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SILENT KILLER

The Epidemic of Native Diabetes in Canada

by

Louise Elliott

**A thesis submitted to the School of Journalism and Communication
in conformity with the requirements for
the degree of Master of Journalism**

**Carleton University
Ottawa, Ontario, Canada**

September 20, 2001

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**The undersigned recommend to the Faculty of Graduate Studies
and Research acceptance of the thesis**

**SILENT KILLER
The Epidemic of Native Diabetes in Canada**

submitted by Louise Elliott, B. A. (Hons.), M. A.

**in partial requirements for
the degree of Master of Journalism**

Thesis Supervisor

Director, School of Journalism and Communication

**Carleton University
September 20, 2001**

ABSTRACT

This thesis examines the growing epidemic of native diabetes in Canada. The central argument of the thesis is that native diabetes is as much a disease of culture -- and cultural loss -- as of biology. It details the effects of the disease on one remote Oji-Cree community of Sandy Lake, where a diabetes study was conducted during the 1990's. The thesis examines the implications of the research, which found that both the community's genetic make-up and the drastic cultural change over the last 50 years have played a role in generating the third highest diabetes rate in world. Political decisions by native and federal leaders have done little to address the epidemic, which epidemiologists say will see a tripling of native diabetics in Canada by the year 2016. The thesis argues for a more comprehensive and integrated public policy, more co-operation among leaders, and sufficient resource allocation.

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I am indebted to the people of Sandy Lake and Sioux Lookout, Ont., for taking me in and sharing their lives. I hope I have come somewhere close to the truth of their stories, and that they recognize something of me in the telling. Meegwetch.

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INTRODUCTION

A silent killer is sweeping native communities worldwide. The killer threatens to do more harm than suicide, addiction, tuberculosis, and all the other ills normally associated with native communities combined, yet few people know about it.

The killer is diabetes, or *Sho-gah-wah-pin-nay-win* in the Ojibwa and Cree dialects of Northern Ontario, one place the disease has flourished and taken root. The insidious nature of diabetes has given it a lower profile in the non-native world than it deserves. It is possibly the most pressing native health problem today.

Media reports often focus on the dramatic: political standoffs such as Oka or Burnt Church, suicide epidemics such as those in Pikangikum Ont., gas sniffing and addiction which are tragically manifest in places like in Shetshatshui, Labrador, where addicted children were evacuated earlier this year. Violence, accidents, unsanitary living conditions, diseases caused by overcrowding, poor sanitation and low immunization have also made headlines where Canada's native people are concerned. These events need reporting. But mainstream society often gets a distorted view of native communities and their concerns.

Native communities are resilient, but they are also fragile. When the non-native population thinks about the native population, it tends to think in terms of a vast swath of people, generally living in the north. This is a fallacy. For example, the Sioux Lookout Zone in northwestern Ontario – a region approximately the

size of France -- has a scattered population of only about 17,000 native people. As a whole, native people make up only 3 per cent of the overall population of Canada.

If continued unchecked, Type 2 diabetes could threaten the very survival of native communities in Canada, and around the world. This fact has already been demonstrated in the United States, where the Pima tribe of Arizona has seen its numbers dwindle significantly since the disease appeared in 1965. Diabetes rates among the Pima in 1965 were almost identical to those seen in Ontario's north over the past five years, suggesting that for our north, the worst is yet to come.

The reasons for the epidemic are complex. Its causes -- and solutions -- are at once biological, social and political. The central argument of this thesis is that the current epidemic of diabetes in native people in Canada is caused by a loss of culture as much as by physical factors such as genetic predisposition, diet and lifestyle. The progress of the disease has been exacerbated by the refusal of both native and non-native governments to read the writing on the wall and do their part in averting what is now a full-blown health crisis.

While the Canadian government has enjoyed a better reputation than the U.S. government in its treatment of native people, some experts contend its record on this issue calls that reputation into question. There is also criticism to be levelled at native governments on the issue. The federal government is now in the process of responding to some of the criticisms raised in this thesis.

The diabetes epidemic that is now hitting native communities can be slowed, and many people can be spared its ravaging effects. Scientific research in the past five years has shown that native diabetes is a physical problem that is, in some ways, unique to First Nations, and so are its solutions. Native diabetes is also and equally a social and political problem unique to First Nations people. So, say experts, leaders and sufferers alike, are its solutions.

CHAPTER I

The Extent of the Problem: Scientific Underpinnings

The oldest person in Sandy Lake sits in her house atop Linklater Hill, on the Roman Catholic side of the reserve, and wishes she didn't have to watch young people die. She's getting too old, she says, as she looks out at the fading light from her window, onto the curving dirt road below.

The lines in Esther Linklater's 90-year-old face run as deep and as dark as the long past she recalls. As a midwife, she delivered half the community, in the days before the white nurses came.

"I was the first person to see your private parts," she tells people wherever she goes, even some of the band councillors.

There was Myrna's baby, that was the first one Esther delivered, when she was just 13. And then much later, Ernie Mamakeesic. Ernie was a tough one, a breach birth -- he came out with a cord wrapped around his legs. A shaman used Indian medicine to heal him.

Later, when the nurses came, Esther helped them do their jobs. There was never a time when she wasn't needed. She was a band councillor and she helped found the community's home care program with her friend, Maida Meekis. Her contributions go back even further -- she helped the legendary chief Robert Fiddler found the community on the banks of Sandy Lake when she was just a

girl – in the early decades of the last century by the white man's calendar. She is the last living person to remember arriving in the early 1920s to establish a farming community to help boost a diet of wild meat that was growing thinner after years of fur trading.

She swings her blue-sneakered foot beneath her patterned dress, holding a cup of tea in her old hands. A thin slip of a woman wrapped in layers of skirts and a sweater, she pulls her knee under her body in a contortion that makes her look limber as a child.

Now, the people are starting to pass away too young, Esther says, and she feels unable to help. After decades of bringing life into the world, she is outliving the babies she helped to deliver.

Sho-gah-wah-pin-nay-win: sugar disease. Type 2 diabetes. A staggering forty per cent of Sandy Lake has some form of it. Esther has it herself, but she's escaped the worst of its effects, not like some of the younger ones.

Esther waits for her daughter, Tina Noon, to come over and warm some moose meat stew on her electric stove in the corner of her large living room. Her days are limited to sitting on the couch by the window or lying in the bedroom. One of her 11 children comes every morning to carry her into main part of the house.

The old woman with soft hands and a warm, toothless smile keeps company with the past. She recalls the time before the disease came, a time when she killed two moose for the community. She didn't have a gun then – she

was only 14. She says she dragged the animals to death after lassoing them and paddling around the lake in her canoe until they grew tired and drowned.

"I was a good hunter," she says. "I never got tired because there was nothing to get tired from."

A native community tucked away in the dark and mysterious pine forests of remote northern Ontario, 600 kilometres northwest of Thunder Bay, Sandy Lake First Nation is a cradle of tradition, innovation and secrets. Its several hundred single-storey homes -- many wood-frame cabins with peeling roofs -- conceal a history as rich as the soil along the shore. There is no road out of Sandy Lake. Winter roads over frozen lakes are the only access by land. Otherwise, travel in and out is by plane.

"This is a place where cars come to die," one band councillor jokes.

The language of the 2,000 residents is Oji-Cree: a cross between the Ojibwa language to the south and the Swampy Cree language to the north. People here share only a handful of last names, each linked to one of the community's five ancient clans -- Sucker, Pelican, Crane, Sturgeon, Caribou. Extended families are clustered in asymmetrical groups of houses according to name -- this jumble is Fiddlers, that one Kakepetums. Some homes are cozy new cabins. Others have no indoor plumbing. Some have yards strewn with cars that resourceful mechanics plunder for parts.

Ingenuity and tradition – two traits this reserve has called upon to fight for its life. Sandy Lake's dwindling number of elders retain a memory from before the white man arrived, when the culture was untouched by outside influences. Time was cyclical then – dependent upon the land and its seasons.

"If you ask them, 'When were you born?,' they tell you, 'When the berries were just starting to get ripe,'"one woman explains.

"Or they say, 'When the leaves were just starting to be the size of a beaver's ear.'"

Sandy Lake is perhaps best known to outsiders for its visual artists. The shape-shifting, colorful portrayal of animals and spirits painted by Carl Ray and Norval Morrisseau (who was once a resident here) dot the reserve's public buildings. New artists draw upon their ground-breaking use of traditional forms and legends for inspiration.

The dramatic history of Sandy Lake's leaders is also kept alive here, in stories and in black-and-white photographs hanging in the community's modern band office. There the austere, high-cheekboned face of the first chief, Robert Fiddler, his body wrapped in a blanket, stares down from the past – nearly a century and an entire cultural world ago. In 1907, Fiddler's father, Jack Fiddler, a Sucker clan leader, was convicted by the Royal North West Mounted Police of murder. Jack Fiddler committed suicide by hanging, rather than submit to the judgment of another culture. Jack Fiddler, his later biographers have noted, was

a man so threatening to the non-native world he had to be snuffed out in his prime before any more of his magic could be brought to bear.

But Sandy Lake has a newer, even more tragic distinction to go with these claims. Since the 1960s, its residents have been living in the shadow of a silent, stealthy killer. In 1996, science confirmed what many had guessed for years: the community has the highest Type 2 diabetes rate in Canada, the third highest worldwide. Everyone here either has the disease, or is related to someone who does.

When the "mysterious" illness began to take hold here, it set in with a vengeance upon a population with few resources or tools to deal with it. In the southern cities, many diabetics live long and productive lives thanks to good management and treatment. But in Sandy Lake, Type 2 diabetes is a death sentence for many.

Four of Maida Meekis' seven siblings are gone, and she thinks of them this morning, like every morning. Nestled just below Esther's house atop Linklater Hill, her house is small and beaten on the outside, with a wooden walkway to keep feet out of the November mud. On the outer door there's a hole where the glass should be. On the inner door a faded prayer beckons the visitor to knock.

When the pretty, bright-eyed woman answers, she's wearing a long blue and white nightgown. She explains that she went back to bed when her husband,

Ken, left for work. Inside, the brown linoleum is worn, and in places, the pattern has all but disappeared, leaving only a faded trace on a white background. The high wall facing the kitchen table is covered in decorations – a fan, an eagle feather, faded prayers on plaques. And a framed certificate from the former member of provincial parliament, Leo Bernier, to recognize Maida's work with Esther, when the two women started home care back in the 1970s. Maida, who is now 60, worked with the program for 25 years. Longer, she says.

"I worked there before there was provincial funding."

A wood stove overheats the room on this sunny November day. The room smells of pine.

There are no pictures of the family she has lost on the walls – her brother Luke Mamakeesic, her sisters Clara McKay and Edna Linklater and Jean Mamakeesic.

"I had Luke living here just before he went out. He was barely able to move around," she says.

Kidney failure claimed Clara, Jean and Edna. Luke lost his sight and half his leg before his heart gave out.

The prognosis for the living is not much better. Her brother, Ernie, was reduced to the mind of two-year-old at the age of 62 by two diabetes-caused strokes, Maida says. She's planning to visit him in hospital in Sioux Lookout, as soon as she can save the money for the 500-kilometre flight. But she has her own disease to contend with.

"It has made a big difference to what I can do – to how much work I can do," Maida says. "Diabetes makes me weak. It gives me the shakes if my blood sugar gets too low."

Maida's husband's family is also affected, she says. Ken's sister, Patsy Fiddler, was flown out to Thunder Bay last night to have her toes amputated. Patsy will also need dialysis for her failing kidneys. She may not be able to return home, Maida says. (Patsy Fiddler later died of diabetes-related complications during the writing of this thesis).

The litany of losses reads like a history book describing the tuberculosis epidemic that wiped out native populations in the 19th century. Except this isn't TB, and it's happening today. Just a few hundred metres from her front door, Maida's relatives lie in Sandy Lake's Catholic cemetery. There, neat white picket fences encircle the graves in a native tradition. The final homes of the dead are marked out, and they lie quietly, in summer and winter, as the sun rises and sets over the nearby lake. Maida visits them often.

The incessant knock of personal loss on her door has taken a toll on her spirit.

"It's very, very hard," she says in a soft clear voice. "I used to be out a lot, now I don't go out visiting. Diabetes touches everyone on this reserve."

Her grandson, Keenan, bursts in the door with his mother, Maida's daughter, in tow. He kicks off his tiny boots, runs into the other room, and

switches on the television, clutching a bag of chips and Kool-Aid in his three-year-old hands.

Sandy Lake is not alone in its struggle. For more than two decades Canadian experts have been noticing the alarming appearance of Type 2 diabetes in native Indian populations across the country. Diabetes is now hitting all native communities – both urban and rural – hard. Other reserves would yield comparable statistics to those of Sandy Lake if they were studied as closely, experts say, but nobody has yet devoted the resources to do a national study.

Broad estimates say native communities are experiencing the disease at about six times the national average, but there is variation between regions and populations. As many as half Canada's natives over the age of 50 have diabetes.

"This is a massive, Canada-wide First Nations problem," says Dr. Joe Dooley, president of the Northern Diabetes Health Network, which serves communities across Northern Ontario.

The recorded rate of diabetes on northwestern Ontario reserves is 10 to 15 per cent, Dooley says. But he adds that an aggressive screening program like that of Sandy Lake would yield far higher numbers, and cases are cropping up faster each year. One community saw a 12 per cent increase in cases in 1999; another saw an 18 per cent jump from November 1998 to April 2000. A longer-

term study cited by epidemiologist Dr. T. Kue Young in the Canadian Medical Association Journal in September 2000, found the diabetes rate in the region has jumped 45 per cent in the last 10 years. In Saskatchewan aboriginals, the rate doubled between 1980 and 1990.

Those numbers weren't available to Sandy Lake residents when, beginning in the 1960s, people began to fall sick and slowly die of a mysterious illness, says Sandy Lake deputy chief Harry Meekis. Diabetes among natives, as with many other health problems, remained largely unstudied. In the remote Sioux Lookout Zone, visits by a doctor were a rare occurrence, with communities relying for months or years at a time on a single outpost nurse and, for serious problems, a trip by air ambulance to the Sioux Lookout Zone Hospital, 500 kilometres south.

Meekis sits behind his desk in the blue band office, sorting a mountain of faxes and making travel arrangements to Thunder Bay, which is 600 kilometres southeast, over the phone.

There's a crate of mandarin oranges on the floor and a metre-high stack of paper for the shredder. On the wall behind him hangs a dream catcher, a calendar from Ministic-Kistigan, the local airline, and a picture of Meekis with Indian Affairs Minister Robert Nault – who is also the local MP – on Parliament Hill.

He hangs up the phone. His uncompromising eyes signal Sandy Lake's high-octane approach to problems: don't mess around.

"We want to be known not just as the community with the (third) highest diabetes rate but as the community that did something about it," he says.

That's why, when a diabetes epidemic like a hurricane whose force had built quietly for years began to ravage the lives and spirit of his community, Sandy Lake leaders did something unusual for a native band: they called in the scientists.

The result was a pivotal collaboration with two doctors: Stewart Harris and Bernie Zinman. In 1991, both were associated with the University of Toronto. Harris was then the medical director of the federally-run Sioux Lookout hospital. The hospital's physicians were then administered by the university. Zinman remains a senior scientist at the Samuel Lunenfeld Research Institute at Mount Sinai, affiliated with U of T's Banting and Best Diabetes Centre. In 1991, Meekis and then-chief Eli Sawanas, along with other community members, travelled south to meet with Zinman and Harris in Toronto. There, the community signed a landmark contract allowing the doctors to study blood samples of community members and the precious DNA they contained, in exchange for part-ownership of the scientific results, and any money that might flow from those results. It was one of the first such contracts in the world, inherently recognizing a thorny history of exploitation of native peoples for the purposes of science, and specifically, drug research.

“The squeaky wheel gets the grease,” Meekis says with a chuckle.

But no-one knew at that first meeting, at which the band members sat incongruously in an austere meeting room at Mount Sinai Hospital, just how squeaky the wheel would have to be. Even with two credible medical researchers involved in the project, the federal and Ontario governments rejected the scientists' proposal.

Determined that the project had merit, Harris and Zinman turned their efforts south of the border. Finally, in 1992, the U.S. National Institutes of Health under the Bush administration gave them an initial \$25,000 start-up grant. The money was a start. Harris then used the U.S. money “as leverage” with the Ontario government, eventually procuring \$700,000 for the seminal data-gathering, which took place between 1992 and 1995.

The results of the study -- kick-started with U.S. dollars -- astounded everyone, including the researchers.

In January, 1996, a report published in the U.S. journal, Diabetes Care, showed 26 per cent of the community had Type 2 diabetes, or “adult-onset” diabetes, the third highest recorded rate worldwide. Another 14 per cent had impaired glucose tolerance (IGT), an early stage of the disease. The numbers were twice what the researchers expected, Harris said.

The numbers are terrifying because of their implications for the younger generation. More than half of Sandy Lake's 2,000 members are under the age of 30, and 750 are under the age of 15.

By the time people reach 50, half of them will have full-blown diabetes, the research suggests.

Native children as young as six in Ontario and Manitoba are also being diagnosed with the disease, which is virtually unheard of in non-native children. In Sandy Lake, five children between nine and 19 were found to have full-blown diabetes, and 11 had IGT. More children have been diagnosed since.

These numbers place the community –and others like it –in a race against time, with the worst yet to come.

"With the complications we've seen in the last few years, this only the beginning," Meekis says. "It's a very difficult situation that we're in, and we're not going to get away from it."

Deep in the forest, the people of Sandy Lake faced a problem, the root of which lay in a complex intersection of factors. Deep in the genes passed down by their ancestors, a ticking time bomb had gone off, somewhere in the 1950s or earlier. It was only in the 1960s that Sandy Lake elders began to see people fall sick and die of a mysterious illness – diabetes had been virtually unknown before.

Their dilemma was compounded by the fact that, despite major leaps and bounds in treatment, much is still not known about how diabetes works.

The pancreas operates differently in Type 1 diabetes (known as "juvenile" diabetes in the non-native population) and Type 2 diabetes (known as "adult-

onset" diabetes). The pancreas of Type 1 diabetics stops producing insulin completely, forcing patients onto insulin injections in order to survive. Insulin operates like a key in the bloodstream which allows blood sugar to be "unlocked" and absorbed by hungry body cells. Without insulin, food energy cannot be absorbed and stored as fat. This leads to high blood-sugar levels which typically cause symptoms such as extreme weight loss, thirst and frequent urination – both caused by the drawing of fluids out of body tissues. This is called an "osmotic" effect. At extreme stages, the high blood sugar can put patients in a diabetic coma, which can lead to death.

Type 2 diabetes slows insulin production by the pancreas to less than the body requires, and makes it harder for the body to use the insulin it does produce. Because of the disease's recent appearance in native children as young as six, the term "adult onset" is now a misnomer. Unlike Type 1 diabetes, Type 2 diabetes is much harder to detect in its early stages. Symptoms – thirst, weight loss, frequent urination – appear gradually as the pancreas slows insulin production, meaning Type 2 patients are more likely to go without a diagnosis, and run a higher risk of complications such as blindness, heart disease, kidney failure and amputations.

Treatment for the two types of diabetes differ. For Type 1, insulin is essential, usually taken in injections. For Type 2, changes to diet and activity levels to control blood sugar levels are common. Type 2 diabetics typically monitor their blood sugar levels throughout the day using a special device called

a glucometer. Drug treatments are also prescribed. These drugs do several things, for example, some stimulate the pancreas to produce more insulin while others improve the sensitivity of the body to the insulin that is produced. Drugs are taken by both types of diabetics.

Two of the most dramatic complications of both Type 1 and 2 diabetes are blindness and amputations. Blindness in diabetics is caused by the growth of new blood vessels in the eye which then bleed and lead to blindness, Zinman says. But he adds scientists do not know exactly how high blood sugar contributes to the growth of new blood vessels.

Amputations are a last resort to deal with severely infected limbs. Diabetes can lead to neuropathy -- the death of nerve endings -- particularly in the extremities. This loss of feeling in limbs makes diabetics susceptible to injury without noticing it, and infection is common for that reason as well as because of the decreased circulation in the body, which is also an effect of the disease. Again, the exact reason for nerve death and decreased circulation is unknown, Zinman says.

"High glucose is the cause, but we don't have the precise mechanism."

Likewise, obesity is linked to diabetes, but its exact mechanism is not understood, except that it increases insulin resistance, Zinman said.

Type 1 diagnosis is more dramatic in its symptoms, and is usually diagnosed in teens or young adults whose blood tests reveal sugar levels that are "through the roof." By contrast, Type 2 diabetics experience a gradual onset

of symptoms and their blood sugar levels, while high, do not usually rival those of Type 1 diabetics. The arrival of Type 2 diabetes among native children as young as six in Manitoba presents a diagnostic challenge to doctors, who may not realize what is wrong with their patients because the disease has until now been confined to the adult population.

Researchers crave more information about exactly how the metabolism of a diabetic works, and seek to devise new ways to stop it. That's why the people of Sandy Lake were so intriguing to Zinman and Harris: the scientists thought that perhaps, with close study, the unique manifestation of diabetes in the Oji-Cree people of northern Ontario and eastern Manitoba would give researchers more information about how to treat all diabetics.

Type 2 Diabetes, Zinman says, is in many ways a different disease among the Oji-Cree people than in the non-native population.

"It occurs earlier and with less obesity," he points out.

But it is still diabetes, he hastens to add, and that means that close study of genetic factors that may contribute to the illness in Sandy Lake could yield information which is of value to all diabetics.

Ten years after the researchers virtually begged for Canadian funding and then sought money from the National Institutes of Health in the U.S., Zinman, Harris and their colleague, geneticist Dr. Rob Hegele of the John P. Robarts Research Institute at the University of Western Ontario, have finally started to garner some genetic clues to the mystery of Sandy Lake's silent killer.

Deciding to focus years of genetic research on Sandy Lake blood samples was a calculated gamble. In the world of medical research, breakthroughs are the holy grails which can lead to wide-ranging treatment possibilities that were not formerly considered. That can mean prestige in the world of medical research, the chance to affect millions of lives, and lucrative contracts with drug companies.

Harris, Zinman and Hegele had some guidance at the outset which shaped their research – a long-standing scientific theory known as the “thrifty gene.”

Zinman explains that a genetic basis for native diabetes is a “reasonable certainty” for two reasons: one, because of studies done on different native families with high numbers of diabetics, and two, because diabetes rates in natives are exponentially higher than in the general population, while other risk factors such as diet and exercise are not that different.

“With the same risk factors such as obesity, et cetera, they have rates much higher than other populations,” he says. “That is a suggestion of genetic susceptibility.”

The thrifty gene theory goes beyond saying that native people are genetically susceptible by suggesting how they are genetically predisposed. The theory postulates that modern-day indigenous peoples possess a genetic trait which allows their bodies to store fat for times of famine. The thrifty gene allows the metabolism to access fat stores more quickly and efficiently, thus allowing

hunter-gatherers to survive grueling periods without food and allowing them to continue to hunt. Extending the theory, diabetes may be more prevalent in natives because of this trait, combined with a sudden change in lifestyle, an overabundance of food and a reduction of exercise. With a change to a sedentary reserve lifestyle and a diet high in refined foods, natives in Canada underwent just such a lifestyle change in the last 50 years. Reserve systems replaced hunter-gatherer lifestyles, and total dependence on the land for food became a thing of the past.

Zinman compares the thrifty gene theory to an oil furnace. If the furnace receives a set amount of oil each month, but burns very little oil, there will be too much oil and the furnace will overflow.

"You end up being fat, " he says. "There is tons and tons of oil in your basement, and depositing food and using high dense-calorie foods (adds to the fat supply)."

The absence of periods of famine is a new phenomenon for a group of people who, for several millennia through to the early parts of the twentieth century lived off the land, Zinman said.

"The question is not, 'will there be a famine,' but 'when? '" he said. Unlike Europeans who descend from centuries of agricultural ancestors, indigenous peoples have adapted to the certainty of nature's uncertainty, he said.

"The thrifty gene theory implies one or several genes that give you an advantage in the context of storing and utilizing energy more efficiently. It would be a real survival advantage. "

In her hilltop house, Esther Linklater remembers being hungry.

She remembers her mother's trips into the bush to find food for her children, back in the 1910s and 1920s, a world ago, when jobs were scarce and the fur trade had dried up.

Day after day she would set snares with fingers bared to the cold, hoping she would catch something. Esther's father died when she was a baby, leaving her mother to raise four girls on her own.

"I used to hear my mother sometimes – she'd come back from the bush with nothing and she'd be crying. We wouldn't have anything to eat and she'd be crying. "

It wasn't until Esther was a teenager that her mother could afford to buy her a .22 calibre rifle to shoot partridges. Warm clothing to protect her was still hard to come by.

At age 14, Esther was chosen to accompany the first Sandy Lake chief, Robert Fiddler, east from Deer Lake to the site where he planned to build a new, more prosperous community for his people.

Some community members say his vision of an agricultural community on the shores of Sandy Lake was partly instilled by missionaries and treaty parties

from Manitoba. There are no written records of the decision. But it is likely the chief thought that by growing root vegetables as missionaries were doing in Manitoba – potatoes, turnips – he could somehow offset the hunger gripping his people in the wake of a radically-diminished beaver population.

Esther remembers, better than most, the difficulties of living off the land, the periods of feast and famine.

“It was a hard life at that time. Not only for us, but for everybody.”

The young people today, she says, don't understand the hardship they went through.

The thrifty-gene theory guided Zinman and his colleagues toward a look at the genetic makeup of the Oji-Cree. But the only other research precedent among native populations was not encouraging in terms of genetic discovery: the Pima of Arizona, who now have the highest known rate of diabetes in the world, at 50 per cent.

Since the 1960s, the Pima have been dying of the disease in record numbers, while their demand for treatment has led to escalating costs to the American health care system and to the tribe itself. Thirty years ago, the Pima had the same rate of diabetes that Sandy Lake exhibits today, and as such, the tribe provides a sober warning for what to expect in the Canada's North if nothing is done. Prevention and treatment programs were not quickly implemented for the Pima, and the results have been disastrous.

While prevention programs have only started in the last decade in the U.S., the country does have primary care for native diabetics, unlike Canada. That means there are regular screening tests and ongoing followup care offered to diagnosed native diabetics through a specific national program. The tragic example of the Pima prompted the U.S. government 20 years ago to institute a primary diabetes screening and care program for native Americans through its Indian Health Service.

The Pima case also produced another positive result, in the wake of tragedy. Several drugs were developed which had a major impact on the treatment of Type 2 diabetes worldwide. Researchers studying the Pima made a major breakthrough in the understanding of insulin resistance among Type 2 diabetes sufferers. The study found that, among subjects studied insulin levels rose during late adolescence and early adulthood, then began to decline because of diminished pancreatic function. This study advanced the treatment of diabetes worldwide by prompting the development of new medications.

The study of the Pima took place over several decades beginning in the 1930s. It was a highly controversial series of tests; the Pima arguably did not benefit from the drug profits yielded by research done on their own blood samples. During the period they were being studied, the Pima faced social and political hardship as their natural fishing area (on the Gila River) was dammed for a hydroelectric generating station, leaving the tribe with no source of food. The government then shipped in food by plane to the reservation, but with little or no

regard for the health of the people receiving the shipments. This resulted in a diet of high-fat, high-sugar foods and little or no fresh food, for a people accustomed for millenia to living off the land. We will return to a discussion of the ethics of the Pima tale, as it pertains to the Sandy Lake situation.

And, while the study of the Pima led to medical breakthroughs, it did not yield any direct link that would bolster the thrifty gene theory. As such, the Pima formed a cautionary tale for Zinman and his colleagues as they embarked on a genetic study of the Sandy Lake people. According to Zinman, the Pima research gives a few hints, but provides no hard evidence of a genetic predisposition to diabetes.

"There's some leads," he says of the Pima research. "But no clear genetic causes."

Nonetheless, six years after their initial research grant, Zinman, Harris and Hegele's gamble began to pay off. In 1997, the researchers found a genetic variant that is unique to the Oji-Cree, and is found in about 40 per cent of people with diabetes in Sandy Lake. The variant -- called a polymorphism, or variation of a gene found in every human -- does not exist in the Pima, or any other studied group of people, Hegele says.

It exists only in the Oji-Cree communities along the northern Ontario-Manitoba border.

"We've looked at every population in the world, " he said. "Even other aboriginal populations. (The Pima) for sure do not have this variant, as far as we can tell. "

The genetic variant, known as HNF1A, can be used as a "predictive test, " Hegele says. That means that if someone in Sandy Lake has the gene, they are 97 per cent likely to have diabetes or to develop it during their lives.

"Of the gene carriers, almost 100 per cent were diabetic over the age of 50," Hegele says. Forty per cent of diabetics have the gene, whereas in the entire Sandy Lake population only 10 to 15 per cent have the gene.

The gene's discovery is considered a major breakthrough because of what it may be able to teach researchers about the metabolism of diabetics, Zinman says.

"The implication is that by understanding why this particular variant increases the risk of diabetes, it allows us to understand how diabetes comes about (in all populations)," he says, adding the scientists are only at "the very early stages" of probing that relationship.

Gene variant HNF1A is only one of two discoveries so far by the team. One other unique gene has also been isolated in smaller segments of the Sandy Lake population, Hegele says.

The second gene, known as PPARG, is found in 20 per cent of all diabetics in Sandy Lake, some of whom overlap with the carriers of HNF1A. Hegele thinks the two discoveries are likely the pinnacle of what the Sandy Lake

study will yield on the genetic front. While the scientists may discover more genetic variations in Sandy Lake diabetics, they will likely not be as prevalent as those already found, Hegele predicts.

Neither HNF1A nor PPARG are to be confused with the thrifty gene, Zinman cautions, nor is their discovery proof positive of the theory. Neither gene works to allow the body to store fat for times of famine, he says.

"The thrifty gene has to be a gene that improves food storage," he said. "HNF1A is a gene that controls other genes -- that makes it so much more complicated."

It will take years, and much genetic detective work, for researchers to learn more about how HNF1A and PPARG work to predispose people to diabetes, Zinman says.

Hegele agrees.

"One can learn more about the pathways that are affected. The gene is a clue to the mechanism -- to what's actually going on metabolically, he says.

Unfortunately, the clues may take a long time to decipher, Hegele says. Developing new medications based on the discovery will take at least 10 years, he says.

"This is a very interesting drug target, " he says. "But if we were to wait for the fruits of this to come forward, we'd see a lot of disease and complications. "

But he adds the discovery of the two genetic traits in Sandy Lake bolsters a long-held belief among scientists that high rates of native diabetes are at least partly determined by genetics.

“There was something unique about these people that would explain why diabetes is so prevalent.”

Unfortunately, tragedies are already visible. The disease has brought a host of life-threatening problems. Last year, Zinman and two other researchers came out with yet another disturbing piece of research, this time about skyrocketing rates of native heart disease which are thought to be linked to the diabetes epidemic.

The numbers Zinman analyzed were hard to come by, as data on native populations and their health usually are. Native health care is under the purview of Health Canada, not the provincial medical system. Until, that is, a native person uses a provincial hospital. Health Canada then covers part of the cost of their treatment, and the provincial or territorial government pays part.

Using admission and discharge data from Ontario hospitals, Zinman compared the rate of admissions for heart disease among the native and non-native populations. The data technique relied on the patients' disclosure of his or her home community. If the community had a 95 per cent or higher native population, Zinman and doctors Janet Hux and Baiju Shah assumed the patient

was native. They compared data on native populations over 10 years to data for the rest of the province.

The results were astonishing: native admissions to hospital for heart disease rose steadily by 145 per cent – from 76 admissions per 10,000 persons in 1984 to 186 per 10,000 persons in 1995. In the non-native population, admissions for heart disease declined steadily from 101 per 10,000 in 1982 to 82 per 10,000 in 1997. That decline is attributed to growing public awareness about the risks of heart disease and voluntary lifestyle changes resulting from that awareness.

Hospital admissions for heart attacks (myocardial infarctions) among native people have also increased dramatically, the researchers found. In 1982, there were just 11 admissions per 10,000 persons in the native population for heart attacks; in 1995, that number had more than quadrupled to 47 per 10,000 - an increase of 327 per cent.

In the non-native population, admissions for heart attacks remained stable over the same time period, ranging from 26 to 29 per 10,000.

The numbers are terrifying in their scope: within one decade, heart disease has become a leading killer in the native communities of Ontario.

A similar pattern was spotted in 1995 in the native populations of the United States, including the Pima of Arizona.

“The Strong Heart Study was initiated in 1988 to elucidate the (heart disease) risk factors for American Indians in selected centers in the

southwestern and midwestern United States," the researchers wrote in Archives of Internal Medicine in June, 2000.

"In particular, diabetes was observed to be the strongest risk factor. "

While such alarming trends might intensify the desire among sufferers for a medical breakthrough in genetic research projects like the Sandy Lake study, those solutions could be decades, if not generations, away.

And, as Hegele points out, the genetic discoveries only go so far in explaining the mystery of the Sandy Lake situation. They also bolster the approach many experts were already calling for.

"It's reinforced the idea of a very low-tech, public health approach, including exercise and diet, " Hegele says. "These people may be more sensitive to changes in lifestyle (and those things must be addressed)."

Science, Hegele stresses, rarely yields all the answers to a such complex problem.

"We are always enamoured by the implications of the human genome project," he says. "But we need to do something to take care of the epidemic of diabetes today."

That's the view taken by many researchers, including epidemiologist Dr. T. Kue Young, who wrote in the September, 2000 issue of the Canadian Medical Association Journal that diabetes among natives "is a chronic disease with multifactorial causes involving the interactions of genetic susceptibility and environmental factors."

Young notes that the genetic discoveries in Sandy Lake have reinforced the need for prevention among native people because of their high susceptibility to the disease. While there is still a great deal of debate about the role played by dietary changes, Young says, the decrease in physical activity among natives has been unanimously found to be detrimental. But how to make healthy changes to diet and lifestyle, what those changes should be, and how they can be made to stick among people in the diverse native communities of Canada, is still very much an open question.

Solutions such as an "improved" diet and increased physical activity, Young says, may appear simple to medical researchers, but difficult in practice. That's because, alongside the genetic mystery of native peoples lies the equally complex phenomenon of cultural change and adaptation -- mental, physical, and spiritual -- to a radically different cultural reality.

CHAPTER II

The problem: Its social and cultural roots

Genetics alone do not explain why diabetes has suddenly appeared in the last 50 years in Canadian native populations, experts say.

In his article, Kue Young refers to the “cultural dimensions” of diabetes, and suggests the problem has its roots in the collision of different world views.

“Many Aboriginal people consider diabetes an example of ‘white man’s illness,’ a new, introduced disease similar to smallpox and tuberculosis in the past,” he says. “The adoption of modern foods and the decline of hunting and fishing are widely believed to be the underlying causes of the epidemic. ”

Just as native people perceive the problem to be one of cultural infiltration, and not just physical change, so do they perceive the solutions in a culturally-specific way. Such solutions can only be found in the context of present-day native reality, which is often fraught with poverty, unemployment, and a host of other problems. As such, they may be beyond the purview of Western medical solutions, but they may be equally important in stopping the hurricane force of the silent killer.

The thrifty gene combined with cultural changes are thought to have occasioned the arrival of diabetes. The disease is also fuelled by poverty, particularly on northern reserves like Sandy Lake, where welfare is the source of income for a

good 80 per cent of the population, and where fresh foods often cost four to five times more than in "southern" cities.

This chapter will explore some of the cultural and social factors which may have led to the epidemic of diabetes in the Sandy Lake Oji-Cree population in recent years. Such a cultural understanding is essential, for if native diabetes is partially a social and cultural problem, so are its solutions.

The people of Sandy Lake had their first contact with the non-native world in the 19th century. Most contact was minimal well into the 20th century, when radio – which arrived in the 1970s – and television – in the 1980s – brought a new view of the world. Before that stretches a millennia-long history of oral cultural tradition tied to the land.

Little has been written about the time of pre-European contact in northern Ontario tribes, but one book, *Killing the Shaman*, (Penumbra Press 1985) by Chief Thomas Fiddler (now deceased) and James R. Stevens, paints a vivid picture by recording the words of Fiddler, who was the son of Robert Fiddler (1860 - 1940), the first nominal chief of Sandy Lake. Robert Fiddler was the son of Jack Fiddler, a shaman and the first leader of the Sucker clan, before they joined other clans and settled to try to live a semi-agrarian existence on the shores of Sandy Lake. The clan system is an ancient organization of families grouped according to the names of animals who were thought to be their spiritual "guide" or "guardian." People who today have specific last names are known to be affiliated with one of five animals common to the region: Sucker, Crane, Pelican, Sturgeon, Caribou. For example,

anyone with the last name Fiddler is known to be a Sucker, which is often told as a joke to outsiders unfamiliar with the name of the fish. The clan system pre-dates the reserve life, and during the days of hunting and gathering it dictated the geographical area where people would hunt and fish, and who would marry whom, thus preventing disagreements and in-breeding between close relatives.

Killing the Shaman is about the 1907 trial and conviction of Jack Fiddler for allegedly murdering a female member of the tribe. Fiddler killed himself before he could be jailed and put to death for the alleged crime.

In the course of telling this vivid tale, the book also records part of an essential history which is now all but lost – the history of life before the white man came.

The tale of the origin of Jack Fiddler's father, known as Porcupine Standing Sideways, epitomizes the mystical underpinnings of Oji-Cree culture, one inextricably tied to the land and its creatures. As the book recounts:

The shamen, Jack and Joseph Fiddler were the sons of the Sucker clan leader, Porcupine Standing Sideways. The origin of their father is steeped in mysticism. He came as a young man into the forest southwest of Hudson Bay in the late eighteenth century. He was not born into the Sucker clan as a baby; he was a personage who stepped from the other world into this one. It is told that at a longhouse village along the Bay or Severn River, all of a sudden a strange young man was seen standing on the roof of a lodge. He appeared, looking like a person who had just descended from the sky. Astounded clan folk approached him and asked; 'Where did you come from?' The stranger replied, 'They call me the Porcupine Standing Sideways, I lived before in this world, now I am here again.' Records of his direct ancestors do not exist in fur trade journals but his arrival from the other world was prior to 1823; in this year he is

listed among the Sandy Lake natives in Hudson's Bay records. He had two wives, three daughters but no sons. His sons, Jack Fiddler, Peter Flett and Joseph Fiddler were born later. (Fiddler, Stevens, 3)

The book goes on to describe the several clans of Sandy Lake and how their members bear some of the qualities of each animal that gives them their name. Clan identification is still strong in Sandy Lake today. The book notes that in the 19th century, around 1820, the disappearance of the beaver – a major food staple – through over-hunting for the fur trade, had left the clans numbering only about 300 people.

Beaver, caribou, even groundhogs had been extravagantly and wantonly killed in over a century of hunting for the fur trade. Summer hunts and winter hunts left the lands almost empty in the days of Porcupine's youth...The fur trade, run with the powerful drug, alcohol, as an incentive for hunting, had reduced the clan folk to a state of destitution. As early as 1804, the fur trader at Osnaburgh House [southwest of Sandy lake] reported that the Sucker clan leader Tinpot's 'whole family nearly starved to death' and to survive had to eat their beaver skins. (Fiddler, Stevens, 4)

Killing the Shaman is joined by only a few other written texts on Sandy Lake's history. In a 1989 education master's thesis written for the University of Saskatchewan, Margaret Fiddler sketches one of the few available histories of the people who came to settle and form the community now known as Sandy Lake in the early 1900s. She writes:

Originally, there were three residential areas. The "Ghost Point people" settled (in Ghost Point) the early 1900s. The "River people" an offspring of Manitoba Red Sucker Indians, arrived in 1928. The "R.C. people," predominantly Roman Catholic, moved to work at the Favourable Lake gold mine 38 miles away, and then returned to the reserve in the late 1940s when

the mine closed. Increased population had created "The Centre," a melting pot of homes, school, band office, nursing station and radio station. However the original sectors remained religiously and politically divided. In 1985, 350 of the Ghost Point people formed a new band named Keewaywin and intended to create a new reserve 30 miles away. (Fiddler, 53)

Beyond these accounts, the period prior to the arrival of the Europeans will likely remain inaccessible in the wake of the residential school system and the pace of modernization, which have both disrupted the transfer of language, tradition and oral history.

However, individuals still living in Sandy Lake, and particularly those with diabetes, can help fill the historical gap with their oral accounts. They help to explain the connection of native people to the land, and what is needed today to stop the epidemic.

Heidi Fiddler's life tells the story of a generation.

He grew up on the trapline, forbidden to go to residential school by his father, Roderick, who resisted the pull of the white man's ways.

Each summer, the family stayed in one place for a month on the shores of the lake where the community stands today. The rest of the time they were on the move--trapping, fishing, going where the animals went. They lived in tents made of skin in winter and log cabins in the summer.

In 1957, at age 18, after he got part-time work with the Hudson's Bay Company store at the far end of the village, Heidi continued in the old ways,

first chief, Robert Fiddler – looked up and down the river before he set out in his boat. He arrived at the store by boat, he left by boat. He checked the nets again on his way home.

But with the new job came new foods, readily accessible, and illness. He was in the bush less. He began to eat candy during the day, he says, and before long his weight had ballooned to 227 pounds from a trim 160. In 1982, at the age of 43, he was constantly thirsty and urinating frequently. He checked in at the nursing station. They told him he tested positive for diabetes.

If Heidi's diagnosis in 1982 had marked the beginning of a prevention program, his mind would rest easier today. Instead, he has just returned from Thunder Bay, where part of his foot was amputated last month in a desperate attempt by doctors to stop the infection from spreading. He won't walk freely in the bush again.

"They couldn't do anything, they tried three kinds of intravenous antibiotics," he says, describing his three-and-a-half-month odyssey between four different hospitals in Red Lake, Sioux Lookout, and Thunder Bay. His tall, dignified figure is draped across the couch in the living room of his wood-panelled house, the wood stove emanating heat, the television turned down low. His grandson, Donald Junior, plays nearby.

The doctors wanted to cut the foot off higher up at the ankle, but Heidi refused.

“Either way, I told him, I don’t want to be cut in pieces before I die. I might as well go like this if I have to go. It’s my life,” he says.

Heidi refuses to die inch by inch, the fate of many diabetics with damaged nerves and blood vessels, even though the smaller amputation makes his risk of contracting a life-threatening infection much greater. While his wife Katie carefully unwraps the white bandages on his foot, he describes his mother’s death from diabetic complications -- one of the first diabetes deaths in Sandy Lake -- in 1965. She had just undergone a leg amputation in Sioux Lookout when Heidi flew down to see her. She died within hours of his arrival, leaving her 26-year-old son to deal with funeral arrangements in an unfamiliar town.

“I went in the next morning to get the body -- that was a hard thing to do, but I’m glad I did it,” he says. Flying the body back to Sandy Lake for burial was a first in the community as well. Until that time, people were buried wherever they died, often strangers in a strange place.

As the lives of other diabetics in Sandy Lake will illustrate, cultural alienation is a component in the disease which makes recovery that much more daunting. Moving to a town the size of Sioux Lookout, let alone a city the size of Winnipeg, even for a short time for treatment, can be a huge obstacle to recovery and managing the disease, because of the cultural and physical shock it entails.

The death of Heidi’s mother from diabetes marked a turning point in the community -- the deaths would come more often from then on. But by the time Heidi

was diagnosed 18 years ago, little had changed: there was still nobody to tell him how to keep healthy. Medical workers at the understaffed nursing station urged him to lose weight and he did, dropping down to 165 pounds – low for his large frame. He recalls asking the nurses when he would start to feel better.

“I asked them how many more pounds I had to lose to be O.K. – I didn’t feel any better at all,” he said. “I didn’t get an answer for that.”

A few years ago, with the arrival of an innovative remedial diabetes project in the community, Heidi began to get the education he yearned for in the early 1980s. Now he’s a trim 180 pounds, he monitors his blood sugars several times a day, and eats a low-fat, low-sugar diet replete with traditional foods such as lean moose meat and baked bannock, a traditional bread. A combination of modern science and traditional lifestyle is finally keeping his blood sugars in check.

But by the time he was managing his glucose levels through diet and medication, Heidi’s complications had already taken hold. As Katie delicately swabs Heidi’s foot, his grandson clambers up on the bed beside him. Soon Heidi will be able to walk without crutches, using just a cane. He stretches his arm out to touch the two-year-old. His voice falters and his eyes well with tears when he speaks of the younger generation.

“I don’t know what’s going to happen to them when they’re 15 or 20, and getting diabetes. They could have complications by the time they’re 30.

“It’s no good,” he says bitterly.

As Heidi's story illustrates, in the decades since the "modern" world arrived in Sandy Lake, people have undergone drastic social and cultural change. Scientists now believe that diabetes among natives is a barometer of the extent of that social change. From an active lifestyle of living off the land -- hunting, fishing, trapping, gathering roots and berries -- to the hemmed-in life of a reserve member, or residential school student, people's bodies and psyches have had to make massive adjustments. It's believed that the thrifty gene -- or some combination of thrifty genes -- predisposes native people to gain weight and keep it on -- one of the key contributors to diabetes.

On the other side of the village from Heidi, Maida Meekis tells of another form of cultural loss-- attendance at residential school--that contributed directly to her development of the disease:

"At residential school we ate army style with big pans," she says, holding her arms wide. "Potatoes and bread (were the main foods). I bought myself a lot of candy," she adds.

Maida went to the MacIntosh school at Vermillion Bay when she was five, in the 1950s. While the oblates, who ran the Catholic school, grew carrots and lettuce, Maida says the main foods were always the same -- high-carbohydrate items which were radically different from the traditional diet of wild meat and berries.

"Then you had no choice what to eat," she says.

Since social custom and tradition play a part in developing the illness, they also are key to keeping people well, experts say.

Young explains how solutions for the epidemic among native people must be culturally-specific, and take into account this radical shift in lifestyle.

“Balance is central to the aboriginal understanding of diabetes. The concept can be used effectively in explaining how diabetes works and suggesting means to cope with the illness. Aboriginal legends can also be incorporated into teaching materials.”

Dorothy Gohdes, an expert in native diabetes in the United States who has studied diabetes among the Pima Indians of Arizona, stresses the importance of using traditional ways to recover the health of native people and, in particular, of the younger generations.

“Traditional activities are an indicator to health...they are a sign people feel they have a stake in their own destiny. The biggest loss in northern Canada was the loss of the ability to trap,” she says.

“The pride and accomplishment of people with skills -- their whole economic (system) -- just got pulled out from under them.”

The Pima, Gohdes explains, farmed the Gila River basin, set in the middle of the Arizona desert, for their livelihood. But when the river was dammed for hydro-electric power early in the 20th century, their livelihood dried up.

Likewise, Gohdes recalled a trip she made to Sandy Lake a few years ago, in which she visited the community's Northern Store – the modern descendant of the Hudson Bay Company trading post of old (Northern Stores are now owned by the North West Company, which has 127 stores across northern Canada).

“Someone brought in a pelt (for sale),” she says. “The price was so low he walked out.”

In Sandy Lake, there are many people like Heidi and Maida – people caught, tragically, between the old world and the new, whose bodies did not respond well to the change and for whom little understanding or education was available. But despite their inability to make a living from trapping, many Sandy Lake elders and even some young people have retained their trapping, hunting and fishing skills.

While the so-called “generation gap” referred to in non-native world is more acute in the northern world, old and new, traditional and modern, native and non-native influences co-exist, and can often be surprising to an outsider. Nowhere is this contradiction brought into greater relief than at a traditional Sandy Lake event: the memorial feast.

Tina Noon, a diabetes worker and daughter of Esther Linklater, announces a memorial feast will be held for a young man, Troy Kakepetum. Everyone is invited, she says. A distinctive Sandy Lake tradition, the memorial feast is held on the

one-year anniversary of a person's death, to remember and also to mark the progress of grief of the loved ones left behind.

Feasts abound in Sandy. A throwback to the days of feast or famine, people here use the time to band together, to reinstate communal ties, to replenish the body, and to give speeches – something not otherwise seen in Sandy Lake with its growing gap between young and old.

Like many feasts before it, Tuesday's will mark the one-year death of a young man. A casualty of the precariousness of existence in the North, where the line between life and death is perilously thin, Troy Kakepetum, 25, drowned last year when his snow machine went through the ice of Big Sandy.

But social ills – suicide, substance abuse and illness – have also claimed many of Sandy Lake's young before him.

People start arriving at the Sandy Lake Revival Church at 12:30 in the afternoon. The church is a burnt-out looking white building with the word JESUS painted on the side in blue letters. Trucks roll up to the door, their rusted-out wheels wobbling on failing axles. The sky is grey and low, looking like snow. The clouds have a bluish tinge.

The feast isn't due to start until 1 p.m. Outside, men stand over sizzling frypans on a makeshift grill over an open fire. Inside, old women stand in groups talking and working. On a raised platform like a stage at the far end, the food is piling up. Two young women – Dolores from the band office and Bernice Kakepetum, the young Troy's aunt—are cutting the meat. I walk over and ask if I can

help. They look at me with shy curiosity, ask who I am. I introduce myself to the grandmother of the dead man, Jessica, and say I'm a reporter.

"If you can find a knife, you can carve that," says Dolores, pointing at a 20-pound ham. I start carving. An hour and a half later, I've carved up five hams, and I'm no longer hungry. Dolores who worked alongside me has carved more. The feast doesn't get under way until after 3 p.m.

While I'm carving, curious children come and stare wide-eyed at the pile of food. Roasted rabbit, moose stew, turkeys, hams, piles and piles of bannock, 50 pies sit in the corner, heaped on an old table. A pulpit with a cross has been pushed to the back of the stage to make way for the crates and boxes of salads, cakes, coleslaw, fried rice. My arm and back are aching as the music blares from a small box at the other end of the church, gospel songs and religious pop.

"It's gonna rain, it's gonna rain," the voice sings cheerfully. Outside, the snow is six inches thick on the ground.

"Sweet Lord revive us," hums the tune.

Tina Noon, a tall woman, rounded at the middle, arrives loaded down with food, and leans over to me.

"I've been up since four," she says, laughing. Cooking, getting ready for the feast, she says. She made chicken fried rice.

"I made it for the Health Minister once," she says. "No, not Rock, the other one. Dingwall. We only had a few hours notice, and everyone said, 'what can we make quickly? Fried rice,' " she says.

"We told him we flew it in from Winnipeg."

Finally, after 3 p.m., the speeches begin. The United Church minister sits at the head table, in front of a giant goblet of cherry Kool Aid and chopped white bread for the Eucharist.

In front of him also sits a large platter mounded with Troy Kakepetum Junior's favourite foods when he was alive: turkey, moose, and ham, cut into bite sized pieces, along with bits of bannock, Fudgeeo cookies, cinnamon cookies, tiny wrapped candies and pieces of cut-up oranges.

One girl, about 10, tired of waiting, grabs a Fudgeeo, twists it apart and starts licking the centre.

Tina offers to translate the speeches.

"They said they were happy they'd made it through the year, the memorial feast was to celebrate that, not to mourn too much – the person had gone to a better place – father didn't talk because it's still fresh if you've lost a son," she says.

"My son died the day before his 19th birthday, ten years ago November 29," Tina adds, matter-of-fact.

"Hypothermia. I was living in Shebandowin, let him go for a summer, we were going to let him try his wings," she said.

"Originally the feast brought back memories for me. I was reliving everything, it helped me to go to the memorial feast – I realized I'm not the only person it has happened to," she says.

Many people here have such a story.

The elders launch into long speeches, repetitious, circular orations in the strangely monotonous yet singing sound of Oji-Cree.

As Tina translates, she drops the elaborate formality of the language.

"The first guy -- Fred Meekis -- said if anyone wanted to say a few words they could," Tina says.

A very old woman in a head kerchief, from the Garden Hill reserve in Manitoba, speaks at length about letting go of grief.

A young Wally Kakepetum -- a local constable and uncle of the deceased -- also says a few words, his black hair glinting under the church lights.

Once speeches are over, the minister -- who was chosen for his oration, not because he's a member of the Revival Church -- stands and says a prayer.

Troy Senior, the father of the dead boy, who looks tired and has stayed quiet throughout the ceremony, sheds a silent tear and reaches in his pocket for a tissue.

A young man with a scar rests his head on his hands during the prayer.

Tina jumps up, as if to shake off the sombre mood that has descended, and says, "I'm gonna serve."

And she starts throwing food onto Styrofoam plates and others begin passing them out, to the family of the dead first.

Nobody gets to choose what they want -- they just eat what they get.

Lasagna and fried rice, moose meat and rabbit heads. Tina, finished serving, holds a pair of rabbit kidneys in the palm of her hand -- they look like tiny smooth pebbles -- and salts them and eats them.

"Good for you," she says.

Elders begin to distribute the rabbit soup, thickened with flour.

"Indian soup," they say in English for my benefit as they pass me a small bowl.

"This is moose meat in here," says Tina looking at the soup. Tiny brown flecks in a thick white soup. Tiny noodles. Also called rabbit gravy, a younger man tells me.

At the beginning of the prayers, there were maybe 60 people in the hall. But by the end, that number has ballooned to more than a hundred, and late-comers stand at the back waiting for chairs. I quickly down my lasagna and bannock, a bit of coleslaw and a piece of apple pie.

Alongside the mounds of food moving from stage to plate, Troy's family passes around the platter of favourite foods, taking a few and eating them as they pass.

Then, they pass around the pictures. Troy's memory is kept alive in image and in substance, as his favourite foods – a strange hybrid of tradition and modernity, the contradictions within which every young person here must live and die – are taken in a kind of informal Eucharist.

Maida Meekis, Troy's aunt, sits quiet and bright-eyed, like a small bird. She eats carefully to manage her diabetes. Many others aren't so disciplined today – the pull of tradition, of the feast, is strong.

At one point an old man comes around with a bucket of tea, and people dip their Styrofoam cups in and haul them-- dripping-- out. The hall has grown very hot

and smells of the warm meat and bannock. There is an open window on one side. I am told the feast will go on for three or four hours.

People at the back begin to shed their puffy jackets as they tuck into their plates.

The food has been paid for by various fundraisers, and partly by the band, Tina tells me. Various women have been in charge of cooking.

Some people were auctioned off as "slaves" to do the work of the feast. Tina was one of them. She gets to leave at 4 p.m. she says, though she doesn't seem in any hurry.

Somehow, everything gets done.

The flags at the band office flew at half-mast today – one Canada Flag, one green-and-white Sandy Lake flag. I am told that there will be yet another feast later this month – this one for an elder.

As the memorial feast for Troy Kakepetum illustrates, traditional and modern activities and foods coexist in Sandy Lake. Rabbit caught this morning on the trapline is eaten alongside cookies and cakes flown in from Toronto, or a plate of fried rice cooked up by Tina Noon.

Eating is still be very much a communal activity. But does tradition always serve health? The display of foods available would suggest not, as many items are high in fat. But on the other hand, some experts would argue the feast is essential

to the physical health of the community, especially due to the prevalence of traditional, healthier foods alongside more high-fat and high-sugar items.

As the consumption of sugary processed foods increases, the newer generations are perhaps even more at risk than elders like Heidi and Maida. This hypothesis is borne out by the fact that the age of native diabetics is growing startlingly younger each year.

At age 15, Ashley Beardy is already a veteran. She found out she was diabetic when she was 10, by playing with her mother's glucometer. Her mother took one look at her sugar levels, and told her to go to the Sandy Lake nursing station. The teenager laughs about her story today, but admits the disease scares her.

"The doctors told me if I don't take care of myself, I'll probably get blind by the time I'm 30."

When she was first diagnosed, she says, she felt "different" from the other kids, and had to learn to avoid junk food.

Now, despite a careful diet and a daily one-hour walk, Ashley says she still struggles with weight, and her sugars can still go out of control, making her dizzy and tired.

Ashley knows that, even with careful management, she has a good chance of getting complications at some point. More than anything, she says, she is hungry for more information about her disease. She dreams of being a social worker.

"I want to know more about how it will affect me in the future, instead of how it will affect me right now."

It's a sad fact that diabetes -- brought on by the loss of culture and tradition -- is also occasioning a further loss of culture in native communities across the country, as poverty-stricken bands are forced to send their members out for treatment.

Isaiah Kakepetum has boarded two flights and crossed one time zone today, and as he stares out the plane window with eyes blinded by illness, he wonders how many more trips he will have to make. He's going home tonight on doctor's orders, after spending a week on a hemo-dialysis machine in a Thunder Bay hospital. Unlike some patients with failing kidneys, "home" for Isaiah means a flight north over 500 kilometres of uninhabited forest to Sandy Lake.

For him, a trip out to save his life is also a trip into another world.

"I hate flying at night time," the 58-year old says softly as he sits at the back of the 15-seat Beechcraft, one frail leg propped up on the seat beside him to aid his poor circulation. A baseball cap sits slightly askew on his head, and his tinted glasses, which reduce the glare from the runway lights, make it even harder for him to see with his failing eyes.

As the plane taxis down the short airstrip in Sioux Lookout, a town of 5,000 and the hub of transportation in northwestern Ontario, the passengers are deafened by its propellers and vibrating steel frame. Two co-pilots chart their course using

instruments and paper log books, while in the dim glow of the reading lights Isaiah leans toward his sister, Sarah Kakepetum, a few seats ahead. As the plane jostles and curves northward, Sarah gazes out the window at the boreal forest below, where a new place lies waiting for them in the darkness.

In the back of the plane, among the packages, lies a box of Japanese mandarin oranges Sarah bought in Thunder Bay. They are one of Isaiah's few remaining pleasures. Since his diabetes worsened three years ago, he must eat carefully, avoiding sweets and fats, so the oranges are a good idea. Except that he can no longer peel them, since the diabetes has killed the nerves endings in his fingers.

As Sarah leans her head against the window to rest, she thinks of the number of times Isaiah has had to leave --this is the second trip out since November -- and she tries hard not to listen to the sound of the propeller slicing against the darkness. She saw a plane crash a few years ago in Sandy Lake, while she was on duty at the airport. An Air Manitoba flight slammed into the ground killing everyone on board. The community erected a stone monument in memory of those killed. She remembers an emergency medevac flight out to Thunder Bay with Isaiah in November. It was so windy the plane was going "like this" as it landed --and she rocks her hand back and forth over the narrow aisle.

Like anyone from this part of the North, Sarah knows flying is the only way to get home from outside the community. In Isaiah's case, it's the only way to get the lifesaving treatment he needs. When he's in Thunder Bay, the hemodialysis

machine filters his blood three times a week, a task his kidneys have slowly given up. In the short term, this week's trip and treatment may save Sarah from having to administer home dialysis four times a day, every day -- Isaiah's usual routine, which she performs in the bedroom of his tiny house. Home dialysis has been the only thing standing between Isaiah's life in Sandy Lake and a permanent move to Thunder Bay, where he may someday have to live in exile, far from his land, his language, his friends family and culture.

When the plane lands, it taxis down the gravel airstrip towards the Sandy Lake airport --a one-room building on a lonely-looking road. The back door of the plane opens and two pilots carry Isaiah down the fold-out steps onto the icy pavement to where Kennedy Fiddler has parked his pickup truck. One of Sandy Lake's eight band councillors, Fiddler jumps out of the truck and helps the pilots place Isaiah gingerly onto the passenger seat. Everyone ignores the minus-30 winds and blowing snow. Kennedy tosses Isaiah's bags into the back of this truck, and idles the engine while Sarah is stopped by two band constables in fur-lined parkas. They search her bags with flashlights for liquor. It's a routine check -- bootleggers thrive on this dry reserve --and as they search, they chat with Sarah. Then Sarah climbs into the truck and they head out.

It's December 13. As he rides over the bumpy roads to his house by the river, Isaiah wonders whether he'll be well enough to stay in the community over Christmas. There's a good chance he will be flown back out. The next morning, before eating and before dialysis, he will call the local radio station, where the

announcer will put him directly on the air. Then, speaking in Oji-Cree the Sandy Lake elder will announce his return to the community which, up until now, has kept him in the world.

Isaiah leans away from the radio as he lies in his bed. He was just listening to Tina Noon's weekly one-hour diabetes show. Isaiah called Tina during the show to correct her pronunciation, something he does regularly.

Tina relies on elders like Isaiah to help her translate the complexities of the disease.

Next to his bed, Sarah is setting up the dialysis machine and donning a white mask. Isaiah is wearing black wool gloves with the fingers cut out, and a yellow T-shirt with the words, "American Indian Movement" splashed in red across the chest. A friend brought it back from a trip to the southern U.S., he says, as he puts on a mask. The two people have to take every precaution to avoid infection.

"I do this four times a day," he says as Sarah moves the rattling IV stand closer to the bed. His bedroom walls are adorned with photos of his children – two girls, two boys, all married. Some live in Deer Lake. He has 13 grandchildren, but no great-grandchildren –"yet" he adds.

Sarah attaches a tube to the plug doctors have implanted in Isaiah's abdomen, and the fluid from his last treatment begins to drain into a bag on the floor. A new bag of the fluid – which removes toxins from Isaiah's bloodstream –hangs from the

IV stand. While she completes the process, the phone rings. Sarah chats for awhile then hangs up.

There is no word in Oji-Cree for dialysis. When the community first grew concerned about diabetes in the early 1990s, dialysis was the furthest thing from the leaders' minds. But with the number of cases skyrocketing, two years ago the band sent a request to Health Canada for its own hemodialysis machine. That fact alone represents a sea-change in the community, says Dr. Stewart Harris, one of the founding researchers of the Sandy Lake genetic project.

"There's enough people now that they can justify it –that's the sad truth," he says.

Health Minister Allan Rock responded to the request in a letter saying it wasn't feasible to put in a machine because Sandy Lake doesn't have the medical staff required to operate the machines, which cost \$250,000 apiece. But Meekis says the cost of sending people out for treatment is growing exponentially by the year.

"We feel it's an issue that has to be dealt with. We need to look at it on a broader basis."

Sandy Lake will continue to lobby for the machine, arguing the community could act as a centre for treating diabetics from neighbouring reserves, Meekis says.

The life of permanent or semi-permanent exile of people like Isaiah makes it hard for the band to offer the required moral and financial support. The band has

to hold fundraisers to help pay the costs of relatives staying with patients in Thunder Bay, Sioux Lookout, and Winnipeg.

"We've assisted families in different requests (for funds). It's hard to do it all --you just can't," Meekis says.

Cultural differences also play a role, he says.

"It's very difficult for people who've never been in an urban centre to end up there --the foreignness adds to the difficulty."

The money raised by the band for families now offsets what could become a staggering cost to provincial hospitals, according to the projections. Each dialysis patient is estimated to cost \$100,000 a year to the system, says Dr. Joe Dooley, president of the Northern Ontario Diabetes Network. That figure doesn't include transportation or accommodation for family members. The problem is so severe that some northern Manitoba bands have built a group of houses in Winnipeg just to accommodate the family members of dialysis patients, he says. The homes are called "Dialysis Row."

For Isaiah, the social and cultural cost has been high. The loss is also great for his family and the larger community, which will lose his wisdom when he is flown out of Sandy Lake to die -- a stranger in a strange place. Today, he sits in his own bedroom, surrounded by the familiar, eating a bowl of oatmeal and waiting for Sarah to give him another treatment. Although he will spend Christmas at home in the

community this year, his illness will force his to relocate permanently to Thunder Bay in January.

Like Heidi, he says he wishes he had learned how to manage his disease sooner. He hopes things are better for the younger generation.

Outside his bedroom door, his three-month old great-nephew lies in a plastic swing near the television, while his niece prepares food at the kitchen counter. On his bedside table sits an orange from the crate, peeled by Sarah.

Diabetes, while resulting in part from a disruption of the culture of native people last century, thus has also occasioned a further tear in the social fabric. Increasing numbers of elders -- which in the native world can be people as young as 50 -- are being flown away from their communities. When people like Isaiah are flown out, the community loses their voice on the radio -- it loses their language, their culture and their tradition, as well as the few living memories of the time before European influence.

People like Heidi and Isaiah were for years unable to get practical help for their diabetes -- help that would take into account their unique dietary and cultural past, with its emphasis on wild foods, living in the bush, and communal activity. Help that would also account for the unique cultural present of Sandy Lake, with its feasts juxtaposed with its day-to-day poverty, its access to processed food and traditional food, and its distance from modern medical treatment centres.

Solutions, however, lie not in a return to the past, but in a solid recognition of the reality of life in Sandy Lake today, and a creative approach to the future.

CHAPTER III

Homegrown Solution: The Sandy Lake Diabetes Program

Sandy Lake Deputy Chief Harry Meekis is talking deals today.

Sitting in his office with the picture of Indian Affairs Minister Robert Nault and himself smiling down from the wall, he is getting ready to sign a 50-per-cent joint exploration venture with Goldeye Explorations. The Richmond Hill, Ont.-based company wants to search the band's territory for gold and minerals.

"We're seriously considering the proposal," he says, fingering papers on his large desk. A picture of Meekis with his wife and children sits propped on one corner. "It would have to be ratified by the community. It's the first offer of its kind."

Innovative deals are Sandy Lake's middle name. They are also the way of the future for northern reserves trying to establish an economic base amid the race to plumb natural resources such as lumber, minerals and even fresh water. Placer Dome recently struck a deal with several native communities in the region to give them a share of the profits and a percentage of the jobs created when the company set up the Musselwhite gold mine near Pickle Lake, Ont., southeast of Sandy Lake.

But in striking a deal with genetic researchers, Sandy Lake further advanced the notion that communities can stake a claim to work on their turf. When it finalized an agreement with Stewart Harris, Bernie Zinman and Robert Hegele in 1995, the community demanded a share of any profits from genetic research performed on the DNA of its community members. The agreement stipulated that the community receive a research credit in any articles or other publications arising from the scientists' work. The community also won a built-in educational component to the project – one that will continue long after researchers depart – as well as an assurance of regular shipments of fresh fruits and vegetables at the local store.

It was a deal with symbolic as well as practical importance. In the past, native communities have often been used as guinea pigs for scientific advancement, with no tangible benefits flowing to the community once the research is done. A case in point is the Pima example, where decades of scientific research led to the development of diabetes drugs still widely used. But while research was being carried out on the Pima in Arizona, none of the benefits of advancing science were brought to bear on the illness within the community. The result has been a staggering number of deaths and a burden of illness that now threatens the Pima's survival.

The Sandy Lake agreement was a fair deal to the researchers, who stand to gain if their DNA gamble pays off. It's too soon to tell what drugs or treatments

may arise from the Sandy Lake study, Robert Hegele says, but if past research in other areas is any indication, billions of dollars could be at stake. But he cautions that because the genetic structure of the Sandy Lake Oji-Cree is so unique, the research may have limited commercial application.

Meekis recalls the diabetes project agreement with pride, saying the community wanted "to be known not just as the community with the (third) highest diabetes rate, but as the community that did something about it."

That took more work than the band or even the researchers expected, Harris recalls, citing the Canadian government's reluctance to fund the project which he started to shop around in 1992.

"There were no funds for aboriginal diabetes programs ... in the early nineties," he says. "(The disease) was under the jurisdiction of a part-time dietitian in Ottawa."

After the federal and Ontario governments showed no interest in his proposal to study Sandy Lake, Harris went south of the border. The U.S. National Institutes of Health under the Bush administration gave them an initial \$25,000 start-up grant in 1992.

That grant was used as leverage with the Ontario government, he says, who gave the researchers a small grant, then a larger grant which added up to \$700,000 for the prevalence study between 1992 and 1995.

Finally, with the data and an agreement signed by the community in hand, the scientists garnered the research dollars which allowed them to reach the

results, first published in 1996, showing that 40 per cent of Sandy Lake had some form of diabetes.

Harris laments the lost time while the epidemic has gathered force. In the U.S., diabetes programs have existed through the Indian Health Service since 1979. But in Canada, squabbles between the federal government, which is officially responsible for health care to First Nations, and the provincial governments, which bear costs like transportation and hospital fees, have contributed to the delay, he says.

"First Nations are always getting caught in jurisdictional battles. The (Ontario government) has dropped the ball on the funding issue ... they need to be more involved," he says.

But quieter seeds were also sown by the project. Its education and prevention components -- fought for by community leaders like Meekis -- have begun to take root and flower in Sandy Lake, despite the odds.

Tina Noon's smile lights the room like the midday sun. Every day is like this one says Esther Linklater's daughter, emerging from her bedroom in her house in the Big Rock neighbourhood. Wearing only shorts, a T-shirt and slippers, she casts large owlish eyes around the room.

She steps lightly outside the door of her two-bedroom "mansion" -- a clapboard house recently renovated -- past the screened porch strewn with her grandchildren's toys and clothes, and into her cluttered yard. A makeshift

sawhorse, built by her husband before he left, tires lying buried under several inches of snow, a garbage box (also built by her husband – "at least he didn't leave me empty-handed" she laughs) and a grey 1985 Ford Mercury (her son will fix it in the spring) litter the slope leading up to the road. Across the way the Severn River meanders toward the protruding brown rock after which this side of the village is named.

She is a tall woman, rounded at the middle, with black hair sweeping off her forehead in a decisive wave. Only a few grey hairs hint that she's over 50 – 52 in fact. As she raises her head to the actual sun, which is rising today behind a bank of moody December clouds, she sniffs the air and guesses: minus 10 or so. Mild.

She steps back inside and opens the door to her wood stove, which sits in the centre of the main room. She adds another log to the coals that have smouldered all night. Using a spoon she digs into a can of Maxwell House and soon there's brown liquid trickling into the coffee machine perched on her microwave.

She pulls on leggings and a white sweatshirt and sits on the couch with her coffee to think about how she will tackle the plague today. She doesn't have the disease, but it's her job to try to stop it.

As an assistant with the Sandy Lake Diabetes Project, Tina's job is not one of generalities or statistics. She works inside the community, on the ground. Tina says she's comfortable with her job, which consists mainly of the fine art of

getting information out of reluctant people and the challenge of winning them over, bit by bit. The project office is her home base, where she teaches newly diagnosed patients how the illness works. The methods are innovative: patients study diagrams of a dissected moose with arrows pointing to its pancreas, showing them the insulin-producing organ in a familiar animal. There is no word for the human pancreas in the Oji-Cree language. In the office, people learn what kinds of familiar foods -- moose meat, bannock, oatmeal -- and which local activities -- chopping wood, shovelling snow, sledding -- will help them control their illness.

In place for several years now, the project office is in fact a split-level townhouse built originally as a teacher's residence. It sits near an open field in front of the community's elementary school.

Upstairs in the kitchen, hand-made posters describe in simple terms the findings of the diabetes project. Mounted on the wall, the posters describe the thrifty gene as a cabin which has generated too much heat. It no longer can contain all the heat, and an excess of fuel (wood) is building up outside the door. Another poster gives the breakdown of the prevalence study -- signalling that the person who has arrived at the office is there for a good purpose.

The kitchen also has posters on the cupboards indicating what healthy food choices might look like. It's like Canada's Food Guide with a twist -- instead of typical steak and chicken, bagels and bread, the posters feature pictures of moose with large antlers, fish, rabbits, caribou, seal, Canada geese and

partridges. In the bread section bannock – a pan-made bread which is traditionally cooked in lard over a fire but which can also be baked – features prominently beside bagels and pasta. In the fruit and vegetable section, corn, turnips and raspberries and blueberries sit alongside more southern choices like bananas and apples. "Eat foods from each group every day for health," the poster reminds visitors.

Downstairs, the diabetes project offices are neatly organized in the basement of the townhouse. In one room, an expensive state-of-the-art body mass index machine stands quietly. Tina explains it is the most important piece of equipment in the office – it can calculate patients' ratio of fat tissue to their total body mass, providing a more accurate indicator of healthy weight than a straight body weight measurement.

Tina also pulls out a glucometer – a key tool of diabetics trying to monitor their blood sugars. New clients, she explains, are introduced to the illness slowly, with one small step taught at each session, instead of all at once. They are given the practical skills of testing their blood sugars at the same time that they learn some of the chemical processes understood to cause diabetes in the first place. Insulin, it is explained, acts like a key that allows body tissue to absorb and use energy from sugar in the bloodstream. Type 2 diabetics, Tina reminds them, do not produce enough insulin, and the insulin they do produce is not easily absorbed by the system.

The project also coaxes people to become more active. This does not have to involve dramatic change, Tina stresses. Common daily activities such as chopping wood, shovelling snow and walking are easy to add in, and the community has had some success in encouraging them, she says.

"All these are activities that will help your blood sugars stay normal," she says.

In another room, Tina's co-worker, Rod Fiddler -- who is also a son of Heidi Fiddler -- sits at his computer. The 24-year-old says he is preparing a high-school education project in which students are planning a dance with healthy foods and drinks. They will benefit from the exercise as much as from planning a healthy buffet dinner, he notes, showing me correspondence with the school's administrators. A prevention curriculum is now being developed by researchers to begin next year in the community's primary school. Students in Grades 3, 4 and 5 will learn the basics of eating and exercising early, to set the ground work for prevention.

Both Tina and Rod are now enrolled in distance education course to become diabetes educators. On top of their regular workload, the evening classes, taught over the radio and by computer through a community college in Thunder Bay, will further certify the pair and prepare them for the work they do.

But the gaps in their own learning process are widened by their location. With their mid-term exam only a week away, the two have been preparing without textbooks -- which were ordered months ago but never arrived.

"We're just winging it," Tina says with a sigh. "What we don't understand, we phone Dr. Harris or Dr. Zinman."

Tina explains that the course will help her not only to better understand the disease, but to convey that knowledge in Oji-Cree to her clients. Many of the other students live in other northern communities, and the pooling of knowledge over the radio waves and the computer has been productive, she says.

"It's going to help me to explain more specifically in the native language, at the same time we're learning how to say different things through other students," she says.

"There's lots of people from all over Ontario – Timmins, Moose Factory, Sudbury, Thunder Bay, Sault Ste. Marie."

Despite the comfortable atmosphere of the project office, it's out in the community where Tina does the lion's share of her work. She steps out onto the blinding white road and heads for Marion Meekis's house, over in the Old Sawmill neighbourhood, where she is due for a home visit. She passes the band office on the curve and veers left, up the road toward where her mother sits in her house atop Linklater Hill. Her dog, Bandit, follows as far as the curve, until Tina raises her voice, picks up a rock and hauls it in his direction.

"Go home!" she shouts, exasperated, her deep voice carrying on the crisp air. She makes a pit stop at the Northern Store.

People have grown so used to her presence in the grocery store, where she conducts guided shopping tours and other awareness campaigns that she

has become something of a symbol for healthy eating, she says. She gestures at a large stack of soft drink cases stacked in the entranceway by the vegetable section.

"I happened to be standing in the store yesterday where all that pop was," she says, laughing. "Somebody asked me, are you guarding all the pop? Are you the sugar cop?"

As if on cue, Tina is stopped in the aisles by a couple seeking advice on how to eat. In her seven years with the project she has become a community signpost, a constant reminder that people need and can get help to cope with their illness.

"People don't really come to the project, because it's an office setting," she says.

"I like to take them into their own environment. They'll sit down anywhere, and in a casual conversation, they'll give you more on how they're coping with their diabetes. They'll talk to you."

When she gets to Marion Meekis' house, Tina enters without knocking. She takes off her boots and stomps into the main room past the front hall with its cardboard-covered floor, calling "Boo-shoo" to Marion. A tall woman with wispy grey hair and scars running down her face and arms looks up from the counter where she is chopping moose meat for the soup pot.

Speaking in Oji-Cree, Tina seats herself at the table. Marion joins her, her long hands picking up a piece of moose hide to which she is stitching tiny glass beads.

Marion starts to speak about her symptoms, which have worsened since she lost her husband to a heart attack a few weeks ago. Her blood sugars have been up and down and she's got ringing in her ears. She's worried about her son, a young diabetic in his 30s, whose foot is infected – part of it is turning black, she says – but he's refusing to see a nurse.

Tina listens, offering suggestions when possible. She is careful to adopt a receptive attitude, knowing that too much advice will ruin her chance to make a difference.

"It's hard to get people here to trust you," she says.

People in Sandy Lake are often restricted in dealing with diabetes due to other traumatic life events, she says. They are often reluctant to go to the project office, either because they are shy, or because they are afraid of being identified as diabetic. Worse, some people don't want to be seen seeking help for something comparatively low on the crisis list of many families, who routinely face more immediate trauma such as sudden death, incarceration, job loss, and other ills.

The intimacy of the home visit has been the cornerstone of trust in a tightly knit community like Sandy Lake, deputy chief Harry Meekis says. That

trust has been the impetus for change, no easy task when food and activity are so closely connected to cultural practices and beliefs.

A key example of success, he says, is that deep-fried bannock -- a staple bread in native homes for years -- is now rarely eaten, he says.

It has been supplanted by baked bannock -- unlike many neighbouring communities in the north.

"People in the community used to use lard, but since eight or nine years ago, the sale of that product has gone down more than 50 per cent," he says.

But education alone can't fight the poverty which makes diabetes so difficult to combat. High food costs at the Northern Store, where southern prices are tripled by the air freight charges, are a huge barrier to health for the community's 80 per cent unemployed.

At the Northern Store, now owned by the North West Company, eggs sell for \$2.85 a dozen and four litres of milk cost \$8.55. Heavier food is more expensive because most of the year it must be flown in. Only during a short window of time can the winter roads over frozen lakes be used by trucks hauling goods.

Fresh foods are also extremely expensive. Red delicious apples sell for \$4.71 a kilogram, and small, anemic-looking oranges cost \$4.55 a kilogram. Dehydrated kiwi fruits cost a whopping \$1.05 each.

By contrast, the less healthy foods are considerably cheaper. A box of Kraft Dinner is \$1.65. A 500-gram tin of cookies costs \$3.99.

Healthy foods sometimes aren't available, despite the community's agreement with the scientists. Broccoli is often absent. There is no lean ground beef available today -- a better choice for diabetics. Regular ground beef costs \$7.99 a kilogram.

Rod Fiddler describes the plight of his best friend, who is on welfare.

"He gets \$165 every two weeks. If he puts all his money into food, he still barely has enough, and nothing left over. He buys baloney, white bread, canned food. Some days, he doesn't bother eating."

Rod, a college graduate, can afford to live well on his salary, but it's hard to look after yourself when you're hungry, jobless, or in despair, he says. And that's far too common in remote reserves. Even in a functioning, informed community like Sandy Lake, a disease linked to lifestyle is a disease linked to poverty.

At noon hour, Gloria Keewaycabo walks over the snowy boardwalk spanning the swampy area between the band office and the police station, where she works security. Sporting sunglasses and a trendy nose-ring, she looks like any downtown working woman who likes to get exercise at lunch. But her casual remarks are telling.

"It helps keep my blood sugars down," she says, as she crunches along, the dry expanse of snowy reeds whispering in the wind. Few other communities in the north would see this kind of awareness about the disease exhibited in

casual conversation, nor the high level of motivation among community member to tackle it.

The boardwalk was built last summer as part of a new 2.5-kilometre walking path designed to get the community more active. It offers an alternative route to the hazardous, winding roads. Last September, the community held an inaugural walk to introduce the new walking path and hopefully to usher in a healthier era for the community. Swirling, choking dust has become a summer health hazard, particularly to children who have developed high rates of asthma as a result. The band council is trying to raise money to pay for a yearly dose of calcium chloride to spread on the roads and keep the dust down, says capital projects manager Joseph Meekis.

In the meantime, the multiple footprints on the new path are another indication of the community's desire and commitment to become healthy.

But despite such blossoming signs, the means of change are still hanging in a tenuous balance.

Harry Meekis sits at his desk, fingering the manual distributed by the Aboriginal Healing Foundation for year-2000 funding. This is the fund's second year of grants to help communities deal with the negative impact of residential schools. He chuckles as he opens the front cover to reveal a shiny disk -- a CD ROM tucked inside as part of the package.

Technology like this hasn't reached many reserves, he notes. Many First Nations in Canada will be hard-pressed to find time and expertise to fill out the 30-page application form, let alone use a computer. The shiny disk is an emblem of the gulf between Ottawa and the struggle to get program dollars, he says.

In his February, 1999, budget speech, Finance Minister Paul Martin announced \$33 million dollars would be devoted to fight aboriginal diabetes under a new "Aboriginal Diabetes Initiative." In November 2000, Health Minister Allan Rock topped that figure up to \$58 million, under the government's "Aboriginal Diabetes Initiative." This was a ray of hope for Sandy Lake, and Meekis applauded the announcement.

But more than two years later, the funding has been slow to trickle out.

"We're always audited and criticized for our spending, but on the other side, you can't get funding from the body supposed to be funding you," Meekis says.

In January, 2000, Health Canada finally came through with bridge funding, which was retroactive to June 1999, and carried the project until June, 2000. Then, almost a year later, the community finally received a five-year funding commitment for the diabetes project, which brings in \$185,000 a year. But Tina and Rod's salaries and their home visits are not covered by the funding, although they still form a key part of the community's strategy, Meekis says. Right now, the program still draws heavily on volunteer efforts.

And Meekis and experts outside the community say they wonder when the government will live up to its fuller promise to devise a First Nations diabetes strategy. The delay is part of a decade-long pattern that has placed the health of First Nations in jeopardy, Harris says.

While governments need to ensure accountability, that vigilance often presents barriers for under-resourced communities. Bernie Zinman says he's worried about how the new diabetes initiative money will be distributed. First Nations don't just need money, he says, they need a plan – a strategy involving people, training and programs drawing on examples like Sandy Lake, if the money is going to be well-spent. He argues that the eight to 10 community-run programs across Canada including Sandy Lake and the Kahnawake First Nation near Montreal, should be given priority funding, if they are to act as models for other communities.

Harris says that, despite the five-year commitment in Sandy Lake, a handful of other programs in Canada may die off.

"Most community-based programs are on the verge of collapse because of funding issues," he says. "The government has a major role to play in developing a national diabetes strategy, and in supporting and establishing prevention programs."

Harris says he's pleased to see Sandy Lake being well-funded, but a real solution will take much more commitment.

"It's a start, but it's not enough. A strategy needed to be in place yesterday," says Harris.

Tina's on the airwaves today, spreading her infectious personality throughout the community. When radio was first introduced in the Sioux Lookout Zone in the early 1970s, it caught on like wildfire in an oral culture which loved to talk, loved stories, and was extremely close-knit.

So it was only natural that, once a week, Tina Noon and Rod Fiddler would drive from the project office over to the community radio station to take their message right into the homes of every community member.

The station is a tiny brown building sitting at the base of the southern face of Linklater Hill, near the nursing station. Plastic sheeting is nailed to its outer walls to conserve heat. The sheeting glints in the sun, giving the station a slightly magical look. On the roof's edge a satellite dish sits directly over an ancient-looking sign which reads, simply, "Radio Station."

Inside, Tina is already on air, telling people the importance of checking their feet. If they don't, they won't know if they have any sores, particularly if the diabetes has caused their nerve endings to go numb, she says.

"You have to look for a pebble in your shoe before you start walking," she says in Oji-Cree. "You're not going to feel it after awhile. My daughter-in-law was diagnosed that way," she adds for emphasis.

A poster on the wall reads "Wendamowin Communications Society."

Affiliated with the regional native radio network, Wawatay Communications, the community station hooks up occasionally for regional programming.

"We said we will be talking about the Christmas feasts during this show," says Rod during a break. Daily Christmas feasts in Sandy Lake stretch for more than a week over the holidays, and typically involve high-fat foods. The phone rings incessantly while the two take turns at the mike and answer the phone. People are calling in with questions about their disease.

"If you notice your blood sugars are low, carry sugar with you all the time," says Rod in English, as a warning to some of the younger diabetics. "If you notice that you're really tired, you'll get some mood swings if your sugars are low."

At the end of 15 minutes, Rod slaps on an Eric Clapton CD for a change of pace. The show will last one hour.

While the strains of "Change the World" drift across the community, Tina turns to the phones, which continue to ring. This afternoon, the community is listening.

CHAPTER IV

National Problem, National Solutions

"The fact that Sandy Lake holds a record as having the third highest prevalence of diabetes in the world is more a tragedy than a source of prestige. The preventable nature of this complex combination of physical and social calamity demands action."
(Harry Meekis, speaking at the Fourth International Conference on Diabetes and Indigenous Peoples in San Diego, October 1997).

Percy Houle is at the conference, too. He has travelled more than 5,000 kilometres to help his grandchildren.

The community elder and advisor from Ebb and Flow First Nation in Manitoba says he's attending the Fourth International Conference on Diabetes and Indigenous Peoples in San Diego because he is afraid of what diabetes is doing to the children in his community.

"A girl of 17 has diabetes and both her legs are amputated," he says, looking incongruous in his baseball cap as he sips coffee in the hotel restaurant looking out over palm trees and an outdoor pool.

"It's very sad."

This conference, where Sandy Lake leaders are making a special presentation about their diabetes program, is proof positive that the epidemic extends well beyond Sandy Lake's borders. In fact, Houle is gathering information and advice from native experts from as far away as Australia and New Zealand, as well as the U.S., on how to help his own people.

Houle says Type 2 diabetes has appeared in children as young as eight in his community of 1,500. Diet and lifestyle, he says, are the primary reasons.

"It's just how we live, and what we eat today," he says, adding that change is difficult, and as a native elder, he feels undereducated about the problem.

"I don't know how much advice I can give."

So far, Houle's none of his nine children and 35 grandchildren have developed the disease. The secret for his family, he says, has been healthy eating habits that rely on traditional foods.

"We didn't believe in junk food," he says of life when his family was younger. "We ate vegetables, fish and wild meat."

But it is getting harder and harder for young people to avoid the disease, Houle says. Lifestyle changes and social pressures are contributing to a pattern of living that is difficult to break. The challenge lies in convincing people to take care of themselves, he says.

"My granddaughter always has two big things of Coke in the fridge," he says.

"I say, 'It's going to hurt you.' But she says, 'all the other kids are doing it.'"

While Sandy Lake has one of the highest diabetes rates in Canada, researchers say rates have reached epidemic proportions in native communities from coast to coast, with a native diabetes rate 3.6 to 5.3 times higher in men and women respectively than the national averages.

Since 1997, when the San Diego conference was held, the number of native diabetics in Canada has continued to soar.

In the September 2000 edition of the Canadian Medical Association Journal, T. Kue Young wrote that several methods have been used to gauge the prevalence of diabetes in natives – a group which has not traditionally had a reliable body of health statistics due to remote and isolated conditions and inconsistent or inaccessible medical care. Vital statistics derived from death certificates, registries of diagnosed cases, health-interview surveys and sporadic screening of blood sugar levels have yielded what little information researchers have on the disease, Young says.

The first – and perhaps most important – finding, he says, is that diabetes rates vary from geographical area to geographical area, and between tribal and linguistic groups. Using Health Canada data from its First Nations and Inuit Health Branch (formerly Medical Services Branch), Young concluded that the

Dene (an Athapaskan tribe) found in British Columbia and the territories have the lowest reported rate among Canada's indigenous people. The Inuit, to date, also show low rates of the disease, and in a 1997 interview, Young attributed this, in part, to the lower levels of contact Inuit have had with European culture, compared to native people further south. He also said some experts hypothesize that the Inuit's low rates are geographically linked, since the disease affected southern natives first, starting with those in the southern U.S. This theory relies on a yet-to-be understood cause which some researchers believe is linked to climate and environment, Young says.

Estimates of diabetes rates in different Algonquian Cree communities in Quebec reveal substantially variation between the communities even though they are geographically close to one another, Young says. Yet, continuous surveillance has yet to be conducted in most communities. Where it has, there is one consistency – almost all communities have rates substantially higher than the national average. And in all communities, prevalence –the total number of diabetes cases --and incidence –the number of new cases – are growing rapidly.

In the Sioux Lookout Zone where Sandy Lake is situated, the approximately 30 communities have seen a 45 per cent increase in diabetes prevalence over a ten-year period from 1984-1994, Young says.

Dr. Joe Dooley, president of the Northern Diabetes Health Network in the region, says the known rate in Sioux Lookout communities is now between 10 and 15 per cent. That's almost certainly an underestimate since aggressive

screening programs have not yet been done. Cases are cropping up faster each year, he adds.

One community saw a 12 per cent increase in cases in 1999, he says, while another experienced an 18 per cent jump in the 18 months from December of 1998 to April of 2000.

In Saskatchewan, the prevalence rate doubled (a 100 per cent increase) between 1980 and 1990, Young notes.

Figures from the 1991 census give a very crude estimate of the number of natives who were diagnosed with diabetes at that time across Canada, Young says. The data was collected and used in the First Nations and Inuit Regional Health Survey Report of 1999. Using raw data, the estimate of people who self-reported as diabetic was 8 per cent among men and 13 per cent among women. When age-adjusted to the Canadian population (the native population as a whole is substantially younger than the Canadian average) that data yielded prevalence estimates 3.6 and 5.3 times larger than the national average for native men and women respectively.

Some communities have done their own screening for the disease. In the two largest Algonquian (Cree) reserves in northern Quebec, and in Sandy Lake, prevalence reached as high as 25 per cent among all adults and 80 per cent among women aged 50 to 64. New cases detected by oral glucose tolerance screening (blood sugar screening) accounted for 40 per cent of all diabetes cases in those studies. That means diagnosed cases do not represent the total

burden of disease nation-wide, Young said, and could be gross underestimates. Many native people are suffering from the disease without even knowing it.

But the number of native people with diabetes or getting diabetes is only part of the story. New Canadian research shows the disease is taking its toll on younger people, and that the disease will likely be more deadly in the native population than in the non-native one.

Dr. Heather Dean of the Winnipeg Children's Hospital is a pleasant, sandy-haired woman who speaks forcefully when she takes the podium in the large conference room in the San Diego hotel. What she is about to say to some of the 600 delegates at this international conference will alter diabetes research and planning for years to come.

Dean has been conducting research for years on northern Manitoba communities to the west of Sandy Lake. What she has found there is, in some ways, worse than the skyrocketing rates in Harry Meekis's home community.

Her studies in communities such as Cross Lake and St. Theresa Point have found that Type 2 diabetes –unheard of in non-native children – is hitting these native children as early as six.

Until now, the disease had been thought to affect only adults, she says, and the new development has disease experts and health workers baffled as to how to treat it.

"Most physicians are disbelievers," the pediatric endocrinologist says in a later interview. "It's important to help them understand this exists."

But for them to understand is less than half the battle, she adds, since doctors don't know how to treat it.

"It's happening so fast, science isn't being involved to try to figure out why."

Dean says she saw her first patient with Type 2 diabetes in 1983, and since then provincial health records show 58 cases have been detected in children under 14 in Manitoba. The number of new cases at last count was rising from one or two per year to 11 per year in 1997. (More recent statistics are not yet available).

Official records show 0.05 per cent of children in the province have the disease, but some Manitoba First Nations have screened their children since Dean's findings were released, and found much higher rates.

Dean says this proves the vast majority of native diabetes cases still go undetected.

"The actual number is two to three times higher (than recorded rates)," she says, adding the sudden increase in cases is cause for concern because two decades ago there were no known cases of the disease in natives.

"We didn't see (any diabetes in natives) before 1983, so you're going from a point of zero," she says.

Another continuing problem is that many Type 2 cases in native children are going undetected or are misdiagnosed, Dean says.

Bertha Flett, a registered nurse from Cross Lake, describes the experience of her daughter, who was misdiagnosed with Type 1 diabetes at the age of eight in 1981. In 1995, her daughter went blind (she was 22), and developed end-stage renal disease (kidney failure), Flett told the conference.

"She always says 'Now I'm in dialysis, I'm going to die,'" Flett says.

Dean, who says her discovery was initially greeted with skepticism by the medical community, says the few physicians who *do* make an accurate diagnosis are unsure how to treat the problem in children.

Adult medications cannot be prescribed in most cases, and no research exists to suggest which drugs would be effective.

Flett is now working with aboriginal children in Manitoba to try to develop better prevention and treatment strategies.

Dean's findings are only part of the picture.

There is mounting evidence that native diabetics suffer more complications and more severe complications than non-native diabetics.

Young writes that, based on Manitoba hospital data, "compared with non-aboriginal patients, aboriginal patients with diabetes have higher rates of hospital separations and re-admissions and longer stays, both in Winnipeg and non-urban areas."

He added that in Kahnawake First Nation in Quebec, more than 60 per cent of patients with diabetes were found to have at least one major complication. What's worse, the number of complications among native diabetics can be expected to increase due to the onset of native diabetes in an increasingly younger age group.

These facts are made even more disturbing by a 1997 projection study by two of Dean's Manitoba colleagues.

The first projection study on native diabetes focused on Manitoba data, but is roughly applicable to natives across the country, said one of the study's co-authors, epidemiologist Chris Green.

"We have an epidemic of diabetes that's just getting going," Green says of his findings. "There's going to be a real need for services to deal with complications to minimize the impact."

Green's report, co-authored by Dr. James Blanchard, chief epidemiologist for Manitoba, revealed that native diabetes rates in Manitoba are expected to triple by the year 2016. That represents an increase from roughly 6,700 people or 16 per cent of the aboriginal population in 1997 to 20,000 people or 27 per cent by 2016. A similar study has not yet been conducted in other provinces because their hospital patient data does not indicate whether a patient is native or non-native. However, a data-collecting process initiated by Health Canada this spring will eventually gather the same type of data across the country, Harris says.

Green's study, which was jointly funded by Health Canada and the Assembly of Manitoba Chiefs, drew on data going back to 1983 for registered First Nations adults over 25. It was based upon the current number of cases, the number of new cases since 1991, and an expected 50 per cent increase in the native population over 20 years.

Green added that because many native people have diabetes without knowing it, the actual number of people in Manitoba now and in the future will be higher than his own projections.

"The overall figures are an understatement, because many people don't seek medical attention until complications set in."

Although comparable statistics from across Canada which could be subjected to Green's methodology are still years away, last year Green used his findings to do a rough projection for diabetes nation-wide.

Based on the current population of natives in Canada and the projected increase in that population, the cost of treating native diabetes in Canada could skyrocket to well above half a billion dollars in the coming decades, Green says. In Manitoba alone, direct care costs -- including hospitalization, doctors' fees, home care and dialysis for native diabetics over 20 -- will rise to \$96.9 million per year by 2025, Green says, from \$22.4 million in 1995. Across Canada, Green says the costs will rise to about \$524 million according to an estimate based upon his study. But even that figure is low, he adds, and would jump substantially when the high number of undiagnosed diabetics is factored in.

In addition, other complications including blindness, heart disease and amputation will drive up the costs --both human and financial --even further.

Taken with Green's projections, the example of the Pima of Arizona should be enough to prompt Canadian policy experts --both native and non-native -- into action, says Dr. Peter Bennett of the American Indian Health Service. It's a lesson the American government learned the hard way, he adds.

In 1965, the Pima Indians had the world's highest known rate of Type 2 diabetes --26 per cent-- the same as Sandy Lake just five years ago.

Today, the Pima rate has ballooned to 50 per cent of the entire population.

Despite that early warning, the U.S. National Health Service waited until 1980 to set up a native diabetes control program -- primary care for those diagnosed with the illness. A concerted prevention and education effort did not come until 1994, he says. Today, diabetes is costing the 9,000-member reservation, which is called the Gila-River Pima, about \$100 million (U.S.) a year, by conservative estimates, Bennett says.

Prevention projects might have stopped that, he adds. In 1994, the U.S. National Institutes of Health launched the world's largest diabetes prevention project, which includes three tribes hardest hit by the disease: the Pima, the Zuni and the Navajo, the latter two from New Mexico. The program is designed to put a dent in those numbers with intensive lifestyle training and aggressive

use of the latest medication, Bennett says.

While the results of the \$150-million (U.S.) project won't be known for another two years, the number of new cases among the Pima has levelled off since 1994. That, Bennett says, is at least partly due to prevention.

The Pima have also installed modern fitness centres over the past three years, using funds from recently-built casinos. In Sandy Lake and other native communities across Canada, such funds are limited, but the need for such aggressive solutions is just as strong, Stewart Harris said in a recent interview. The disease, he says, needs to be prevented in younger people if the skyrocketing rates are to be slowed.

Tragically, those who already have the disease now have pressing needs as well.

"Diabetes has arrived (in native communities)," Harris says.

"Now we're going to move into the era of complications, and it's going to be devastating."

Sadly, Canadian policy makers have yet to respond to the example of the Pima, or to learn the lessons their experience can teach. That is despite nearly two decades of warning signs, researchers point out. As a result, much is thought and said about what needs to be done to address the problem

nationally, while little of that advice has transpired into practice in the nearly four years since the San Diego conference took place.

However, one thing has become clear, experts say. If native diabetes is to be tackled, the tools to do it must be culturally attuned to the communities involved. If not, prevention and intervention measures are bound to fail.

In his overview for the Canadian Association Medical Journal, Young makes several recommendations. Education projects aren't enough, he argues. A "supportive environment conducive to behavioral change" is also key, he says.

Respect for culture features prominently in Sandy Lake's program, as well as recent projects in Kahnawake and B.C.'s Okanagan First Nation, he says.

These participatory research projects, with intervention sites in schools, stores and the community at large, respect aboriginal culture, traditions and learning styles, and have achieved high community support and awareness. A project focusing on physical activity and directed at gestational diabetes was initiated in Saskatoon.

But it's not only prevention and research programs that need to be culturally specific, he adds. Clinical care and education need to be geared to the needs of each particular community: "Health care professionals who serve aboriginal people need to adapt their treatment plans and education programs to the culture and social environment of their patients."

While each aboriginal grouping in Canada is distinct according to language, culture and tribal origins, or any combination of those factors, some concepts are universal Young notes, and should be used by workers. The concept of balance is central to aboriginal understanding of disease, he says, and can be used along with specific local myths and legends to educate people about the illness.

Young also notes that obesity is a cultural concept, and that some cultures have differing views of what the terms, "weight" and "overweight," mean, and what they signify with respect to health.

Even the country's 1998 clinical practice guidelines encourage physicians to understand cultural issues if they hope to treat native diabetes. All native people over 45 should be screened for diabetes every three years, or more frequently in higher risk natives, the guidelines stipulate.

That is not currently the case.

Prevention programs must also respect and be sensitive to language issues, as many native diabetics do not speak English, or do not speak it well, the guidelines also note.

In Nova Scotia, a small 1995 study found that ethnographic (culturally determined) factors were essential to understanding the development of diabetes among the Mi'kmaq Indians, and by extension, the best treatment practices.

There, a 25 per cent diabetes rate in native people over 40 is thought to reveal only the tip of the iceberg – further screening could yield numbers comparable to Sandy Lake's. The study posits that higher prevalence of Type 2 diabetes in native communities in the more southern regions of Canada could be caused by "increased acculturation" to Euro-Canadian ways due to greater and longer periods of contact.

The Mi'kmaq, says study author Kim Travers, were among the first in Canada to come into contact with Europeans. In several interviews with members of the Membertou band the history of forced relocation of the Mi'kmaq reveals itself over and over to be a contributing factor to the development of the disease.

Their description of how the forced relocation of Membertou in the 1920s influenced eating and lifestyle provided an example of the influence of policy, specifically land claims, on risk factors for (Type 2 diabetes). Membertou's original location on the banks of the Sydney River was fertile for agriculture and made for easy access to water for fishing as a source of traditional food. The reserve was forcibly relocated away from the river to a swampy area accessible by only one road (and now surrounded by the expanded city) . For the first time, the reserve offered absolutely no opportunity for fishing, hunting or agriculture. People were made totally dependent upon the market for food with the move; they remain so today.

The Membertou experience shows the disease's prevalence in different regions with vastly different traditions than Sandy Lake's, and even without the isolation factor. Travers argues that even though the reserve is located in downtown Sydney, its residents can't always get to, or don't make a point of

driving to, the better-stocked grocery stores in town. People often rely on the less-healthy selection on-reserve:

With respect to food shopping, Membertou Band members have an advantage as the urban location means ready access to supermarkets with variety and lower prices. However...although there is a larger community with two grocery stores within 15 kilometres, such a trip requires access to reliable transportation...The reserve stores stock primarily high turnover foods such as soda pop, candy bars and high-fat snack foods. "The reserve stores stock primarily high turnover foods such as soda pop, candy bars and high-fat snack foods. Fruits and vegetables are notably absent, or if they are available, only in a limited number of canned varieties. Fresh meats are also not available.

The pattern of losing a traditional living from the land –in this case primarily through fishing –is all too familiar. Money was cited as a key obstacle to healthy eating choices:

The expressed lack of access to traditional sources of food and the resulting necessary reliance on store-bought foods is indicative of how money has become a necessary precondition for nourishment and health. Many participants expressed concern about the cost of purchasing nutritious foods on their fixed incomes.

The Membertou band has had no project like that of Sandy Lake to kick-start their reserve store-owners into action. Because Membertou residents had no access to even the minimal training and prevention dollars funnelled into the community through the work of Tina Noon and Rod Fiddler, their solutions to their dilemma to date have been sketchy. But at the time of the study in 1995, they initiated some short-term strategies including convincing reserve store owners to look into stocking

healthier foods at reasonable prices. Elder women in the community were also planning to host "community kitchens" where younger band members would learn to prepare traditional foods while socializing and sharing the cost associated with meal preparation.

Tiny steps such as those taken by Membertou are key in any consideration of a wider initiative to bring strategies to native communities nation-wide. That's because any good prevention and education initiative will be community-driven, says Cam Mustard of the University of Toronto's Public Health Sciences Department.

Mustard spent three and a half years working with the Sioux Valley First Nation outside Brandon, Man. developing nutrition and exercise programs for diabetics at the community's request. From 1991 to 1995/96, Mustard used a \$500,000 grant from the National Health Research and Development Program to work with the Sioux community's and council to develop programs to help diabetics in the reserve's population of 1,500.

While the program funding eventually dried up, and community diabetes rates have continued to rise, strong levels of community participation were achieved, Mustard says. The researchers' findings were key to understanding what may or may not work in other native communities, he says.

Six or seven native communities were funded in a competition set up by the NHRDP, he says.

"I got a phone call from Sioux Valley saying 'We've got a real problem,'" he recalls. "We implemented an incredibly tiny program for the scale of the problem."

Mustard recalls his own incredulity when he arrived at the community nursing station to learn there were no figures on how many residents had diabetes.

"They said, 'we're not really sure,' because (Health Canada) had not directed the nurses to provide diabetes help in nursing stations," he said. "There was no national or regional program on diabetes care."

Despite the community's obvious need for help in treating its already existing group of diabetics, band leaders insisted the researchers focus the bulk of their efforts (and funding) on prevention initiatives.

"The chief and council said, 'Oh no, it has to be prevention,'" Mustard says. "We said it would be hard, and they said, 'We don't care.' The elders said the same thing."

In the tiny, closed community, home visits were the only way to reach the women who were, by and large, in control of the family's food intake.

"The way to get to people who have needs is to go knock on their doors," Mustard said. "Women were targeted because the role stereotypes were clear –they bought the food and cooked the food."

Researchers soon realized that women were more willing than men to take the initiative, Mustard added.

"They were the people who took risks in the community to change household practices," he said. "Women were the people prepared to make changes."

A good 30 per cent of the community relied on traditionally hunted foods like deer and elk, Mustard said.

The grocery store, however, presented many with a challenge to health.

"Everybody was struggling to make sense of what was in the supermarket."

Workers quickly learned that formal cooking classes at the local school for adults would not work. Instead, informal cooking clubs were formed with some of the more gregarious women as leaders.

"The classes were dull, and they failed," he said. "Some of the women were more comfortable when nutrition educators visited. They established relationships of trust and if that worked, there was an invitation to come back sometime."

Meanwhile, the women who felt comfortable with each other would join together to cook in groups, he said.

"The households with diabetics were more willing," he said. By the end of the project, workers were routinely connecting with more than 50

per cent of the reserve's households and had more requests for visits than they could meet, Mustard said.

The physical-activity component of the project was harder to promote, he said, but in the end its success was also dependent upon workers who were sensitive to the tendencies, desires and history of the community. While exercise classes at the local school were sparsely attended, a walking club began to form early on and led to wide-scale participation by more than 25 per cent of the community.

"It was extremely powerful from a number of vantages," he says. "We learned very early on that the community had a low sense of what it was capable of –it was a very marginalized community."

That meant high-activity goals would not work. But when members were asked what kind of activity they liked, many said their traditional form of exercise was walking, he said. People said walking had fallen out of practice – "it just wasn't done", Mustard says –partly because wild dogs in the community were threatening.

"But everybody said, 'Yeah, I love to walk.' So we got 10 or 15 of the bolder characters to do it. Pairs were seen walking in the community.

Soon, there was a large sign in the band office tallying how far they had walked.

Mustard said the physical-activity co-ordinator, along with the other workers and researchers, left the project feeling it had been a success,

having achieved an overall participation rate of 70 per cent. The community has since procured grant funding to keep a member of the original staff working on a primary-prevention agenda including a school program and home visits. Mustard said researchers left with a better estimate of the community's prevalence rate --17 per cent with full-blown diabetes, and five per cent with an early stage of the disease.

But, "people continue to die," he says. "The profile of the disease is higher than when we worked there."

Why does diabetes continue to grow in places like Sioux Valley, where modest prevention programs were employed by a well-organized band and dedicated researchers and community members? The answer, says Mustard, is lack of stable long-term funding. He adds the biggest obstacle to finding national solutions to the native diabetes problem lies in the sporadic funding and lack of long-term vision which allowed important pilot projects like Sioux Valley to fall by the wayside. The lessons those projects could offer to other communities have also been lost along the way, critics have charged.

That's starting to change, Stewart Harris says. In Sandy Lake, funding has been secured for another five years during which researchers will try to record the program's successes in a template for communities across the country, he says. A large part of the funding is coming from a

\$2.5-million grant awarded to Kue Young this spring, to be distributed among projects such as Sandy Lake's in an effort to synthesize findings and develop a strategy for communities from coast to coast.

The funds, which come from Interdisciplinary Health Research Teams (formerly part of the National Health Research Development Program), will also go to the Kahnawake First Nation program in Quebec, Harris said.

"The project is to find out what works and distill it down to what's worked (in both places) because they are completely different communities," he says.

Unlike the Sandy Lake project, which began in the community and moved into the schools, the Kahnawake project began as a school curriculum project which eventually moved into the community, Harris says.

The funding will also develop two key areas of the research, Harris said. A screening protocol will be developed for predicting complications before they take hold, he says. Such indicators are now critical to native communities as the disease continues to strike more people and at younger ages, he says.

"What are the rates and the associated risk factors that can predict who gets the disease?" he says.

The Sandy Lake project also won an \$800,000 grant from the Canadian Institutes of Health Research, which will be used for a follow-up prevalence study to see if the project's education and prevention components have put a dent in the epidemic, he says.

But the funding is still far from enough, even for the relatively tiny needs of Sandy Lake's population of 3,000. The band has not been able to find funds to support the work of Tina Noon and Rod Fiddler, the community's two diabetes workers, even though the two are the backbone of the prevention programs which have been evolving for five years.

"I don't know where they're going to get the funding," Harris says. "Our research dollars are not going to support them."

While communities like Sandy Lake struggle to get funding for projects that other band councils can only dream of developing, Chris Green has continued to probe the underlying causes of the epidemic. While the thrifty gene theory may have gained more credence as the result of the Sandy Lake research, he hastens to add that a purely genetic explanation must be rejected for scientific and political reasons.

Green has spent the four years since his data was first made public studying geographic variability of diabetes in First Nations around the world. His findings cast considerable doubt on the genetic hypothesis as

being the predominant cause of the disease. Instead, socio-economic conditions, including access to food, water, education and wealth, are stronger predictors than any genetic predisposition, he says.

"Being aboriginal isn't really the important risk factor," he says. "It's being poor and disempowered. There's an increasing amount of literature suggesting you can have non-genomic mechanisms that are multi-generational."

That means genes aren't the only health determinants passed from parent to child, Green explains. For example, a high blood sugar level in pregnant women is thought by some researchers to be a risk factor for diabetes which is non-genetic.

"It hard-wires the fetus for later diabetes," he says, "and then if they're in social conditions that promote (diabetes), they are at higher risk."

What's more, social factors have been demonstrated by data collected by Green and others to be a major factor in determining the likelihood of diabetes.

"Unemployment and larger social conditions are more important," he says, adding that after North America's native people, African Americans and American Hispanics have the highest known diabetes rates in the world.

While Green is careful not to dismiss the thrifty-gene theory, saying it has some credence, he cautions that governments may very well use it to escape responsibility in what is, in many respects, still a preventable disease.

"The thrifty gene literature plays an ideological role in absolving governments of responsibility," he says. "It's part of the larger human genome project idea, that somehow if we find these genes we'll be able to do something miraculous. The possibility of finding a single gene (to unlock diabetes) is probably very remote."

Dr. Joe Dooley of the Northern Diabetes Health Network agrees.

"The problem with saying the disease is genetic is you imply that it can't be prevented," he says. "And that's just not true."

Frazier Meekis moves towards his visitor carrying a huge bag of roots and dried leaves, a piece of root brandished in his wrinkled hand.

He pops it into my mouth before I can say no, and I taste the pungent bitterness of the medicinal herb, carefully collected from the bottom of the Severn River by Frazier's wife, Adelaide, who is skilled in traditional healing.

"The white doctor prescribes pills, I have to take them every four hours," says Meekis. "But this I can drink as much as I need, he says,

pointing to a huge aluminum cauldron on the kitchen stove in his tiny house, where the roots boil in water to form a potent tea.

Sitting down on his living room couch next to a Goldstar television and a stack of videotapes, Frazier tells my translator that he eats as little "white man's food" as possible.

"I had fish for lunch," he says. "I've been monitoring my sugar today and in the morning my sugar was down as low as eight."

Frazier, like many elders, treats his diabetes on all fronts, using modern glucometers alongside traditional remedies designed to cleanse and balance the body.

"There's a big change in my life since I was diagnosed," he says, his Brooks sweatshirt and baseball cap contrasting his quiet, thoughtful demeanor.

The thing he hates the most is that his eyesight, failing as a result of the disease, now prevents him from hunting.

"If I could hunt I would be the first one out there," he says, adding that this autumn was the first in which he did not join other residents in moose-hunting season.

"I really get upset when I think about the whole community coming down with diabetes," he says. "What I'm wishing for is that they would find the cause and if they could prevent future generations from having that disease, that would be a very good thing."

Meekis' own remedies, such as the tea, help to cleanse his pancreas he says, but he laments the younger generation's resistance to traditional ways.

"A lot of kids can't even snare a rabbit – what is that?" he asks, adding that he blames the schools. "They have to learn the white man's way and not the traditional way. That's why we're losing the traditional way."

But he also admits that youth just don't seem interested, even when given the opportunity.

"They'll turn their nose up –they don't want to eat that. They only eat fast foods from the store."

Frazier hesitates before explaining why he fears the disease cannot be stopped in Sandy Lake, despite band councillors' best efforts.

"It's very hard for me to answer," he says. "There's lots of times when people start programs up here, and it's not only this program – it doesn't even get off the ground."

The fallibility of programs, dependent as they are on sporadic intermittent funding from far-away governments, hold Sandy Lake's future in the balance, he says. "People are going to try to stop the programs," he says.

CHAPTER V

Politics

Frazier Meekis' distrust of government-funded programs seems well-founded.

Years of no funding at all from the federal government have been supplanted by piecemeal trickles of a year or two here and there. Experts agree that the First Nations desperately need a comprehensive plan to combat diabetes and long-term funding to back it up.

"I remain very angry at the failure of (Health Canada) to deal with this problem," says Cam Mustard, who led the prevention program in Saskatchewan's Sioux Valley First Nation, a program that fizzled down to one part-time worker in the mid-1990s due to lack of funds.

Mustard claims Health Canada has ignored the problem while the epidemic has gathered force. The department – charged with responsibility for native health care under the Indian Act – has not researched how its approximately \$1-billion annual native health budget should be spent, and whether it's sufficient, he says.

"Up until recently they did nothing (for diabetes)," he says. "They did nothing to understand the disease of diabetes or what to do about it."

In particular, he says the department's failure to collect even the most rudimentary data on the epidemic through its nursing stations has led

to an information gap. He says most voters could reject such a performance by voting the party out of office, but native people make up only 3 per cent of the total population -- not enough political clout to change a government.

"The thing that disturbs me the most about (Health Canada) is that in the last 15 years they have spent a huge amount of money, but put no money aside to do intelligence-gathering about what they are doing," he says.

"Any corporation sets aside (research and development) money. Any department sees what's coming at it, and what its response should be. Had (Health Canada) taken even \$50 million, or five per cent of one billion, it would be a small amount of money for a private corporation to spend to ensure its product was good."

Instead, the results have been disastrous, and threaten to become worse as native diabetes continues to go largely unchecked, Mustard says.

"Health Canada didn't spend anything and got caught by a horrible epidemic," he says. "They couldn't have prevented it, but we could be five to six years ahead of where we are now."

New money should be going as much toward prevention as to primary "disease response" for those already suffering from the illness, Mustard adds.

In November, 2000 when Allan Rock announced \$58 million for native diabetes under the Aboriginal Diabetes Initiative, the hope was that some communities with established programs, like Sandy Lake, would benefit. That has not been the case, sources say. Workers like Tina Noon and Rod Fiddler – front-line staff working to keep the disease at bay – wonder if they will be able to procure funding for one more year. Because the community's program is not run by the band council, but through a relationship with outside scientists, it is not eligible for funds. Sandy Lake is left to weave its way through the maze of grant applications, hoping for a grant here, a top-up there that might carry the workers through the next season.

In the meantime, researchers like Zinman and Harris have managed to generate more than \$1 million for their efforts, mainly through funding designed to go to medical researchers. Harris notes the inequity that, as a southern scientist, he has received funding while front-line community workers, whose efforts have arguably a more direct impact on the community, go without funding.

Programs like those in Sioux Valley and Sandy Lake are at a continual risk of falling through the bureaucratic and political cracks, Harris argues, even with the \$58 million now trickling down.

In a spring, 2000 interview, Mustard noted that if the money is evenly distributed among communities with no regard to how prepared

they are, little good will result. In fact, after administrative costs of evaluating applications and distributing the money, \$58 million divided among the country's some 800 native reserves works out to less than \$20,000 per community, Zinman says.

Mustard argued for a better mode of distribution.

"Some part of the \$58 million should be allocated, not on a distributional justice basis, but to make sure there are opportunities to do excellent work in the hope we will learn what to do with the next round of money."

But that didn't happen, according to a source close to the government's funding plan, who declined to be named for fear of recrimination.

The source said that the funding has worked out to be too little, too late. This is as much a failure of native politics, with leaders insisting that the money going only to band councils, as it is of the bureaucratic red tape requirements of federal funding, the source said. Also, the process for evaluating community proposals has not been rigorous enough, the source said, leaving communities with functioning or semi-functioning prevention programs in the lurch. The source said both native and federal politics are to blame.

“Everything we had hoped to avoid, certainly in Ontario, is happening,” the source said. “It’s not enough (money) for any particular community.”

That approach has stood in the way of the solution advocated by most epidemiologists, including Mustard.

Several pilot projects should be underway, nation-wide, to find “best practices” which can then be boiled down into a national strategy, he says.

“It sounds like (more) research,” he acknowledges, suggesting about 20 to 30 demonstration projects be set up across the country “to test out novel ways of doing things, and to see if we could learn from sharing that information.”

Instead, a handful of other potentially life-saving programs have died off, Mustard said. Sandy Lake and Kahnawake First Nation near Montreal are the only remaining Canadian native communities with anything approaching a comprehensive diabetes strategy. Places like the Okanagan First Nation in B.C. have seen their attempts fail for lack of funds.

In the meantime, Harris and Zinman are using dollars procured from medical research bodies to do their own best-practices study – a comparison study between the diabetes programs at Sandy Lake and Kahnawake. A yet-to-be-determined community will be chosen for a seed project that will implement the best aspects of the two programs, Harris said. Those medical research dollars are now paying for the crucial public

health work some would say is the responsibility of Health Canada under its fiduciary obligation to native people.

It is impossible to discuss native diabetes and politics without discussing poverty.

As Chris Green argues, and his research seems to bear out, the key determinant of diabetes across cultures is socio-economic status, not genetics. While Green allows that genetics do play a role – and he acknowledges that Zinman, Harris and Hegele have made important genetic discoveries in Sandy Lake – he is quick to point out the political implications that such discoveries could have, particularly among governments already failing to do their part.

To say something is genetic in our culture often suggests that it is not preventable and, as Joe Dooley of the Northern Ontario Diabetes Network points out, that is simply not the case.

Poverty, however complex, can be changed. That is the tack taken by many native leaders, most recently and vocally by Stan Beardy, grand chief of Nishnawbe-Aski Nation in Thunder Bay, which represents 49 communities in northern Ontario and by Matthew Coon Come, national chief of the Assembly of First Nations.

While the socio-economic status of Canadian native people varies geographically and between native communities, by and large it has been documented to be far below the average Canadian's.

The Sioux Lookout Zone contains one of the poorest clusters of reserves in Canada. Its 80 to 90 per cent unemployment rate only hints at the kinds of conditions in which people live. For example, routine overcrowding of houses in places like the Mishkeegogamang (New Osnaburgh) and Lac Seul reserves near Sioux Lookout has led to outbreaks of tuberculosis in recent years.

The lack of a steady income in most homes means many children go to school hungry, and in places like Sandy Lake — a relatively prosperous reserve by Northern Ontario standards — that problem has led educators to institute a breakfast program in the schools not unlike those offered to inner-city children in large cities.

Homes, which often have eight to 10 family members crammed into a two- or three-room structure, vary widely, from trim log cabins built recently by the band to drafty shacks with no running water and badly in need of repair. Many are fire-traps, and several homes burn down each year, too often taking the occupants with them.

The grim fact of poverty finds various forms of social expression in the North. In Pikangikum, a community of 2,000 to the south of Sandy Lake, poverty has contributed to the highest known suicide rate in the

world, according to international experts. There, young children play on sharp-edged pieces of aluminum wainscoting, while their older siblings -- youths as young as 13 -- routinely try to hang themselves. Eight girls hanged themselves there last year, many of them 13 and 14. Experts also say that a closed school and infrastructure problems have raised the degree of despair and helplessness, thus contributing to the suicide epidemic. People have few financial resources and little or no opportunity to improve their lots, either individually or collectively.

While the suicide epidemic is tragic in its scope, encompassing most northwestern Ontario reserves, poverty also has a more subtle impact on health. As Green argues, it is the underlying reason native diabetes hit the roof and kept on climbing. This happens in many ways: by preventing basic public awareness and education about diabetes, by keeping overall education levels down, by preventing many healthy recreational activities and by reducing people's motivation to attain and maintain good health.

At a basic level, poverty prevents people from eating well. Food costs in the north are far higher than in southern communities due to high air transport costs. Surprisingly, those prices have already been subsidized by the federal government's food mail program. The program, which has been criticized for being ineffective in reducing food costs, subsidizes Canada Post for mailing food to communities.

In Sandy Lake, it's easier to eat junk food than healthier alternatives, as we saw in Chapter 3. In November and December of 1999, apples sold for \$4.71 a kilogram, and kiwis were \$1.05 each. By contrast, a box of Kraft Dinner cost \$1.65. A 500-gram tin of cookies cost \$3.99. Canned meat (Klik) sold for \$1.10 a can. Fresh meat was often not available.

In a 1990 report following a review of the food mail program, the authors stressed that subsidizing northern food costs is a social necessity in communities wracked by poverty. They noted the health consequences of high food prices – especially on fresh, perishable items – in the North:

“Reduced consumption of imported nutritious perishable food, at a time when reduced access to country food and concern for its safety are limiting its use, would seriously jeopardize the nutritional status and health of northern residents. The impact would be greatest on infants, children and pregnant women.”

Those effects have already taken hold, say native leaders critical of the air mail program.

Stan Beardy is a compact, intense man with quick, darting eyes and features common to his home community of Muskrat Dam First Nation in the Sioux Lookout Zone.

He's made his way into the grand chief's chair at Nishnawbe-Aski Nation in Thunder Bay, in no small measure due to his own personal determination.

When it comes to the woes facing Northern Ontario reserves, Beardy has a one-track message: economic development.

That means, in a region known for its largely untouched boreal forests and rich mineral and gold deposits, First Nations need to lay claim to what Beardy considers their right—the land which, under treaties signed early this century, nominally belongs to First Nations as part of their traditional hunting and fishing territories.

Until First Nations develop a sustainable economic base of their own, with the jobs and sense of pride and well-being which accompany such control of a land and its resources, they have little hope of resolving their health and social problems, Beardy argues.

Beardy and others know the battle will not be easy. Matthew Coon Come, the latest and perhaps most independent- ever leader of the politically-beleaguered Assembly of First Nations, has been a vocal advocate of First Nations seizing what he considers to be their right and proper share of the land and resources which were taken from them centuries ago by the Europeans. His style is quite different from the predecessor he defeated in the last AFN election, Phil Fontaine, who took

a conciliatory stance with Indian Affairs and had a style characterized as too complacent by many leaders.

But the stronger, more outspoken proponents of native self-determination, such as Beardy and Coon Come, do not seem to have made much headway with the Liberal government under Jean Chretien. The reasons for this are complex, but the effect is uniform: sluggish or damaging government responses to native communities faced with crises, and heavy-handed approaches to native standoffs such as the ongoing lobster-fishing dispute at Burnt Church, N.B. There, federal fisheries officers have engaged in several violent clashes with native fishermen who argue their rights to fish had been ratified by a recent Supreme Court ruling (1999, Marshall). But non-native fishers in New Brunswick uniformly say the government is “too soft” on the Indians and should stop subsidizing their fishing activities.

In another recent conflict, Indian Affairs Minister Robert Nault gave control of Pikangikum’s finances over to a third-party manager in London, Ont. The move set a precedent because the band, unlike other communities faced with third-party management, had never run a deficit. During different interviews, Nault has variously cited “social” and “financial management” reasons for his decision.

The political context of the decision in Pikangikum is Nault’s vow to open up the Indian Act to review in the fall of 2001, despite the opposition

of Coon Come and many other native leaders. (It is interesting to note that, in the past, native leaders have been the most vocal critics of the Indian Act and have repeatedly called for the dissolution of the federal department responsible for administering it.) As this is written, a 30-day moratorium had interrupted Nault's "consultations" with native communities about the Act.

But the decision to take over finances in Pikangikum has been decried by native leaders as a line in the sand -- a symptom of Ottawa's growing refusal to acknowledge native treaty and constitutional rights, or to negotiate in good faith. There is a general fear among native leaders that the Department of Indian Affairs will deal with all communities in a similar way.

But at the same time, native leaders have a sad record of mismanagement of funds and acting in their own self-interest. Salaries over the hundred-thousand-dollar level are still too common on reserves where poverty rules. Many people in the north complain of a corrupt native upper class which is pocketing crucial development dollars for personal use.

One of the key features of native-federal political relations in recent years is the way in which the rhetoric of self-determination has been used and misused by the federal government and also by native governments.

Such rhetoric has played a key role in letting decisions about native health care grind to a halt. It also shapes the battle now underway by communities struggling to take control of their own health-care funding through a process known as “transfer.” Many communities are still ill-equipped to take over the administration of health care.

Even when they are equipped, many communities are leery of the language used by Health Canada and the Department of Indian Affairs in promoting such transfer agreements. Often, native leaders say, both departments will use the language of self-determination to justify insufficient funding of programs. Communities are told they have to choose, based upon their newly-granted control over health decisions, which items are a priority to them.

Native leaders say such language is often used to absolve the departments of their responsibility to provide sufficient funding and guidance during the transfer period and after. When asked by the media, for example, why a community does not have a particular heart-starting device, Health Canada officials respond that it is up to the community to decide what its health priorities are. That answer can often be deceptive, given that communities are often faced with impossible choices about where to direct their funds. they might, for example, have to choose between buying the heart attack equipment and providing immunization to children.

The reverse is also true: native governments sometimes manipulate the language of self-determination as well. They will argue that only they can determine how money should be spent, instead of demonstrating that their funds are reaching the intended targets in their communities. They sometimes use self-determination as a stall tactic when direct and decisive action is needed.

Accountability measures should be in place for spending and native leaders should be held to account for their actions; however sufficient funds must also be granted to provide services at a level expected in the rest of the country. Native health care standards are still far below the norm.

Transfer is widely viewed by both native and non-native leaders as necessary to getting health services up to standard and bridging what experts call an appalling gap between native and non-native health care. Under current health care conditions, chronic diseases like diabetes are, of necessity, often placed on the back burner to deal with more pressing emergencies like heart attacks and trauma patients. That is, until diabetes reaches the stage of causing heart attacks, kidney failure and the like.

Poor health care is standard for both remote and non-remote native communities, as Mustard says in describing the Sioux Valley reserve, located just 50 kilometres down the TransCanada Highway from Brandon, Manitoba.

“These people had every reasonable opportunity to be getting diabetes care which was as good as that of a non-native person, and they simply weren't,” he says.

Nowhere is the disparity greater than in Ontario's northwest, which for years has been a system in collapse. A closer look at the politics of health care in that region will help to delineate the context in which native diabetes must be addressed nation-wide. It goes a long way to explaining just how the epidemic continues to go largely unchecked in Canada's native population.

Harry Meekis, Sandy Lake's maverick deputy chief, says his community had four full-time permanent nurses in 1999, and that was a high point, even though the community needs 11 to be fully staffed. The summer before, the nursing station staff went down to two nurses and the station was closed by Health Canada for several months, he says. Emergencies only were seen and flown out, leaving the community of 2,000 with no primary health care.

While a shortage of medical staff is nothing new to northern reserves, a recent series of acute shortages in northwestern Ontario has damaged an already understaffed system, native leaders and medical officers of health have said over the past two years.

"After a certain point, what is enough?" Meekis says. "The communities want better services, but that's not happening. The level of care is nowhere near what's happening elsewhere."

Despite Meekis's protestations about Health Canada and the provision of nurses, local band politics has often played a role in keeping or driving nurses out.

For example, in the neighbouring Pikangikum community, nurses have been frequently "BCR'd" or banned from the community by what's called a "band council resolution." Frequently provoked by the nurse doing something he or she feels is required by standards of professional conduct, such as prescribing birth control pills to someone who is being sexually abused, the band council resolution has been known to discourage other nurses from taking jobs in certain communities. Some nurses refuse to cooperate with band council rules which go against their own personal convictions.

More broadly, fighting between communities in the Sioux Lookout Zone has at times contributed to low medical staffing because of the instability it generates. Currently, a dispute among doctors which has been fed by rivalries among tribal councils, has cast a pall over practice in the entire region, making it less attractive to southern doctors. Uncertainty about whether a signed deal to build a new amalgamated hospital will go

through, and about who is administering health care services in the region, have added to the uncertainty for both doctors and nurses.

Remote health care depends heavily on the skills and abilities of the outpost nurse, who performs a role more complex than urban nurses and even many physicians.

There are no doctors in Sandy Lake. Doctors from the Sioux Lookout Zone Hospital now visit twice a month, but that service has also been disrupted recently. Nurses must cope with the multiple challenges of emergency cases, infectious diseases, language barriers, interfering community leaders, remote living conditions and grueling call schedules, all in a region with one of the highest suicide rates in the world.

Anna Moller, now a nurse practitioner at a community health center in Barrie, Ont., worked as an outpost nurse in the North from 1985 to 1997, and was Sandy Lake's nurse-in-charge from 1990 to 1993.

Moller recalls the fight she had to put up against Health Canada bureaucrats just to keep a basic piece of cardiac lifesaving equipment which is still not available in northern Manitoba reserves, even though shopping malls and golf clubs now have the inexpensive device.

It took until this year for 16 reserves in the Sioux Lookout Zone to get cardiac defibrillators installed in their nursing stations. The \$3,000 piece of equipment uses electric paddles to jump-start the heart. It's a vital

piece of equipment in places where the nearest hospital is hundreds of kilometres away, there is no road out, and the diabetes rate is causing a rapidly increasing number of heart failures.

“Seven years ago, I watched diabetics die (of diabetes-related heart attacks) right in front of me because defibrillators weren’t available in Health Canada nursing stations,” Moller says.

The workload of outpost nurses has grown intolerable in recent years, Moller adds.

“You are responsible for all the health care – continuity of care for chronic disease, acute care for emergencies, and public health, which includes prenatal care, immunization, ongoing care for the chronically ill,” she says. “It’s a route to burnout, and if you don’t have the team to support you, you’re sunk.”

Since she left the North in 1997, Moller says there has been a dramatic decrease in the quality of care as the number of experienced nurses has dropped and Health Canada has tried to fill the gap with short-term contracts and temporary placements.

Many replacement nurses are unprepared for the challenges.

“If you get this poor, green nurse with six months’ experience in a southern cardiac unit, how are they going to do looking after prenatal cases or someone hemorrhaging from a snowmobile accident, or a child

with a respiratory illness? It can be pretty scary when you have a child who can hardly breathe and the person in charge doesn't know what to do."

Short-term nurses also spell disaster for long-term care, Moller says. Basic services like chronic care for diabetics, mental-health counseling and immunization have fallen dangerously below standard.

Nursing in northern Ontario has become so compromised that one medical officer of health said he was beginning to see the cracks.

"Immunization rates are low and falling in many First Nations, and it's not the nurses' fault – they're swamped," said Dr. Pete Sarsfield, medical officer of health for the Kenora-Rainy River district, in an April 2000 interview.

Sarsfield, who served as acting public health officer in the Sioux Lookout Zone until July 1998, says it's only a matter of time before an outbreak of an infectious disease kills unimmunized children in the north.

"It's not just 'if,' but 'when,'" he said. "In some communities where the rates are very low, pertussis (whooping cough) and measles are inevitable."

In December 2000, several cases of whooping cough cropped up in a group of unimmunized and partially-immunized children in Pikangikum. Three children, ranging in age from a few weeks to two years, were flown to Winnipeg's Health Sciences Centre with severe cases of the illness, says Dr. William de Groot, a pediatrician who has worked in the North for

25 years. While modern medicine has greatly reduced mortality rates from infectious diseases, the North is facing a potentially huge problem if immunization does not pick up, de Groot said.

Officials at Health Canada confirmed there have been cases of whooping cough in infants in the region. James Adams, acting Sioux Lookout Zone director for the department, said there were five confirmed cases of pertussis between October and January 1999. Nursing follow-ups were done, but Adams said there was no region-wide problem. He acknowledged that an internal report conducted by Health Canada found immunization rates too low, but blamed the findings on "a data-entry problem."

"When people went back and checked, they found people had been immunized, but it wasn't recorded," he said.

Other stark examples of a system in collapse have started to emerge, Moller says. In one community where she still has close ties, a woman in her twenties, with a post-natal infection, did not receive a prompt diagnosis. The infection raged out of control, and the woman was finally flown out to a hospital where doctors amputated all four limbs in order to save her life. The nurses involved in the case were unable to speak on the record for fear of losing their jobs. Moller says that fear, combined with the isolation of remote nursing stations, is keeping many such stories from being told.

"If you saw that down here (in southern Ontario) would that not have hit the front page of the newspaper?" she asks.. "That woman will never be able to cuddle that baby."

A working group struck by Health Minister Allan Rock in June of 2000 has been trying to find solutions to the crisis in the Sioux Lookout Zone. The situation seemed to have reached its nadir in April 1999, when a group of chiefs held a hunger strike at the Sioux Lookout Zone Hospital, a small two-storey building which had been closed since July 1998 due to a doctor shortage.

Administrators at the hospital had managed to attract a full staff of 22 doctors -- the highest number ever -- in the winter of 1997-98. But in April 1998, the University of Toronto terminated its contract with Health Canada to recruit and employ doctors for the area. That triggered a landslide of departures, as doctors were asked to work without a contract for several months.

McMaster University finally picked up the contract in November 1998. The number of full-time doctors has slowly improved, and now stands at nine, which is still less than half the number four years ago. Several chiefs, including Vernon Morris of Muskrat Dam, questioned Health Canada's slow response to the warning signs, saying the

department waited too long, after U of T pulled out, before recruiting new doctors.

Sarsfield says the fact the Sioux Lookout Zone has had no full-time medical officer of health for more than two years is a sign of long-term mismanagement.

"This is not good," Sarsfield says. "It's very, very dangerous."

While the Pima of Arizona have had 16 dialysis machines since 1985, some northern Manitoba bands have had to build houses in Winnipeg for the families of dialysis patients who must accompany their relatives down for lengthy, often heart-rending treatment.

Mustard says that it's a sign that, despite the Canadian government's reputation for treating its native people better than the U.S., it is not always the case.

"For at least the last eight or nine years, the Indian Health Service has had a diabetes-control program," he says.

"Each native person must have a standard of care no different than the Canadian Diabetes Association has for (Canadians)," he says.

"It's a very impressive system."

The service ensures that those native people diagnosed with diabetes will be sought out for ongoing follow-up care – something

unheard of in Canada, Mustard says, where the national health department has yet to do basic screening for the illness among natives.

The politics of native diabetes is driven by money.

According to Chris Green, a conservative estimate places the annual cost of primary care for native diabetics at above half a billion dollars by 2025. That figure could double when undiagnosed cases are included. Diabetes would thus eat up the entire \$1-billion annual budget for native health care.

In 1998, two years after the Sandy Lake study was completed, experts commissioned by Health Canada to devise a national policy came up with three recommendations:

- access to prevention programs,
- better treatment and health care, and
- better surveillance and research

Harris says some of those goals are starting to be addressed. A plan is in place, if not underway, to start gathering national statistics on the disease, for a national projection study using Green and Blanchard's methods. The data will be gathered under an Aboriginal Diabetes Surveillance System, which is an adjunct of the new Health Canada National Diabetes Surveillance System. An aboriginal coordinator has recently been hired.

Health Canada has also begun to give Aboriginal Diabetes Initiative funding to the flagging National Aboriginal Diabetes Association, which has waned in scope over the last several years.

But in the meantime, both federal and native politics seem to be more of a hindrance than a help in getting key initiatives off the ground to address the problem. On a national level, diabetes does not figure high on the Assembly of First Nations' list of priorities – possibly because it is less pressing than recent political crises. It is also less visible, and therefore less marketable as a platform issue.

Local band and tribal councils such as those in the Sioux Lookout Zone have also proven to be ineffective in mobilizing and sharing resources. Given Sandy Lake's close proximity to several reserves, more information-sharing would be an obvious course of action between communities. Yet, the Zone communities, like many others, remain islands unto themselves, separated by long-standing political divisions as well as a divide-and-conquer approach by some federal politicians.

Epidemiologist Jeff Reading contends that if similar rates of the disease were found in non-native Canada, there would have been instant action.

"There's a major crack in the system," he says. "We know what works and we want to start doing it. Otherwise diabetes is going to involve huge suffering."

He notes the collective cost of doing nothing.

"We're going to be spending billions on this problem in the next 10 to 15 years (in rising health care costs)," he says. "It's pay now, or pay more later."

But in the midst of both federal and native political shortcomings, the epidemic continues to grow. Native health care continues to fall far below the national standard of care. The responses of the elected leaders have not met the human, social and economic challenge of the disease.

CHAPTER VI

New Culture, New Solutions

John McKay sits at his desk, a man in his early thirties who has just taken the job of health director for the community. He's doing what the community needs, he says.

On the floor beside his desk lies a pair of moccasins made of blue denim, with a pair of beaded guitars on the toes. He plays guitar in his spare time, he explains.

McKay's youth qualifies him to deal with health in a community where about 75 per cent of the population is under 30. Sandy Lake is not unique in this regard – native communities across Canada have a similar demographic.

McKay realizes he is in an age group that immediately precedes a massive challenge to policy makers and health planners. The mountain of people now under thirty in native communities across Canada – the majority under the age of 10 – creates special challenges for native health. Unlike the mainstream baby boomers who are now middle-aged, the native baby boom is just learning how to walk and talk. They will hit their stride in 20 years. The demographic shift is factored into projection studies like Green's, which show native diabetes could cost a billion dollars

annually by 2025 – the entire amount now allotted to native health care in Canada.

With his feathery hair and wire-rimmed glasses, McKay looks a bit like what he is: a philosopher, a community sage. He talks of the challenges facing the young people of Sandy Lake. The past is gone, he says, and yet vestiges of it must be preserved for their health and well-being – physical, social, spiritual.

But McKay is also a realist.

“I can’t imagine living off the land the way our grandparents did. Realistically, no,” he says.

“For our generation and the generation coming we’re in a transition, we’re right in the middle, right on the bubble.”

He balances his long thin hands on an imaginary scale, one side representing the past, the other the future.

“The more we see things realistically, we’ll see, yes, we’re closely connected with the land and we’ll never go away,” he says. “But the generation to come is going to have to live with different rules.”

Those rules must take into account the irreversible influences that air travel, television, radio and roads have had on Sandy Lake in the last 20 years. They will have to account for change, for modernity, he says.

"Our survival will depend upon becoming part of the mainstream and at the same time keeping close connection to the land through whatever means we have."

McKay's ideas could be a blueprint for the future. Many in the North believe that only a hybrid culture, which incorporates modernity and traditional ways, will allow native people to retain their health, their independence and their cultural uniqueness.

McKay describes an idea of his – a pet project. He'd like to design a three-dimensional computer program that would allow young people to visit the past, to experience the lives of elders only a generation or two ago. The lives of Esther Linklater and Heidi Fiddler, before the white man came.

His biggest regret, he says, is not having the time to write a detailed history of his people. Oral accounts have gone unwritten for millennia, he says.

"We spread our history by word of mouth and sometimes things get lost in the passing on," he says. "We need somebody to sit down and say, 'this is the history, this is what happened.'"

Resting uneasily on the bubble between what was and what is to come, McKay represents a generation with one eye on the past, rushing headlong into the future.

Outsiders call it a nowhere place, but the land breathes its life into the people still. This morning the young men will fan out across the lake on roaring snowmobiles, cutting through the slanted morning sunlight over blinding snow, following Walter Kakepetum across the ice. Away, away, finally they will leave the community behind. The band office, the few winding roads, the low houses clustered close, dwarfed by satellite dishes. It will be difficult in the winter sunlight for the men to recall the webs of darkness on the reserve. They will move, they will stop, they will move again, deeper and deeper into the bush, rebuilding a connection to the land that was always the source of life, the very reason for being, here, in this place.

Walter Kakepetum hasn't forgotten. The 63-year-old elder is training unemployed young people to fish and trap using old wisdom and new equipment. He's trying to stem the tide of loss in Sandy Lake – of bush skills among the young, of the sustaining culture which has been eroded by television, welfare cheques and change. He grew up a trapper before the reserve began to hem people in, before they became separated from the land by a "solution" imposed by outsiders.

"Nineteen six-the-four."

Walter declares the date when his two-year stint as Sandy Lake chief ended, along with his political aspirations. After helping to build and run the local airport for the Ministry of Transportation back in the 1970s, he

turned to being an entrepreneur, running his own store, sawmill and gas pump. He's a compact, wiry man with curly greying hair sprouting out beneath a Toronto Maple Leafs cap. He speaks in a militant half-shout that masks his gentler, joking nature. Walter is a man who likes to work, and he says he has no patience for the slow way things get done – or don't get done – in the political world.

The band councillors who recruited this half-Ojibwa-Cree, half-Scottish rebel poke fun at his age, calling him "sort of an elder." But they respect him because when he turned away from politics he turned toward the land. Now, he will teach the young men and a few women something that once seemed to come as naturally as breathing.

This morning at 9 a.m. while the councillors and band employees are shuffling out of their boots at the band office, a blue building with fluorescent lights and fax machines, Walter and the trappers meet at the bunkhouse.

A sprawling expanse filled with beds, showers and a camp-sized kitchen, the bunkhouse is usually home to visiting workers in the summer. In winter, which stretches from September or October to May or even June, it stands empty as construction contracts grind to a halt.

The air fills with nervous energy as the trappers arrive on skidoos and clomp in the door, shedding heavy boots and jackets as they come. Many have never trapped before in their life. Many of their parents went to

residential schools and had no bush skills to pass on. For some of them, trapping is a distant memory – something they watched their grandparents do once, long ago.

The men gather around a stainless steel coffee urn, or lean against tables set along one wall, trading jokes and laughing as the sunlight slants in through the bunkhouse window. Talk veers from hockey – the rink hasn't been flooded yet, will the Chiefs and the Wildcats make the Northern Bands finals this year? – to how Fraser Meekis nailed his skidoo back together one time, after it caught fire and melted.

"How long is your underwear?" asks Fraser, sporting a backwards ball cap. He leans toward me in mock seduction as the others laugh.

"Down to my ankle," I answer and Fraser, leaning over to look, spills his coffee on the floor. The others roar: this will be the joke of the day.

The trappers have all been on unemployment insurance, which means they've all had work in recent years, unlike most of the community's unemployed who rely on welfare to get by. But their insurance has run out, making them eligible for the six-week course. Four women were also planning to take the course but they backed out at the last minute, Walter says.

While the others joke, Troy Kakepetum stands mesmerized before the centre table where Walter is busy laying out yesterday's catch. Looking deeply at the animals, he strokes his goatee.

"Do you ever feel sorry for them?" I ask.

"Sometimes," he replies. "Especially the small ones."

He holds up a marten, a sleek reddish animal like a weasel, by the tail, then puts it down again.

At the age of 34, this is Troy's first time learning how to trap and fish. He says he loves being out in the bush. He plans to trap and fish to supplement his family's diet, because he says wild foods are healthier than much of what he can get at the Northern Store.

"You get stronger with (traditional food)," he says. "Trapping gets you outside, and it's good for you that way."

Absolom Kakekayash, one of the older men in the group, stands silent as a pillar in the corner of the room. He knows how to trap, but not with the new more humane equipment known as conibear traps, which kill the animal instantly. That's what he's here to learn. He is a burly man, and wears tinted glasses and a grey fur hat that make him look uncomfortable indoors.

Bernie Crow writes in a spiral-bound notebook. Instead of notes on algebra or Canadian literature, he's drawn diagrams of different animals lying on their backs, their legs stretched out. Below each, he has written skinning instructions: "1. Cut skin at rear paw...". He's also marked down the animals' names in Oji-Cree: "marten – wabisheshe;" "rabbit – waboose;" "otter – ningwk;" "large beaver – kitchi amik."

At the table, Walter declares he likes to eat beaver. Some of the younger men protest loudly. They don't like it, they say.

"We don't need to eat beaver – we aren't starving anymore," says Fraser. "We've got Big Macs now."

There are different forms of starvation. Having enough to eat is no guarantee of health in the community, and Walter knows it. He talks of cultural starvation – how little the younger generation knows of their history on the land.

"Most of the people in this community have never even seen Big Sandy," he says, outraged. Big Sandy Lake is the main part of Sandy Lake. The community is nestled on a smaller inlet in the lake's northwest corner.

Walter knows the land like his hand, needs no map.

"They didn't even know what traps to order," he complains of the band's corporation, which is paying for the course. "I had to use my own beaver traps."

One day, when the group was learning how to skin marten, Walter pulled a wire stripper out of a box and held it up, incredulously. "This is what they sent us," he said, instead of the proper skinning tools that would cut through the fur at the base of the animal's leg, marking the start of a

delicate peeling process that would, with skill, result in a marketable piece of fur.

Diabetes is yet another form of starvation that has gripped Sandy Lake, Walter says. The result of adopting the white man's food is plain, he says: it's made people sick.

Walter is realistic: the clock can't be turned back – modernization is here to stay. He knows the men won't be able to make a living at trapping and fishing, no matter how good they become. Marten pelts sell for about \$20 to \$30 now, compared to \$200 when he was young. Southern mink farms and the anti-fur lobby have lowered the demand considerably. But he hopes the men will use the skills they learn today to supplement their own incomes and diets. Hopefully they will get out on the land more often. Such a hybrid culture may help to offset the craving for Western ways that grow more acute as the outside world continues to dig its way into the North.

Speeding across the lake behind Absolom, his feathery black hair waving in the wind, the air is unbelievably cold – much colder than the actual temperature of minus 12 Celsius. As his speedometer inches closer to 90 kilometres an hour I duck behind him to try to say warm. We head west, the morning sun at our backs, out onto the medium-thick ice toward the West Arm of Sandy Lake.

When we finally stop, we are at the mouth of a creek winding inland – Swan Creek, Walter says, or “Wabezee Zeeb” in his language. There are no wild swans anymore, he says.

“Ho wah,” exclaims Absolom, rising from the Skidoo. It comes from the gut after our cold ride.

The others are here already with their axes, chopping through three or four inches of ice which have formed over holes where they sunk their beaver traps only two days ago. The line of trappers steps along the thin creek ice toward the traps, covered in spruce branches to keep the snow off. To the left stretches a line of large paw prints, the claw marks at the tips of the pads visible in the powder.

“Wolf,” says Walter, gesturing hip height to depict how tall the animal is. Its claw marks are the size of my baby finger.

Troy is pulling branches off one of his traps. When he pulls up the large metal trap, sunk on a thick pole into the water, it's empty. A tiny skewered piece of fish in the center shows it hasn't been touched.

“No – no beaver,” shouts Walter once all the traps are checked.

Troy looks thoughtfully out at the creek as the men retreat to the Ski Doos, to head inland and check the marten and mink traps.

“That's his food,” he murmurs, pointing. I have to look twice to understand what he means: a pile of half-chewed branches, stumps and twigs lying along the shore.

"That's how you know he's there – so you know he's working," Troy says, turning back to the path.

At 10:30 a.m. the Bearskin Air Lines plane from Sioux Lookout sweeps across the limitless blue, heading for the community. The trappers barely glance up before jumping on their machines and starting onto the winding, narrow path through the bush. Branches whack their faces and legs as they burrow deeper, toward some conibear traps set by John Goodman, "Trapper John" as he's jokingly called.

The thin body of a marten is visible hanging from the trap. Humane traps, these conibears are called, because they are designed to kill instantly. But this time, the marten isn't dead – it's caught by the nose.

"He was too quick," says Walter, striding toward the animal. He hits its head three times with the blunt end of the axe, killing it quickly. He then opens the trap – two taut wire frames which spring closed into a deadly grip – and puts on the safety catch. The men have learned that conibear traps are not perfect. Sometimes the animals will still live, and the men are sobered and quiet.

But John is glad, at least that his first trap yielded an animal.

"It's the first one, but it won't be the last one," he says.

After burrowing through the bush, the trail opens out to a ford over a creek. This is where they caught the large otter earlier in the week. But when the trap is pulled up, it's empty and shakes loosely on the muddy pole.

"Who set this trap? Look at how clumsy it is," says Walter. "Give me a couple of poles – look at this – loose."

Walter breaks into a singsong while the men watch his repair job.

"Show me the way..." he intones, pushing the poles into the brackets, anchoring them fast on the mount.

"That's how you miss things – if they're loose, eh?" he says, replacing a piece of fish bait and sinking the trap once again.

It's time for a coffee break, and the men cluster around their Skidoos, pulling metal thermoses out of rucksacks and lighting cigarettes against the cold. A man named Charlie stands wearing wrap-around sunglasses, clutching a cigarette in his weathered hands, the letters F-U-C-K tattooed on his knuckles.

Fraser's skidoo shows the evidence of his hot-rodding. One of the skis is nailed on with the fabled six-inch nail, which is bent to keep it in place. The windshield is cracked, and an entire section is held in place by guy wire.

"I hit a log while cutting wood in the bush," he says by way of explanation.

Leaning against his seat in the large clearing, Walter offers me coffee from his thermos. It's decaf, sweetened with Sugar Twin, he says.

"I can't drink caffeine when I'm diabetic," he explains. "It's hard enough trying to get sleep when you're a diabetic."

Despite a careful diet, Walter's blood sugars have been shooting up lately. A recent angiogram found some heart problems, he tells me as he sips thoughtfully from the thermos cap. His cholesterol is high, and he's on medication now to thin his blood. For an active man, the disease has taken a toll on his lifestyle, he says.

Walter mentions Heidi Fiddler, the fellow Sandy Laker who recently had his foot amputated. Heidi and Walter have a long history fishing together.

"One of his sons married my daughter," he says.

More Skidoos arrive carrying Jackie and John Goodman. In their sled lies another marten, frozen solid in the cold, from one of Jackie's traps.

"It'll go for fifty dollars," Walters says, jumping on his Skidoo.

By the time we hit the winter road and start heading west, the sun is slowly making its way around the horizon, casting its long midwinter shadows. It's much colder here on the open expanse.

During the break, Absolom told me he worked as a guard on the winter road last year, between January and March. A network of snow-packed highways crossing the north, the winter roads provide communities with their only land access for a brief period every winter. The road to Sandy Lake crosses frozen lakes and snakes through the forest from Red Lake, the nearest town, through the North Spirit Lake First Nation a hundred kilometres to the southeast. From Red Lake the drive takes six to seven hours, depending on your load – it's a harrowing ride for a semi truck, but less treacherous than the old route, which wound north from Pickle Lake, a town 300 air miles southeast. The route from Pickle crosses several lakes, and now goes only as far as Keewaywin, a smaller reserve on the south side of Sandy Lake. The road from Red is mainly over land.

There's a popular story in Sandy Lake of an exasperated trucker who took a wrong turn at a junction on his way up from Pickle and ended up in the wrong community, hundreds of kilometers east of his destination. He never drove the winter roads again, the story goes.

Absolom says he's not sure the band will give him a guard job again this year when the road is finished, sometime in January. The job is tough, he says, because you often have to bust your own friends for smuggling liquor and drugs onto the dry reserve.

"It's hard," he says. "You don't want to have to do that."

Absolom told me one of his sons had been arrested for smuggling three mickeys into the community by plane. His voice was matter-of-fact. At \$150 each, the mickeys could have brought a small fortune if he'd been successful. This son became a father himself the day before, Absolom told me, in the same matter-of-fact tone.

Ten minutes into the ride on the winter road, Absolom veers to the side suddenly and stops. With no explanation, he stands up quickly and walks down the bank of the road toward the bush in the bone-crunching cold. Others stop and follow.

In a clearing he kneels before a trap he has constructed in the old way, at the base of a tree, using a complicated structure of twigs and heavy logs to crush the animal who enters its small shrine.

"Somebody put bait there," he says, pulling out the large tail of a fish. An act of kindness by another trapper, but it has been placed in such a way that the lever twig is blocked, disabling the trap.

Trapper John comes up behind Absolom and watches intently. "It's the first time I've seen a trap like that," he says with admiration. "It's pretty neat."

Absolom re-learned the traditional technique recently from a friend. He had been taught it as a boy, but had forgotten, he says. The trap takes

about half an hour to build, but he lays the groundwork months before, driving the supporting stakes into the ground in the summer.

"The ground is nice and soft then, eh, and I get it ready for fall," he says, clearing away some of the branches around the trap, rubbing the fish on the twigs and logs to spread the scent.

Back out on the winter road, Fraser's battered Skidoo has taken another beating. In an uneven area full of potholes in the packed snow, Fraser has broken a ski in half.

"Too many stumps," says Walter, surveying the damage.

The men have threaded a slender branch between the skis to keep them in place, and to keep the broken one on track. "It'll be all right," says Walter.

"Ho wah," the others exclaim driving up, disembarking to examine the machine.

They decide to leave the Skidoo at the side of the road. Fraser will ride in the sled behind Walter for now, rather than risk further damage on the trail to come. He grins devilishly as Walter pulls away in a cloud of exhaust.

Soon the bush opens onto a wide, marsh leading onto the ice of the west arm of the lake. We speed up, the confinement of the trail giving way

to a wild ride along the marsh, driving straight into the low-hanging sun. The trappers snake off to the left and right, blowing powder in their wake. Across the marsh, we reach camp, where the charred remains of last week's fire whisper to the cold and the hungry that warmth and food are on the way.

Within minutes, the men have chain-sawed several logs out of dead trees, and yellow-white spruce smoke is billowing upward, the clean smell of pine filling the grove, clearing the morning away. One of the trappers circles the fire with a video camera, making a record of the day for the trappers to refer to later, in the classroom.

Food is pulled from bags, cans of beans and beef stew, bags of bread, sugar and flour and carefully wrapped packages of cleaned walleye, fresh from yesterday's catch.

For the trappers, the sight of the fish conjures up images of yesterday's trip to the nets, which were strung out 500 metres the lake ice. The men worked quickly, hauling up the net and chiming in with Walter's cheerful cry of "Pickerel! Pickerel!" each time a walleye appeared. They stood in the gleaming slanted sun, five men lining each side of the net, working hard against time with their hooks to pry the fish loose before the nylon web froze into uselessness. Yesterday's work makes the fish taste better today.

"Wine for our dinner," Walter says, pulling a bottle of Italian olive oil out of his bag. The fish is dipped in flour and dropped with the oil into pans, as Fraser watches carefully. It's the first food to disappear from plates.

The men are lined up on logs, facing Walter from the other side of the fire, their figures distorted by the waves of welcome heat, pulling plates from bags and digging into beans. Walter sits on the corner of a log, eating baloney and ketchup sandwiches, waiting for the beans to come his way.

"Water's boiling," he shouts. "Someone wants coffee, someone wants tea – fight over it, fight over it. Flip a coin."

He laughs as people drop two, three teabags into the large quart can boiling on the logs. Indian tea is strong, boiled with the teabags in before it's drunk.

In a final ritual, Walter pulls out a pouch of what he calls "wacky tobacky" and offers it around.

"It looks pretty legal to me," says Troy, passing out rolling papers. Walter says he hasn't smoked in 20 years.

"So you're offering 20-year-old tobacco?" someone asks. Everyone laughs, repeating the joke.

Talk warms up again, veering from lines by native comedians to stories about what so-and-so did last week when he was drunk on home brew.

As stomachs fill, the men grow quiet. The fire lowers to embers, the day shifts perceptibly into afternoon.

Absolom speeds eastward now on the winter road. The day of trapping is over. He knows the road well. He passes the Sandy Lake car dump – a huge expanse of broken-down vehicles with nowhere left to go. A dog looks out the window of one car – it's made the dump into a home.

"I brought my car home to die," a band councillor once joked to me.

The cars that have been accumulating here since the late 1960s are starting to mar the snowy landscape. On the other side of the road, two ravens sit together high in a white birch, beak to beak, ruffling their thick black necks and uttering their deep-throated cries. The trees paint themselves brilliant white against the blue. As the sun slowly makes its way toward the horizon, Absolom shivers and pulls on the throttle.

In the bunkhouse classroom the next day, Harry Meekis, dressed in jeans and a sweatshirt, explains why the young men have the right to hunt anywhere in their treaty area. It wasn't always the case, according to provincial laws. In 1945, the province imposed a trapline system. Before that, trappers had operated on a territories system based on respect for the hunting and trapping grounds staked out by individuals and bands for

generations. Trappers could hunt on each other's territory, as long as they respected the priority of the person whose land they were using.

"With the trapline system came tremendous hardship for native trappers whose boats, nets and equipment were confiscated and burned if the province found them to be trapping off-season," Meekis says.

The law disrupted traditional trapping routines. The attitude toward the land became one of ownership, not stewardship, Meekis says.

In 1986, a landmark Supreme Court case ruled a native trapper had the right to trap on so-called private land, based upon his treaty rights and aboriginal title. The Cheechoo case reaffirmed that native people had the right to trap anywhere in their treaty areas – Treaty 9 in the case of Sandy Lake.

"But let's say you go to Red Lake and put up a snare in someone's yard – chances are you are going to be charged under the (town) bylaw," Meekis says.

"But you can put up snares in Samelin's backyard," jokes John, who has a friend in Red Lake. Everyone laughs, then turns to the questions Harry is reading aloud, preparing them for their written test at the end of the course.

"If you fall through the ice, what do you do?" Harry reads out the question.

"Option three, wait and drown."

Someone at the Ministry of Natural Resources has a sense of humour and the men roar with laughter.

Conclusion

Diabetes may be a disease of poverty fuelled by cultural loss, but most people in Sandy Lake feel that despite the advantages of their pre-European diet and lifestyle, there is no going back. A hybrid culture is here to stay.

The north is, more than anything, a place of apparent contradictions. Several decades of rapid change, from an isolated semi-nomadic way of life to modernization in its various forms have created an evolving culture – one distinctly different from the modern world further south, but borrowing many of its elements. Nowhere is this contradiction more evident than among the reserve's children.

It is not unusual for a teenager to spend several hours a day watching satellite television and eating fast food from the local Chester Fried Chicken outlet – the closest thing the reserve has to a McDonalds. But that same teenager will often also speak Oji-Cree, eat moose meat stew and may also, as we've seen, join a trapline course to re-learn the ways of the land.

The course in and of itself is not a solution, nor is it a return to the past. Rather, it shows how modern ways can incorporate traditional elements – for example, trapping for food and fur – to motivate people to stay well.

Motivation is something which Sandy Lake's residents possess to a greater degree than some of their northern neighbours. The reasons for this are complex, and to some extent, unfathomable. However, generally speaking feelings of disempowerment – be they political, social or economic – contribute to a lack of motivation where personal health is concerned. Sandy Lake has maintained strong leadership for several decades, and that leadership, despite some problems, has no doubt fostered a certain degree of community pride and self-sufficiency. Those traits came into play in getting the diabetes study and program off the ground.

In fact, the Sandy Lake program is unique not just because of its groundbreaking genetic work, but because of its consideration of how cultural factors play a role in people's illness, and particularly, how different generations within the community perceive their own health and illness.

Although diabetes is a chronic illness influenced by personal habits - a "lifestyle" disease in current parlance, it is also a disease whose course and severity can be strongly affected by public policy, and particularly, by public education and health care initiatives. To this extent, politics – federal and native – play a significant role in the epidemic.

Working a few years ago as a reporter for a weekly newspaper in Sioux Lookout, Ont., some of my most memorable conversations took

place between the assignments which saw me running breathlessly from ribbon-cuttings to town council meetings to phoning nearby reserves to get a story. In one discussion, I told a friend – a native person who had worked as a journalist – about my frustration with the federal government. They stonewall constantly, I said to the man, and won't answer questions about their role in things.

While he was sympathetic, the man offered one cautionary phrase that stuck with me.

"The days of government-blaming are over," he said, raising his hand for emphasis. "Make no mistake."

The man's words represent a new line of thought among many Canada's First Nations – a shift toward personal accountability and a refusal to remain the victims of the actions of Europeans and their descendants. To be sure, not all native people have embraced this idea; many remain angry about the abuses of the past.

But I did see manifestations of this attitude in people from various parts of the region when I worked in the North, and again three years later when I visited Sandy Lake, this time as a Toronto Star reporter, in 1999. Here was a reserve facing an epidemic of Type 2 diabetes which would terrify any community, native or non-native, and with few resources and a grim demographic which promised the disease would only get worse.

Yet, the people of Sandy Lake had started to deal with the problem, calling in outside experts and striking a landmark deal. The results were manifest in the Sandy Lake project, and in a renewed motivation in the community to get and stay well. The walking path, the community walks and the trapping course for young people were all signs of a higher degree of motivation than is found on many reserves.

While community motivation is sometimes hard to find, it is also true that governments – both federal and native – are all too ready to shrug off the epidemic as something only the communities can deal with. The explanation given is that native peoples want to set their own agendas for self-determination. This argument is spurious. It suggests that the responsibility for well-being is wholly dependent on individuals or small groups – it evades a larger social and political responsibility.

The language of self-determination now used by native leaders across the country is no substitute for them taking meaningful action on diabetes; it is also no excuse for federal inaction on a public health problem of such large proportions. All citizens of this country deserve equal health care.

To draw a direct causal link between Canadian government policy and the epidemic of Type 2 diabetes is an oversimplification. No one party is to blame for native diabetes. But past policies – in particular the expropriation of land as well as hunting and fishing rights, and the effect of

cultural assimilation by the residential schools as recognized by the Royal Commission on Aboriginal Peoples in its 1996 report – created the right conditions for the epidemic to take root.

Many experts interviewed agree that the federal government should be encouraging and funding a series of pilot projects, nation-wide, to determine a best-practices model. That model should then be implemented as a national aboriginal diabetes strategy, they argue.

The federal government should establish a native liaison office to deal with the often misinformed bureaucracies of the Department of Indian Affairs and Health Canada, as well as the bureaucracy of the Assembly of First Nations. Such a liaison could appoint and train a national action team that would help implement the strategy by working with front-line community members. Expertise on basic matters is sorely lacking, and it is something native people could easily implement.

Above all, a renewed political commitment needs to be made and affirmed in both government departments and among native leaders that native diabetes is a top priority for policy and planning.

To the extent that native diabetes is a disease of poverty, the tale of its emergence is an indictment of public policy on the issue so far. Just two years ago, the federal government acknowledged its own role in the residential school drama, when then-Indian Affairs Minister Jane Stewart apologized to native people for abuses perpetrated at the Church-run,

government-planned schools. But natives say the unilateral announcement by Minister Robert Nault this spring that he intends to open the Indian Act to revision despite widespread native protest symbolizes yet another replay of the past. This process needs to be bilateral, they say.

Yet, native governments must also improve their effectiveness if progress is to be made on key issues like diabetes. Native leaders must learn to lead by example – not by dictate – and to be role models, refusing to imitate the example of the worst non-native politicians . Otherwise they have little chance of effectively dealing with problems like rampant diabetes. They must stop the infighting that often leads to program failure and the misdirection, if not outright misappropriation, of funds. They must learn to work together, and to cooperate more fully with health-care workers.

If the efforts of non-native and native governments fail, the roles of both could very well be viewed posthumously as sins of omission in the face of a wide-scale epidemic now threatening the very fabric of native culture and a substantial number of native lives.

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