



# Public Health Research in Eeyou Istchee:

Reports, current projects and a  
summary of research on diabetes

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This report presents an overview of the public health research program of the Cree Board of Health and Social Services of James Bay (CBHSSJB). As an Eeyou governed health and social services institution in Quebec, the CBHSSJB carries out research, evaluation and public health surveillance as part of its regular operations and most of these studies happen through public health. Research is always a supportive activity carried out to help improve programs and services

Beginning with a list of projects that are taking place in 2001, the principal section of this booklet presents an overview of the organisation and management of research within the CBHSSJB. The next section summarises research on diabetes that has been sponsored by the CBHSSJB. This is one of the most urgent health-care issues in Eeyou Istchee and a challenge shared with many other First Nations across the country. Finally, the last section lists the reports and documents that have been produced since the last bibliography.



## I **Approved projects being planned**

### **Community nursing model project:**

*'An investigation of how to integrate a model for community nursing into the context of Eeyou Istchee'*. Public Health.

**CBHSSJB Research Ethics:** *'A research project to develop a CBHSSJB Code of Research Ethics from the Cree language'*. Research Committee.

### **Community perceptions of teenage pregnancy:**

*'Babies are always wanted: implications of teenage pregnancy in Eeyou Istchee'*. Public Health.

### **Evaluation of the young child dental health program.**

Public Health.

### **Study of Cree leukoencephalopathy.**

Eeyou Awash Foundation, CBHSSJB with other partners.

### **Study of Cree encephalitis.**

Eeyou Awash Foundation, CBHSSJB with other partners.

## **Projects in progress**

### **Controlling diabetes: learning from Eeyouch who do it well.**

Karyne Cordeau, Caroline Levac, David Dannenbaum, Robert Harris, Jill Torrie.

### **Children's dental health: an evaluation of a pilot project that intervenes with parents of young children.**

Jacques Verroneau and Malika Hallouch.

### **A study of overweight and obesity in children.**

Noreen Willows, Kim Raine and Katherine Gray-Donald.

### **Infant feeding practices in Chisasibi: a qualitative study.**

Tanya Verrall and Katherine Gray-Donald.

### **Assessment of exposure to lead in country food among the Whapmagoostui Cree.**

Elizabeth Robinson, Tom Kosatsky, Laurie Chan, Naomi Adelson.



**Evaluation of diabetes education in Eeyou Istchee.**

Jill Torrie & Mavis Verronneau.

**Diabetes and mental health: a comprehensive literature review.**

Melanie Rock, Jill Torrie, Louise Richard, Aline Sabbagh.

**Public food services intervention and evaluation in Eastmain and Mistissini.**

Olivier Receveur; Johanne Cheezo, Stanley Gilpin, Wendy Moses, Jane Blacksmith, Bella Moses Petawabano, Beverly Quinn, Laurie Chakapash, Caroline Jimiken, Lorraine Paquette, Jill Torrie.

**Evaluation of an intensive family-intervention pilot project.**

Suzanne Roy, Bob Imrie, Laurent Brunet, Christiane Guay.

**Reanalysis of the Head Start needs assessment interviews in three communities.**

Catherine Godin, Rosie Bosum, Tina Fireman, Jessie House, Jane Blacksmith and Jill Torrie.



## **2** The organisation of research within the CBHSSJB

### **Background**

For over twenty years, the CBHSSJB has been sponsoring, carrying-out and promoting public health research in Eeyou Istchee. Organised in 1978 as a result of the James Bay and Quebec Northern Agreement (1975), the first comprehensive land claims settlement in the modern period, the CBHSSJB was the first regional health and social services institution under First Nations' control in Canada.

As an Eeyou institution within Eeyou Istchee, the CBHSSJB has a responsibility to show how research can reflect and respond to the questions, concerns and needs of Eeyouch, the nine communities and Eeyou entities. As an Eeyou institution within Quebec, the CBHSSJB is responsible for ensuring that research is carried out according to accepted standards recognised in law and by the research institutions of Quebec and Canada.

Although not responsible for all research on health and social issues in the territory, the CBHSSJB is the primary organisation carrying out research in this field. It has the authority to control how research is done within its jurisdiction. It either owns, or has the power to negotiate the terms of ownership of, data and results from research. It plays a key role in setting the priorities for research and in promoting collaboration and partnerships between all those who carry out research on these broad topics in the territory.

Besides its role in promoting research, the CBHSSJB is also responsible for protecting and safeguarding the rights and heritage of Eeyouch as the First Nation people of Eeyou Istchee and of Eeyou as individual members of their families and communities, whenever they are involved with research. The CBHSSJB does this in two ways. When the research is carried out under its jurisdiction, the CBHSSJB has set up open processes and procedures to make the research process transparent and accountable. For other research carried out in





the territory, the CBHSSJB leads by example by promoting and financing community-based and controlled research, keeping an up-to-date inventory of all research past and present, keeping an inventory of research data sets, developing a procedural manual for carrying out research, preparing a Draft Code of Research Ethics, sponsoring a project to develop a Cree language code of research ethics, and participating as a partner on research planning teams and committees outside of Eeyou Istchee.

Now the organisation is focused on promoting a greater Eeyou perspective on and involvement with the research agenda. This means an Eeyou perspective on and a Cree-language approach to the research questions that are asked, the methods that are used to ask the questions and the way that research is used in the organisation and the communities.

This also involves conscious planning to make research a tool that is used by entities, organisations and local governments to meet local needs. While research is always a means for furthering an understanding of the area researched, the research process can also be used for other purposes. A research project can be an excellent, hands-on training experience for research assistants. Projects often provide quality local and regional employment. Through a project, local communities and regions can gain access to experts and professionals that would not otherwise be available to them. (The gestational diabetes project gave four communities the services of two professional nutritionists during the field-work years of the project. The food services project is providing a large team of experts - professional chefs, dietitians, a certification program, and an expert in human nutrition - to two communities). And, research can be used to open up local discussion of difficult questions by providing an acceptable process that allows people in the community to begin to discuss the issues.

### **The complexity of research activities within the CBHSSJB**

The CBHSSJB runs an annual Public-Health Research Grants Program with Québec that is worth just over

\$100,000 per year; carries out 'in-house' research and evaluation projects, promotes participatory research projects with local governments and community groups within the territory, sponsors projects carried out by university-based partners, uses research findings to improve and develop programs and services and is developing a Cree language code of research ethics along with an Eeyou approach to developing processes to implement the code .

Public health research involves all types of 'participatory' research. The more innovative projects have provided means for local groups to carry out their own research or assessment processes, without help from professional researchers (La Rusic and Torrie 1995; Petawabano 2001). By contrast, Tanya Trevors reviewed charts on high birth weight babies (Trevors 2001) in a study that involved a partnership between the CBHSSJB and McGill. By its nature, this was not a particularly participatory study except at the administrative level. However, the dissemination of the findings from the study will involve the CBHSSJB in a planning exercise with the clinics and communities and the findings from this study point the way towards future, community-level, community-controlled studies.

The Public Health Research Grants Program (Québec) has allowed the CBHSSJB to target a great deal of prevention and health promotion research and evaluation to its own regional and organisational needs. This has been extremely valuable for carrying out small projects that are directed to improving programs and services and it has permitted the organisation to experiment with innovative approaches to participatory research. At the same time, the region benefits in many ways from its association with universities.

## The role of research within the CBHSSJB

Research within the CBHSSJB is carried out for purposes of furthering the primary goals of the organisation: to improve the health and well being of the people of Eeyou Istchee and to deliver comprehensive, effective and efficient health and

<sup>1</sup> Through different administrative channels, the Board also carries out research for administrative and planning purposes. This type of research is not discussed here.



social services. The organisation sponsors research that is designed to:

- respect and strengthen healthy community traditions and encourage understanding of community strengths;
- promote an Eeyou perspective;
- promote community, family and individual well-being and healthy lifestyles;
- profile the status of Eeyou health and well-being along with furthering understanding of their determinants;
- study issues related to ill health, bad lifestyle choices, and social problems for purposes of understanding how to prevent and change these situations and to recognise the protective features existing in situations where these problems do not exist;
- improve the capacity of the CBHSSJB and its partners to meet their responsibilities and obligations to the people of Eeyou Istchee, including collaboration and partnership with other organisations and local governments and training.

## **Planning research within the CBHSSJB**

Research is planned within the context of a young and fast-growing population of over 13,000 living in nine communities and bush camps in a territory of 375,000 km. To put this in perspective, Eeyou Istchee is equivalent to the size of Newfoundland or it is half the size of Alberta.

Typically, public health research is planned because of the intersection of four interests. First there are regional priorities and concerns that lead naturally to planning a project on the topic. Anaemia in infants was identified clinically as an issue. CBHSSJB staff set up a screening program for nine-month old infants. But to understand more about this, the CBHSSJB proposed the topic to a professor of nutrition who interested a doctoral-level student in the topic. The information from the study was taken back directly to the CBHSSJB staff and to the communities to help them better address the issue.

Second, there are provincial priorities. While Eeyou Istchee has a different population and health status profile than

many other regions, the provincial priorities have been identified because they are the guiding trends in how to address public health issues in Quebec. As well, the CBHSSJB receives money to develop programs and strategies in some of these identified areas, which are often issues at the regional level as well. For example, the work on developing a Cree school health curriculum met regional needs but is also recognised by the province.

Third, all research projects require special budgets. Here, the CBHSSJB benefits from the Quebec Public Health Research Grants Program – one of the very few regional-level research programs of its type. The CBHSSJB also benefits by tying into the resources of the universities. When a contract researcher is hired, the CBHSSJB must pay the entire professional costs of the project. When that work is done by a university-based researcher, the university is already paying that person.

And finally, in a vast region with a small population, research happens because someone – a researcher or a manager – has an interest in the topic and is willing to take it on. Research projects are intrusive in many ways and they make extra work. In a small region that always feels understaffed, a topic only becomes a project because someone is willing to do it.

## **The organisation of health research within the CBHSSJB**

Research and evaluation activities are co-ordinated through the Research Committee for the Board of Directors and the administration. The research office of the Public Health Module acts as the secretariat for the Committee and maintains the inventory of research projects and the registry of data storage. The Public Health offices in Montreal and Chisasibi have document repositories.

The Committee's members represent the Board, various sections of the CBHSSJB – administration, social services, health services and public health, and two community-based, Public Health Officers. Five of the nine members of the Committee are Eeyouch; three represent local governments.



The Committee reviews all discrete research and evaluation projects involving the CBHSSJB and its employees. At the present time, the Committee is playing two roles: planning, promoting and soliciting research and evaluation projects that involve the CBHSSJB, and acting as the regional 'watch-dog' to protect CBHSSJB interests as well as the interests of Eeyou individuals, families and communities in the face of research. While these two roles are complimentary, they also give the Research Committee contradictory interests in research that, at times, become apparent.

All projects pass through the Research Committee for either approval or recommendation to the Board or the Executive. Projects that always require Board approval include: all projects seeking direct financial support from the CBHSSJB; all projects that will directly involve the population in the communities; and, all projects for which Research Agreements are signed with outside research agencies and researchers.

### ***Letters of Understanding and Research Agreements<sup>2</sup>***

The CBHSSJB promotes accountability, partnerships, transparency in the process, joint decision-making, extensive reporting and, when appropriate, community control for research projects.

All projects are co-ordinated with a Letter of Understanding developed in the project-planning phase. This document sets out: the responsibilities and obligations of the parties; details on how project finances will be set up; decisions about ownership of, control of, access to and storage of the data from the project in the short and long-term; how issues of consent and confidentiality are to be handled; decisions about reporting the results; and, decisions about publishing the data including approvals for publications, rights of response to publications and so forth.

The Letter also sets up a CBHSSJB steering committee for each project that consists of the principal researcher, a contact for the Research Committee, and a principal contact

<sup>2</sup> See Torrie, J. (1999c). *Procedural manual for researchers conducting public health research with the Cree Board of Health and Social Services of James Bay, Cree Board of Health and Social Services of James Bay.*

for the CBHSSJB. The role of the principal contact is to help the project develop an implementation strategy within the organisation. This can be complex when different departments are involved and when significant staff time will be required.

For projects involving researchers from universities or other research institutes, a formal Research Agreement is developed from the draft Letter of Understanding and signed by representatives from each institution as well as the researchers. The organisation is developing a Long Term Agreement to govern continued use and access to project data after the termination of a project's Research Agreement.

### **Planning how the results of the project will be shared and used**

The CBHSSJB promotes transparency throughout the process of carrying out projects. This means that all partners are to be fully informed at all stages of the project and the results are returned to the organisation and communities of Eeyou Istchee in ways that are useful and coherent. This always involves popular language summary reports and often involves local communication systems such as radio interviews, news broadcasts and community meetings.

While the first interest of the CBHSSJB is to distribute and use the findings from research inside of the territory, the organisation also strongly supports general, scholarly publication of research results for a wide audience. In general, the organisation promotes publications in peer-reviewed journals where reasonable.

In some cases, a researcher may be obliged to ask permission to publish and to have all publications approved by the organisation. In other cases, a researcher will have the right to publish without approval by the organisation. However, the researcher will be obliged to submit the draft publication to the CBHSSJB and the CBHSSJB will retain the right to respond within the publication itself, either as an editorial comment in the journal or as an editorial comment within the article.





### **3 Research on diabetes in Eeyou Istchee and its role in programming**

#### **The place of research on diabetes**

Like other First Nation regions in the country, diabetes is one of the major health care challenges in Eeyou Istchee. Driven by its service mandate, the organisation has solicited, sponsored and carried out research into different aspects of the condition to help plan and develop services (clinical, social and preventive) to meet the needs of Eeyouch, the communities and the CBHSSJB.

While the numbers of studies may look impressive, especially compared to regions where there is no research tradition, the research on diabetes in Eeyou Istchee has provided only a little opening into some aspects of this 'epidemic'. The CBHSSJB has excellent, current information on the seriousness of the situation. It does not know much about how to change those trends. From the first notice of a growing problem, the organisation has shown willingness to support diabetes initiatives; but for a long time it lacked the resources. At the same time, standard programs like the Mother and Child Program, have also been seriously under-financed. It is ironic that, during the first decade or so of the 'epidemic', money for research was often more available than money for training, materials and programs.

#### **From research to services, programs and partnerships**

Since 1988, when nurses first alerted the CBHSSJB to the need for help in the clinics to meet the needs of the growing numbers of people with diabetes, diabetes planning has evolved step-by-step. It took ten years to find a budget to begin planning a Diabetes Program. During this time, research studies were invaluable for defining and marking out the issues to which the organisation and communities needed to develop appropriate responses. While the need for staff positions dedicated to diabetes was justified through the research studies, the budgets to permit these have only existed recently. In the interim, the CBHSSJB continued to do more studies and





some people worked on diabetes even though that meant fewer resources for other health-care issues.

In general, the evolution of diabetes planning has proceeded through identification of one aspect of the diabetes issue, research to define and understand that aspect, organisational changes to better address it (staff positions, new organisational structures, new programs), and a reassignment of budgets to support the organisational changes. While the organisational changes have been the key to improving the planning for and services to people with diabetes, they have been identified and justified through the research studies. For example, the implementation of a diabetes management system in the clinics, including clinical guidelines, has been very important for people with diabetes. These were put in place because people on staff were permitted to decide to work in this area.

In a similar way, the organisation supported staff when they proposed, initiated and provided the logistical support for the Cree Diabetes Network. This network is a partnership of CBHSSJB staff with people working at the level of the local government in the communities. It has been important for raising awareness about diabetes and for community mobilisation through the annual Sadie's Walks, special car-free and other topical days, health fairs and other activities of this type. Before there were any designated budgets for diabetes, the CBHSSJB supported these activities because the research studies showed the seriousness of the problem.

### **When you are reading about research on diabetes, don't just think about the research...**

Below are listed the research reports and work-in-progress on diabetes carried out in Eeyou Istchee since the late 1980s when diabetes first became a topic of research concern. The reports and articles were written to present the results of specific research or research-intervention projects. In turn, these projects were developed from and leading into other non-research activities in the communities and the region, such as clinical observations and community awareness activities to name only two.

## List of diabetes-related research projects from the earliest to the most recent<sup>3</sup>:

- 1983-1984: Cree Health Survey : random household screening for chronic lifestyle diseases (gathered non-fasting blood glucose levels): all communities
- 1989-1990: Study of numbers of cases of diabetes: all communities
- 1989-1991: Santé Québec Cree health study (included fasting blood glucose levels, and nutrition and lifestyle questions): all communities
- 1990-1991: Diabetes education: pilot project and evaluation: Mistissini
- 1990-1991: Study on children's overweight and physical activity: Chisasibi and Eastmain
- 1991-1993: Study of Cree women's diets: Eastmain and Wemindji
- 1992-1993: Eating habits of Cree schoolchildren: Chisasibi and Eastmain
- 1995-1996: Cree experience of diabetes study: all communities
- 1995-1997: Gestational diabetes project: Chisasibi, Mistissini, Waswanipi, Wemindji
- 1996-2000: Diabetes registry project: all clinics
- 1997-2002: Diabetes education evaluation and program implementation: all clinics
- 1998-2001: Market foods and the quality of the Cree diet project: Eastmain and region
- 1998-2000: Study of high birth weight babies: all clinics
- 1999-2000: Diabetes special screening project: Eastmain and Waswanipi
- 2000 summer: Diabetes and stress project: Chisasibi
- 2000-2003: Overweight and obesity in Cree children: all clinics and likely 3 communities
- 2000-2003: Infant feeding beliefs and practices: Chisasibi
- 2001-2002: Public food services project: Eastmain and Mistissini
- 2001 summer: Diabetes control project: Chisasibi and Waskaganish

<sup>3</sup> The dates indicate approximately the time when projects were obvious within the region from the approval of the project to the end of the fieldwork component. In most cases, reports appeared much later.

## Dates of the CBHSSJB Diabetes Program:

1998 -2000: CBHSSJB diabetes program: planning phase

from 2000: CBHSSJB diabetes program

## Studies counting the numbers of people with diabetes and setting up a permanent diabetes registry

According to anecdotal reports, in the 1960s physicians working in the Cree region rarely encountered diabetes. Unfortunately, by the 1980s this situation had changed.

The first incomplete count of the numbers of people with elevated sugar levels was done as part of a health survey carried out between 1982 and 1984 among the Cree and Inuit of Quebec (Ekoe, Thouez et al. 1990; Thouez, Ekoe et al. 1990). A more comprehensive study by the Public Health Module Cree Region established the numbers of people with diabetes in 1989 and published the results as a popular summary (Brassard 1989), in a thesis (Brassard 1991) and in several journal articles (Brassard, Robinson et al. 1993; Brassard, Robinson et al. 1993).

In 1993, Mavis Verronneau, the late regional diabetes educator, updated the 1989 work for purposes of internal planning and identified the need for a permanent registry. Developed in 1996-97 and sustained primarily because of the continuing commitment of Dr. David Dannenbaum<sup>†</sup>, the Diabetes Registry and management system has become a permanent surveillance program of the CBHSSJB with results reported in an annual publication for the region and each community (Dannenbaum, Verronneau et al. 1999; Cree Board of Health and Social Services of James Bay Serial (from 1996)) and in the on-going profile of Cree health maintained by public health (Schnarch, Robinson et al. 2001).

In 2000, the validity of the Registry was assessed against the results from a comprehensive screening for diabetes of residents aged 10 and over in two communities (Dannenbaum

<sup>†</sup> Dr. Dannenbaum took-on the responsibility for the registry when working as a family physician in Waskaganish. Since returning to Montreal in 2000, he has not only continued to return to work in the community one week a month, but has also continued his leadership role with the registry.

2001). This was a joint project of the Cree Nations of Eastmain and Waswanipi and the CBHSSJB.

In the mid-1990s, at the request of the CBHSSJB, Katherine Gray-Donald of McGill University and Elizabeth Robinson the co-ordinator of public health for the CBHSSJB, began a study to establish the number of women with gestational diabetes and to evaluate a dietary intervention with pregnant women (Rodrigues 1999; Rodrigues, Robinson et al. 1999; Rodrigues, Robinson et al. 1999; Gray-Donald, Robinson et al. 2000; Rodrigues, Robinson et al. 2000). (See also Hall 1999).

## **A diabetes program and diabetes education**

The groundwork for the diabetes program was laid in public health and later moved to the CBHSSJB services<sup>5</sup>. When the numbers of people with diabetes began to increase in the late 1980s, the Public Health Module organised Brassard's study and, in the early 1990s, hired Mavis as a part-time diabetes educator. In late 1995, the CBHSSJB made diabetes a health priority and established a Diabetes Task Force as an innovative structure within the organisation to integrate all the services and programs related to the condition. However, the organisation was not able to find a budget to begin program planning until 1998. In 2000, Louise Richard, a nurse and diabetes-educator, took on the formidable task of setting up a diabetes program in the region with nutritionist-educators and specially trained Community Health Representatives (CHRs).

Public health has organised three research-evaluation projects on diabetes education, as this is the basis for a diabetes program. In the early 1990s, a pilot diabetes education project was evaluated in Mistissini (Lavallée, Robinson et al. 1994; Lavallée, Robinson et al. 1994), before diabetes was declared a priority by the organisation. In the late 1990s, the Canadian Diabetes Association provided a travel grant to carry out a pre-and-post evaluation of the readiness of clinic staff for delivering diabetes education (Torrie and Verronneau).

<sup>5</sup> In Quebec, public health plans and organizes prevention and health promotion approaches at the regional level, but it does not deliver the actual services.



The first stage was completed but the second has not yet taken place<sup>6</sup>

However the principal study in diabetes education was the multi-faceted, gestational diabetes project in the mid-1990s that was built around a diabetes education intervention with pregnant women (Gray-Donald, Robinson et al. 2000). Sponsored by the CBHSSJB, this was a collaborative study between four communities, the regional board and the university. The final report in 2000 from the primary study appeared in conjunction with a commentary from a group of Cree women (Special Working Group of the Cree Regional Child and Family Services Committee 2000).

## Other studies on diabetes

As part of the evaluation of the pilot project on diabetes education in the early 1990s, the researchers looked at how people were able to control their blood sugars while living away from the permanent community in a bush settlement or in a bush camp (Robinson, Gebre et al. 1995). In the mid-1990s, a team of researchers and CHRs studied how Eeyou patients and their families experienced diabetes along with the views of health-care workers – primarily non-Eeyou – on diabetes care in the region (Bobbish-Rondeau, Boston et al. 1996; Boston and Jordan 1997). The Diabetes Task Force was given the responsibility of implementing the recommendations from the study.

The frequency of high birth weight babies and the numbers of them with mothers who had gestational diabetes was the topic of several studies by students of Dr. Gray-Donald (Armstrong, Robinson et al. 1998a; Armstrong and Robinson 1998b; Rodrigues, Robinson et al. 2000; Trevors 2001).

The first part of the evaluation of diabetes education in the late 1990s (Torrie and Verronneau) showed that health-care workers in the region were generally unaware of the psycho-social implications of diabetes. This led to a medical student project in the summer of 2000 on diabetes and stress (Cordeau and Harris 2001), a literature review that is in

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<sup>6</sup> The implementation of the diabetes education program was delayed by a labour strike of nurses, planning for the diabetes screening project, and the illness and death of the diabetes educator, Mavis Verronneau in 1999-2000.

progress on diabetes and mental health (Rock, Torrie et al.) and a medical student project in the summer of 2001 on how people control their glucose levels (Cordeau, Levac et al. 2001). These reports will be used to plan and develop a training module for health-care workers.

## **Other studies on topics related to diabetes**

Studies on nutrition and overweight, including size at birth, have either direct or indirect implications for our understanding of how to prevent diabetes. Overweight is an important risk factor for Type 2 diabetes in Eeyou Istchee (Dannenbaum 2001) and high birth weight may be linked to gestational diabetes.

However, studies in other areas such as family violence, inadequate housing, and services and school health are also indirectly important for understanding how to prevent diabetes and to help people with diabetes achieve good control. At first blush, family violence and housing may appear to be unrelated to the topic of diabetes. However, some researchers have associated diabetes and poor diabetes control with stressful living conditions. If this is true, then initiatives to prevent family violence (Mistissini Native Women's Association) improve housing (Harris-Giraldo, Soares et al. 2001; O'Neil 2001) and promote healing and wellness (Nemaska First Nation 1999) should be included in research on topics related to initiatives to prevent diabetes<sup>7</sup>.

## **Thoughts on the direction of research in the future**

Contrary to screening projects in other First Nation communities, the screening study in Eeyou Istchee did not find high numbers of people with undiagnosed diabetes. This was because most people had already been diagnosed by the clinics. The study found that the major challenge for diabetes prevention in Eeyou Istchee is overweight and obesity (Dannenbaum 2001). This was also one of the findings of the gestational diabetes study. In the future, diabetes research will likely involve studies on issues of nutrition, physical activity and

<sup>7</sup> The studies in all of these areas – nutrition, family violence, inadequate housing, services and school health – are addressed in the main bibliography to avoid repetition.



how to carry out effective interventions with people with diabetes. Future research will also encompass evaluations of innovative approaches that adopt holistic approaches to diabetes prevention and promote changing community lifestyles from an Eeyou perspective.



## 4 Reports and current projects

This update lists most of the research projects concerning health-related topics carried out since the 1993 bibliography (Lavallée and Robinson 1993). Some studies, from 1993 or earlier, that are still in use are also included.

### Public Health Research In Eeyou Istchee

#### CHILD HEALTH

The Public Health office keeps a birth registry for Eeyou Istchee and publishes an annual summary for distribution in the region (Public Health Module Cree Region of James Bay 2001).

One baby in four or five is born to a teenage mother (under age 20). Around 330 babies are born in the region each year: **Teenage pregnancy** was the focus of an interesting paper by the paediatrician, Dr. Johanne Morel (Morel 1989), a report by Dr. Joyce Pickering and Cathy James (Pickering and James 1991), and a thesis by the latter (James 1992). In the late 1990s, a small survey in Chisasibi of women who had been teenage mothers was poorly designed and difficult to interpret. Now, the CBHSSJB is planning a synthesis report on teenage pregnancy that will include consultations within the communities in the Cree language (Public Health Module Cree Region of James Bay).

In the 1990s, the largest project on child health has been the gestational diabetes study (Gray-Donald, Robinson et al. 2000) which was discussed under the topic of diabetes research above. This study gave rise to a number of unanticipated, but related, studies on **birthweight** done by students of Dr. Gray-Donald from the Department of Dietetics and Human Nutrition at McGill. Unlike other regions in the country, babies in Eeyou Istchee are more likely to have a high than a low weight at birth. Although in general high birth weight is positive, it was not known at what point high birth weights began to cause problems for the babies and the mothers. The relative numbers of high birth weights were explored in a paper (Armstrong, Robinson et al. 1998a; Armstrong and





Robinson 1998b). A side-study to the thesis on gestational diabetes by Shaila Rodrigues looked at the relation of high birth weights to mother's gestational diabetes (Rodrigues, Robinson et al. 2000). And a master's thesis by Tanya Trevors recently showed the extent to which babies over 4000 or 4500 grams experience problems compared to babies under those weights (Trevors 2001).

Besides the recent work of Trevors on injuries of high birth weight new-borns, the only other published study on children's disabilities is one from the late 1980s (Pelchat and Larson 1985; Larson, Pelchat et al. 1988). The recommendations from this study were repeated and a rough count of disabled children up to age six was included in the regional needs assessment report for the Head Start Program (Torrie and Petawabano 1999b).

In the mid 1990s, Dr. Johanne Morel, the consulting paediatrician to the coastal communities, promoted systematic testing of infants at nine months of age for **anaemia**. From this clinical observation of a potential problem, the CBHSSJB sponsored the research of a doctoral candidate, Noreen Willows, also a student of Dr. Gray-Donald, to carry-out a comprehensive study of the problem (Willows 2000; Willows, Morel et al. 2000; Willows 2000; Willows, Dewailly et al. 2000). (See also (Godel 2000)).

For her post-doctoral research at the University of Alberta, Dr. Willows is now exploring the relationship between infant feeding, gestational diabetes and children's growth patterns up to the age of five years to determine if breastfeeding is a protective factor in preventing **overweight and obesity in children** and the role played by gestational diabetes in children's growth (Willows, Raine et al.). In its second year, this study will work with women in several communities to explore the dynamics of breastfeeding and how adults perceive the size of children.

- ◆ At present, the region does not have a system in place
- ◆ to track rates of breastfeeding. In 1994, in a community-based
- ◆ study in Mistissini, Dr. Joyce Pickering described the low rate and
- ◆ made recommendations to help improve it (Pickering 1994).

A study that is presently being completed compared data sets for 1988 and 1993 collected by Health Canada in most of the communities (Koczorowski, Levitt et al.; Health and Welfare Canada 1990). The 1999 community-directed needs assessment studies for the Head Start Program gathered some data in each community (Torrie and Petawabano 1999b) and a Chisasibi initiative carried out focus groups and open-line radio shows in the mid 1990s (Harris-Giraldo). Since the summer of 2001, all data that exists on breastfeeding is compiled in the Public Health statistical profile (Schnarch, Robinson et al. 2001).

Elements from all of the separate investigations of infant feeding are being brought together in a qualitative study on parents' **understandings and practices of infant feeding** in Chisasibi by Tanya Verrall, another doctoral candidate working under the direction of Dr. Gray-Donald (Verrall and Gray-Donald).

In 1999, each community carried out a Head Start needs assessment study (Torrie and Petawabano 1999b). Three communities, Chisasibi, Mistissini and Oujé-Bougoumou are participating in a computer-assisted analysis of their interviews that were previously counted by hand during each community's study. The computer-assisted analysis will give them a more complex **portrait of the families with young children** (Godin, Bosum et al.).

The **dental health of infants** (12-24 months) and children has been the focus of an evaluation of a pilot project by the region's public health dentist, Jacques Verroneau (Verroneau and Hallouch). At present, he is also planning a new dental health intervention program for infants 12 to 24 months with a strong evaluation component (Verroneau and Hallouch).

The CBHSSJB has been involved in two genetic studies in the 1990s. In the mid 1990s, several families from Waskaganish, the Cree Nation of Waskaganish and the CBHSSJB participated in a national study of spina bifida (Arbour 2001). At present, the CBHSSJB is working with the Eeyou Awash Foundation in Chisasibi to help them arrange research into Cree leukoencephalopathy (Eeyou Awash Foundation 2000-2001) and Cree encephalitis (Eeyou Awash Foundation 2000-2001). This has



involved developing appropriate processes between the Eeyou Awash Foundation and the CBHSSJB and between the region and outside researchers to ensure that Eeyou interests are protected while research is promoted.

## DIABETES

See the section on diabetes research

## ENVIRONMENTAL HEALTH

In the mid 1990s, Dr. Elizabeth Robinson did a directive for the Community Health Program on drinking water quality (Robinson 1995). In part because of the *James Bay and Northern Quebec Agreement* and the *Cree Naskapi Act*, the responsibility for certain areas of environmental health is not always quite clear. At present, a resident in community medicine is examining the role of public health with drinking water quality. Confusion also exists in related areas, such as public food service inspection.

**Mercury** has been the largest public health research program in the region, however the administration of the program was separate from public health. Most of the studies involving the region were included in the 1993 bibliography (Lavallée and Robinson 1993) with only a few written after that time as the program was winding down (Girard 1994; Comité de la Baie James sur le mercure 1995; Girard and Dumont 1995; Chevalier, Dumont et al. 1996; Dumont 1996; Girard, Noël et al. 1996).

When indicated by certain clinical symptoms, a doctor may order a test to rule out **lead poisoning**. In the late 1990s, some children and adults in Whapmagoostui showed higher than normal lead levels. Because of this, more monitoring was ordered and a study initiated (Robinson, Kosatsky et al.). The source is suspected to be lead shot. As the manufacturing of lead shot for hunting waterfowl is now illegal, lead levels in humans will fall and the situation in Whapmagoostui will be followed until the levels have returned to normal.

## FAMILY VIOLENCE

Project Chiyaameihtamuun (Harmony): Mistissini Family Violence Project carried out a large community survey and is planning to involve the other communities in discussions about strategies to address violence and promote harmony (Mistissini Native Women's Association).

## HEALING, WELLNESS AND HEALTH SERVICES

In the early 1980's, a Cree-language publication from Mistissini discussed Cree medicines (Blacksmith 1981). More recently, three reports have looked at Eeyou practices in relation to healing and wellness. Traditional healing practices are documented in a draft report that will be available soon. This was a project from the early 1990s that grew out of activities in Chisasibi. (Marshall, Diamond et al. 1989; Marshall and Chiskamish-Neepash 1996). Another study from Chisasibi looked at how to approach palliative care from an Eeyou perspective (Harris, Iserhoff et al. 1999a; Harris 1999b). A study from the early 1990s remains the only published source to discuss Eeyou approaches in relation to formal Social Services (Niezen 1992), although this is the topic of a project that is beginning at present (Roy, Imrie et al.).

In the late 1990s, a study on introducing transcultural nursing care concepts into the region had not been completed because of the death of France Belanger, the manager responsible for the project (Torrie and Roy). Recently, the CBHSSJB has agreed to expand the scope of this project to look at the issues in implementing a **model for community health nursing** into the region that would include notions of **cultural competency and transcultural care** (Caron, Torrie et al.).

In the area of **mental illness**, Sheila Hardy and Joyce Helmer prepared a report on the results of interviews with people with mental illness and their families (Hardy and Helmer 2000). CBHSSJB Social Service workers, who are also students in the Bachelor of Social Work Program, did the fieldwork for this study as part of their research training.

Using a very different approach, some members of the Native Mental Health Research Team in Montreal re-analysed



the Santé Québec health study data from 1991 with a focus on all the questions pertaining to **psychological distress**. (Kirmayer; Boothroyd et al. 2000). Prince, a psychiatrist who had worked in the region, published a paper in the early 1990s on pathological grief reactions (Prince 1993). In the mid 1990s, the Mindes, a husband-wife, psychiatrist-psychologist team, published a summary of one hundred consultations with children and adolescents without telling anyone or seeking any permission to use CBHSSJB files (Minde and Minde 1995). This paper caused great distress in Mistissini. The community was identifiable in the paper. As well, the Mindes described a small group of adolescents with identifying characteristics – recognisable as a known group to anyone from the community – and claimed that half were being abused in their homes.

A joint project of the Cree Nation of Mistissini and the Inland CLSC, one of the CBHSSJB service centres, used self-assessment tools to examine Mistissini **helping services** in 1999. In 2001, they carried out a shorter re-assessment to determine what had changed in the interim. Their report (Petawabano) will reflect on the process.

In 2000, this self-assessment model was also adapted for work on **integrating services** – or how services can work together for the benefit of the clients (Torrie and Petawabano 2001). The CBHSSJB financed a large regional workshop on the topic in the summer of 2000 (Petawabano and Torrie 2001).

Formerly, the Public Health Module used to analyse out-patient health services every few years (Bjerre and Pickering 1994; Bjerre and Pickering 1994). At the moment this aspect of public health surveillance has been put-on-hold waiting until the new systems are in place in the clinics and CLSCs. Ever so slowly, several computerised systems linked to a federal, Health Information System for immunisations, and to the new provincial system for the CLSCs, are being implemented.

Public health is also responsible for the protocols and sub-programme directives for the Community Health Program of the CBHSSJB. Recent updates have included an overview of community health (Robinson 1995), maternal and child health (Caron 1995), notifiable diseases (Smeja 2001), tuberculosis (Desrosiers, Caron et al. 2001 (1999)), hepatitis B (Smeja and

Robinson 1995), enteric infections (Smeja 1995), influenza (Beloin and Smeja 1995), HIV (being revised), rabies (Pickering 1996), in-school screening (Beloin 1995), dental health preventive program (being revised), school nutrition (Leclerc 1995), adult health (Public Health Module Cree Region of James Bay 1995), bush kit program (Beloin 1995), mercury exposure (Noël 1992) and water quality (Robinson 1995).

## HEALTH STATUS

The public health office maintains a birth and death registry for Eeyou Istchee and contracted a comprehensive report on mortality in the mid 1990s (St-Pierre 1995).

Recently, public health has organised a binder and CD-ROM that compiles all statistics on Cree health status in one source (Schnarch, Robinson et al. 2001). This will be updated periodically and used within the region by those planning health and other services. Besides data from the region and from the Ministry of Health and Social Services in Quebec, the principal source for the binder is data from the 1996 census.

The last official report from the 1991 Santé Québec Cree Health Survey appeared in late 1998 (Daveluy, Lavallée et al. 1994; Daveluy and Bertrand 1998). However, two recent studies, respectively psychological distress (Kirmayer, Boothroyd et al. 2000) and detailed examinations of comparative nutrition (Receveur, Godin et al.), have demonstrated that health survey data can produce very rich results when re-analysed for a particular question, even ten years after the data has been collected.

## HOUSING

Several years ago, the public health team in Chisasibi began a summer project with the Cree Nation of Chisasibi to examine the problem of mould in homes. This year the final report was completed (Harris-Giraldo, Soares et al. 2001), along with a survey of the literature by Prof. John O'Neil from the University of Manitoba (O'Neil 2001), and presented to a federal parliamentary committee.



## INJURY PREVENTION

Injury prevention was the subject of a detailed study by Dr. Peter Barss in the mid-1990s. In the end, longer reports were prepared on two topics, suicide (Barss 1998c) and falls (Barss 1998b), while short, four page reports were produced on suicide (Barss 1997b), falls (Barss 1998a), drowning (Barss 1997a) and guns (Barss 1997c).

## NUTRITION AND DIET

The principal study on nutrition and diet in the 1990s was the Santé Québec Cree Health Survey (Daveluy, Lavallée et al. 1994; Daveluy and Bertrand 1998).

In the early 1990s, **overweight in Cree schoolchildren** was studied in Chisasibi and Eastmain in relation to diet, physical activity and television watching (Bernard and Lavallée 1993; Bernard and Lavallée 1993; Bernard, Lavallée et al. 1995). In the late 1990s, the Cree Nation of Eastmain carried out interviews with school children, children's parents, elders and teachers and found that many children were not eating breakfast because they were going to bed too late at night and rising too late in the morning (Cheezo, Godin et al. 2001).

During the same period, women's diets were studied by Delormier in Wemindji and Eastmain (Delormier and Kuhnlein; Delormier, Kuhnlein et al. 1995; Delormier 1995).

As mentioned earlier, Willows carried out a comprehensive study of **children's anaemia** (Willows 2000; Willows, Morel et al. 2000; Willows 2000) and she is presently studying **children's obesity** in relation to breastfeeding and gestational diabetes (Willows, Raine et al.). Verrall is working with parents to understand the role of **infant feeding practices** in relation to anaemia and other problems so that appropriate health promotion approaches can be developed (Verrall and Gray-Donald). Unfortunately, the region does not yet have a systematic surveillance of **breastfeeding** rates. Surveys in 1988, 1993 and interviews as part of the Head Start needs assessment studies in 1999 showed that while regional rates tend to be high in relation to Quebec, there is great variation between communities (Schnarch, Robinson et al. 2001). (See also (Koczorowski, Levitt et al.; Harris-Giraldo)).

A study on Market Foods and the **Quality of the Cree Diet** carried out a meta-analysis of all the literature on Cree diabetes, anthropometry and nutrition and found an association between overweight and quality and quantity of fat consumed (Receveur, Godin et al.). As part of this work, Receveur and team carried out a detailed reanalysis of the nutrition data (Daveluy and Bertrand 1998) from the last health survey (Daveluy, Lavallée et al. 1994), showing just how important health surveys are for gathering comprehensive data that can be used to understand changes in health status.

The Quality of the Cree Diet study was started through a request from the Cree Nation of Eastmain. Although that study did not have a community-based component, it did have community partners. In 2001, the project moved into the Public Food Services Project as a means to take its findings to the communities in a practical way (Receveur, Cheezo et al.). Working with restaurants, childcare centres and helping with other public food services, this project provides a chef, dietician, and a certification program as resources for these local businesses and services. Karoline Gaudot, a student in nutrition from the University of Montreal, is evaluating the project.

### **PHYSICAL ACTIVITY**

In the conclusion to the section on diabetes, physical activity was mentioned as an area that will most likely receive more research attention in the near future. The studies in this area were all carried out from the late 1980s through the early 1990s (Lavallée 1987; Lavallée 1990; Lavallée 1990; Lavallée and Robinson 1991; Lavallée and Valverde 1992; Lavallée and Valverde 1992; Valverde and Pickering 1993; Lavallée 1994; Bernard, Lavallée et al. 1995).

### **RESEARCH**

In the early 1990s, the CBHSSJB funded an innovative approach to **participatory research-self-assessment**. La Rusic and Torrie used the Eyestone System to develop tools to permit a community self-assessment of social services (La Rusic and Torrie 1995). As mentioned above, these tools were used by the Cree Nation of Mistissini and the Inland CLSC to





examine the helping services in Mistissini in 1999 and 2001 (Petawabano). In another project, they were adapted for the Head Start needs assessment studies (Torrie and Petawabano 1999a). In this project, the tools permitted the communities to carry out a complex study with many parent interviews, key informant interviews and community data-gathering on their own, including data analysis and presentation of a report (Torrie and Petawabano 1999b). The model behind this approach was also used to organise the project on integrating services (Petawabano and Torrie 2001).

In 2000, the CBHSSJB encouraged another new approach to participatory involvement of local people in formal research studies about them. The final report of the multi-faceted gestational diabetes project focussed on the actual intervention with pregnant women (Gray-Donald, Robinson et al. 2000). This intervention had not made a difference. A group of Cree women in the field considered, in hindsight and in print, how the study might have shown better outcomes through a more intensive planning to build greater community involvement with it (Special Working Group of the Cree Regional Child and Family Services Committee 2000). A non-Eeyou working for public health served as their editor. This research report and commentary were the subject of a letter to the editor (Macaulay, Gibson et al. 2001) and a response (Torrie 2001)<sup>8</sup>.

As set out in the first section, the CBHSSJB has been developing its research processes over the past number of years (Torrie). At present, public health uses a procedural manual to guide the various types of researchers (Torrie 1999c) and the Research Committee has a draft code of research ethics (Torrie). The Committee is also planning a study to develop a code of research ethics, along with procedures for applying research ethics in and from the Cree

<sup>8</sup> Some people have asked how the commentary was written. It was compiled in the following way. The Special Working Group met through teleconference, fax and e-mail and commented on a summary of the study that had been vetted by the principal author. Their comments were edited into the form wanted by the CMAJ. This edited version was then further edited by the CMAJ. After the questions about the authorship appeared, the women who had participated went through the published commentary and their own notes and documents to identify which person had contributed which ideas. The researcher had contributed summary statements, references and the condensing necessary to meet the 800-word limit. This was similar to the role of the CMAJ editor.

language (Research Committee 2001). In 2001, the Committee is working on expanding its use of checklists for assessing projects.

Concern about research ethics has been highlighted with the planning for genetic research into Cree leukoencephalopathy (Eeyou Awash Foundation 2000-2001) and Cree encephalitis (Eeyou Awash Foundation 2000-2001). The CBHSSJB has benefitted from the expert advice from ethicists at McGill and the University of British Columbia.

### **SCHOOL HEALTH**

In the mid-1990s, the CBHSSJB signed a Protocol with the Cree School Board setting out how they should work together and commissioned an implementation study (Petawabano 1998; Petawabano and Torrie 1999).

Since the late 1990s, the Cree School Health project has been a collaborative project between the two Boards (Murphy 1997; Barrington 2000; Barrington 2001; Barrington 2001).

### **SEXUALLY TRANSMITTED DISEASES**

Eeyou Istchee has continuing high rates of some sexually transmitted diseases, especially chlamydia. Last year, the CBHSSJB targeted HIV-AIDS as a prevention priority for the region.

There have been two small studies on HIV-AIDS. The first looked at knowledge and attitudes of secondary school students (Coubeil 1993) and the second was an AFN sponsored pilot project for a community-based approach to studying risk factors (Desminathan, Anderson et al. 1998). This pilot project took place in Mistissini and Waswanipi. In Waswanipi it was linked to a local study planned by the clinic that remains incomplete (Cree Board of Health and Social Services of James Bay 1998).

### **SOCIAL AND OTHER SERVICES**

The region has not had much research on social services. The study of Niezen looked at traditional helping systems in



relation to social services (Niezen 1992) and a study being planned will look at developing a more Eeyou focus on working with problem families (Roy, Imrie et al.). As well the CBHSSJB developed self-assessment tools that would permit communities to sit down and examine their services (La Rusic and Torrie 1995). Mistissini and the Inland CLSC carried this out in two stages in 1999 and 2001 (Petawabano 2001).

The organisation of services in general is an important issue, especially in light of serious chronic diseases like diabetes that are preventable at the population level. Obviously, everyone in the community and region needs to work together to prevent a condition like diabetes. Obviously this is easier to say than do. When the CBHSSJB established the Diabetes Task Force in the mid-1990s, it was leading the way by creating a structure within the Board to integrate all services (Petawabano 1998; Petawabano and Torrie 2001; Torrie and Petawabano 2001) dealing with diabetes (Verronneau 1999). In 2000, the CBHSSJB sponsored a workshop on the topic of integrating services (2001; Torrie and Petawabano 2001).

### **TOBACCO AND DRUG USE**

In 1996, the CBHSSJB participated in a First Nation youth inquiry into tobacco use (CIET). Money from the solvent abuse program was used to extend this participatory research to look at the abuse of other drugs. Richard Shecapio and Issac Iserhoff from Mistissini completed a community-level study (Shecapio and Iserhoff 1996) and the consultants prepared a regional level report (CIET 2001).

### **TUBERCULOSIS**

In earlier years, tuberculosis was a significant public health problem in the region. Public health maintains an active tuberculosis program with an updated protocol within the Community Health Program (Desrosiers, Caron et al. 2001 (1999)). Dr. Christina Smeja, responsible for infectious diseases at public health, and Dr. Paul Brassard, who carried out the first study on the number of cases of diabetes in 1989, prepared a recent paper on the current situation of tuberculosis infection in Eeyou Istchee (Smeja and Brassard 2000).

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**Ex. 2**

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**AUTEUR**

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CREE BOARD OF HEALTH AND SOCIAL SERVICES OF JAMES BAY  
- PUBLIC HEALTH TEAM AND RESEARCH COMMITTEE

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**TITRE :**

PUBLIC HEALTH RESEARCH IN EYYOU ISTCHEE :  
REPORTS, CURRENT PROJECTS AND A SUMMARY OF  
RESEARCH ON DIABETES

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**Ex. 2**

