS, provided that this will not pose an unreasonable risk to other schoolchildren. Moreover, the threshold for what constitutes such an "unreasonable risk" is quite high, as courts have obliged schools to take reasonable measures to alleviate the risk of HIV transmission in schools, thereby encouraging the full participation of HIV-positive children in regular classrooms.<sup>66</sup>

Although the U.S. courts generally have prohibited the exclusion of children with HIV from the classroom, one American case raises a particular situation in which a child's removal may be considered justified. In *Martinez v. School Board of Hillsborough County, Florida*,<sup>67</sup> Eliana Martinez, a six-year-old mentally disabled child infected with AIDS, was barred from attending her special education classes. The court found that because Eliana was incontinent and unable to control her bowel and bladder movements, her behaviour posed an increased risk to other schoolchildren. The court also held that the potential harm was exacerbated by her inability to understand the risk she posed to others, or to exercise the precautions required to prevent HIV transmission. Without engaging in any analysis of the school's obligation to accommodate Eliana's particular needs, the court concluded that the decision to remove her from the classroom was justified in the circumstances.

The *Martinez* case reveals a problematic issue that could arise in the Canadian context. This decision suggests that there may be a stronger tendency to legitimize the exclusion of a child with AIDS or HIV who is also intellectually or emotionally challenged. As such, even if the current state of the law seems to protect children against exclusion, there may be some specific cases in which their removal from classrooms or daycares is considered legitimate. In such circumstances, the child's basic right to participation in the educational context may be infringed. Yet, this

---

<sup>66</sup>See e.g., *Thomas v. Atascadero Unified School District* 662 F. Supp. 376 (C.D. Cal. 1987); *Ray v. School District of DeSoto County*, 666 F. Supp. 1524, (M.D. Fla. 1987); and *District 27 Community School Board v. Board of Education*, 502 N.Y.S.2d. 325 (1986).

<sup>67</sup>675 F. Supp. 1574 (M.D. Fla. 1987) [hereinafter *Martinez*].

may be avoided by requiring an educational institution to take certain measures to accommodate the child's particular needs, and thereby preserve her integration in the school community. Although this inquiry was not undertaken in the *Martinez* judgment, it is not beyond the role of the judiciary to consider the adaptations that schools and daycares may make to protect the rights of children with HIV.

A second complexity that emerges in the U.S. caselaw is less obvious than the potential exclusion of HIV-positive children with intellectual disabilities. In judgements other than *Martinez*, the courts held that children with HIV had the right to re-enter and remain in the classrooms from which they had been removed. Yet, although these decisions appear to recognize the basic right of participation in an integrated educational setting, the courts did not consider other rights of HIV-infected children that also may be susceptible to infringement. In particular, these children may have serious concerns about the protection of their privacy, dignity and equality rights within the school community.

It thus appears that the rights of HIV-positive children may be at stake in two different contexts within the school setting. At a basic level, children have a right to participate in integrated classrooms and daycares with their peers.<sup>68</sup> As *Martinez* demonstrates, children with emotional or intellectual disabilities may be most vulnerable to an infringement of this right. At a second level, HIV-positive children have a right to dignity or "comfort" and equal treatment once in the educational and social framework of a school or daycare. Yet, the American jurisprudence seems to suggest that this right has received less recognition, and thus weaker protection, from the legal community.

To ensure that each of these rights receives adequate legal protection, the Québec legislature must develop a policy that obliges educational institutions to accommodate the needs of HIV-positive children. Such accommodations must seek to preserve their rights to participation, equality and dignity within the school community. Yet, before this can be accomplished, the definition and scope of the duty to accommodate imposed on Québec schools and daycares must be assessed. This requires the formulation of specific measures that educational institutions can implement to bring the legal rights of HIV-positive schoolchildren into line with the principles established in the U.N. Convention.

---

<sup>68</sup>It should be noted that "integrated" in this context does not necessarily mean that children with special needs who have HIV should be placed in mainstream classrooms. Addressing this issue is not within the purview of this paper. Rather, what is implied here is that having HIV does not justify the removal of children from their classroom environments. Thus, this argument would support the "re-integration" of Eliana Martinez, a child with AIDS and an intellectual disability, into her special needs classroom. That is, it advocates allowing a child like Eliana to re-enter the classroom from which she had been removed and to which she was accustomed.

**(C) “Reasonable Accommodations”**

In *Eaton* Sopinka J. gave a wide interpretation to the duty to accommodate persons with physical disabilities when he wrote:

Exclusion from the mainstream of society results from the construction of a society based solely on ‘mainstream’ attributes to which disabled persons will never be able to gain access. Whether it is the impossibility of success at a written test for a blind person, or the need for ramp access to a library, the discrimination does not lie in the attribution of untrue characteristics to the disabled individual. The blind person cannot see and the person in a wheelchair needs a ramp. Rather, *it is the failure to make reasonable accommodation, to fine-tune society so that its structures and assumptions do not result in the relegation and banishment of disabled persons from participation, which results in discrimination against them.*<sup>69</sup>

Based on this understanding of the duty to accommodate adopted by the Supreme Court of Canada, it is clear that a social institution will not satisfy its obligation in this regard merely by affording disabled persons the same services as those provided to the ordinary public. Rather, specific measures that encourage the meaningful participation of these individuals must be undertaken. These accommodations must start by protecting the rights to equality, dignity and privacy of such persons once they are within the institutional context.

An expansive notion of the duty to accommodate has been conceptualized and developed by Professor Martha Minow whose ideas on social difference contribute significantly to identifying and dealing with problems of discrimination. According to Minow, discrimination often is rooted in our perception of the disabled as “different”. Yet, this understanding changes once the locus of “difference” shifts away from the particular individual to her relationship with the norms and institutions that exist in society.<sup>70</sup> Once the label of “difference” is removed from the individual, it becomes easier to place the onus of adaptation on social institutions to ensure that they can be accessed by all persons equally. By revisiting the institutional *status quo* and questioning how it can be made more accommodating, it will become possible to allow for the full and meaningful participation of disabled persons in every realm of society.

Although Minow’s arguments significantly broaden the duty to accommodate imposed on social institutions, this is acceptable given that such institutions are in the best economic and strategic position to undertake the required adaptations.

---

<sup>69</sup>*Eaton*, *supra* note 65 at paragraph 67 [emphasis added].

<sup>70</sup>M. Minow, *Making all the Difference: Inclusion, Exclusion, and American Law* (Ithica, New York: Cornell University Press, 1990) at 53-56.

Moreover, such extensive accommodations are necessary for alleviating the stigma of difference from disabled persons, and maximizing their participation and comfort in social institutions. This analysis is quite instructive for understanding what accommodations are “reasonable” to require from schools and daycares with respect to children with HIV. A broadened duty to accommodate calls for modifications that will permit the initial entry of these children into educational institutions, and further, will encourage their full interaction and socialization once within them.

Thus, at a basic and minimum level, accommodation requires schools and daycares to safeguard the child’s right to “participation”. As such, education policies must permit children with HIV to enter and remain in their classrooms, even where their conduct or physical challenges may cause them to be perceived as too “high-risk” to be educated with their peers.<sup>71</sup> Furthermore, although the *Martinez* decision suggests otherwise, intellectual disability alone does not justify a child’s removal from her classroom or daycare. Rather, schools are obliged to make reasonable accommodations to ensure the inclusion of HIV-positive children while at the same time protecting the health and safety of others in the school community. Appropriate measures would include adopting routine safety procedures for handling blood or body fluids, administering first aid, and managing common child injuries, such as bite wounds and nosebleeds.<sup>72</sup>

Although these initial measures will protect the basic right of children with HIV to attend schools and daycares, a second level of accommodation is required to promote the meaningful participation of children in these institutions. Fulfilling the duty to accommodate at this level requires a more concerted effort to promote viable and substantive equality for HIV-positive children in the classroom. This will involve the implementation of two separate policies. The first of these should focus on the protection of the privacy and dignity rights of children and their families. Schoolchildren with AIDS or HIV likely will have legitimate concerns about the confidentiality of their medical condition. Although, in some cases, it may be compulsory to report known cases of HIV in schools where a legitimate public health objective is at stake,<sup>73</sup> school officials should not be required to inform the parents of other children or public health authorities if a schoolchild is HIV-

---

<sup>71</sup>For HIV-positive children, “high-risk” behaviour or characteristics would include physical aggression, biting, susceptibility to nosebleeds, an inability to control bladder or bowel movements, or an inability to understand the nature of HIV and how to prevent its transmission.

<sup>72</sup>See: Infectious Diseases and Immunization Committee, Canadian Paediatrics Society, “A Bite in the Playroom: Managing Human Bites in Day Care Settings” (1998) 3:5 *Paediatrics & Child Health* 351; Foster *et al.*, *supra* note 54 at 274. The principles recommended by Foster *et al.* were adopted by various school boards in Québec, including the English Montreal School Board (“EMSB”). See EMSB, *General Directorate on AIDS and HIV* (1988), article 2.

<sup>73</sup>See J. Hamblin & M.A. Somerville, “Surveillance and Reporting of HIV Infection and AIDS in Canada: Ethics and Law” (1991) 41 *U.T.L.J.* 224 at 237. However, these authors note that the circumstances in which a legitimate public health objective will require cases of HIV to be reported are quite limited.

positive.<sup>74</sup> Although this position contrasts with the law in Ontario<sup>75</sup>, it should nevertheless be adopted by all school boards in Québec in order to respect the privacy rights of children and their families.<sup>76</sup>

At the present time, Québec law enables the council of any provincial municipality to make by-laws to establish a board of health that has all the powers the council sees fit to promote public health, and to provide precautionary measures against the introduction and contagion of infectious diseases.<sup>77</sup> This legislation requires amendment to limit the measures that may be created by the board of health to prevent the spread of infectious disease. Its decisions must be guided and circumscribed by the right to dignity, honour and reputation, and private life, which are guaranteed by human rights legislation in Québec. As such, while certain approaches—such as education about HIV and its prevention—are appropriate, disclosing the identity of a schoolchild affected by this illness to her community would run counter to articles 4 and 5 of the Québec Charter, and possibly section 7 of the Canadian Charter.<sup>78</sup>

In addition to the protection of privacy rights, children with HIV require assurance that their schools will take reasonable steps to protect them from stigmatization and exclusion by their peers. Although schools cannot dictate social perceptions and attitudes towards persons with HIV, the effort it makes to accommodate children with this illness can set a remarkable example for the community. Fostering notions of equality for children with HIV will require that schools and daycares implement policies to encourage their full participation in every type of academic and extra-curricular activity. As such, children with HIV will be guaranteed the right to be educated in integrated classrooms, and to engage in all school-related social activities.

Schools and daycares also have an important social responsibility to help dispel the ignorance and prejudice that continues to persist in our communities. This can be fulfilled through the creation of programs that aim to educate teachers, administrators and the general school community about HIV. Within this context,

---

<sup>74</sup>This position was taken by M.A. Wainberg, the director of the Montreal AIDS Centre and A. Renaud, the administrator of the McGill AIDS Centre, in their editorial written in response to the exclusion of Jessica Dos Santos from her daycare centre. See, M.A. Wainberg & A. Renaud, "Daycare Expulsion Based on Ignorance" *The [Montreal] Gazette* (3 March 1994) B3.

<sup>75</sup>Under the *Education Act*, R.S.O. 1990, c. E-2, s. 265(k), a school principal is obliged to report any suspicions of a communicable disease in her school to the school board.

<sup>76</sup>The respect for the privacy of persons with HIV in schools has been incorporated into the policy adopted by the EMSB, *supra* note 72. Under article 12 of this policy, the identity of a student or employee infected with HIV or suffering from any HIV-related illness must remain strictly confidential. Note, however, that this policy leaves open the door to reporting the presence of HIV in a school, even though the identity of the carrier must remain undisclosed.

<sup>77</sup>*City and Towns Act*, R.S.Q., c. C-19, s. 413(I)(1).

<sup>78</sup>Foster *et al.*, *supra* note 54.

law has an important role to play in two respects. First, legislation that encourages education and information about pediatric HIV bears normative force, fostering the objective of full equality for children affected by this illness. In addition, the law also functions as a mechanism for regulating and resourcing informational programs within communities. Legislation crafted in this area has the potential to mandate the creation of these programs, regulate how they are to be carried out, and ensure that they receive adequate funding from public sources.

Educational programs structured by such legislation and policy would be consistent with article 24(e) of the U.N. Convention which states that all segments of society, particularly parents and children, must be informed and have access to basic education about child health and hygiene and the prevention of accidents. Moreover, article 24(f) obliges states to develop preventive health care guidance for parents, as well as education and services concerning family planning. As public institutions devoted to education, schools will be the most effective bodies through which the state can carry out these responsibilities.

Programs designed to provide education about HIV should aim to instruct parents and educational professionals about the nature and effects of this illness, and the minimal risk of its transmission in a classroom or daycare setting. Such programs can effectively educate school and daycare staff and others in the community about HIV, and may foster a greater sense of tolerance towards HIV-positive children in the classroom.<sup>79</sup> A pilot project undertaken in response to Jessica Dos Santos' exclusion from her Côte-St-Paul daycare centre<sup>80</sup> indicates the potential impact of such programs on a community. Through this project, 108 information sessions about HIV in the daycare setting were delivered to parents, daycare staff and administrators. Results indicated that the knowledge and attitudes of participants towards the inclusion of children with HIV improved significantly as a result of these information sessions. Moreover, the research reported that 37% of the daycares that participated in these information sessions subsequently developed their own policies for ensuring the integration of children with HIV.

Although programs directed at adults within the school or daycare community are important for promoting the rights of HIV-positive children, including education about HIV within a school's curriculum is likely to be even more critical. While instruction about HIV must be consistent with the age, maturity and level of understanding of children, it must be recognized as an essential component of their education. Programs through which children may learn about HIV should be designed to pursue two objectives. First, it must focus on eliminating discrimination and encouraging children to be more accepting of peers who may be infected with

---

<sup>79</sup>C.K. Burr & L.J. Emery, "Speaking with Children and Families about HIV Infections" in Pizzo & Wilfert, *supra* note 7 at 926.

<sup>80</sup>A. Renaud *et al.*, "Knowledge and Attitude Assessment of Québec Daycare Workers and Parents Regarding HIV/AIDS and Hepatitis B" (1997) 88:1 Can. J. Public Health 23.

HIV. Second, it should strive to educate children about HIV and its transmission in an attempt to reduce the prevalence of this disease among young people.<sup>81</sup> Through these combined efforts, a greater recognition for the rights of dignity and equal treatment can be realized for children with HIV within their school communities.

#### **(D) Summary of Recommendations to the Québec Government**

In light of the vulnerability of privacy, dignity and equality rights for HIV-positive schoolchildren, a clear legislative policy is required to preserve and promote these rights in the context of educational institutions. So that the ideas enshrined in the U.N. Convention are upheld by schools and daycares throughout Québec, the development of this policy should be guided by the following principles:

- recognition that the exclusion of a child from a school or daycare is not legally justified and would constitute a violation of her right to equality and freedom from discrimination, guaranteed by section 15(1) of the Canadian Charter, and article 10 of the Québec Charter. It also would infringe upon the child's right to privacy, dignity and security of the person, protected by section 7 of the Canadian Charter, and articles 4 and 5 of the Québec Charter. The story of Jessica Dos Santos, although never litigated, reveals how the exclusion of HIV-positive children brings each of these rights into play.
- Given that HIV normally does not impair a child's cognitive abilities, her removal from an integrated classroom or daycare will not be in her best interests. In light of the harm likely to result from this, it is clear that any claim that such exclusion will promote substantive equality for the child is unfounded.
- Although current law and policy suggest that children with HIV cannot be legally removed from their classrooms or daycares, their rights require additional protection in two respects. First, where a child is considered to pose a greater risk of transmitting HIV, her exclusion may be considered justified. Second, the equality, privacy and dignity rights of such children have received little attention and recognition from the legal community.
- To ensure that these rights for children are adequately protected, accommodations must be undertaken at two levels. As a basic step, children with HIV must be permitted to enter and remain in classrooms and daycares.

---

<sup>81</sup>The policy adopted by the EMSB, *supra* note 72 is developed along these lines. Article 16 requires that education about HIV be included in a school's curriculum, and requires that such education be provided for all school personnel. This article reflects the recommendations made by Foster *et al.*, *supra* note 54 at 273-74. It should be noted, however, that the EMSB's policy does not discuss providing HIV education for the parents of schoolchildren, nor for the general school community.

Schools and daycares in the province thus must be urged to formulate routine safety procedures for situations in which there may be a risk of contact with a child's blood or bodily fluids.

- Moreover, accommodation is required to protect a child's right to freedom from discrimination once in the school or daycare. As such, Québec schools and daycares must develop programs committed to education about HIV and its transmission. These programs should be targeted at schoolchildren, as well as educational staff, administrators and parents within the community.
- Schools and daycares also must strive to preserve the privacy rights of children with HIV and their families. Law and policy in Québec thus must plainly state that families are not obliged to divulge information about a child's illness to educational authorities. In addition, if a staff member of a school or daycare becomes aware that a child is HIV-positive, there should be no requirement to communicate this information to co-workers, administrators, public health authorities or parents of other schoolchildren.
- Finally, there must be a commitment to ensuring the wide dissemination of this policy to educational institutions across the province so that the state of the law is made known to all educators and administrators in schools and daycares throughout Québec.

## **Conclusion**

The role that the law has to play with respect to improving the quality of life for children with HIV is not all-encompassing. Although jurists can carve out distinct rights for children and seek to protect and enforce them, the law cannot guarantee that a treatment or cure for pediatric HIV will be discovered. Similarly, while the law can establish the parameters of acceptable social conduct towards persons with HIV, it cannot force members of society to perceive and treat these individuals with tolerance and compassion. Thus, while legal work is critical for certifying the rights of HIV-positive children, it must be carried out alongside the endeavours of other professions to ensure that the needs of these children are fully met. It is only by working with practitioners and academics in the fields of medicine, bioethics, social work and education that jurists will be able to successfully respond to the particular legal challenges that face children living with HIV in Québec.

Although the issues and complexities that arise with respect to pediatric HIV cannot be resolved solely through legal reform, scrutinizing law and policy to ensure that it adequately upholds the rights of children with HIV is necessary. If properly formulated and applied, the law can effectively push children to the forefront of the concerns of all professionals who tackle HIV-related issues. One of the most important ways that jurists can accomplish this objective is by designing

legislation and policies that perceive and present children as bearers of distinct legal rights. Relying on the U.N. Convention, which obliges all states to uphold these rights for children, would lend legitimacy to any such domestic legal developments.

In Québec, the need for legislation that establishes clear rights for children with HIV is particularly relevant, given that the province's pediatric HIV rate is likely to be the highest in Canada, and it appears to be growing. To protect the interests of these children, two key rights must be recognized and pursued for them: the right to the highest attainable standard of health, and the right to dignity and equality in the educational context. As this essay has demonstrated, it is not beyond the reach of the law to protect and preserve these rights for HIV-positive children. Nevertheless, this work also has discussed problematic aspects within the current state of the law that may hinder a full recognition and enforcement of these rights. As such, reform is necessary to render legal policy and practice in Québec consistent with the principles set out in the U.N. Convention.

The recommendations presented in this paper are intended to serve as a starting point for undertaking this type of reform. Although they may not respond to all concerns that may arise in every case of pediatric HIV, they attempt to address the broad issues likely to be encountered by HIV-positive children. By considering, refining and implementing these recommendations, Québec jurists will have taken a positive step toward improving the lives of children with HIV. Bearing distinct legal rights, these children will have greater hope for a life where their dignity and privacy are respected, where they may learn and socialize with their peers, and where they may enjoy the greatest state of health that is medically possible.

Finally, thinking about children with HIV in this light forces us also to consider how the law interacts with children more generally. Developing law and policy that promulgates and promotes the rights of HIV-positive children communicates a message that *all* children hold enforceable rights, even if their individual needs and interests may vary. As such, this project can be understood as contributing to the development of a larger and more important framework. In this broader construct, children are perceived as autonomous individuals in their own right, who also have distinct needs and interests that call for our attention, respect and compassion in ensuring that they are protected and preserved.