Community empowerment for the Primary Prevention of Type 11 diabetes: Kanien’kehá:ka (Mohawk) ways for the Kahnawake Schools Diabetes Prevention Project.

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Abstract
This chapter outlines the experiences of an innovative and continuing program for the primary prevention of type 2 diabetes developed in the Kanien’kehá:ka (Mohawk) community of Kahnawake, near Montreal, Canada. In the early 1990s community members and community researchers entered into a partnership with academic researchers, to develop the Kahnawake Schools Diabetes Prevention Project (KSDPP). This project aims to mobilize the community for the promotion of healthy lifestyles, with the long-term goal of preventing diabetes and so ensuring good health for present and future generations of Kanien’kehá:ka. (The Seven Generations). Throughout this process, the community of Kahnawake has taken the lead for the direction of the project, incorporating Kanien’kehá:ka traditions into decision-making at all levels and ensuring sensitivity to cultural ways.

Successful components of the developing the project were documenting the local prevalence of diabetes and complications associated with diabetes and returning these results to the community, using community–based participatory research to develop the community-researcher partnership, developing a Code of Research Ethics to guide this partnership from intervention to dissemination of results, ensuring community members are equal partners with the researchers, integration of intervention and evaluation teams to create synergy, being responsive to changes with organisational and programmatic flexibility, and building local capacity by making the project a learning opportunity for all. The numerous, multi-faceted interventions in the elementary schools are reinforced by multi level community interventions that are developed to promote living in balance. Strategies of teaching, enabling, reinforcing, networking and role modeling aim to develop individual capabilities. Interventions are often effected in partnership with other community organisations, with ideas either originating from the project or initiated by other organisations. Evaluation of community governance shows that decision-making is considered to be shared among multiple community partners. Throughout this initiative sharing an interest for keeping children healthy has continually reinforced the collective responsibility of the Kanien’kehá:ka for the Seven Generations. The Seven Generations is an Aboriginal concept referring to the seven generations following the present. It is used in a way so as to require the present generation to give serious consideration to present words and actions – to consider the effect that current decisions will have looking seven generations to the future.

Vision Statement of the Kahnawake School Diabetes Prevention Project
All Kahnawakero:non (the people of Kahnawake) are in excellent health. Diabetes no longer exists. All the children and adults eat healthily at all meals and are physically active daily. The children are actively supported by their parents and family who provide nutritious foods obtainable from family
gardens, local food distributors and the natural environment. The school program, as well as local organizations, maintain programs and policy that reflect and reinforce wellness activities. There are a variety of activities for all people offered at a wide range of recreational facilities in the community. All people accept the responsibility to co-operatively maintain a well community for the future Seven Generations.

KSDPP Community Advisory Board 1995

Introduction

Demographically, Aboriginal peoples in Canada represent a small segment of the overall population. Approximately 3 percent of the Canadian population self-identify as Aboriginal in origin. Of the 1 192 600 Aboriginal persons living in Canada, 507 200 are Registered Indians, 57 000 Inuit, 205 800 Metis, and 422 600 are classified as non-status/other. Aboriginal peoples live in 596 bands and 2284 reserves across Canada. There is considerable linguistic diversity among Aboriginal peoples living in Canada with 11 major language groups and more than 58 dialects. The Aboriginal population in Canada is 10 years younger than the general population with an average age of 25.5 years. Forty-four percent of the Aboriginal population is under age 20 compared to 28 percent of the national population. [Anonymous, 2003 #325]

While Aboriginal peoples in Canada represent a small percentage of the overall population, they are over-represented in the prevalence of type 2 diabetes. For Aboriginal peoples, the national age-adjusted rate of type 2 diabetes is three to five times greater than in the general population (Young et al. 2000) (Bobet 1998), (Anonymous 1999), and in some communities the age-adjusted rate for the entire community is as high as 26%, with half of individuals aged 50 having developed diabetes (Harris et al. 1997). These elevated rates of type 2 diabetes are in turn causing high rates of complications of cardiovascular risk factors such as elevated blood lipids (Harris et al. 1997), cardiovascular disease (i.e. heart attacks and strokes) (Anand et al. 2001) (Harris et al. 2002; Howard 1999), high blood pressure (Young et al. 2000; Anonymous 1999), amputations and poor peripheral circulation (Fabitz 1999), and kidney failure leading to kidney dialysis (Young et al. 2000). These complications contribute to prolonged suffering and premature death (Mao et al. 1992). Additional concerns are a younger average age of onset of type 2 diabetes (Bobet 1998) and increased rates of gestational diabetes. (Harris et al. 1998) No longer just a disease of adulthood, the diagnosis of type 2 diabetes in young children and adolescents leads to diabetes complications in young adults (Dean 1998). As in the general population, screening of community members repeatedly uncovers previously undiagnosed cases of diabetes (Harris et al. 1997) (Delisle and J.M. 1995), so the current known figures may represent a conservative estimate.

In Aboriginal communities, chronic diseases such as diabetes are considered indicative of the negative socio-cultural changes, the long term results of colonisation, disempowerment, (Friedman and Starfield 2003) (It takes a community: framework for the First Nations and Inuit fetal alcohol syndrome and fetal alcohol effects initiative. 1997) (Joe 2001) (Durie 2003) decreased land base, loss of traditional ways, social stressors, and a lifestyle that is increasingly mechanized and no longer includes the former high level of physical activity for daily living. Nutrition is also changing from traditional foods that are closely connected to the land to highly refined foods available in abundance in numerous stores. The results of changes in physical
activity and traditional eating patterns are high rates of obesity in adults (Young 1996) and children (Hanley et al. 2000), which in turn predisposes to diabetes.

Given that diabetes is a population-wide problem in Aboriginal communities, there is an urgent need for implementing a population approach to diabetes prevention. Such an approach aims to lower exposure to risk factors across the whole population (Rose 1985), as opposed to only focussing on those at high risk. This approach parallels the traditional Aboriginal philosophy of ensuring well-being for all, in contrast to providing benefits for a few (Bird 2002). A population approach can emphasize the full range of influences on a community, including society’s political context and the role of public policies and laws directed toward multiple sectors, enfranchisement, and community empowerment (Friedman and Starfield 2003). Research driven by a population approach recognises the multiple levels of influence on diabetes prevention (i.e. personal, family, school, workplace, organizations, neighborhood, community, inter-community, health care system, regulatory policies, local and external governments) rather than limiting its focus on the individual (Smedley and Syme 2001). One population-level approach to community health utilizes community participation to ensure that locally identified program needs are founded on and incorporate local traditions, values and culture (Israel et al. 1998). For Aboriginal communities the importance of restoring control for health has been clearly stated in Canada by the report of Royal Commission of Aboriginal Peoples[Peoples, 1994 #212] and on an international level in the context of cultural revitalization (Smith 1999). It is within this context of cultural revitalization that we present KSDPP.

**Primary prevention of type 2 diabetes**

This chapter outlines the experiences of an innovative program developed for the primary prevention of type 2 diabetes with the Kanien’kehá:ka community of Kahnawake, near Montreal in Canada. The key to the success of this project has been the ongoing community commitment to the central vision that type 2 diabetes is a preventable disease (Harris and Zinman 2000). The people of Kahnawake have taken a collective responsibility to prevent the development of diabetes in its future generations.

The Kahnawake Schools Diabetes Prevention Project (KSDPP) is demonstrating that this can be accomplished when a community comes together at all levels to incorporate community traditions and values into such a project and works towards living in balance. Drawing upon its participatory democratic roots (Alfred 1995), KSDPP reflects the active participation of community members as professionals and part of the extended family in decision-making related to community-based diabetes prevention, as expressed by one community health professional:

“(Traditionally) we operated under what is called a direct democracy, we actively sat in and problem solved and built consensus around the direction our communities, our clans wanted to go. We used our collective wisdom, our communities were learning systems and from there we used that wisdom to make our decisions and to plan the future of our communities and how we were (going to) function. So if you take it now to service delivery, what I see happening is that it’s a practice that’s been inherent in us.”

With the people of Kahnawake directing the course of the project, KSDPP is more accurately a reflection of the values of Kahnawake:non (the people of Kahnawake) a strength of the people.
working together to take control, to protect and promote the health of the present and future generations of Kanien’kehá:ka (Seven Generations). This is the story of KSDPP -- a story of community empowerment and cultural revitalisation -- told in the hope that it will inspire other communities to begin their journey.

Kahien’kehá:ka community of Kahnawake

Figure 1

The Mohawks of Kahnawake are members of the Six Nations Iroquois Confederacy or as is common in their Kanien’kehá:ka language, members of the Haudenosaunee "People of the Longhouse". They have existed as a sovereign nation long before the arrival of Columbus and the European settlers (approximately 1300 years). The Mohawks taught the European settlers how to survive the northern climate, how to live off the land and new ways of governing themselves democratically.

As the Mohawks influenced the European way of life, European practices and beliefs also affected them. By signing a peace treaty with the Haudenosaunee, first in 1667 and again in 1700, the French were secured in fulfilling their two main objectives: securing a military and political alliance and establishing Christian missions in Mohawk territory. Reduced tensions led many French settlers to move onto Mohawk territory, with the Mohawks acting as a buffer between the French and the other five members of the Iroquois Confederacy: the Oneida, Onondaga, Cayuga, Seneca, and Tuscarora nations. Jesuit missionaries, determined to "civilize" the Mohawks, established Christian missions with the sole intent to convert the natives. The Francis Xavier mission is an example and testimony to this process. Many forms of spirituality now exist on the reserve, Traditional Beliefs, Catholics, Protestants, and some Jehovah's Witness as well.

The Iroquois People are unique because of their social and political structure. They are governed by the Great Law, an accord among the Six Nations of the Confederacy that bans bloodshed and ensures peace as a way of life. The Iroquois social system is both matrilineal and a matriarchy, the bulk of the political power lies with the women of the society. Family names and clans are passed down through the mother to the daughter and so any children then belong to the mother's clan. It should be noted that in this social structure, both men and women were considered equal, neither being superior to the next. The traditional political system also relies heavily on the clan structure. The decisions are made through consensus of the people, making the Iroquois Confederacy one of the world's first true democracies. Thomas Jefferson studied and later presented the political structure of the Iroquois Confederacy to the thirteen colonies. The American democratic system as we know it today is based upon the values and beliefs of the Iroquois people.

The Mohawks of Kahnawake have appeared prominently throughout history, not only in North America but in the world as well. Military allegiances with Mohawk warriors were coveted by many Dutch, French, British, and later American generals throughout the colonial wars. Later in World War I and World War II, the Mohawks contributed many soldiers and support personnel. Once again, many volunteered for Korean, Vietnam, and Gulf wars. Although Kahnawake Mohawks have a strong warrior tradition not all our exploits have been through conflict. In 1884, fifty-six Mohawks from Kahnawake helped the British map and navigate the cataracts of the Nile river in Egypt; our reputation as expert boats-men of the St. Lawrence river earned us this
Traditionally, tìohnhnhkwë (the foods needed to be healthy) were obtained through agriculture, fishing, hunting and gathering. Agricultural staples included corn, beans, and squash, named the Three Sisters. The Three Sisters are rooted in the story of creation that tells of their nurturing properties. In addition to providing good nutrition, these foods store through the winter and so ensure the survival of the women and the next generation. In the late 19th century agricultural and trading practices were gradually replaced as men became involved in the structural steel industry across diverse locations in North America. These are the famous high steel workers who built many of the early bridges and buildings in the major cities in the USA. By the 1950s, farming, local fishing and food gathering virtually disappeared due to expropriation of community lands and most of the riverfront to build the St. Lawrence Seaway, increase participation of men in the iron-working industry, and people acquiring employment in nearby Montreal.

Kahnawake, situated across the St. Lawrence river approximately nine miles southwest of Montreal, has a population of 7,200 (2002). An additional 1,868 people live outside the community. Men continue to work in construction with an increase of men and women in local white-collar careers stimulated by community development, and high numbers of students gaining further education at trade schools, colleges and universities. While the Mohawk Council of Kahnawake is the federally recognized government of the community, traditional government through the Longhouse system is still strong. Community strengths include decentralisation of power with control through locally elected boards of directors, endorsed by the Mohawk Council of Kahnawake, governing community education services (1967), health services (1970), youth recreation (1972), social and community services (1972) and the Kahnawake local court (1979). Community control of local services came as community leaders successfully negotiated for greater autonomy from the federal government of Canada. Through this high level of community governance came programs developed by the community specifically for the community. As in the past, the women of Kahnawake have taken a leadership role in many community initiatives related to protecting and promoting the health of the present and future generations of children.
Their active involvement in the governance and program implementation of KSDPP illustrates cultural continuity in their traditional maternal role in caring for the children

“One thing I have to say here, in Kahnawake, in this community, education has always led the way. Who was the first group to say to the government, no we’re not following that policy? It was the school committee. The school committee, those women of the school committee were the first ones to say to the government, no, we’re not doing that....” (Kahnawake community member.)

In the 1990s local economic development services, together with a new community co-operative banking system, rapidly facilitated a variety of new community owned small stores and businesses. [Macaulay, 2003 accepted for publication #201] Today Kahnawake is recognised as one of the leading Aboriginal communities in Canada.

Origins of KSDPP
In the early 1980s a young Kanien’keha:ka doctor, together with one of the established family physicians working in Kahnawake, undertook a chart review that documented a prevalence of type 2 diabetes among 45-64 year-old persons living in Kahnawake that was twice that of the Canadian population (Montour and Macaulay 1985) Their second study showed that for this same age group, almost half of those with diabetes also had severe heart disease as a complication of diabetes. In addition, persons with diabetes had six times the complications of heart disease, stroke, kidney complications and amputations than those without diabetes. This study also documented very high rates of obesity in both those with diabetes and those without diabetes. (Macaulay, Montour, and Adelson 1988) (Montour, Macaulay, and Adelson 1989).

From these baseline studies, the physicians had planned a third research initiative to document the predisposing factors leading to the complications of diabetes in Kahnawake. At the same time, due to a promise they made to return research results to the community, they began, in the spring of 1987, a series of presentations which would change both their own, and the community’s perceptions of diabetes. Contacts with community members including elders and community leaders in health, education, culture and politics were made through several formal one-hour presentations, and a radio presentation followed by radio phone-ins. (Montour and Macaulay 1988) In response to these presentations, key community members and elders requested that action be taken to prevent diabetes:

“People came to us and asked us to do something. Do something about diabetes. That was their reaction.” (Family physician working in Kahnawake.)

Moreover, based upon these research results and other observations concerning the increasing rates of obesity of the school children, the type of preventive action requested was specific:

“They’re finding that more and more children are coming to school already obese, because of their change of lifestyle... they’re looking at trying to prevent children from having diabetes...everybody understands that we all come together for the welfare of the children.” (Kahnawake community member.)
In response to this request, the family physicians changed track from a clinical orientation focussing on diabetes complications, to a diabetes primary prevention agenda centred upon the children. As a family physician working in Kahnawake stated: “We realized this was a much more important topic with which to get involved.” The community reaction was part of a process in which key community members shifted their perceptions about diabetes as being not only a threat to individuals, but also a threat to the community. This process, described as “legitimizing diabetes as a community health issue” embodies structural, social and cultural community conditions, along with a set of strategies alerting the community to the research findings (Bisset et al. Submitted 2003).

Prior to the presentations in 1987, diabetes was described as being a pervasive health problem that was encountered daily, and perceived as something to live with, when a community member said “If you didn’t get it you were lucky” and if you did you would eventually require the care of a physician and the diabetes education team. This familiarity with diabetes, together with an increased awareness that diabetes risk factors such as obesity were increasingly manifested among the school children, set the stage to raise levels of consciousness about a familiar problem. The baseline studies uncovering a relative health disparity within Kahnawake were presented in an open, interactive forum, allowing key community members to ‘self-diagnose’ diabetes as a relevant health issue. Where:

“Just hearing it spoken and seeing the figures had a big impact, as peoples’ own results were given back to them.” (Family physician working in Kahnawake.)

The impact of this message was an unexpected consequence of two physicians with credibility, sending a message through various channels, strategically directed to different levels of the community, in a culturally appropriate way. Three factors set the stage for KSDPP. First, community-level solutions to this health problem were not imposed nor suggested. Traditionally, Kanien’kehá:ka:

“Actively sat in and problem solved and built consensus around the direction our communities, as our clans wanted to go. We used our collective wisdom.”
(Kahnawake community member.)

Secondly, the credibility of the messengers influenced the reception of the message in Kahnawake. Credibility was facilitated by one messenger being Kanien’kehá:ka, both having occupational status “Letters behind your name” (Kahnawake community member), espousing Aboriginal values, and caring for community wellness. Lastly, the message raised consciousness around an emotional issue. The elders spoke openly about being fixed in their ways of eating, being frequently overweight, having already undergone heart by-pass surgery or suffering from a stroke or amputation of a limb, and that for them it was “too late” (Kahnawake community elder). They however wished a different future, one free of diabetes, for future generations, and so specifically asked that any new program focus on the young to protect their children and grandchildren from carrying the same burden of disease (Montour and Macaulay 1988). This request was facilitated by the well established and comprehensive diabetes education program, developed and coordinated by a Kanien’kehá:ka nurse educator at the community hospital, for those already diagnosed with diabetes. (Macaulay, Hanusaik, and Delisle-Diabo 1988)
From the elders’ request the seeds were sown for what was to become the Kahnawake Schools Diabetes Prevention Project (KSDPP). The new goal was to establish a research project with both intervention and evaluation components. To accomplish this goal the community-based professionals from health and education, who had also developed early research skills, first came together and then invited academic researchers from two neighboring universities to join the team for their expertise in health promotion design and program evaluation.

“I think Kahnawake was very lucky that there was another family physician and myself to start the research. You know, most research is academic, it’s bench research and it’s Ivy League people in their towers coming down to the poor masses.” (Kahien’kehá:ka family physician)

After seven years of discussions and unsuccessful grant applications, in a time when there was little monies available for health promotion, KSDPP was finally launched in 1994 funded through a national research grant (Macaulay et al. 1997). A doctoral thesis has since documented that it was a national lobby effort for diabetes in the early 1990s, including the physicians from Kahnawake backed by the original Kahnawake data, which had convinced a national research granting agency to release grant monies specifically for diabetes in Aboriginal peoples (Rock 2003).

“My involvement was with the Canadian Diabetes Advisory Board, which was struck in the mid ‘80’s. We were an advisory committee to the Minister of Health, to report to him on the state of diabetes in the nation. So, this was not just Aboriginal, it was national and from that group spun off the national competition for Aboriginal diabetes research, which is what funded KSDPP.” (Kahien’kehá:ka family physician.)

For KSDPP the academic researchers were absolutely essential as they contributed their academic expertise to developing the initial grant proposals to secure national research funding. These grant proposals were a first collaborative success whereby academic content and Kanien’kehá:ka ways were integrated after community reviews. The strength of the final and successful proposal was reflected in the partnership forged by all the researchers with community members and community organizations.

A participatory approach to community-based research
From the beginning, KSDPP was planned as a community-based participatory research project, where researchers and community members would partner to share expertise in support of a vision to prevent diabetes. (Green et al. 1995) (Macaulay et al. 1999) [Schulz AJ, #1651] (Reading 2002) (Gibson, Gibson, and Macaulay 2001) While framed as participatory research by academic researchers, the underlying philosophy of KSDPP converged with a longstanding tradition of consensus decision-making by the Kanien’kehá:ka. This participatory approach is the opposite to ‘helicopter’ research where researchers make decisions on behalf of the community, and the voice of community members is not equally heard (Model Tribal Research Code. With checklist for Tribal Regulation for Research for Indian Health Boards 1999). This ‘helicopter’ way of research had also been experienced in Kahnawake.
« In the past outside research teams had swooped down from the skies, swarmed all over town, asked nosey questions that were none of their business and then disappeared never to be heard of again” (Kanien’kehá:ka family physician)

KSDPP Community Advisory Board
Building on a rich history of community control, the KSDPP Community Advisory Board (CAB) was formed to direct the intervention and research components. In keeping with traditional practices of the Kanien’kehá:ka, CAB is based on voluntary participation with representation of community members from all walks of life. The volunteer members have varied in age from 26-80 years. Membership includes representatives from various community organizations such as health, social services, education, the environment office, the cultural center, spiritual groups, the Kahnawake Youth Center, as well as interested community members. These members are very dedicated, the strength of their commitment guided by the need to protect and promote the health of the Seventh Generation and from experiencing, first hand, the toll that diabetes has taken on themselves and close family members.

« MY STORY? How do I put into words someone’s life? What name do you give the space in a family that is missing a daughter? What comfort can you give to a mother who outlives her child? What do you say to nieces and nephews who depend on Kairwah Ienné (Aunty Sarah) to make the best homemade bread in the whole wide world? What happened to the cousin who was always dependable to help in any way she could? Where did the friend go who would always save seats for everyone at the bingo hall? Where is the Grandmother who dropped by every day just for hugs and kisses because she considered them a bonus? What answer do you give to grandchildren who say that she’s not even 60 years old, therefore she’s not even old enough to die? Where did she go? How do you explain to a four year old that she’s not just playing at sleeping? How do you say to her that Ma was in the hospital for six months because of a broken arm resulting from a car accident? How can you explain Ma missed you so much that she would ask about you every day? Explain to a child that hospital rules don’t allow a four year old visitation, especially when Ma’s arm was turning gangrene so badly that the whole room smelled like you wanted to get sick. Can anyone explain how a nurse who was at her bedside since the day she came to the hospital broke down and ushered the four year old right through the security guard, daring him to say something or make a move to try to stop them because she was determined that Ma would see her grandchild for the first time in six months because she was a model patient and deserved it! Can you imagine the look on Ma’s face when she saw that four year old with her handful of picked flowers? Where do you put those kind of memories? What do you think about the day she came home from the hospital? There was so much to do, so many people to visit, so many places to go. She was like a bird set free from a cage. How many hours did she count to midnight? There she was at the window in the moonlight, very visible. I asked her “Ma, why are you still awake?” Ma said “I can’t sleep I’m so happy to be home.” What do you do when that happiness is broken. Ask yourself the question, why didn’t she wake up the next morning? We will be asking that question every day for the rest of our lives. Dare we ask if diabetes is a killer? Amelia Tekwatonti McGregor 2003
CAB members meet monthly to direct the project. Their tasks are all encompassing and include:

- ensuring cultural relevance of the project,
- promoting KSDPP objectives in their homes and organizations
- role-modeling healthy lifestyles
- advising on the design and implementation of research protocols
- shaping the interpretation of research results
- reviewing abstracts, scientific articles and this book chapter
- participating in the dissemination of project activities and research results to both Aboriginal and scientific audiences
- co-teaching with researchers on participatory research and ethics at academic institutions, national and international workshops
- participating in administrative activities i.e. reviewing applications and interviewing candidates for KSDPP positions

CAB members actively participate in the life and direction of the project, as shared by a CAB member:

“If there’s a general community event we’re [CAB members] also asked to volunteer some time or some food. I mean there are always phone calls coming in once a month, can you make soup or sandwiches. For example, the trade show at the arena this summer, there was a booth there so they asked CAB members to go in and volunteer some time. So there’s also direct involvement from the CAB members representing KSDPP.”

CAB has incrementally taken a more active role in the life and direction of the project. Nine years since its inception, KSDPP, which was originally linked with the Kahnawake Education Centre, has now become an independent organization. As of 2003 CAB has formed an executive committee to provide the leadership required to govern the project.

The KSDPP Code of Research Ethics

One of the first major achievements of the community-researcher team was in developing a code of research ethics, a code that continues to provide researchers and community members with a set of guidelines for negotiating issues. In 1994, CAB and researchers came together to formalise the partnership and develop guidelines to promote the sharing of leadership, power, and decision-making among all team partners. At this time, the primary partners included community members, community-based researchers and academic researchers. The development of this code began with a review of the literature and other research codes. The KSDPP Code of Research Ethics (www.ksdpp.org) is founded on two policy statements: 1) the Kanien’kehá:ka of Kahnawake are sovereign to make decisions about research in Kahnawake, and 2) research should benefit and contribute to community empowerment

« ...because we’ve got a guide for research, we don’t have to keep repeating that all the time, make sure that you do this, make sure you do that. We know that it’s written right into the agreements. Plus we have the new research council, so we know that the research is going to be done right and that it’s going to be owned by the community of
The KSDPP Code of Research Ethics continues with an understanding of the principles of participatory research: all the partners should be involved at all stages of the research process: design, implementation, data analysis and interpretation, and dissemination of the results. All partners contribute ideas and resources that strengthen the project and its outcomes.

The document begins by outlining the obligations of the academic researchers, community researchers and the community throughout the research process. It ensures that the data are owned by the community and must be returned to them after analysis is complete. It also ensures that the research benefits the community, as voiced by one CAB member:

“I think it’s been to look at the work that’s being done, to try to set some guidelines to make sure that the work is work that the community benefits from and that we’re comfortable with and that is acceptable to the community.”

One innovative section states that new any researcher wishing to join the team, be they students or established researchers, must be accepted by both the community and the researchers. This means that new senior researchers cannot automatically join the team, and researchers do not alone have the authority is allowed to bring a student into the team or give the KSDPP data to a student to analyse. All students are first invited to meet with CAB, to discuss their proposals which can then be accepted, modified or rejected by CAB. For any study, once data has been analysed, the results are first interpreted by the entire team, and then returned to the community of Kahnawake, before dissemination outside of the community. If the community and researchers do not agree on the interpretation of the findings, then the dissemination process allows for dissension and the inclusion of two different interpretations of the findings in the same oral dissemination or publication. As far as we know, this last clause is unique and, to date, has not been applied. Developing the KSDPP Code of Research Ethics took a period of eight months. At the time, this seemed very long. In retrospect, the discussions and negotiations were important steps to understanding academic and community cultural practices and to building trust among team members. Both steps were necessary to develop the concept of equal partnership blending together different types of expertise, with no partner having authoritative status. (Macaulay, Delormier, et al., 1998).

The KSDPP Code of Research Ethics showed foresight in developing clauses that protected not only individuals, but the entire community from potential stigmatization, which reflects current developments in ethics to develop guidelines to protect the collectivity or community. (Weijer, Goldsand, and Emanuel 1999) (Guidelines for Ethical Research in Indigenous Studies 2000). In the words of another CAB member:

“Help the researchers, O Wise Ancestors, when they sit in their universities and do not look into the eyes or see the faces of those they research. We must educate the researchers to see that we are a people who must be involved from the beginning of any research. We want an equal partnership with involvement in the decision making process. In our project, the moral and ethical guidelines (Code of Research Ethics) are an
important component to empower all the community participants and researchers to work together in a successful relationship. Through this empowerment comes the ownership and the commitment to work together for a healthier community. As Onkwehonwe (The Real People), we ask our Ancestors to help us to ‘look inwards’ to ourselves, our culture and our spirituality for a healthy lifelong journey. 

The KSDPP Code of Research Ethics has been used as a model by the Kahnawake Onkwatakari’tahshera Health and Social Services Research Council (the Kahnawake research council which reviews all research requests), other Aboriginal projects and organizations in N. America. (Alaska Native Science Commission: Code of Research Ethics 1997) (First Nation and Inuit Regional Longitudinal Health Survey 1999. Code of Research Ethics; Appendix 4 (A-54) http://www.naho.ca/finc/rhs) and has served the project well for the last nine years. KSDPP is currently revising the Code to include guidelines for knowledge translation, new aspects concerning the storage of tapes and qualitative data, the enhanced review process of abstracts and scientific articles before public dissemination, and to ensure that KSDPP is up to date with concepts from other guidelines developed in the last nine years by Indigenous organizations and national granting agencies. (Weijer 1999) (Guidelines for Ethical Research in Indigenous Studies 2000)

Kahnawake Schools Diabetes Prevention Project
The KSDPP model of community-based intervention
KSDPP embodies an integrated community wide (ecological) and (w)holistic approach to diabetes prevention. Like many other Aboriginal cultures, the worldview of the Kanien’kehá:ka is based on the complex web of relationships that exist between people, animals, spirits, natural forces, plants and landforms that comprise the ecosystem (Battiste 2000; Battiste and Henderson Youngblood 2000; Dei, Hall, and Rosenberg 2000; Smith 1999). The interdependence of life forces that forms the basis of the Kanien’kehá:ka worldview is combined with a (w)holistic view of health emphasising living in balance, the ideas of which are reflected in the continuity of the circle which has no beginning and has no end. (Bopp and Project. 1985; Montour 2000; Morgan and Slade 1997) The circle represented by the Medicine Wheel symbolizes the ideals of interconnectivity, (w)holism and living in balance, that mirror the way Aboriginal peoples strive to live their lives. (Bopp and Project. 1985)

How does KSDPP respect and incorporate Kanien’kehá:ka culture? A qualitative analysis of the KSDPP intervention shows that the implementation of diabetes prevention activities is directed toward living in balance (Delormier et al. 2003). Living in balance signifies being well in mind, body, emotion and spirit, embodied in the KSDPP Vision Statement that introduces this chapter and the traditional Aboriginal philosophy of health (Bird 2002).

The vision statement clearly outlines living in balance through a positive attitude, healthy living and the overall community goals needed to support a future free of diabetes. Each year at the annual KSDPP community day this vision is re-visited, to maintain the energy needed to continue to ‘walk the talk’.
The logo for KSDPP, designed by Kim Delormier - a community artist - embodies the vision for KSDPP.

«The circle» is the main symbol found in Onkwehon:we cultures. It represents life: the past, present and future, no beginning or end. There is strength and unity in the circle. The three clans of the Mohawks of Kahnawake sit on the circle. The bear, wolf and turtle represent the unity of the people in preventing diabetes in the future generations. The lacrosse player symbolizes in importance of daily physical activity through the traditional Iroquois game of lacrosse. The sun, our elder brother with his life giving energy and strength reminds us that we all possess this energy and strength in the wellness journey for ourselves, families and community. The food represents the importance of healthy eating. The corn is one of the Iroquoian lifegivers or ‘Three Sisters’, the strawberries are the first fruit of the season in the Northeast, while the apples last the longest on the trees into the fall. The elder and child reminds us that the wellness of our future generations is everyone's responsibility as Onkwehon:we. The eagle feathers represent the gifts of the eagle, the brother who flies highest and closest to the Creator. His vision, wisdom and courage are gifts that we each possess. The colour purple is known to us as a healing colour». (www.ksdpp.org)

It is with an ecological and holistic approach to health that KSDPP aims to decrease the future occurrence of type 2 diabetes, through the short-term goals of increasing healthy eating and daily physical activity, and the adoption of a positive attitude. How does this unfold in the context of community practice? An ecological approach to diabetes prevention, such as employed by KSDPP (Delormier 2003), recognizes that the adoption of healthy behaviours can be enhanced if consistent messages are provided in multiple settings (e.g., school, home, community) and through multiple sources (e.g., teachers, parents, media). (Killip 1987)

There is a general consensus that an ecological approach provides a more comprehensive framework than just individual-level approaches. Some of the limitations of the earlier individual approaches were associated with a tendency to attribute behavior change failures to shortcomings on the part of the individual i.e., “blaming the victim” (Pearce 1996) By contrast the ecological approach, espoused by KSDPP harmonizes with Kanien’kehá:ka values of involving the entire community (i.e., organisations, families and individuals), and of creating opportunities for participation and capacity-building. Moving towards a diabetes-free future requires that the intervention contains a host of multi-target, multi-setting intervention strategies designed and implemented by the community for the benefit of community. As requested by the elders, the project focuses on the current and future generations of children. Implementing
interventions in the school are not seen as sufficient to modify the health trajectories of children. Children require ongoing support from those who nurture and shape their development. The following describes the interventions in the elementary schools and the community and how the two elements of the KSDPP intervention are intertwined in the overall goal of reaching the whole community.

“We always keep our focus on the children and that it’s important to give them some kind of role model.” (Kahnawake community member.)

Elementary schools interventions to educate young children
At the heart of the KSDPP model is a health education curriculum (described below) that is supported by extra-curricular activities in schools. The majority of elementary school children attend an English language school or a Kanien’kehá:ka immersion school in the community, where since 1994 the total number of children in Grades 1-6 has varied from 401-458. The schools are under the direction of the Kahnawake Education Centre, which is governed by the Kahnawake Combined Schools Committee whose members are parents of children from kindergarten to high school.

In partnership with the schools and the community hospital, KSDPP supported the introduction of a new health curriculum into the elementary schools, with the goal of having this curriculum delivered by the teachers (as opposed to health care professionals). The Kateri Memorial Hospital Centre Health Education Program for Diabetes Prevention© was created by a dietitian and two community health nurses from the community owned hospital with input from the teachers and KSDPP staff. The curriculum was written in English and then translated into Kanien’kehá:ka for the Kanien’kehá:ka immersion school, with sections on nutrition, fitness and physical activity, diabetes and healthy lifestyles. The ten, 45-minute lessons per year for Grades 1-6 use practical experiences in addition to inter-active and cooperative learning techniques. Lessons incorporate traditional learning styles with hands on interactions and high visual content and include story telling, games, food tasting, experiments, puppet shows, crafts and audiovisual presentations. The nutrition section discusses healthy eating, balanced meals, healthy snacks, avoidance of high fat foods, nutrients and their roles, label reading, factors influencing eating habits, body image and healthy weight. This section incorporates traditional foods, as well as foods commonly eaten in the community. The fitness section includes the benefits of different types of activity: aerobic, strength building and flexibility and emphasizes the pleasure of daily physical activity. The last section links lifestyle to disease, describes diabetes with its’ consequences and how it can be prevented.

During the first year, in order to increase knowledge and build capacity, the community health nurses and the dietitian, delivered the curriculum in the presence of classroom teachers, who are mainly from the community and themselves parents and grandparents. Then the teachers received training and by year three began to deliver the program themselves with the support of the KSDPP intervention team. (Macaulay et al. 1997)

“I think because the teachers are the ones that are the closest to the children, the teachers have to be the ones that...need to be taught. They need to know, we need to know about this disease” (Kahnawake community member.)
KSDPP successfully lobbied the Kahnawake Combined School Committee to reinforce a the schools’ nutrition policy that had been introduced prior to KSDPP.

« Well, we were always concerned about the quality of foods that children were bringing into the school with the high sugar content and a high fat content, and so it was a decision made by administration that we would just not allow children to bring things that were not healthy for them. And it took a lot of work. First we tried persuasion and education and information and when that didn’t work fully, we then we started to take things away from kids or if they brought things into the schoolyard, any junk food we took it away from them. ” (Kanien’kehá:ka educational leader)

Therefore the nutrition policy ensures that children bring only healthy foods to schools for lunches and snacks. Junk food is not allowed, and there are no machines selling sodas and other convenience foods in the schools. (Macaulay et al. 1998)

« And now for the Nutrition Policy in the schools, we have made a better list for teachers to understand. Teachers want to know what can be brought in and what’s not allowed. When there is a parent-teacher night we try to reinforce the nutrition policy with the parents. We’ve rated different snacks that kids bring to school, to show parents what was healthy. » (KSDPP intervention team member.)

Other KSDPP school initiatives have included healthy breakfasts and lunches prepared by parents for staff and students, snow sculpture contests to increase wintertime physical activities, and a one mile run ‘Racers for Health’ in the early summer which now attracts 100-200 students from other Kanien’kehá:ka communities.

KSDPP is different to many other programs in showing that the teachers role is not limited to just classroom teaching. Many of the teachers have assumed a major role: in addition to delivering the health education program many teachers reinforce the messages by walking with the children in the school grounds before school or at recess, making sure that all classroom treats are healthy snacks and role-modeling healthy lifestyles. Some teachers incorporate health education program lesson plans into other studies, such as using food label reading in their math class. Currently, KSDPP is developing a health curriculum for pre-school children, and will begin to work more closely with families of this age group.

Community interventions to promote living in balance
Another KSDPP goal is to ensure that the immediate and extended families acquire the same knowledge as the children, so that they are in a well positioned to be good role-models and to support their children. To complement the school based program, community wide interventions are designed to increase community awareness, to develop positive attitudes towards healthy lifestyles and to provide all ages, families and extended families fun opportunities to eat healthily and be physically active. It also underlines that learning is not limited to the classroom, and that schools do not operate in isolation from the community, but rather offer support to and are supported by the community (Killip et al., 1987). Healthy living is supported by healthy community environments, and another early success of KSDPP was to develop a partnership
with other organisations to plan and build a new one mile recreation path along the waterfront where people can walk, jog, bike and roller blade in a safe and positive environment.

Community interventions are actively promoted through a variety of channels. KSDPP uses the local radio for numerous public service announcements, and conducts talk shows where listeners can phone in with their questions. We have used regular half-page advertisements in the local newspaper to provide short and behavior-oriented information about healthy lifestyles, and to advertise upcoming activities. Now there is a new TV channel in the community that KSDPP will start to use.

KSDPP undertakes intervention activities to offer good opportunities for families to be physically active and eat healthily throughout the year. For example, community walks with incentives for the families with the most participation and the earliest registrations, bowling parties, food tasting events, cooking classes, food demonstrations, walks for young mothers with baby carriages, walking for all ages including elders at the arena in cold weather, roller blading for the youth, and family sledding parties in the wintertime. Many of these events include a healthy meal, such as soups, chili and sandwiches. Meals are frequently prepared by the participants as food is central to tradition and the opportunity is there to role model healthy food preparation and healthy eating.

« We keep the messages the same, but change the colour of the table cloth and the paper it is printed on…it keeps it interesting to put a new look or twist on a repeated activity, but we are always looking to try something totally new. » KSDPP intervention team member.

Interventions are planned to reach as many people as possible not only at invitational community events but also by meeting people in their own environments. This may involve chatting with the men when they pick up their coffee at 5-6 am at a local coffee shop, and visiting community organizations during the workday to bring information to both men and women about making healthy food choices and being physically active. From the beginning KSDPP chose to build on pre-existing strengths and thus to partner and support existing community groups and events that could help attain the KSDPP goals. Partnering with organizations such as the Kahnawake Youth Centre, co-sponsoring walking clubs (e.g., Mohawk Miles), and attending health and harvest fairs, and several sporting competitions has been critical to promote capacity building and sustainability. By coming together under the umbrella of a same community event, partners created opportunities to optimize community resources to promote healthy behaviours: [Levesque, 2003 In Press #205]

« We had started to work together on different initiatives, because we are all promoting health. It was better for us to join forces rather than doing individual work. It reinforces everything we are doing…it makes (carrying out activities) so much more fun if everyone does a little bit and it makes the booth all that more exciting. » KSDPP intervention team member.

From qualitative evaluation of the interventions, we have found that most KSDPP interventions are planned and implemented in collaboration with other community groups. For example in
1996-97 two-thirds of the collaborations around physical activity interventions occurred in response to invitations received by KSDPP from other community groups. [Levesque, 2003 In Press #205] This suggests that KSDPP is well accepted and is perceived as a good health promotion community resource. We hypothesize that this proportion may increase as KSDPP continues to expand. (Potvin et al. 2003). KSDPP is a good example of community mobilization, where a community actively chooses to solve a community problem (Green and Kreuter 1991) (Ottawa Charter of Health Promotion 1986).

Examples of the strategies applied by the KSDPP intervention team to promote participation in intervention activities are shown in Table 1.

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<tr>
<td>i. Continuity of the message from activities, settings and population groups. A teacher appreciation breakfast was offered at school, and a few weeks later a pot-luck breakfast buffet was coordinated for the children. Later in the spring a mother’s day illustration contest reflecting on healthy breakfast for mom was held among the children at school to reinforce the message; all participants’ names were entered into a draw with a winner from each of 53 classes taking home a basket of healthy breakfast groceries for their mom.</td>
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<td>ii. Taking the message to the people. During parent teacher interviews at the schools, booths were set up and intervention staff invited parents to participate in the booth activities.</td>
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<td>iii. Incentives to engage participation and reinforce the message. The walking club offers incentives as participants reach intermediate levels on the way to their ultimate completion goal. Incentives included water bottles, rain coats, t-shirts and work-out gear.</td>
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<td>iv. Capitalizing of pre-existing events, occasions and opportunities. The annual community harvest fair, organized by the Environment Office, was co-hosted with KSDPP to take advantage of this food centered, local event to promote KSDPP messages.</td>
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<td>v. Using multiple strategies in a single intervention. A nationally coordinated community walk of 7km commemorates the work of a dedicated diabetes prevention worker who died tragically in British Columbia. After the walk, a healthy lunch donated by CAB is offered. Age appropriate incentives are given to all participants, with chances to win prizes for a draw i.e. a bike for children and wagon of healthy groceries for adults.</td>
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<td>vi. Responding to concerns raised by the community. Participation in the monthly meetings of the Kahnawake diabetes working group informs KSDPP of areas of needed intervention activities.</td>
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<td>vii. Embedding culture into the intervention. Having meals offered at events that are provided by community volunteers reflects the importance of eating together and sharing food among family.</td>
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<td>viii. Creating a social environment for participation. Walks are organized so that families as well as co-workers can walk together.</td>
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<td>ix. Blending old with new activities. Setting up informative and interactive booths at strategic community locations is a KSDPP time tested activity and many new ways of doing this are always in the works.</td>
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<td>x. Collaborating with community organizations and groups. Where an event was being planned by a new youth group, KSDPP became involved with sponsoring the snacks for the evening and providing support to the youth to prepare the food.</td>
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</table>

Using these practices KSDPP has become embedded in the dynamic social, recreational and educational structures of the community. In all these activities community knowledge and ideas are incorporated throughout. (Delormier et al. 2003) This is a very ‘bottom up’ project, and the participatory research team supports the community vision. Because KSDPP intervention staff and CAB members are all Kanien’kehá:ka, the intervention activities, together with the accompanying decision making, all naturally incorporate local values and Kanien’kehá:ka traditions.
Reflections on the KSDPP model

In KSDPP the intervention and research components have been integrated to strengthen the overall project. (Potvin et al. 2003) Both the intervention team and research assistants for the evaluation team are based in Kahnawake, in contrast to many research projects where evaluation teams are university based. However, there are also researchers who work outside of the community and only attend research team meetings in the community. Research needs to answer academic questions, but should not be answering hypothetical questions developed outside the community. Research is richer when community context is informing the research questions. (Koelen, Vaandrager, and Colomer 2001) and the intervention team has been strengthened by assimilating research concepts and developing community researcher skills. The KSDPP research component is seen as integral to the project i.e. in 1997 the overall impact and visibility of KSDPP was decreased in that year, as lack of funds prevented school data collections. Compared to three previous years, parents were not asked to sign consent forms, the evaluation team was not in the schools to measure the children and incidentally answer many questions, children did not complete questionnaires or run in the fitness tests. This confirmed to us that the annual KSDPP evaluation activities were a constant reminder to students, teachers and parents.

Another priority for KSDPP has been to build local capacity and promote sustainability. KSDPP provided training in specific skills i.e. collecting the anthropometric data, telephone surveys and data entry, and summer students to assist in research projects. After working as a research assistant one community member has enrolled as a PhD candidate, another used KSDPP data to complete her Masters degree before entering medical school, and others collaborate or play leading roles with national agencies. Team members co-present and run workshops to scientific and non-scientific audiences, which both builds capacity and sends a strong message through role-modeling the research partnership to others. (Potvin et al. 2003) Today KSDPP employs eleven full time people including nine community members, and hires additional community members at times for specific tasks such as data collection.

Challenges

KSDPP was implemented in an era of scarce research funding and needed to find new funding sources after the first three-year research grant ended. Due to early success of the project and a high level of community support (Macaulay et al. 1998), three community organizations (the Mohawk Council of Kahnawake, Kahnawake Shako'tiia'akehnhas Community Services, and the Kahnawake Education Center) chose to continue funding for one year, but could only afford to support continuation of the intervention component and the two community staff positions. The evaluation component, together with the position of the evaluation coordinator, were necessarily discontinued. The following two years both intervention and evaluation components were funded by private foundations combined with community contributions. This critical period of bridge funding allowed KSDPP to continue, and two years later the team was well positioned to apply for innovative national research grant monies designated for university–community partnerships, which led to five years of infrastructure funding. This history certainly documents the precariousness of long term community based research projects needed to accomplish lifestyle changes, and underlies the importance of promoting early capacity building and sustainability.
Participatory research promotes learning, respect and trust of both researchers and community. Internally, priorities and activities evolve requiring discussions between the various partners. It requires commitment, time and more time, and continued and ongoing negotiation processes. Over the years challenges have included deciding on priorities, reconciling community and academic timelines, adapting to changing different funding environments, community questions, opportunities and agendas, changing personnel, academic sabbatical leaves, academic students with different interests, and individual strengths and varying time commitments. Other Aboriginal communities recognize that Kahnawake is creating innovative approaches to diabetes prevention; this is a source of pride in the community.

Reflecting on community governance
KSDPP is one of the few community-based prevention programs showing evidence of sustainability. Indeed, the driving and sustaining forces of KSDPP are borne from active community participation in designing the intervention program to developing the Code of Research Ethics to committing to local capacity-building and overseeing the financial administration of the project. The strength of the community in shaping and directing the project builds on the strong history of the Kanien'kehá:ka in reclaiming their right to governance.

Speaking from the voice of a researcher, those who participate in KSDPP on a day-to-day basis quickly come to know that ideas require discussion which often result in something that reflects what neither the community nor the academic researchers initially put on the table. The end result often reflects something in between, an accommodation of academic and community interests for mutual benefit. This is where KSDPP departs from many other projects. History tells us that Aboriginal communities are dissatisfied with the “helicopter research” alluded to earlier in this chapter. While the impetus for many community intervention research projects has come from external academic influences with transference of ownership to community with time, our experience suggests that communities like Kahnawake can direct the process from the inception. KSDPP quantitative research shows quite clearly that community partners have been perceived as the primary owners of KSDPP since the beginning and that they carry the greatest influence across all domains of project functioning. (Cargo et al. 2003 In Press)

To date the discourse in health promotion literature has revolved around the “transference of ownership” from academic researchers to community partners, particularly for researcher-initiated projects (Bracht 1994). This discussion is not relevant for KSDPP because the project was initiated by community members and leaders, who then invited academic researchers to join the partnership for their expertise in community research. Indeed it is almost the opposite, where community partners have had a major impact on the academic researchers.

Conclusion
Social justice is about having the same opportunities and choices, without discrimination as others in a society. This has not been the case and has been difficult to achieve for Indigenous peoples because of the history of governmental and colonial racism. KSDPP shows an example
of a community taking responsibility to ensure a healthy future, by confronting the many challenges it faces to restoring a well community.

The high level of ongoing community commitment and the shared community decision-making of KSDPP have been critical to the success and longevity of this project. Other key factors are the integration of the intervention and evaluation components. KSDPP may be considered innovative from both an intervention and research perspective for implementing an “ecological model” and for espousing an “empowerment” philosophy. KSDPP is now offering training in community mobilization for diabetes prevention to other Aboriginal communities. We believe that other communities will need to adapt the Kahnawake experiences, to build on their own pre-existing strengths and to incorporate their own traditions and values.

We have reflected on some of the reasons for success earlier in this chapter. Other reasons likely include the pre-existing strengths such as community control of health, education and other services, sharing the early research results with the community, a pre-existing comprehensive diabetes education program developed within the local hospital, health professionals from Kahnawake, other health professionals with long service in the community, always keeping the community informed and external academic researchers who espoused community control of this project.

However, we postulate that the predominant reason for longevity and success is that Kahnawake applied traditional approaches to problem-solving and did not just adopt an outsider model or philosophy to diabetes prevention. Community ownership of KSDPP is in keeping with the strong autonomous roots that characterizes the Kanien’kehá:ka (Alfred 1995) (1984) and with current approaches to implementation of community interventions (Barnes 2000). With respect to program characteristics, the Kanien’kehá:ka community of Kahnawake gathered around the issue of diabetes prevention as it was not viewed as socially disparaging and, as a disease diabetes posed a threat to the well being of those faces yet to come. Sharing an interest for keeping children healthy reinforces the collective responsibility of the Kanien’kehá:ka for the Seven Generations (Alfred 1995). This may reflect a timely fusion of Kanien’kehá:ka culture with its’ emphasis on participatory democracy (Morgan and Slade 1997; Wallace 1946) and the value of social justice underlying health promotion (Ottawa Charter of Health Promotion 1986)

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Please visit www.ksdpp.org for further information on KSDPP. This includes a twenty-five minute video of the experiences of KSDPP, the KSDPP Code of Research Ethics, Three Sisters Cookbook, information on intervention activities and research findings. For information and purchase of the KMHC Health Education Program for Grades 1-6 please contact Sheila Arnold, Community Health Unit, Kateri Memorial Hospital Centre, Box 10, Kahnawake, PQ J0L 1B0, Canada.

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