Type 2 Diabetes and Children in Aboriginal Communities: The Array of Factors that Shape Health and Access to Health Care

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The human costs of unrestrained development on our traditional territory, whether in the form of massive hydroelectric development or irresponsible forestry operations, are no surprise for us. Diabetes has followed the destruction of our traditional way of life and the imposition of a welfare economy. Now we see that one in seven pregnant Cree women is sick with this disease, and our children are being born high risk or actually sick.1

I. Introduction

The history of Canada’s Indigenous peoples would be incomplete without examining and recounting the ravaging toll exacted by illness on their civilization. First contacts between Aboriginal communities and European explorers and settlers were marked by an onslaught of disease and war, resulting in significant population declines among Indigenous communities, and in rare cases, the virtual extinction of Amerindian nations.3 By the 1870s, European expansion and industrialization resulted in the relocation of Indigenous peoples onto reserve territories where pestilence and famine continued to plague their communities.4 Through legislation and treaties with Aboriginal leaders, the Canadian government promised to provide for and protect the health of Indigenous peoples, and thereby guarantee the welfare of future generations. Nevertheless, these issues continued to be ignored by the government throughout most of the twentieth century.5

In recent years, Canada’s federal government has begun to consider Aboriginal claims regarding land, resources, health, social welfare, education, and employ-

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2 The terms “Indigenous” and “Aboriginal” include three distinctive groups in Canada: Indian, Metis and Inuit peoples.
4 See O.P. Dickason, Canada’s First Nations: a History of Founding Peoples from Earliest Times (Toronto: McClelland and Stewart, 1992) at 287-305.
ment. Although section 88 of the Indian Act provides that general provincial laws are applicable to Aboriginal persons, this is subject to Aboriginal treaty provisions, and to Parliament’s overarching constitutional jurisdiction over “Indians, and lands reserved for the Indians.” As such, Aboriginal affairs in Canada are governed primarily by Parliament, subject always to Aboriginal rights. At the same time, provincial legislation of general application, that is not inconsistent with Aboriginal rights or federal laws, also extends to Aboriginal peoples.

While Parliament has the jurisdiction to devise policies related to Aboriginal health and social welfare, those which have been developed to date have not been sufficient to overcome the shameful history of neglect toward Indigenous peoples. In the area of health alone, numerous studies reflect the disproportionate burden of illness sustained by Indigenous communities in Canada. In contrast to the non-Indigenous population, Aboriginal peoples have higher mortality rates across all age groups, and their infant mortality rate is twice to three times the national average. Moreover, their propensity for diabetes, cancer, heart disease, hypertension, and arthritis is much higher than that of Canadians.

The impact on the health of Aboriginal adults is not the sole legacy of their historical marginalization. Aboriginal children suffer from excessive rates of meningitis, otitis media, respiratory illnesses and iron deficiency anaemia. The most striking disparity between Aboriginal and non-Aboriginal pediatric health is found in the increased rates of Aboriginal children with type 2 diabetes. Arguably, the psychosocial health of Aboriginal youth is an equal or greater cause for concern: depression, suicide and substance abuse rates among Aboriginal teens are alarming. Like psychosocial illness, diabetes is cyclical, bearing the potential to pass from one generation to the next. Both diseases also have their roots in the effects of colonialism, and both are gravely exacerbated by poverty and social marginali-
A move away from a diet based on hunting and gathering food to a sedentary way of life and poor nutrition have contributed to an epidemic of this illness among Canada’s Indigenous peoples.\textsuperscript{14} Health Canada’s First Nations and Inuit Health Branch indicates that the prevalence of type 2 diabetes\textsuperscript{15} in Aboriginal communities is three to five times higher than in the non-Aboriginal Canadian population. Complications from this chronic disease are serious, and include kidney disease, cardiovascular illness, blindness, and amputations.\textsuperscript{16}

Although type 2 diabetes was previously unknown to children and youth, Canadian researchers have recently found Aboriginal children afflicted with this illness.\textsuperscript{17} The rates of pediatric diabetes within some Indigenous communities in Canada have been estimated to be among the highest in the world.\textsuperscript{18}

In light of the correlation between diabetes and the social and economic history of Canada’s Aboriginal people, this example provides a fertile ground for considering how culture, race and poverty may affect the state of children’s health, as well as their ability to access quality medical care. This paper begins with a factual overview of pediatric diabetes among Aboriginal children in Canada. A discussion of the legal rules that structure Canada’s health care system, as well as their inability to meet the needs of these children, then is considered. The deficiencies of Canada’s health structure for Aboriginal children have resulted in government researchers and Indigenous communities developing special programs designed to promote pediatric health. A series of recommendations aimed at modifying, improving and adding to these programs is presented in the concluding section of this work. These suggestions are intended to protect the health care rights of all children in Canada whose well being has been compromised by poverty, or racial or cultural discrimination.


\textsuperscript{15}Type 1 and type 2 diabetes are described and distinguished in the discussion below. See infra note 22.


\textsuperscript{18}“Native Leaders Mount Fight Against Diabetes” The [Toronto] Star (6 July 1990) D5.
II. An Overview of Pediatric Type 2 Diabetes in First Nations Communities in Canada

1. Historical and Current Presence of Type 2 Diabetes in Indigenous Communities

Prior to Canada’s colonization by Europeans, the country’s Indigenous population was organized into groups of hunting and gathering communities. Within these societies, inactivity and obesity were uncommon. Aboriginal people’s genetic make-up had evolved over time to cope with alternating periods of abundant and reduced food intake by producing increased insulin and by developing excessive insulin resistance. However, colonial expansion, industrialization and urbanization produced a ready and continuous food supply within Indigenous communities. As a result, obesity rates rose dramatically and quickly. Diabetes, an illness linked to obesity, began to appear within Aboriginal communities in North America in the 1940s, and in Canada over the last two decades. Moreover, a rapid transition from hunting and gathering to sedentary, reserve-based lifestyles, as well as a switch from a high-fibre, low-fat diet to one based on low-fibre, high-calorie foods, exacerbated the prevalence of obesity and diabetes among Canada’s Indigenous peoples.

Type 2 diabetes traditionally is related to obesity with associated insulin resistance, and decreased uptake of glucose by the cells, leading to excess glucose in the bloodstream. Although the scope of this paper does not allow a full analysis of diabetic illness, the primary distinctions between type 1 and type 2 diabetes should be highlighted. In type 1 diabetes (which mainly affects children) the pancreas stops producing insulin. Injections of insulin are thus required to secure the survival of the person with diabetes. In contrast, type 2 diabetes is an illness that usually starts in adulthood and, until ten years ago, did not affect children. It occurs where the insulin produced by the pancreas is not properly used at the cell level, resulting in excessive insulin within the body. This in turn leads to decreased use of glucose by the cell, and increased levels of circulating glucose. At an initial level, type 2 diabetes is treated through lifestyle modifications; an elimination of foods high in sugar and fat, an increase in physical activity and reduction in weight. Oral medications and insulin injections may also be administered.

Although type 2 diabetes was previously known as “adult-onset” diabetes, recent research indicates that this form of the illness now affects an increasing
number of children and adolescents. This is particularly true for Aboriginal youth in Canada, who suffer from type 2 diabetes at seven times the rate that Caucasian Canadian children are afflicted with type 1 diabetes. Although the specific causes of type 2 diabetes among Aboriginal children are uncertain, research has shown that youth who sustain this illness typically have family histories of type 2 diabetes, particularly in the form of maternal diabetes or gestational diabetes. Most of these children also struggle with their weight, with keeping active and maintaining a healthy diet.

Given that pediatric type 2 diabetes is a relatively new illness, researchers have had difficulty predicting its consequences for Indigenous communities. Nevertheless, in adults, long-term complications include neuropathy, cardiovascular disease, renal failure and blindness. Affliction with type 2 diabetes during childhood might suggest an even longer list of complications, or their earlier onset. Moreover, the fact that most youths with this illness are female is alarming, as the onset of diabetes before or during pregnancy bears a potential impact on the health of a developing fetus. The cycle of poor health in Aboriginal communities is therefore likely to be perpetuated.

2. Potential Barriers to Prevention, Management and Treatment

The health implications presented by pediatric type 2 diabetes necessitate the development of strategies for preventing, managing and treating the illness among Aboriginal children and youth. As such, several researchers have undertaken studies in Indigenous communities to further assess the impact of type 2 diabetes, and develop programs that help children, families and communities understand and cope with the illness. These initiatives have combined suggestions related to healthier and more active lifestyle modifications, diabetes screening programs, and pharmacological treatment programs within Aboriginal communities. Although some of these initiatives have been quite beneficial, researchers have identified several factors that threaten their success. They include social and cultural ap-

27 Ibid.
28 Ibid.
30 See, e.g., the Kahnawake Schools Diabetes Prevention Project which is described below. See discussion, infra text accompanying notes 71-73.
proaches to the illness, economics and poverty, geographical and environmental obstacles, and biomedical limitations.

i) Social and Cultural Obstacles

Dr. Katherine Gray-Donald, who has conducted diabetes research among Cree communities in northern Québec, has observed that the primary obstacle to creating and implementing effective diabetes prevention programs is ensuring that such programs are meaningful and helpful to Aboriginal communities. Although Cree communities have been open to research and eager to learn about prevention and treatment strategies, a greater challenge lies in delivering health care and information about health in a way that enables behaviour modification, to make these interventions effective. Behavioural modifications are further complicated where children are involved, as the required changes involve altering the lives of entire families, rather than just those of the particular individuals afflicted with the illness. As such, this context reveals the importance of recognizing and including the network of relations that ultimately shape children’s health. In this way, it illustrates the theme of social interdependence which constitutes a fundamental dimension of health care rights understood from a relational perspective.

The etiology of diabetes is complex, and involves both genetic and lifestyle factors. In Aboriginal communities, it is impacted by the historical and current social, economic and cultural considerations discussed above. Added to these considerations is the lack of access to routine health care providers in many communities. Those located in remote areas, such as the Cree, are visited by a rotating staff of non-Indigenous physicians and nurses from urban centres. Frequently, messages and information delivered by one set of care providers may conflict with those given by others, frustrating efforts to provide clear information to community members about the best course of behaviour to follow to prevent or treat illness.

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31 Telephone interview with Katherine Gray-Donald, Director and Associate Professor, McGill University School of Dietetics and Human Nutrition (5 January 2000).
32 Telephone interview with Dr. Ann Macaulay, supra note 22.
33 Elsewhere, I have argued that rights for children and health care rights are most viable when they are conceived of as being held by individuals connected within a larger network of social relations. All of the players within this interdependent network bear responsibilities to each other, and their particular roles are determined by context and the nature of their connection to the individual or group whose rights are in issue. See: A. Campbell, “Stretching the Limits of ‘Rights Talk’: Securing Health Care Entitlements for Children” (2003) 27:2 Vermont L. Rev. (forthcoming).
34 Both Dr. Katherine Gray-Donald and Dr. Ann C. Macaulay brought this factor to my attention. Moreover, Dr. Macaulay emphasized a lack of nutritionists who work within Aboriginal communities. Currently, the Medical Services Branch of Health Canada funds one nutritionist devoted to Aboriginal issues per province. Such a ratio is insufficient to deal with the needs of Aboriginal peoples, and has had an important impact for diabetes within their communities, given the essential role of healthy eating, increased physical activity and achieving a healthy weight in the prevention of type 2 diabetes.
Cultural barriers create additional hindrances to accessing adequate and appropriate health care for Aboriginal children and youth. For example, many teens have a fatalistic understanding of diabetes, having witnessed other family and community members experience the dreadful consequences of the illness. Many also blame insulin, a primary medication used to treat the illness, for the loss of limbs and death that may result from diabetes, and thus refuse to accept this treatment. Finally, given the historical association between western medicine and disease and death in Aboriginal communities, a reluctance to accept and implement suggestions from non-Indigenous care providers would be understandable, particularly if delivered in a culturally-insensitive, or culturally-neutral manner.

**ii) Economic Obstacles**

In addition to cultural factors, economic considerations also may bar access to appropriate care for Aboriginal children with diabetes. Although the economic status of Canada’s Indigenous population varies, a 1991 Aboriginal Peoples Survey reported that the rate of unemployment among Aboriginal adults was almost 25 percent, while that among Canada’s total population was merely 10 percent. Moreover, Indigenous persons living on reserves were found to have the highest unemployment rate in Canada, at 31 percent. Total income for Aboriginal adults also was the lowest in Canada, with 54 percent earning less than $10,000 per year, compared with 35 percent of Canada’s total population. This report further indicated that Aboriginal people generally live in poor housing, and many communities lack adequate water supplies and waste disposal.

Canada’s Department of Indian and Northern Affairs indicates that this situation has improved since 1991, but significant problems still remain. By 1996-97, most Aboriginal people remained at or below the poverty line. In major western cities, four times as many Aboriginal people as other citizens lived below the poverty line. The Department further notes that approximately 20 per cent of on-reserve homes are over-crowded (compared with one-third of such homes fifteen years ago). Finally, it is noted that 96 per cent of reserves now have adequate water supplies and 92 per cent have adequate sewage disposal.

A more recent report suggests that the problem of poverty among Aboriginal peoples is far from resolved. The Canadian Council on Social Development, in its report entitled “Urban Poverty in Canada” issued in the year 2000, found that

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35 Dean, “Treatment of Type 2 Diabetes”, supra note 23, at 267.
38 *Ibid*.
Aboriginals living in cities had among the highest poverty rates of all groups studied, averaging at 55.6 per cent.40

While poverty is no doubt a striking problem for many Indigenous persons, it is arguable that this should not impede access to quality health care, given the Canadian Medicare system, as well as the promises made by the Crown in Treaty no. 6. By the late nineteenth century, Aboriginal leaders, witnessing their communities being eroded by disease, war and famine, agreed to sacrifice their land to the Crown and relocate their communities to reserves and villages in return for special rights. This was done with the hopes of guaranteeing a secure future for Indigenous persons in Canada. Negotiations between the societies were concretized in a series of “Indian Treaties”. Treaty no. 6, signed between the federal government and the Plains Cree, contains the sole explicit reference to health in any treaty. It obliged the government to protect treaty Indians from pestilence and famine, and to provide a “medicine chest” in the home of every Indian Agent.41

This treaty right continues to bear relevance to Aboriginal health issues for two reasons.42 First, it establishes federal jurisdiction over Aboriginal health. As a result, changes or budgetary shortcomings in provincial health policies should not have any bearing on Indigenous peoples. Second, Treaty no. 6 could—pursuant to the broad, purposive and meaningful interpretation in favour of Indigenous peoples that treaties are meant to have43—be construed to extend “non-insured health benefits” to Indigenous peoples. As such, they arguably secure rights to services that are not covered by Canada’s public health insurance program, such as prescription drugs, dental care, or special psychosocial health services and programs.44 As Rotman writes:

Where treaties promised money, schools, or a medicine chest, it is logical to suggest that, as constitutional documents, treaties ought to be read in an evolutionary way...[I]f treaty promises of schools or a medicine chest were intended to provide education and health care in a manner appropriate to the time, then those promises should also be translatable, in a modern sense, to the building of schools and hospitals or medical clinics.45

Such an argument could, however, be difficult to sustain. In R. v. Johnston,46 the Saskatchewan Court of Appeal responded to a claim that the terms of Treaty

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41 See O’Neill, supra note 5 at 563-64.
42 Ibid.
44 O’Neill, supra note 5 at 563-64.
46 (1966), 56 D.L.R. (2d) 749 (Sask. C.A.).
no. 6 guaranteed free hospital services to Indigenous persons by the federal government. Culliton C.J. rejected this argument, stating:

I can find nothing historically, or in any dictionary definition, or in any legal pronouncement, that would justify the conclusion that the Indians, in seeking and accepting the Crown’s obligation to provide a “medicine chest” had in contemplation provision of all medical services, including hospital care.47

While access to free medical care in Canada, coupled with the arguable scope of Aboriginal treaty health rights, diminish the extent to which economic factors might impede access to health care, poverty may constitute a bar in other respects. In particular, it prevents access to more nutritious food that is sometimes more costly and may involve extensive time to make and prepare. In addition, poverty, and the social marginality that is often concomitant, may limit a family’s ability to express itself fully and articulately. It might also preclude relocation to areas where optimal health care can be obtained.48

**iii) Geographical and Environmental Obstacles**

Geographical and environmental factors also play a significant role in the ability of Aboriginal families and communities to prevent and manage pediatric type 2 diabetes. Where children live in isolated, northern areas, several factors contribute to inactivity. These include frigid weather, a presence of threatening wildlife in some communities, lack of exercise facilities, lack of adult supervision for youth activities, a scarcity of athletic leaders or role models, and a concern for personal safety.49 Moreover, geographical and environmental considerations often preclude physical access to care, given the distance between many Aboriginal reserves and urban centres where health facilities are concentrated, and the remote locations of many Aboriginal communities that are frequently difficult to access.

**iv) Biomedical Obstacles**

A final potential bar to accessing adequate and appropriate care for Aboriginal children relates to the realities of medical research. In most Indigenous communities, only a small fraction of children have been tested for diabetes. Yet, given that most diabetic youth are asymptomatic, their illness will remain unknown until they are screened. Given that effective management of type 2 diabetes rests primarily on its early detection and treatment, researchers have urged that all

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49 Dean, *ibid.*
Aboriginal children be screened for the illness.\textsuperscript{50} The cost of such a strategy, however, would be immense, and thus requires public support. Yet, until now, governments have remained unresponsive to calls for assistance in this regard.\textsuperscript{51}

In addition to this type of screening initiative within Aboriginal communities, biomedical research also is required to test the safety and efficacy of medication used to treat pediatric diabetes. At the present time, many drugs are administered to children without data to determine appropriate doses for patients of their age and physical size. Given that research on these medications often is carried out exclusively on adult subjects, their effects and safety for children remain unknown.\textsuperscript{52} Until the specific effects of pharmaceutical agents on children are investigated, health care for children afflicted with diabetes and other illnesses will remain substandard.\textsuperscript{53}

\textit{v) Surmounting Obstacles}

As this discussion reflects, a series of potential obstacles may bar access to the health care required to prevent, manage, and treat pediatric type 2 diabetes in Aboriginal communities. Canada’s universal system of medical care, as well as a broad interpretation of Indigenous specific treaty rights should remove major financial obstacles to accessing medical care. Nevertheless, these economic entitlements have been insufficient to prevent the erosion of Aboriginal children’s health. As the example of type 2 diabetes illustrates, access to care that guarantees a child’s well-being rests on more than simply the economic ability to acquire medical resources. Rather, health interventions must respond to historical and current realities that have been largely shaped by cultural, economic and environmental factors.

\textsuperscript{50} Association of Operating Room Nurses, \textit{supra} note 26; Dean, “Treatment of Type 2 Diabetes”, \textit{ibid.}, at 266.
\textsuperscript{51} “Diabetes Epidemic in James Bay Cree Communities” \textit{Canada NewsWire} (3 May 1999), online: LEXISNEXIS (Canada News File).
\textsuperscript{52} Dean, “Treatment of Type 2 Diabetes” \textit{supra} note 23 at 268.
\textsuperscript{53} By advocating for more extensive pediatric research, I have not ignored the significant risk that this may pose for children. The involvement of children in such research raises serious legal and ethical issues, given that children may lack legal and physical capacities to consent to engaging in this process. At the same time, children cannot and should not be treated as “little adults”, administered drugs which, though proven safe for adult subjects, may place them in jeopardy. Resolving this dilemma presents a formidable challenge. However, attempts to do so must be made given the risk to children’s health posed by their exclusion from research and the administration of medication that is unsafe for them.
III. Law and Policy: Canada’s Medicare System and Aboriginal Health Initiatives

1. A Historical Overview of the Canadian Medicare System

Canada’s health care infrastructure is premised on a principle of equal and universal access to free medical care for all citizens. A brief history of the Canadian health system provides an understanding of the meaning of the “right” to health care in this country. Throughout the twentieth century, the objective of eliminating financial barriers to accessing medical care has guided attempts to develop public insurance plans for medical and hospital services. After World War II, the federal government created a social security plan and other reconstruction measures, and encouraged the provincial governments, which maintain jurisdiction over health care, to do the same. Yet, given the costs of a publicly funded and administered health system, the provinces initially opted not to follow suit. Nevertheless, by 1947, the province of Saskatchewan set up its own health insurance plan, and by 1950, three other provinces had done the same.

These changes were accompanied by mounting pressure for federal involvement in health insurance. Thus, in 1957, Parliament enacted the Hospital Insurance and Diagnostic Services Act, holding out financial incentives to provinces for providing health insurance. By 1961, all ten Canadian provinces were operating hospital insurance programs, with the provincial and federal governments dividing their costs equally.

Shortly thereafter, Canada’s health insurance program was extended beyond hospital insurance to physician services. Following a 1964 Royal Commission Report that recommended the creation of a federally-subsidized, yet provincially-administered, medical insurance plan, Parliament enacted the Medical Care Act in 1966. By 1971, all provinces adopted hospital and medical insurance programs that met the four conditions set in the legislation to qualify for federal funds covering one-half of the programs’ cost. The Medical Care Act required provincial insurance programs to be: (1) comprehensive (that is, coverage was extended to all

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55 Section 92(7) of Canada’s Constitution confers jurisdiction over “the establishment, maintenance and management of hospitals, asylums, charities and eleemosynary institutions in and for the province, other than marine hospitals” upon provinces. Constitution Act, 1867 (U.K.), supra note 8. Over the years, it has generally been accepted that constitutional jurisdiction for the provision of health services and health insurance rests with the provinces. See Crichton et al., ibid. at 28. At the same time, Parliament maintains a level of jurisdiction to legislate in the area of health. See M. Jackman, “The Constitutional Basis for Federal Regulation over Health” (1996) 5:2 Health L. Rev. 3; and M. Jackman, “Constitutional Jurisdiction over Health in Canada” (2000) 8 Health L. J. 95.
56 S.C. 1957, c.28.
57 S.C. 1966, c.64.
health services provided by hospitals, medical practitioners or dentists), (2) universal (that is, all insured individuals were to be entitled to insured health services under uniform terms and conditions), (3) transferable (that is, residents moving between provinces would be covered during a waiting period by their former province) and (4) administered by a public nonprofit authority, subject to a federal audit.

By the mid-1970s, a period of rampant inflation led the federal government to impose a series of wage and price controls. To recoup for the lost income that resulted, Canadian physicians began to exact extra billing charges from patients. Although this practice was permitted by some provinces, a concern that extra billing was eroding access to care quickly arose. A Royal Commission appointed to study the matter issued a report in 1980 criticizing the imposition of surcharges and hospital user fees on patients. As a result, the Canada Health Act\(^58\) was enacted in 1984 and provided that provinces that imposed or allowed physicians to impose direct charges on patients would lose federal grants proportional to such charges. This statute thus added a fifth criterion to provincial eligibility for federal health insurance subsidies: accessibility. It required that insured persons have reasonable access to insured health services “unprecluded or unimpeded ... by charges or any other means.”\(^59\)

The legal infrastructure created by the statutes and policy objectives described above have crafted a legislative right to health care for Canadians. While this framework secures access to routine medical examinations and treatment, it does not create an absolute guarantee to scarce or extraordinary medical resources and procedures. Although citizens cannot be denied access to health services covered under provincial health insurance plans for lack of funds, they may be denied access to care where medical resources are in short supply.\(^60\)

Resource shortages have become manifest for Canadians in a variety of situations. A dramatic drop in nursing professionals, and a shortage of physicians and other health care providers in some locations—particularly in rural and remote areas—precludes access to care for many people in Canada.\(^61\) Access can also be hindered by lengthy wait lists for diagnostic and surgical procedures across the country. While these procedures are ultimately provided to Canadians, they often fail to be delivered in a timely manner, thereby limiting their efficacy.\(^62\)

Yet this shortcoming within the Canadian health care system has not been the major impediment to health care for Aboriginal children, particularly for those

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\(^58\) S.C. 1984, c.6.
\(^59\) Ibid. at s. 18.
\(^61\) Romanow Report, *supra* note 10 at 91ff, 159ff.
\(^62\) Ibid. at 137ff.
with type 2 diabetes. Rather, as described above, challenges in modifying behaviour and lifestyles, cultural misunderstandings about the illness and its treatment, an inability to afford nutritious food, geographical isolation, and a shortage of safe and effective medication for children have exerted the most significant impacts on their health and ability to access quality care.

At first blush, an obvious solution to this dilemma might be to improve on-site health care management and the availability of health professionals in Indigenous communities. Yet, as considered below, this approach has been limited by virtue of its failure to account for the family and community relationships that play a fundamental role in shaping children’s health. This relational component has been an integral part of certain pediatric health care programs designed by government officials and researchers for Aboriginal children. These strategies have looked beyond the question of medical entitlements within the Canadian health system, and instead have tried to integrate an understanding of how children’s social relations can affect and ultimately improve their access to health care. The discussion that follows highlights some of these initiatives, providing a critical examination of their ability to secure the health care rights of Aboriginal children in Canada.

2. Aboriginal Health Initiatives

In Canadian politics, calls for government attention to particular matters of concern frequently are responded to with an injection of finances into agencies responsible for administering the issue in question, or into research programs designed to study and improve the situation. Where the concern is perceived to merit public assistance, a cash contribution is understood to be the most effective means for reaching a solution. Government responses to health care dilemmas within Canada’s Aboriginal communities have followed along these lines. This is exemplified by strategies employed to deal with rising diabetes rates. In 1994, the Health Ministry of the Province of Ontario committed $450,000 to fund Aboriginal diabetes programs.\(^63\) By 1999, the Ministry offered another $3.3 million to sustain additional diabetes programs, primarily for Aboriginal communities.\(^64\) Similarly, the Federal budget announcement in 1999 provided $55 million over the following three years to combat diabetes. In so doing, the government indicated that this would lead to a greater understanding of why diabetes has been so prevalent in Aboriginal communities, and what must be done to ameliorate the situation.\(^65\)

Such initiatives are excellent starting points for improving health and access to medical care within Indigenous communities. Without adequate funding, the development of effective strategies for combating diabetes in a community be-

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\(^{63}\) “Grier Announces $450,000 for Aboriginal Diabetes Programs in Southern Ontario” Canada NewsWire (20 December 1994), online: LEXISNEXIS (Canada News File).

\(^{64}\) A. Artuso, “$3.3M for Diabetes Programs” The Toronto Sun (3 November 1999) at 22.

comes impossible. Nevertheless, other interventions demonstrate that their success depends not only on the availability of financial resources, but also, on the involvement of Indigenous communities, as well as a recognition and incorporation of their cultural values and needs in creative and meaningful ways.

The Aboriginal Head Start initiative was established by the Canadian federal government in 1995 to promote “child development and school readiness” for preschool-aged Aboriginal children.66 Through a focus on their emotional, social, health, nutritional and psychological needs, the program aims to ensure that Aboriginal children are fully prepared to begin their schooling. A primary feature of this initiative is the federal government’s financial contribution to projects related to child and youth development.67 At the same time, the objectives of Head Start reach beyond this. There are six stated components of Head Start: culture and language, education, health promotion, nutrition, social support and parental involvement.68

Essentially, the project considers the emotional, cognitive and physical dimensions of children’s well-being, and fosters measures aimed at securing their health and development. This is achieved by encouraging projects and strategies controlled by Aboriginal communities that aim to instill a sense of cultural pride and a desire to learn, provide skills for parents, promote emotional and social development, and improve family relationships.

As such, Head Start adopts a comprehensive understanding of pediatric health, recognizing that a young child’s well-being rests not only on her physical health, but also, on her emotional strength and family affiliations. Moreover, because a key goal of Head Start is to foster locally designed and controlled intervention strategies,69 projects developed within this rubric will solidify Aboriginal communities’ involvement in children’s health. Head Start’s recognition of the broad array of factors that affect a child’s health has helped contribute to its success in stimulating cultural awareness and pride among pre-school aged chil-

66 When Head Start was initiated in 1995, it was restricted to “off reserve” programs, to enhance the child development of Aboriginal children living off reserves, in urban centres and large urban communities. However, in 1998, the program was expanded to include “on reserve” programs designed to secure the health of all Aboriginal children and their families. See Health Canada, First Nations and Inuit Health Branch, ECD Strategy for Aboriginal Children: Expansion of Aboriginal Head Start (AHS) (January 2002), online: Health Canada <http://www.hc-sc.gc.ca/fnihb/cp/publications/ecd_abs.htm> (date accessed: July 30, 2002).


68 Ibid.

Although these developments do not pertain directly to a child’s physical health, they contribute to a comprehensive vision of well-being by fostering self-identity and instilling self-confidence among the youngest members of Aboriginal communities.

The importance of community participation in programs aimed at improving Aboriginal pediatric health also is witnessed in interventions that target children at risk of developing type 2 diabetes, or those already afflicted with this illness. The Kahnawake Schools Diabetes Prevention Project (“KSDPP”) was a three-year community-based program that developed strategies for preventing the onset of type 2 diabetes within a Mohawk community near Montréal, Canada. A perceived increase in obesity among children in this community led to the design of this intervention which was aimed at encouraging changes in their dietary and exercise patterns in the hopes of reducing the future occurrence of type 2 diabetes. Based on the Mohawk tradition of caring for future generations, the program focussed on elementary school children, yet incorporated the participation of family and community members.

As a result of the KSDPP, 63 different diabetes prevention strategies were undertaken. These included the integration of a Health Education Program in schools, the formation of a new Community Health Advisory Board, the creation of a community recreation path, and the development of community-based activities that promote healthy and active lifestyles. These steps toward ensuring pediatric health can be attributed to the KSDPP’s inclusion of the entire Mohawk community, in particular, local educators and school administrators. Through the Health Education Program, a curriculum was created by a dietitian and community nurse to inform primary school children about the importance of nutrition, fitness, and about the causes and effects of diabetes. Creative modes of teaching were used to make this information intelligible to young children, such as story telling, puppet shows, crafts and audio-visual presentations. In addition, school canteens eliminated all “junk food” and offered only healthy choices, and one school in the community implemented an additional physical education class in its curriculum.

Projects like Head Start and the KSDPP are instructive and inspiring and reveal the importance of community leadership and administration in projects designed to promote health care rights for Aboriginal children. At the same time, their effects are enjoyed by only a small segment of children in Canada’s Aboriginal communities. Few initiatives as innovative as the KSDPP have ever been undertaken in other parts of Canada, and Head Start serves only a fraction of Aboriginal children. Initial reports reveal the important contributions it has made to Aboriginal youth. In addition to teaching children about their cultural heritage, Head Start projects have also sparked their interest in learning and in reaching their full potential as students. See S.J. Green, “Rituals of Renewal for Preschoolers Provide a Vital Link to the Teachings of the Past” The [Toronto] Star (10 July 1999) J2.

A.C. Macaulay et al., supra note 29.

Ibid.

Ibid., at 781, 784.
As such, additional recommendations for modifying, improving and adding to these projects are necessary to ensure that the rights of Aboriginal children to access adequate and appropriate health care remain protected and enforced.

IV. Recommendations for Securing Health Care Rights for Canadian Children

In attempting to improve access to health care for children, it is essential to begin by identifying the inability of Canada’s universal health care system, as well as particular Aboriginal rights recognized in Canada, to secure full rights to appropriate medical care for Aboriginal children. The recommendations presented here start from this premise and suggest specific health care measures that reflect particular issues related to Aboriginal health. They consider how the distinct culture and history of Canada’s Indigenous peoples have both affected, and been affected by, their state of health.

These recommendations are based on the shortcomings in the health care system witnessed through the example of pediatric type 2 diabetes in Aboriginal communities. Nevertheless, they are intended to reach beyond this particular context and are framed in a more general way such that they may serve as a basis for improving health care access for all Aboriginal children. In some cases, they may extend even further and provide guidance for improving health care for all children in Canada whose communities have been, or continue to be, socially and economically disadvantaged.

1. Recognizing the Importance of Preventative Care

Projects like Head Start and the KSDPP are preventative in nature; they aim to circumvent pediatric health problems before they even arise. As such, one could argue that they do not fit within a discussion on “access to health care”, as they appear to be concerned primarily with the protection of “health.”

Yet, although several authors have underscored the distinction between “health” and “health care” rights, these two concepts are in fact inextricably

74 According to Richard Budgell, Health Canada’s national manager of the Aboriginal Head Start program for urban and northern communities in 1999, the programs served only 3,500 to 4,000 children in that year, while there were 27,000 off-reserve children between the ages of three and four, and an additional 13,000 who lived on reserves. See Green, supra note 70.

More recently, Health Canada has reported that Head Start serves about 7700 children living on reserves (representing about 12% of children living on reserves, aged zero to six). The most recent off-reserve statistics published on Health Canada’s website are from 1995. In that year, Head Start served about 3200 children (representing about 7.6% of Aboriginal three to five year olds) living off reserve. See Health Canada, ECD Strategy, supra note 10.

75 For instance, Chapman stresses the importance of recognizing a right to health care, which she envisions as broader than a right to “health.” The former encompasses rights to an array of services, including preventative, curative, therapeutic, rehabilitative, mental health and auxiliary social services. See A.R. Chapman, “Introduction” in A.R. Chapman, ed., Health Care Reform: a Human Rights Approach (Baltimore: Georgetown University Press, 1994) 1 at 21-26.
linked. Children’s right to health care includes more than simply access to medical procedures and services required to treat and cure illness after its onset. Rather, preventative care that aims to secure and maintain “health,” such as that provided by Head Start programs or the KSDPP, must be included within children’s health care rights. A focus on preventing pediatric illness through the provision of education about illness, as well as routine check-ups, immunization and disease screening, will decrease illness among children, and thus the need for treatment which may be more costly and less effective than primary care. If the “right” of children to access such care is recognized, it follows that they have an equal right to the enhanced quality of life and “health” that ensues from the prevention of illness.

In this context, a failure to recognize how children’s place within their immediate and extended families and communities affects their health will yield only marginal benefits for them. Parents, grandparents, teachers and community members all play a key role in educating children about pediatric illness and its prevention, and in supporting children who must make significant lifestyle changes in order to preserve their good health. As such, ensuring full health care rights for children requires an understanding of how social relations affect the day-to-day decisions that impact pediatric health. Thus, in order for programs such as Head Start to be successful, family and community members must share integral roles as volunteers, leaders in governance and in the community, and as the beneficiaries of educational initiatives.

2. Recognizing the Potential Limits of Health Care Initiatives Currently in Place

Programs like Head Start and the KSDPP reveal the potential successes of initiatives designed to tackle challenges to pediatric health within Aboriginal communities. Nevertheless, some recommendations for broadening the scope of these programs and ensuring their long-term efficacy are required. These suggestions apply not only to Aboriginal health initiatives currently in place, but also, to new programs developed to foster further improvements.

Head Start is based on an approach that emphasizes local design and management of strategies aimed at improving the health and well-being of Aboriginal children. But legislators and community leaders may want to revisit and refine this premise. While local control of these initiatives helps to ensure that Indigenous communities take active leadership roles in securing the health of their children, the example of the KSDPP reveals that too strong an emphasis on local administration and design could preclude promising projects from receiving Head Start funding. Initiatives undertaken by non-Aboriginal researchers, such as those who designed the KSDPP, may not fall within Head Start’s ambit, if they are seen as being created and controlled by individuals outside of the community. Yet, while non-Aboriginal medical researchers designed the KSDPP, the Kahnawake community actually played the most important role in administering and controlling the health interventions that were part of that project. The KSDPP thus seems to meet the goals and basic premise of Head Start.
For this reason, Head Start’s mandate should be clarified to ensure that all initiatives involving Aboriginal control and administration remain eligible for federal subsidies issued within the program’s rubric. This should be the case even for initiatives designed by non-Aboriginal individuals, provided that community members accept these initiatives, and voluntarily integrate them into their own health strategies.

3. Including Family and Community Members to Ensure the Success of Child Health Programs

Effective strategies for dealing with pediatric health care challenges must take a holistic approach that examines all dimensions of children’s health, and all of the social affiliations affecting their well-being. As programs like the KSDPP reflect, preventing and coping with illness is facilitated by a nurturing environment in which families and communities understand an illness and its prognosis, and provide support and encouragement for those undergoing treatment or attempting to change life behaviours. In the context of preventative pediatric care for type 2 diabetes, children have a much easier time making healthy food choices and remaining physically active when family and community members understand the correlation between obesity and diabetes, and realize the importance of behaviour modification for reducing the risk of affliction with this illness.76

Given the significance of a child’s network of relationships to her well-being, projects designed to improve children’s health and secure their access to adequate and appropriate medical care cannot focus exclusively on the individual pediatric patient. Instead, a holistic approach that bridges the gaps between children, families, community members and social institutions is required to secure health care rights for children. In Aboriginal communities, this approach to health care is particularly important, given frequent geographical and environmental realities. Aboriginal persons living on reserves located in remote areas frequently lack access to a full range of medical personnel and resources. As such, a serious injury or illness that cannot be treated on a reserve could result in the patient’s relocation to an urban centre far from home. Although this removal from family and community may be required for a patient’s physical health, it will likely exert a negative impact on her emotional, and thus her overall, well-being. In addition, the family members and friends left behind also will suffer the absence of a loved one.

The difficulty of this situation is amplified where the patient involved is a child. Inextricably connected to and dependent on other individuals in her life, a child’s relocation will be impossible without the accompaniment of at least one parent or other adult. Yet, such an occurrence threatens a family with upheaval, given that other family members—including other children in the family—will

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have to be left behind. Given these particular realities for many Aboriginal communities, a multi-generational approach to health care which assesses the needs of children, as well as those of their families and community members, is inevitable.

4. Recognizing a Need for Cultural Understandings

The example of Aboriginal health reflects the far-reaching implications of cultural factors for a society’s ability to access quality medical care. A legacy of neglect has weakened the health and socioeconomic strength of Aboriginal communities in Canada. This situation has been exacerbated by the historical experience of Aboriginal communities with the Euro-Canadian cultural and medical practices imposed on them over time. On the other hand, Canadian officials have historically viewed traditional Indigenous healing practices suspiciously, considering them sacrilegious forms of superstition and witchcraft. As a result, many Aboriginal healing ceremonies were banned and pushed underground by government officials throughout the late nineteenth and early twentieth centuries.77

The current crisis in Aboriginal health reflects the impact of these efforts to disparage the cultural identity of their communities. Redressing these harms will require a coordinated series of efforts that strive to improve health, and instill confidence and hope in the future of Indigenous peoples in Canada. Each of these endeavours should aim to achieve the following three objectives. First, as exemplified by the Head Start and the KSDPP programs, community leadership over, and involvement in, Aboriginal health initiatives is imperative for ensuring the success of programs designed to promote their children’s well-being.

Second, given that most health care professionals working in Aboriginal communities are not Indigenous persons,78 cultural liaisons must be established to facilitate the delivery of health care and the transmission of information about health. This should be done by improving efforts to recruit and retain Aboriginal health care providers within their communities. It also requires appropriate training for non-Indigenous health care providers to enable them to deliver health care to Indigenous communities in a culturally-specific manner.79

As a third objective, law and policy in Canada must recognize and respect traditional healers as a vital asset to Aboriginal health. The government of Ontario has taken an important step in this direction. The Regulated Health Professions Act,80 exempts Aboriginal traditional healers and midwives who provide services

77 Contenta, supra note 21.
78 In 1997-98, Aboriginal health care workers comprised just one percent of all health care workers in Canada, which is far lower than the proportion of Aboriginal peoples to the general population of Canada. Romanow Report, supra note 10 at 220.
79 Ibid. An example of a culturally-specific health-care delivery program is the KSDPP initiative to create primary school nutrition classes that discussed the nutritional value of traditional Mohawk foods, as well as pow-wow dancing workshops for children. See Macaulay et al., supra note 29.
80 S.O. 1991, c.18, s.35.
to Aboriginals or in Aboriginal communities from its requirements, thereby allowing them to follow their own standards of care. This type of initiative should be followed in all other Canadian provinces. In addition, funding for Aboriginal health should extend to training programs for traditional healers, and should be used to cover the fees of holistic treatment. Finally, non-Aboriginal health care providers and traditional healers should be encouraged to develop a working relationship in order to serve the multi-faceted health care needs of Canada’s Indigenous peoples.

These measures would take important steps toward recognizing that rights to health care cannot be generic, but rather, should be culturally-appropriate. Such rights are partial if the care guaranteed fails to recognize and accommodate religious and cultural norms fundamental to an individual’s identity and value system. Although culturally-distinct care is not guaranteed as part of the statutory structure of health care rights in Canada, it is a normative conception imperative to a system of care committed to extending full and fair entitlements to all children. As such, this cultural dynamic should be considered as an integral component of children’s rights in this regard.

5. Recognizing the Need to Fund Child-Specific Medical Research

Access to adequate and appropriate health care for children depends on the existence of effective treatment for illness. Yet, as the example of pediatric type 2 diabetes reflects, the lack of biomedical research that assesses the safety and efficacy of drug therapies for children poses a dual risk to them. First, if effective treatment is available, but has not been approved for use in children, they will have to forego medication that might otherwise treat or cure their illnesses. On the other hand, if the administration of such medication to children were permitted, additional risks to their health emerge, given that the side effects and safe dosage ranges for pediatric patients have not been identified through clinical studies.

Resolving this dilemma requires the development and pursuit of research that aims to determine whether a specific treatment will be safe and beneficial for children. At the same time, these studies must be properly controlled and monitored to protect children from intolerable risks or harms as research subjects, and to ensure that proper consent requirements have been met. This objective requires input from government in the form of financial support to fund pediatric research, as well as in the creation of ethics committees who can establish clear ethical and legal policies to regulate the enrollment of children as research subjects. Initiatives from the medical professional community also are necessary, as clinical investigators

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81 Contenta, supra note 21.
82 The lack of biomedical research in child populations is considered in E.J. Jameson & E. Wehr, “Drafting National Health Care Reform Legislation to Protect the Health Interests of Children: Children’s health interests have not been a high priority with health plan administrators or the institutional purchasers of group health coverage” 5 Stan. L. & Pol’y Rev. 152 at 155 (Lexis); J.L. Blumer, “Off-Label Uses of Drugs in Children” 104 [suppl] (1999) Pediatrics 598; and M. Bonati et al., “Closing the Gap in Drug Therapy” 353:9164 (1999) Lancet 1625.
must undertake the task of designing research protocols for studying the effects of different treatments in children.

6. Recognizing the Need to Improve Social and Economic Factors Underlying Health

As described above, the cultural marginalization of Aboriginal communities in Canada has resulted in their social and economic disempowerment. These factors have significantly impacted the overall state of health of Aboriginal peoples, as well as their ability to access adequate and appropriate health care. Thus, alleviating the onerous burden of illness currently sustained by members of these communities necessitates strategies that look beyond the physical determinants of health, and seek to tackle the underlying social and economic causes of illness. As such, child health initiatives must recognize the wider array of circumstances that may be affected by a child’s social and economic background, such as housing, the availability and quality of child-care, and opportunities for employment and education. In light of the correlation between these factors and pediatric health, strategies that focus on them and thereby aim to alleviate the burden of child poverty inevitably will lead to improved conditions of health for children.

V. Conclusion

Canada’s history is marked by the continuous and pervasive social, economic and cultural marginalization of Indigenous peoples. The legacy of this past is reflected in the substantial burden of illness that Aboriginal children sustain, as well as their lack of access to adequate and appropriate medical care. Although disparities between Aboriginal and non-Aboriginal children’s health exist in a range of illnesses, they have been particularly striking in the context of type 2 diabetes. This illness, previously undiagnosed in pediatric populations, has recently afflicted children in Canada’s Indigenous communities. Moreover, given the increased diabetes rates among Aboriginal adults, their children face a heightened risk of developing this illness in later years.

As this paper has discussed, the legal rules that structure Canada’s health care system have been unable to meet the health needs of Aboriginal children. Programs like Head Start and the KSDPP have attempted to respond to this reality by tackling specific challenges to pediatric health in Aboriginal communities. Although these strategies provide an excellent starting point for securing and promoting the health care rights of children, they have been unable to completely achieve this objective. As such, this paper has proposed a series of recommendations for law and policy changes based on modifications and additions to current health initiatives.

These recommendations are premised on a notion of rights for children in the context of health care. Rights in this regard are partially grounded in the federal statutory Medicare scheme. In this way, rights act as a legislative prerogative for all citizens, including children. Yet, at the same time, health care rights must reach beyond current legislation, and rest on a recognition of children’s cultural contexts, as well as their social connections to family and community. Initiatives that acknowledge and incorporate these relationships will take greater steps toward the objective of protecting children’s health, and ensuring access to comprehensive medical services when they are needed.