

# Empowering Words of First Nations Women



Manual for speaking out  
About Life, Health and... Diabetes



This book is also available in French under the title:

**Paroles et pouvoir de femmes des Premières Nations**

**Manuel pour une prise de parole sur la vie, la santé... le diabète**

The manual was originally written in French. In case of discrepancy, the French version takes precedence over the English version.

Graphic Design: Christiane Vincent

ISBN 0-9687619-1-7

**Empowering Words of First Nations Women –**  
Manual for Speaking Out about Life, Health and... Diabetes

**This project is an initiative of the**

**FIRST NATIONS OF QUEBEC AND LABRADOR  
HEALTH AND SOCIAL SERVICES COMMISSION (FNQLHSSC)**

250, Place Michel-Laveau, Wendake, Quebec, G0A 4V0

Telephone: (418) 842-1540 - Fax: (418) 842-7045

Web site: [www.cssspnql.com](http://www.cssspnql.com)

Project Manager: Bernard Roy, Health Anthropologist

Associate Researcher (analysis-drafting): Katia Fecteau, Health Anthropologist

Field Investigation:

Anastasia Bacon, Katia Fecteau, Geneviève Mercille, Bernard Roy

Research Work Supervision Committee:

Chantale Bacon, Jane Gray, Annette Malec, Anne St-Onge, Francine Vincent

**We would like to thank:**

The communities visited: Wemotaci, Manawan, Opitciwan, Mashteuiatsh, Mingan, Natashquan, La Romaine, Listuguj, Gesgapegiag.

The management of the Betsiamites Innu health services, which gave financial support for Bernard Roy's doctoral research on diabetes among the Montagnais. With the authorization of this organization, large segments of Mr. Roy's doctoral thesis were used in the development and implementation of the FNQLHSSC project.

The project was subsidized in part by the Centre d'excellence pour la santé des femmes (Centre of Excellence for Women's Health), Consortium Université de Montréal (University of Montreal Consortium), through the Canadian Centres of Excellence for Women's Health Program.

The photographs were kindly provided by the Ministère de l'Éducation du Québec and by the Bernard Roy collection. They may not be reproduced without permission.



## TABLE OF CONTENTS

Introduction .....	3
Diabetes and First Nations Women .....	5
The extent of diabetes among First Nations persons . . . . .	5
Risk Factors and Consequences of Diabetes . . . . .	6
Does increasing people’s knowledge of diabetes help? . . . . .	8
Philosophy of this manual .....	9
Where did the raw data for this manual come from? .....	11
Who is the manual for? .....	12
How to use this manual.....	13
Toolbox for forming and facilitating discussion circles .....	14
Who may facilitate a group discussion? . . . . .	14
Recruiting members for the discussion group. . . . .	14
Time and place for discussion group meeting. . . . .	15
How to hold a meeting . . . . .	16
How to facilitate group discussion. . . . .	17
Creating self-help groups.....	20
The Need for Self-help in First Nations Communities . . . . .	21
Characteristics of Self-help . . . . .	24
The Paradoxical Role of Professionals in Self-help . . . . .	26
On the Principle of Equality: The Legend of Wésukechak and the Wild Geese . . . . .	27



Appendix: The circle of health or the “concept of health”: an Example from the Unamen Shipu community (La Romaine)..... 29

    Why do we define the Unamen Shipu concept of health? ..... 29

The Unamen Shipu popular concept of health ..... 31

    Family and health ..... 31

    Health and the individual. .... 31

    Food and health ..... 33

    Community, culture and health ..... 33

    Social role and health ..... 35

    Health, sickness and health professionals ..... 36

    Conclusion ..... 37



## Introduction

This manual is the product of two years of concerted efforts by many persons. The idea to develop a manual to prevent diabetes among First Nations women in Quebec came after the FNQLHSSC attended the 4<sup>th</sup> International Conference on Diabetes held in San Diego in 1997.

With support from a grant in 1998 by the centre for Excellence in Women's Health (a consortium of Université de Montréal) the FNQLHSSC secured the expertise of Mr. Bernard Roy to direct the creation of the manual. Mr. Roy had previously gained extensive experience in First Nations Health issues, stemming in part from his doctoral research on diabetes in Betsiamites. Through his research, he has developed hypotheses based on his in-depth knowledge of diabetes among Quebec First Nations peoples. The result is this manual, which presents an original and innovative approach to the problem. Three experienced professionals - Katia Fecteau, Anastasia Bacon and Geneviève Mercille - worked with Mr. Roy to complete the manual. Ms. Fecteau, an anthropologist specializing in gender and health issues, co-directed the project and conducted field research. Ms. Bacon, a nutrition technician originally from Betsiamites, and Ms. Mercille, a nutrition consultant for the Atikamekw Nation, both closely involved in First Nations health issues, helped carry out the field research. The compilation and analysis of the vast body of information that was gathered, and the preparation of the manual were entrusted, again under the supervision of Bernard Roy, to Katia Fecteau.

The introduction first provides an overview of the scope of diabetes among First Nations persons, including its causes and consequences. It then describes the process which led to the creation of this manual and the way in which it is to be used. It concludes with a number of reflections on self-help, or peer counselling, and on the conditions that foster its emergence.





# Diabetes and First Nations Women

## The extent of diabetes among First Nations persons

Type II diabetes is an alarming phenomenon among First Nations and is beginning to reach epidemic proportions, particularly among middle-aged women. It is also a relatively new disease to First Nations people. In fact, diabetes was rarely seen in the First Nations populations of North America prior to World War II. Some of the data even tends to suggest that this disease of the endocrine system was totally unknown at that time. However, the decades following the Second World War saw a steady and rapid increase of the rate of diabetes among the Native populations of Canada. Some examples in Quebec is the diabetes prevalence rate in 1995 for Opitciwan, one of our First Nations communities, which had reached 37.4% among persons between 45 and 64, whereas the rate for Quebec overall stood at only 3.6%. Among persons 65 years of age and older, in the same community, the rate was 57.5% compared to 7.2% for that same age group in all of Quebec<sup>1</sup>. Similarly, many Cree can testify to the fact that diabetes was very rare in the past, just as they will tell you that obesity was rarely seen in their midst. From being totally absent among the James Bay Cree, diabetes soared to, within the space of a few decades, a very high prevalence rate.<sup>2</sup>

By mid-1999, no fewer than 96 Innu persons in an isolated community La Romaine were found to be suffering from type II diabetes.<sup>3</sup> For a total population of 892 inhabitants, according to the most recent figures for the community, this works out to a diabetes prevalence rate of 10.7%. Such an observation is even more alarming when we consider that the population of this particular community in La Romaine is relatively young, whereas diabetes is generally a disease that affects older persons. If, for purposes of comparison, we examine the diabetes prevalence rate by age and gender for the Innu isolated community of La Romaine and for the Quebec population in general, we find that for the 25-44 year old group, the diabetes prevalence is 12.5% in La Romaine, whereas it is only 0.7% for the population of Quebec, or 18 times lower. Overall, Quebecers aged 45 to 64 years of age suffer from diabetes at the rate of 3.5%, whereas the rate for the same age group in La Romaine is 39.8%. Lastly, in the age category of 65 or older, 22.5% of the Innu population in La Romaine currently suffer from diabetes, whereas the rate for that age group in Quebec overall is 6.5%. These are disturbing figures, among which are included statistics showing the gap in the occurrence of diabetes among men and women. For the 45-64 age group and the 65 and over age group, there are twice as many women as men suffering from a diabetic health problem. An even more troubling fact is that a majority (53.3%) of Innu women in La Romaine between the ages of 45 and 64 are affected by this chronic disease. Moreover, the average age at which the disease is diagnosed among those who are currently affected in La Romaine is 38.5.



It appears then that diabetes has become a widespread and ever-growing problem among most First Nations. Current statistics in Canada indicate that the diabetes prevalence rate among Native populations is much higher than the rate for the Canadian population. In addition, a greater diabetes prevalence rate among First Nations women than men is observed for most age categories and in most native communities throughout Canada, than in the general population of Canada, for which this difference has not been observed.<sup>4</sup> It has also been observed that the average age for the onset of diabetes is approximately 41. Young First Nations people between the ages of 18 and 29 are generally not affected by the disease, but the prevalence rate quickly increases for succeeding age categories.<sup>5</sup> On the other hand, research has shown that type II diabetes is beginning to appear at increasingly younger ages among certain Native populations, and even as early as adolescence. There may be a correlation between this observation and the observation of increasingly higher rates of obesity among young people.

### **Risk Factors and Consequences of Diabetes**

Diabetes is directly linked to the rapid increase in the occurrence of numerous other diseases and to decreased life expectancy. The most widespread complication associated with this disease is arteriosclerosis. This condition occurs most often in the coronary arteries, as well as in the cerebral and ocular systems. Thus, diabetics between the ages of 45 and 64 are four times more at risk of suffering from a cardiovascular stroke. Along the same lines, arteriosclerosis of the peripheral vessels may lead to the eventual partial or even total occlusion of the blood vessels that supply blood to the lower limbs. As a consequence, many diabetics will one day develop problems of lameness in the lower limbs, with increased risk of gangrene. Many other short-term or long-term health problems are caused by diabetes. These may include visual problems (which can lead to blindness), kidney failure, neuropathy, high blood pressure, and increased vulnerability to infections of the skin, the urinary system, the lungs and the circulatory system. Mention must also be made of the numerous risks associated with pregnancy, including the high mortality rates of infants born to diabetic mothers, a rate which is four times higher than the rate for non-diabetic mothers.

The exact cause of diabetes is still not known today, but there are several factors which are known to contribute to its onset. Obesity, which affects eight out of ten diabetics is one of those factors. However, not all diabetics are obese. Distribution of body fat must also be taken into consideration.



Moreover, the decrease in the level of physical activity by an individual or by an entire population is a determining or etiological factor linked to diabetes, as is diet. Excessive caloric intake, the imbalance in the proportion of certain trace elements, an excess of refined carbohydrates, the lack of essential nutrients such as chrome and zinc, and low fibre intake are all suspected factors in the development of diabetes.

Lastly, stress must also be considered as a biomedical factor in the etiological model. It would seem that psychosocial stress increases the glycemic levels in both diabetics and non diabetics.

Consequently, there is an abundance of contemporary epidemiological research focusing on a range of factors. The swift onset and increase of diabetes prevalence rates are new challenges confronting health professionals. But the alarming fact is that both care providers and researchers are discovering that despite prevention and promotion programs, the diabetes prevalence rate is going up, and in some instances, has even reached epidemic proportions. Even though health services have established rigorous follow-up procedures, First Nations diabetics tend not to comply with the treatments prescribed with regard to their state of health. Therefore, in accordance with the statistics given above, we should expect to see numerous diabetes-related complications within a relatively short time frame.



## Does increasing people's knowledge of diabetes help?

Diabetic First Nations women are constantly exposed to the discourse of health professionals, which unfortunately seems to have a limited impact in the prevention and the control of diabetes. It seems necessary, then, to call into question traditional prevention approaches to diabetes. Health professionals usually link the diabetes prevalence rate and diabetics' poor control of their condition with a lack of knowledge and of understanding on the part of the public. Research, however, has shown the extent to which native populations are not only aware of but also very knowledgeable regarding this disease.<sup>6</sup> Moreover, knowledge of diabetes, its related risk factors and the way to control it does not necessarily lead to changes in behaviour. This has been experimentally proven and corroborated in studies. For example, a study by Joseph and Patterson has shown that knowledge is not a sufficient cause for the change of lifestyle behaviours:

“This study showed that there was no difference in the blood sugar levels of clients who were well informed and those who were not. In nursing, there is a basic hypothesis for care providers which states that if we can correct the lack of knowledge, the solution to numerous problems will emerge ( i.e. control of metabolism). It is evident from this sample that most of the clients were very well informed, but that no link could be established between knowledge and control. In practice, nurses must go beyond the knowledge aspect and pay more attention to other attitudes and behaviours which might be linked to control. “<sup>7</sup>

A study on health needs in First Nations communities indicates that behaviour modification in the case of diabetics must follow a different path or take an approach different from one based on the teaching and the dissemination of biomedical knowledge. This study added that a common first reaction to the failure to change habits was to point an accusatory finger at the individual or the populations involved. It would seem more appropriate to question the types of approaches currently being used by health services and to seek more appropriate intervention measures.<sup>8</sup>



## Philosophy of this manual

Women need new and original initiatives which draw on sources that are not derived from traditional medical discourse. Such initiatives should stem from and promote the knowledge of First Nations women as well as the expertise that they have acquired in their daily struggle against diabetes. Furthermore, any new initiatives must give priority to existing women's networks as models for the planning and implementing of actions aimed at health promotion. Such initiatives must also seek to engage women as full-fledged partners for the design and adoption of health promotion tools for women. In our view, the focus must be on actions that really work for diabetic women in their day-to-day lives rather than on normative strategies that serve only to increase their feelings of guilt.

That is why we chose to consult diabetic First Nations women<sup>9</sup> who have succeeded in controlling their illness within their family and social environment and have enhanced the quality of their health and lives. We asked them, in their capacity as the real experts on this condition, to tell to us about their experience, their suggestions, their concerns, and especially their strategies of taking control, and to help us develop a working tool for promoting good health among other women in their communities.

We believe that the very process by which this study was conducted, culminating in the creation of the manual, triggered or stimulated deeper reflections in the communities we visited and allowed some First Nations women to recognize that a new and simpler working tool was emerging, one which would not only make interventions easier, but which would also foster changes and improvement to the situation of First Nations women regarding diabetes and health in general. This working tool, or if one prefers, this tool for change, is as simple as the discussion circle. The discussion circle is a very straightforward and accessible method, which casts light upon forces which up until now have been far underestimated.

The discussion groups proved to be an excellent way of allowing First Nations women to share their knowledge and experience about a health issue that affects them in particular. Above all, the discussion groups gave women the opportunity to see themselves as experts or specialists genuinely involved in the issue rather than as mere recipients forced to listen to the advice proffered by the specialists. All of the researchers working on this project got very positive and encouraging feedback from the discussion groups. Women appreciated the fact that they could speak freely about themselves and the problems that affect them. They also appreciated being listened to attentively and being able to talk with other women who had experienced the same problems. In some places, the women even requested that the discussion groups be repeated again in the future.



Woven around women is a web of gender-based standards and surveillance norms which tend to prevent them from expressing themselves independently. Yet this expression is vital to the control of diabetes. Careful analysis of the data has shown that surveillance, for various reasons, can be particularly harsh on women, because in many First Nations communities, surveillance is everywhere and everything is known and commented on. Thus, in many communities, a woman cannot engage in an activity as simple as going out for a walk without raising suspicions of adultery and possible violence at the hands of her husband.

Our goal is to provide all First Nations women with the winning strategies that were successfully adopted by diabetic First Nations women for the daily control of their illness. This manual emphasizes the necessity of creating women's self-help networks. It has been designed for both prevention and action in the hope that it can be used to help women and health workers alike become more actively involved in the fight against a disease that is increasingly afflicting First Nations women.

Although the manual deals specifically with diabetes, it goes much further. It addresses a major aspect of health promotion, that of integrating women and their experience into the planning of any health actions that affect them.

The preparation of this manual has shown clearly that...

- when input from women is sought out for the creation of health promotion tools that affect them,
- when women are consulted in their capacity as specialists on what controlling diabetes among First Nations women means and requires,
- when there is an incentive for women to open up and relate their experience, their suggestions and their concerns in order to construct a working tool which can be used to improve the health of other women in their midst and which can be made available to First Nations decision makers,

...we are engaging in a strategy aimed at making First Nations women struggling with diabetes partners with whom we can pursue the search for a solution to this illness, which is now reaching epidemic proportions.



## Where did the raw data for this manual come from?

The testimonies at the heart of this manual were gathered during the research that we conducted in nine villages among the Atikamekw, the Micmac and the Montagnais nations. The survey allowed us to reach more than 50 First Nations women suffering from diabetes. We conducted both individual and group interviews, which were used to construct the different sections of the manual. The main criteria for selecting participants were as follows:

- the women must be 40 or older.
- they must have displayed in their day-to-day life the willingness and the capacity to take responsibility for their diabetes, in order to attain a decent quality of life.

The communities visited were chosen on the basis of their diversity and pluralistic nature (different Nations), their location (urban vs. isolated) and the second language that they used (English or French).

The stories that these women told allowed us to identify how they were able to make decisions for themselves which increased the amount of control they had over their disease and helped them attain the level of health and well-being they themselves desired. Such a rich corpus of interviews also made it possible for us to identify some of the main difficulties these women encountered in their lives and to identify the community strategies that reinforce the behaviours labelled in health circles as “risk” behaviours. Lastly, the interviews allowed us to identify the strategies adopted by these women to develop self-help networks and strategies that made it easier for them to stand fast by their decisions and to develop behaviours and attitudes, which were very frequently identified by their neighbours as being non-conformist in relation to community standards.

The manual has been adapted to the realities of the life of First Nations and takes into account the diversity within communities. Its purpose is to foster the development and the dissemination of diabetes prevention and control strategies based on the actual experiences of women, who, although from different backgrounds, have developed acute awareness of this very new disease and of the strategies required to control it. The manual is also intended to promote the creation of self-help groups and networks for diabetic women in First Nations communities.



## Who is the manual for?

The manual is intended for First Nations health workers who wish to make use of an innovative prevention/action approach for diabetic women in the communities. These workers should be deeply concerned with the development of self-confidence and independent action of these women, and should have a strong interest in developing their own knowledge and skills. The workers who use this manual are called upon to take part themselves in the creation of self-help groups and networks, considered to be the cornerstone of health promotion.

The manual is also intended for all women who want to learn more about the independent, self-affirming strategies of diabetic women, and who may want to organize discussion groups for the women in their community.

The various sections of the manual can be profitably used by diabetic women taking part in group discussions organized by health workers. It is our hope that the manual will also be a source of inspiration and motivation to other women who, by learning about the experiences of women with similar problems, will find tools of practical benefit to their daily lives.

It must be stressed that this manual is not a teaching of notions for the control of diabetes from a medical point of view. Its purpose is to make known the experiential knowledge of diabetic women for the benefit of other women in similar situations. It is woven of the ideas, the strategies and difficulties faced by the women who took part in the project. It takes for granted that once the basic knowledge needed to control diabetes is acquired, such control will stem directly from strategies and attitudes developed in one's actual experience, and that only the persons most affected by this problem, the persons who have diabetes, are able to understand and communicate these strategies and attitudes. In a word, women are the experts when it comes to their own lives.



## How to use this manual

Designed first and foremost for action, the manual has been divided into sections which can be used as workbooks for facilitating discussion groups. The introduction will help users become familiar with the manual as a whole, with group facilitation techniques, and with the basic concepts of self-help. The next six sections are meant to be easily accessible and are therefore quite straightforward. Each one is related to a particular theme which emerged from the analysis of the testimonies gathered from diabetic women.:

- **Theme 1** - How I found out that I had diabetes
- **Theme 2** - When everything changes because of diabetes
- **Theme 3** - Conflicting demands
- **Theme 4** - Women diabetics and the community
- **Theme 5** - Women diabetics and the medical profession
- **Theme 6** - Women diabetics facing themselves

The various themes correspond to the stages which women diabetics go through once they have been diagnosed as diabetic. They help to situate these women within the community environment, in their relationships with health professionals and finally in relationship to themselves. As the themes do not depend on each other, they can be used in any order, except for Theme 6, which provides a review of the first five themes and offers a brief conclusion.

After recruiting participants, the health worker should organize a minimum of 6 meetings, which will ideally lead to the creation of one or more self-help groups, according to the wishes of the participants. The six thematic workbooks serve as preparatory reading and as a guideline to facilitate the discussions. Each workbook contains:

- a life story illustrating the theme in question
- sub-sections presenting particular aspects of that theme
- suggested questions for discussion, which are given in the margins of the text and at the end of the section

The workbooks are copied and distributed to the participants. Workers familiarize themselves with the aspects to be treated under group discussion. They can write their own comments in the margin of the text, as well as any other questions they might think of after reading the text. The questions suggested for facilitating the discussion constitute a resource bank. Facilitators can use all of them or some of them. There is no particular order in which they are asked.



## Toolbox for forming and facilitating discussion circles<sup>10</sup>

As stated above, the manual consists of themes designed to help create and facilitate discussion groups. The experience which we gained during the survey and which led to the development of the manual has convinced us that discussion groups have tremendous potential as a means of support and that there is a strong trend among women to share their experiences in a group for the benefit of others. Moreover, the discussion groups that were held in at least one First Nation community in Quebec (Betsiamites) showed that these group discussions are conducive to the creation of self-help groups, the benefits of which can be considerable for both the individual and the community.

### Who may facilitate a group discussion?

Any persons who adheres to the philosophy of this manual may organize and facilitate a group discussion. It is preferred, however, that women do so since they are more inclined to open up and share their experience with other women. Health workers (community health representatives), teachers and any persons interested in the prevention of diabetes, including woman suffering from diabetes, may act as discussion facilitator. It would be better if these persons were not too formally linked with health care, as nurses are. In fact, even though such a health professional may be very open and may seek to promote the independence of the members of the group, it is possible that the role of this type of person, as seen by the eyes of the group, will influence their attitudes and what they are willing and not willing to say or affirm. Finally, someone from the same community, who shares the same language, and who has had similar life experiences will undoubtedly be in a better position to act as group facilitator.

### Recruiting members for the discussion group

The first step for actively using this manual is to recruit the members of the discussion group. The group that you should target for recruitment should be: any women from your community who are interested in discussing the issue of diabetes, whether they are diabetic or not. The members of the group will be the same for the six or more meetings that you plan to have with them. In fact, before they have gained the confidence to share their life stories, the women may want to know that there will be a certain continuity in the group. This continuity will provide them with the commitment or guarantee of group cohesion and will ensure that confidentiality, so important in First Nations communities, is respected.



Recruitment might prove to be one of the greatest difficulties that you will encounter, according to the experience of self-help facilitators in Betsiamites. Recruiting techniques could include radio announcements over the community radio and pamphlets for distributed. These steps might not be sufficient to recruit candidates, but at least they will help to get the information out and will create greater credibility for your initiative. However, it would appear that the best way to contact the individuals that you would like to see in your group is to telephone them directly. When contacting them by phone, explain to them the objectives of your project and reassure them that the confidentiality of meetings will be respected. You can also ask them to bring someone else, if possible, or ask them for the names of other people who might be interested in joining the group.

You might want to begin by organizing an initial information session where you will be able to answer the questions of participants, as well as set a suitable date for the first circle of discussion meeting for those who would like to register. Once they feel they have all the information and have freely consented to join the discussion group, the members will be much more comfortable about sharing their private experiences. It is at this initial meeting that you should hand out a copy of the first thematic workbook to all those who are interested in the group.

### **Time and place for discussion group meeting**

There are six suggested themes in the manual, each of which can form the basis of at least one discussion or even more. The sessions should take place within a set time frame, and you may want to organize meetings either once a week or once every two weeks. If the time between meetings is any longer, you will risk losing the interest or the commitment of the participants.

Because all of the group's members have commitments and responsibilities (taking care children or grandchildren, working outside the house, etc.), it would be a good idea to choose a time during the week, when participants are free and better disposed to discussion. Once chosen, the date should not vary from one meeting to the next, unless everyone agrees to change it. There are many advantages to having the meetings at the same time during the week: suffice to say that knowing the day and the time for the meeting is a factor itself for success.



Many First Nations communities have small populations. As you can well imagine, only a few women may want to participate in a discussion group, and even a smaller number may be interested in diabetes. Thus, you should not be disappointed if there is a small turnout. In a relatively large community like Betsiamites, 8 to 10 people attended the group discussions, which developed out short-term programs such as “YAPP” and “Let’s start off on the right foot.”

The place you choose to hold the meetings is a very important factor for the success of your initiative. A small room with a warm atmosphere, preferably not the health centre, is ideal. In fact, it is important that you choose neutral ground. And, by keeping the same place, you increase the participants’ sense of belonging. This will also strengthen awareness that the story “is to be continued.” Between meetings, members can phone each other or the facilitator, if necessary. At the end of the initially scheduled series of meetings, some of the participants may request additional meetings. This is how real self-help begins. In the Montagnais community of Betsiamites, longer running self-help groups were formed this way. They usually have 2 or 3 members, and in exceptional cases, a few more. A group of 2-3 members, in addition to the facilitator, may seem quite small, but it is actually quite satisfactory for the members. It can be extremely difficult to establish bonds of trust when more participants are involved.

### **How to hold a meeting**

The discussion circles should begin after you have waited ten minutes for latecomers. Waiting any longer might spoil the atmosphere and is not very propitious for creating feelings of mutual respect. The facilitator may prepare coffee or refreshments.

Moreover, discussion groups should end at a set time. Therefore, the amount of time that you have at your disposal is limited. In fact, you should decide, with the group, both the starting time and the length of the discussion, which is usually two hours. In this way, everybody will know what to expect and will manage their time in consequence, ensure that they have transportation to and from the meeting, and make sure that their personal or family obligations are taken care of (particularly finding someone to take care of the children).

16

The establishment of a climate of trust and sharing depends to a large degree on the attitude of the facilitator. It will be to her to advantage to identify the participants as specialists from the outset, thus placing them in a position of strength. There are suggested questions for the facilitator in the thematic workbooks, which she can use as a framework for facilitating the meeting.



## How to facilitate group discussion

If you are a case worker, and especially a healthcare worker (nurse or other), you will find facilitating discussion groups quite different from your usual work. That is because this time you won't be the expert, the one who is expected to deliver knowledge. Whether or not you are a case worker, your role as a facilitator is to be at the service of the word that emerges, of the experience of the group members, of the growing feeling of belonging, independence and self-help. This is why the attitude that you adopt will be crucial. In fact any questions that you might have about your role can be cleared up by this principle.

To prepare adequately for each session, you will first have to read the corresponding thematic section. The fundamental purpose of this reading is to allow you to develop a greater sensitivity and the broadest possible awareness of the multiple dimensions that characterize the theme under discussion. The thematic workbook will help deepen your thinking and lead to the development of your critical capacity. Throughout the course of your reading, you will discover the questions that have been placed in the margin of the text as Suggested questions for facilitators: they are meant as proposals, not straightjackets. Feel free to add your own comments and ideas. The various suggested questions are grouped at the end of each section. You may use this bank of questions to create your own framework for facilitation. However, it is never your role to use the workbooks for teaching purposes.

It is recommended that the group members be given a copy of the workbook prior to the meeting. The experience acquired by the self-help groups at Betsiamites have shown that some of the women will indeed read the material handed out. Particularly inspiring are the testimonies that are part of the thematic workbooks. Let's not forget that one of the objectives of the manual is to disseminate the knowledge of diabetic women.



## ATTITUDES AND BEHAVIOUR OF THE FACILITATOR

- \* The facilitator's attitudes are characterized by empathy, including understanding, sympathy, acceptance and an emotional closeness based on an affective awareness of the feelings felt by others.<sup>11</sup>
- \* Even though she demonstrates empathy, the facilitator must also remain neutral and open so as to enhance the free expression of opinions. Nor should she ever take a position on any issue. Therefore, she doesn't express her own opinion and ideally seems never to either agree or disagree what is being said.
- The facilitator shows calm and patience to give participants time to think and to allow for ideas and testimonies to emerge. She does not ask a barrage of frivolous questions.
- The facilitator uses words carefully to avoid putting distance between herself and the other members.
- Through her openness, the facilitator strive to make the discussion and the discourse as free as possible.
- The facilitator should avoid being needlessly directive, even though her questions provide a certain "structure" which will allow participants to follow the theme being discussed.
- The facilitator avoids asking questions for which there are already suggested answers.
- The facilitator should ask plain and simple questions. We should mention here that the questions suggested in the manual cannot be asked "as is". They must be adapted to each situation and formulated in a language that is as natural and as meaningful as possible for both the facilitator and the group members.
- If the facilitator senses a reluctance to talk about a given question, she may reformulate the question as an impersonal illustration, for example: "Suppose someone decides to go out alone for a walk, every night in the village. What will others think about the person?" Or she can use a simulation activity such as: "I just learned that I have diabetes. What will people around me think when they find out?"
- No one should ever be put under a spotlight, by being pointed out directly. Every member of the discussion group has the right to withhold her opinion. If some members tend to do all the talking, it would be a good idea to summarize their comments and then redirect the question to the others.
- The facilitator must be ready to listen to what participants say. This idea might seem self-evident, but it is never to be taken for granted. The facilitator can avoid re-asking the questions that have already been answered by summarizing the opinions that have been expressed.
- Since the facilitator is not acting as an expert for the purposes of the group discussion, she herself should not answer the questions, but instead should redirect the questions to the whole group.



## GROUND RULES FOR GROUP DISCUSSION

To ensure that the group runs smoothly, it is a good idea to set some ground rules right from the beginning with the participants. The list of ground rules in the following box are suggested as a model. This model has been used successfully in one of the Montagnais communities. However, the group can decide together whether it wants to modify the proposed list or whether it wants to add additional ground rules. Once the ground rules have been established for the group, give each member a copy of the rules or post them in the meeting room. These rules are not meant to turn the meetings into rigid, formal affairs, but rather to serve the interests of the group and to help them acquire the principles of self-help. They are not meant to be strictly enforced.

### Ground Rules for Group Discussion<sup>12</sup>

- Everything that is said within the group is confidential and is not to be repeated outside the group.
- When a person is talking, the others will listen without interrupting and will wait for their own turn to respond.
- Everyone will talk about what they themselves are feeling or thinking and not about the behaviour of someone else.
- Everyone has the right to talk and may freely do so.
- Everyone has the right not to talk. However, it must be remembered that what any person has to say may be helpful to another participant.
- Out of respect for the group, anyone who expects to absent or late for a meeting, should advise the facilitator ahead of time.
- The group's strength is based on its trust, respect for oneself, respect for others and confidentiality.



## Creating self-help groups

The ultimate goal of this manual is to lay the groundwork that will permit the emergence of self-help groups. In fact, the roughly six discussion groups that you will organize should lead to the creation of conditions that are favourable to and act as an incentive for the creation of self-help groups by the participants. The self-help experience of the Innu community at Betsiamites emerged for the most part from a series of more formal meetings. This leads us to believe that the same will be true here.

Self-help groups usually consist of between 2 and 5 members, plus a facilitator. They can continue for as long as they are beneficial or as long as the members need them. Such groups set their own operating or ground rules, timetable and schedule of activities. The facilitator's role in such a group is even more informal than her role in the regular discussion group, especially as the members become increasingly independent and assume their own leadership. They may become completely independent of the facilitator or they may wish to continue working under the same method that they began in the discussion group.

It may happen that the members of a self-help group will want to consult a health professional in order to be informed of some particular aspect of diabetes treatment. The health professional or any other "expert" must be considered therefore as resource persons who will attend group sessions only by invitation. Inviting a professional to attend the meeting must be considered as coming under the group's right to exercise its independence, and the meeting must be always conducted in such a way that the group maintains its position of strength.



## The Need for Self-help in First Nations Communities

The need for space and time to let self-help really take root was expressed both directly and indirectly on numerous occasions by the diabetic women that we met. We were also told about the numerous benefits that stemmed from the self-help circle. The following testimonies should provide sufficient evidence of the necessity of establishing discussion groups, which we hope will lead naturally to the emergence of self-help groups.



“It takes, I’m not sure, a house, resources for self-help.”

“I’m alone, and it’s been really hard. I need some resource persons; I would like to join a group, a self-help group for example. I think this would be very encouraging for me. I might develop a little bit more willpower to do something when I’m with others. I guess I’m just like that, I need people around me to do things. It’s as if alone I have no willpower. I need help. And I’d like to get involved, because I want to do something for myself and then also help others. I feel like joining a group so that I can help others, to help anyone who needs support, just like I needed support.”

“I’m really ready to help others, and I know I would also be helping myself, that’s for sure. That’s why I’d like to be in a group or in an association in order to find some practical means of doing something. I know that if I can, I will help others, and so I’m ready to get involved. I’d also like to see what’s happening in other communities. I’m ready and available to help others, and I know this would also help me. It’s also for myself, because I’m constantly in fear that my children will get diabetes too. That’s why I’d also like to work on prevention, for them too. Even though I suffer from this disease, I don’t want my children to suffer and if they’re not careful, there is the danger that they will get it. If I knew more about it, I would be able to talk to them about it and then possibly be helpful to my grandchildren. But I’ve got my own limits; there’s an awful lot of things I don’t know, just as I’m telling you, and I still have a lot of difficulty living with it today. I know it’s not doing to go away and I know that I’ll always have it, but there are ways, after all, to be more careful. I also want to get help so that I might be able to help others. In any event, just as I told you, I’m available if ever you need me in the group.”





“It would be a good idea to get the testimonies of diabetics, the way I talked about what I did to get my sugar down. I think this is the area where we need to help each other.”

“At first I kept asking myself the question: “Why am I diabetic?”

I asked a lot of questions, and then I started asking diabetics questions. How were they able to accept it?

How did they deal with it? These people were the ones who really helped me to take control of things by myself.”

“When there’s no way to answer all the questions from your family or from your immediate network, let’s say, is that when you need the circle?”

Yes. Sometimes I want to call them, but it’s not because my sugar has gone up, but just because I need to talk. Sometimes I begin to think that I can’t go on this way. I say to myself, “Why are you keeping this all to yourself?”

Then I start to feel a little bit more secure, because I’m part of the circle, and I know I belong. I know that what I to say won’t go beyond the circle. When I have contact with other women, I know that it’s hard on all of us. If there is a women who is emotionally upset, we all stick together, and take her by the hand so that she knows that we’re supporting her. We try to ease her heavy burden. That’s it. Sometimes I need the same thing. I don’t feel so alone.”



Life in First Nations communities is such that there is a great need for self help, particularly for diabetic women. Both our subsequent research and the testimonies that we gathered show that the requirements necessary for controlling diabetes are often in conflict with or counter to situations deemed to be normal or desirable in community life. This includes diet, the way the women spend their spare time, their capacity to take time out for themselves, and even the way they walk down the street, without eliciting all kinds of comments.

Diabetic women, just like all the other members of the community, find themselves caught up in a web of standards and surveillance. The individual strength of some women or the support that they get from their close friends and relatives are often the determining factors in their attempts to adopt a lifestyle conducive to the control of their diabetes. However, not all women get the kind of support they need. As a result, they often feel marginalized or even excluded by their friends and family. They feel like they don't have the right to be different and that they will run into major difficulties when it comes time to make their own decisions. It is already difficult enough to change one's habits, but this situation is compounded by the difficulty they will encounter in trying to get their families, their neighbours, their friends, their communities, and even health professionals to accept these choices. The decision to take control of their situation must first of all come from themselves. However, the very fact of organizing and joining a group is an excellent way of developing willpower and independence at several levels.

There are many factors to explain why groups help their members. Above all, groups provide an alternative to the individual's natural setting, that is, her family and circle of friends. The family is an essential component in the concept of health for many First Nations people, as recent studies have shown.<sup>13</sup> However, the family does not always fulfil the role expected of it, that is, it does not provide the support one might expect or it is a space fraught with conflicts and anxiety. Moreover, in natural groups "it is not always possible to change one's role, to extend one's range of behaviours or to express certain emotions."<sup>14</sup> In a group, each person has the feeling of being less marginalized. Thus:

"persons with similar needs see the group as a source of support and self-help, as well as the means of solving certain problems; the group also generates situations by which the individual can recognize and express feelings that society has repressed. By sharing their concerns with people who are in similar situations, individuals do not feel so alone, so abnormal or so alienated; they receive reinforcement not only through the support they get, but also by the support they give."<sup>15</sup>

The above statement shows the way to a description of the specific features of self-help.



## Characteristics of Self-help

Frank Riessman<sup>16</sup> was the first person to identify the major characteristic of self-help, namely, that when people give help, they are at the same time helping themselves. Through counselling, encouraging or listening, persons fulfil some of their own fundamental needs, such as the need for self-esteem, the needs for belonging, affection and acceptance, and the need for security.<sup>17</sup> In this way, something that appears to be a problem (diabetes for example) can in fact become something positive, in the sense that our experience of it allows us to be empathetic towards others and to guide them.<sup>18</sup> Rather than passively suffer from an illness, people with health problems can actively engage in contributing to the well-being of others through the intimate experience they share with them.

Self-help has even greater potential due to the fact that it occurs in a group. According to some, “the group and its members constitute the most astounding source of energy that human beings have ever produced.”<sup>19</sup> This energy finds its source in the individuals themselves and is then expressed in the effort to reach the common goal that binds them to the other members of the group.<sup>20</sup> When it is well-channelled, this energy allows all the members to accomplish much more than they could ever have achieved individually. In fact, the members of a self-help group not only succeed in satisfying their own fundamental needs of recognition and support, but they are also able to draw on the experience that the others have had, and thus might eventually become actively engaged in a social movement.

Other several well-known features of self-help underlie the necessary conditions for success of the group. Not only are these features essential for self-help actions to be triggered, they are also essential for self-help to take place over time. Usually self-help is born from a background of suffering and common aspirations, and finds its motivation in the need to break through one’s isolation and to find and give support in a context where everyone is able to share their common life experiences, where relationships are based on equality and the giving freely of oneself.

“Common life experience” is the fundamental characteristic of self-help. Being able to share similar experiences and to recognize the same emotions with respect to this common lived experience is the most powerful determining factor for the success of self-help, because it allows the pain of others (as well as their small and big victories) to resonate in the group, the members of which are then able to express feelings of compassion.<sup>21</sup> It is essential for the members of a self-help group to share the same experiences of life, which pushes them forward, which requires them to surpass themselves in order to be able to cope on a daily basis. The group’s members are also marked by the desire to hold out a hand to other persons in their community to give and receive compassion, help, advice and encouragement- or just an attentive ear.



Owing to its intrinsic nature, self-help is freely given and without charge.<sup>22</sup> That is because the benefits gained by everyone through his or her participation in the group are measured in human, not monetary terms. Just like the practice of traditional native medicine, it is a service that is freely given, or rendered in service to others, without calculating an immediate return. It is its own reward. In giving, we also receive. Like love and friendship, this kind of help cannot be bought; therein lies perhaps the true measure of its value. No one is obliged to join a self-help group; and the persons who join exercise their independence, by expressing the desire to act as a helper. By this very act, they affirm their power over their own life, their capacity to make choices for themselves and their sense of belonging to a community. Due to the very fact that such actions are not based on any kind of compensation, self-help is more flexible and can come in many forms as varied as they are unpredictable. Since it is free, it may take place at any time outside of the meetings which have been scheduled.<sup>23</sup>

Helping one's peers is usually proof of an attitude and behaviour towards others that are characterized by equality.<sup>24</sup> This third characteristic of self-help displays itself when participants recognize the similarity in the nature and effects of their situations:

“Above all, it is suffering or a crisis that helps to bring out the feeling of equality. Any two individuals who have experienced a similar upheaval in their lives tend to be drawn toward one another on a footing of equality, despite any potential differences.”<sup>25</sup>

The feeling of equality is not as evident as it might appear to be at first glance. In fact, if anyone is in a position of being able to offer help, it is because that person has not only shared a similar experience, but was also able to a certain extent, to overcome the difficulty. There is bestowed on that person a kind of “superiority” over the person who has not yet found the strength or the resources to do so. In the case of diabetes, several women suffer on a daily basis from their feeling of being inadequate, incompetent or even “bad diabetic patients.” Even though such a feeling of inequality may be felt at several stages, it can be overcome, once all members recognize that their experience is unique, rich, valid and potentially beneficial to other members of the group. This discovery of their own potential, of the capacity of every individual member of the group to help someone else is the very heart of the solidarity which emerges out of the self-help group.



## The Paradoxical Role of Professionals in Self-help

In any self-help group, the distance between the facilitator and the participants will be less than in any other kind of helping relationship<sup>26</sup>, because the help and the leadership may come either from the group or from the facilitator. This type of context makes it possible for the members to reclaim power over their own lives. The participants may often have been considered to be powerless, without resources and with little knowledge, but once they become helpers, they regain their confidence, independence and self-esteem.

If you are a professional working in health care or any other sector, you must be willing to set aside your role as an expert. Doing so will help reverse the unequal relationship between the “helping person” and the person being “helped.” In this way, the group and its members will learn to assume the responsibility of defining their situation as they see it, to say things in their own words, to analyze their collective situation, to set their own course and to determine their own goals and means of action. Removing inequality is a condition which favours the participants’ capacity to speak out and to acquire a new consciousness for social or political power.

Thus, the role of professionals represents a paradox: they have been trained to give help, but in the group context the help they do give consists in ceasing to be the help expert and in leaving the field free for the emergence of self-help within the group. Leaders may emerge from the group. This phenomenon is both natural and desirable, and should be encouraged. The legend below will give some food for thought in that regard.

In summary, in a self-help group, responsibility for leadership may be shared.<sup>27</sup> Various members of the group at different levels and in their own way might take on the role of leader. Someone might be good at summarizing the group discussions, whereas someone else might be good at proposing new subjects when the pace of discussion slackens. One member might be quite good at prompting others to participate, particularly those who don’t often take part in the discussion. These are just some of the many attributes of leadership. No single person will have them all, but they can be acquired with increasing participation in the self-help group.



## On the Principle of Equality: The Legend of Wésukechak and the Wild Geese

### Wésukechak and the Wild Geese<sup>28</sup>

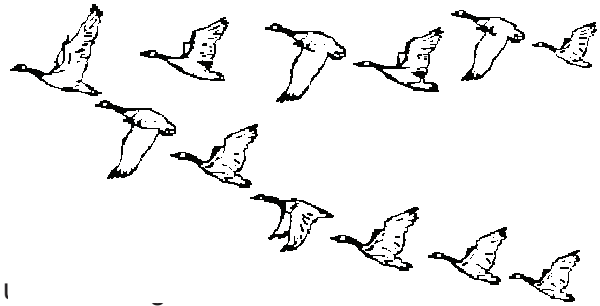
- One day when he was bored, Wésukechak contemplated the Immensity of the Spirits and saw a flock of wild geese migrating to warmer climes. He saw that they were in a V-formation and exclaimed:

- That's a stupid way to fly, when they could follow behind a single chief, who would blaze a trail in the sky, making it possible for the other geese to rest in his wake. I will convene a meeting of the chief geese to explain this to them.

Wésukechak met with the chief geese and explained to them his thoughts on how they should fly towards the warmth of the summer sun.

The first chief answered him:

- If we fly in a V-formation, it is because we wish to allow each goose and each gander the experience of being a leader, and to allow the others the opportunity to learn by remaining in the rear, but be ready to take the lead at the least sign of fatigue from the goose or gander who is leading the community.



Wésukechak replied that his way of seeing things, a leader was best and that the geese were fools not to follow his advice.

The wild geese held a council and reminded themselves that Wésukechak was of the World of Spirits and therefore knew better than anyone else what true leadership was.

They also said that that since he had made the effort to counsel them on this issue, maybe their method was outdated.

- Maybe the millennia we have spent flying in this formation have taught us nothing. Let's try the method that this spirit, this trickster has suggested. We'll see later if he is right or not.

The flock of wild geese, which are also known as Canada Geese, resumed its flight southwards, to the land of warmth during the season of cold in the north. But this time they followed a single leader and flew in a straight line, one behind the other.

Migisi, the great eagle, seeing the wild geese flying in a straight line said:

- This is the first time that I have ever seen Wéwé fly like this! This will make a good meal for me. The most powerful of all birds flew very high up into the Immensity of Spirits and followed the geese. Then he dropped down onto the last one in the line and devoured it. None of the other geese saw this. He repeated the same strategy and kept devouring the last one in the line until only the leader was left. And when he was devoured by Migisi, the wild geese no longer had any problems with leadership."

From: Bernard Assiniwi, 1998, Windigo et la naissance du monde. Hull, Éditions Vents d'Ouest, pages 75-77.





## Appendix: The circle of health or the “concept of health”: an Example from the Unamen Shipu community (La Romaine)<sup>29</sup>

### Why do we define the Unamen Shipu concept of health?

Defining such a concept is more than just a mere formality. Although it is mentioned in several texts, including the definition given by the WHO, health is much more than just the absence of disease.<sup>30</sup> Even though in medical practice, disease is always defined in precise scientific terms, we see how health and disease can vary considerably from one culture to the next or from one society to another, and even from one social group to another: amongst all peoples, the concept of health refers to the quality of life.

The main lesson we can learn from the elderly Montagnais is that health is basically a question of quality of life.<sup>31</sup>

This notion of the quality of life varies not only from one people to another, but also from one social class or group to another:

People in the poorer social classes attach less importance to health than people from the more privileged classes, because they usually put more priority on immediate satisfaction, rather than on the long-term perspective (...) popular lifestyles place a fundamental value on day to day life, on the feeling for the present, and even on the joy of life<sup>32</sup>.

There is a new approach to health which tells us that we have to take into account all the dimensions of human experience, and not just the presence or absence of sickness or disease. This approach is based on the concept of health promotion that was developed at the First Conference on Health Promotion. Health promotion is thus a relatively new and innovative paradigm, which is quite distinctive when compared to the conventional approaches to prevention. For example, disease prevention must focus on specific pathologies, but health promotion will concentrate on the networks in which the problems arise; whereas a prevention is based on a directive and persuasive approach health promotion aims at capacity building and facilitation, etc<sup>33</sup>.



As mentioned by René Dubos (1973), the notion of perfect health is for all intents and purposes a man-made utopia. However, we do have to recognize that this utopia has a certain dynamic aspect. As we cast our gaze onto the issue of health, as we try to breathe new life into the popular conceptions of health for the men and women of La Romaine, we are at the same timing gazing through a global prism as we observe the evolution of this community. The prism allows us to decompose the universe and to focus on certain of its contemporary or even its past features. The concept of health can act as a point of departure which allows us to move on to examine other issues related to lifestyle conditions.<sup>34</sup> In this context, the popular concept of health can be understood as the putting in place of the framework for both a societal project and for projects, which although more modest, are just as essential as those which involve the development of health promotion programs.

Question 3.10 of our survey was aimed at defining the broad lines of the popular concept of health. It was stated as follows:

“From the following 12 proposals, choose five, which in your opinion, are the most important for the formation of the circle of health.”

In order to answer this question, respondents had to symbolically close the circle by filling the empty boxes with the number that they had chosen. Again, we should repeat that the proposals that were used in question 3.10 were suggested to us, for the most part, by the participants who attended either focus groups or individual interviews. We did however add other possible choices, derived from research conducted in First Nations communities and presenting many similarities.



Photo : Claudette Fontaine, coll. M.E.Q.



# The Unamen Shipu popular concept of health

## Family and health

Of the twelve proposals that we included, one was chosen by more than 8 out of 10 respondents (81.9%) This proposal was clearly central to the Innu concept of health in La Romaine: it was “the family”. In fact, 86.4% of the respondents indicated that what was important to completing the circle of health was to “be at ease in one’s family.” Moreover, men as well as women, including most of the age groups, had a remarkable unity of thinking on this issue, as they all put family in the first place in their definition of health.

The choice of family unity in the first position, which means that it was the most important element in the popular concept of health is, in our opinion, highly significant. It is an extremely important indicator for all individuals who intend to work for health improvement among the Montagnais population of La Romaine: from all evidence, health promotion must take into consideration the family unit and must even seek to consult the family in the process.

## Health and the individual

The concept of “community” is often evoked by health professionals, by community health case workers and by a host of other thinkers who have spent time reflecting on First Nations issues, particularly those pertaining to health. It is often said that this concept should be put first in order to develop strategies that are designed to improve health conditions. Without automatically relegating this concept to second place, we should mention that the exercise that we conducted with the members of the La Romaine community led us to the realization that the concept of “individual” has often been underestimated in the development of the broader concept of health among the Innu of La Romaine.

We saw that in question 3.10 there are three answers that evoke the idea or the notion of individuality and these answers were chosen in second, third and fourth places, in terms of importance. The proposed choices were as follows:

- “to be comfortable in your skin ( with yourself)” (71.8%);
- “to be able to take care of yourself” (61.0%);
- “to be able to make your won decisions” (41.2%).



The fact that the respondents chose these three options with such frequency is an indication, in our opinion, that the Montagnais perceive the individual as having prime responsibility for the development of his own potential, in the maintenance and in the development of his health and happiness. After indicating that the well being that derives from the family entourage is the main influence on the circle of health, the respondents then confirmed that the individual has an important role in the development of his own future potential.

We should also point out that the Innu of La Romaine, by their choice of answers, followed pretty much the same direction with regards to health protection: “the path which leads individuals to greater control and improvement of their own health.”<sup>35</sup> The first purpose of health promotion is to ensure that individuals have better control over the determinants that impact their health, which does not in the least imply that families or communities no longer have any role at all to play.

Moreover, woman, more often than men, demonstrated a greater tendency to identify the choices of “being comfortable in your skin” and of “being able to take care of yourself.” And even more revealing, it was the young people and the young adults who identified all three of the above mentioned proposals. The response percentages, by age group, drop sharply as the age category rises. Here are a few of the percentages, indicating the results to each of the three proposals, by age category:

#### **Being comfortable in your skin (with yourself )**

- Youth: 73.8%
- Young Adults: 78.9%
- Middle Age: 54.8%
- Elderly: 44.4 %

#### **Being able to take care of yourself**

- Youth: 71.4%
- Young Adults: 61.1%
- Middle Age: 51.6%
- Elderly: 44.4 %

#### **Being able to make your own decisions**

- Youth: 54,8%
- Young Adults: 36.8%
- Middle Age: 41.9%
- Elderly: 22.2 %



## Food and health

Immediately after the option, “being able to make your own decisions”, comes the relationship to food. This proposal, that reads as follows, “eat healthy food” received 40.1% of the responses. In other words, four out of ten respondents considered that healthy eating was a important component to health. But as formulated “eat healthy food” is still a rather vague proposal. What does “healthy eating” mean for our respondents. The meaning behind this proposal is probably embedded within a network of meaning to which members of the community refer. It is also likely that certain elements were learned from the knowledge transmitted by the team of health professionals; but it is clear that the meaning of this proposal is also derived from the popular knowledge handed down over several generations or transmitted through various interest groups in the community. By way example, did our respondents understand “healthy eating” to include the traditional food of the community? What are the criteria to distinguish healthy food from non healthy food? Does “healthy eating” also include notions of pleasure, sharing and conviviality?

Whatever the underlying understanding may be, this proposal was chosen by 40.1% of the respondents which means that this proposal falls within a group of proposals that must be distinguished from the entire block of proposals, because they define the popular concept of health among the Montagnais of La Romaine. However, in the previous section we saw that “poor or unhealthy eating” was not considered by our respondents to be an important etiological factor of the illness, when compared with other factors such as violence, alcohol or drugs.

## Community, culture and health

The concepts of “culture” and “community” fall into sixth position with regards to the conditions that favour the development of the circle of health. The proposals related to “community” and health” read as follows: “to be comfortable with the members of your community” and to “act in accordance with your culture. “Both scored equally and received a response rate that was just slightly below the 37.3%.rate for the previous category.

In the First Nations milieu, “community” is a place, which in relation to a certain discourse, assumes a much broader significance than what the “village” or “neighbourhood” might represent for others. “Community” is of course a milieu which is much more extensive than the family and it is often the space, which in the eyes of some people is equated with the notion of “country.” It is the homeland for the entire group which identifies itself through its cultural features, its history, its political demands, its narratives and its stories. It is the place where self-help and networks occur.



However, even though the proposal garnished just under 40.0% of the responses, in our opinion, community does not appear to have the same significance that we are sometimes led to believe by certain thinkers. In the light of the responses given, it would appear that in the eyes of the respondents, the community could not exist without individuals and without families. In other words, community does not appear to precede the family and the individual. It seems rather to be tributary of the latter. However, it also seems to have significant influence in the forming of the circle of health for each individual.

Although it was identified by four out of ten respondents as being an important component of health, “cultural conformity” does not however seem to be one of the central tenets behind the Innu concept of health. Since we were working in Montagnais territory, we might have supposed that culture would have assumed greater importance in the formation of the circle of health. Without going so far as to think that culture has been marginalized to the extreme, we do however have to admit that it has been somewhat eclipsed by the five first positions. This fact should certainly send a message to many of the specialists who are working on health issues in the First Nations environment.

Another proposal on our questionnaire mentioned “acting in accordance with ones beliefs”, which of course might have referred to spiritual values. However, in native environments, the “cultural” and the “spiritual” are often closely associated. Therefor the proportion of respondents choosing this proposal was relatively low (20.9%, or 10<sup>th</sup> rank).

Both of these proposals (“acting in accordance with ones culture” and “acting in accordance with ones beliefs”) have one very noticeable point in common, when we take a closer look at the respondents by age and gender. On the one hand, and in keeping with the appropriate proportions, these proposals were more readily recognized by men than by women. When we examine the same elements by age, we see that middle aged people and the elderly gave such a massive response to the choices of culture and belief that their responses had an impact on the overall results. Whereas one out of four young people between the ages of 15 and 24 mentioned the latter two elements, the proportion nearly doubles for the elderly, who identified the same elements in a proportion of 7 out of 10. The same variance holds true for the proposal of “acting in accordance with ones beliefs”. Overall, from the age of 45 onwards, the percentage of respondents identifying both elements nearly doubles. How should we interpret these results? Does this data mean that Montagnais culture is not a necessary component in the well being of young people? If so, does that mean that “being Montagnais” is less and less significant for young people? This would be the same as saying that being Innu is only a question of obedience to traditional precepts. On the contrary, culture must be considered as a very vital element in life in La Romaine as it is constantly renewed through contact with modern realities. In this sense, being Innu is does not mean that all daily



activities have to be performed in a traditional context, just as being Québécois does not mean wearing the ceinture fléchée. Above all, the important thing is to ensure that there is coexistence among the generations, each one with its own understanding of what it means to be Innu at the dawn of the twenty-first century and each one with its own strengths. Moreover, it also appears, that for many young native people, particularly for young women, being Aboriginal refers to a “quality of being” (tenacity, courage, etc.)<sup>36</sup>. To ignore these varying conceptions of the identity of First Nations, be they related to the genus, the generation or the individual, would appear to be perilous, and might even generate serious consequences for the physical and mental health of the population. Therefore, it may be judicious to give more thought to the possible links that may exist between problems of identity and the problems of substance abuse and even of suicide.

### Social role and health

This refers to the proposal whereby the circle of health is constituted from “being able to carry on one’s daily business”, which received a score of 33.9%. The proposal refers directly to the role played by the individual on a daily basis within a particular unit. The unit may be small and limited, such as the family, or larger, such as the community. However, it must be remembered here that in the First Nations setting, we often deal with extended families, although even this reality may differ from one place to another. The individual may have a wide variety of activities or business to attend to; it may be the mother who has her daily lot of work to do in order to ensure the well-being and happiness of her family. She will have to be ready to do the laundry, prepare the meals and all the other tasks that are expected of her by her milieu, her culture or by her social class. For a different individual, his role will be to paint according to the dictates of his imagination so that he may understand the realities that are being experienced by his peers. “Being able to attend to your daily business” might also be linked to the need or the desire of feeling needed or useful. The proposal “being able to attend to your daily business” was ranked seventh by the respondents, therefore it must be seen as being of lesser importance, yet one out of three respondents felt that this proposal should be considered as one of the five most important elements in the circle of health. It must be pointed out that in the selection of answers, there is a considerable gap between male and female correspondents. The gap is sufficiently considerable so that if we were to review the results in isolation for each gender, we would find that men would rank this proposal in fourth position whereas women would only place it in the ninth position. Up to this point, we notice that the men’s answers surpass the women’s answers whenever the question or proposal refers to “acting” (act in conformity with one’s culture, act in conformity with one’s beliefs) or “actions” (being able to carry out one’s daily business). Should we therefore conclude that men are more pragmatic than women? In our opinion, we believe that this is a question that is worth examining, especially since women, for their part, were more apt to choose the proposals “being comfortable in one’s skin and “being able to take care of oneself”.



Therefore at first glance, it would appear that males put greater emphasis on “acting” and particularly acting in conformity with a standard or a code (beliefs, culture) whereas women seem to give greater value to the qualities of “being” in the individual capacity. This might be a very interesting line of investigation, which likely refers to the entire mechanism for the construction of male and female Innu identities in La Romaine.

### Health, sickness and health professionals

Elements chosen in the eighth, ninth, and eleventh ranks as being important to our respondents for the formation of the circle of health all had a common reference point, which was the reference to a definition of health that is specific to the biomedical domain:

- “Not having any illness” (32.8%)
- “Listening to your doctor” (22.6%)
- “Listening to your nurse” (14.1%)

The “absence of sickness” is not therefor one of the five constituent elements to health for two thirds of our respondents. Does that mean that someone from La Romaine who suffers from a sickness might consider himself or herself to be healthy? If we take into consideration what we now know about the popular concept of health, we can in effect confirm that someone who is “comfortable with his family”, “comfortable in his skin”, “able to take care of himself”, etc., even though he is afflicted with diabetes, such a person can consider himself to be in good health. The presence of sickness therefore, in popular terms, does not equate to the loss of health. In brief, we are probably dealing with the notion of quality of life, which must be correctly understood when planning health promotion actions. In fact we have to consider how such actions can be of benefit to the well-being of the family, and of the individual members of the community.

As far as compliance with advice from the health professionals, it comes last on the list of the constituent elements of health in the eyes of the Innu of La Romaine. Complying with the advice from health professionals figured very low in the circle of health, and this should be considered as an unequivocal message from our respondents.



## Conclusion

In the preceding lines, we believe that we have outlined the central pillars on which the popular definition of health has been built and which corresponds to the aspirations of men and women in the Montagnais community of La Romaine. The development of an operative popular concept of health will be a major challenge that Health Care Services will have to face in upcoming years. This challenge should broaden the notion of health, which must go beyond the biomedical concepts that are based on epidemiological indicators, which more or less coincide with the presence or the absence of illness. It has been interesting to find that for many segments of the Montagnais population the presence or the absence of illness is of minor importance, when it comes to defining what health is or is not. Of their own initiative, the respondents clearly situate health in the framework of their lives, in their capacity to feel well and at ease with themselves and with their loved ones. More than anything else, they have given us a positive definition of health.



## References

- 1 Bernard Roy, Le savoir populaire des Atikamekw d'Opitciwan et la santé. Étude de besoins de type exploratoire. Une approche qualitative. Master's thesis, Laurentian University, Sudbury, Ontario.
- 2 C. Lavallée, E. Robinson and M. Verronneau, Développement et évaluation d'une intervention éducative destinée aux patients crûs diabétiques, 1989-1992, Research Report. Module for Northern Quebec, Public Health Unit, Montreal General Hospital.
- 3 Bernard Roy, "Le diabète chez les autochtones. Regard sur la situation à Betsiamites, Natashquan et La Romaine", Recherches Amérindiennes au Québec, vol. XXIX, no 3, 1999.
- 4 E. Bobet, Diabetes Among First Nations People. Information from the 1991 Aboriginal Peoples Survey carried out by Statistics Canada, final draft, Health Canada, page 5.
- 5 FNQLHSSCC, Report on the analysis and interpretation of the Regional Medical Survey, Quebec Region, January, 1999, page 47.
- 6 Bernard Roy, "Le diabète chez les autochtones. Regard sur la situation à Betsiamites, Natashquan et La Romaine", Recherches Amérindiennes au Québec, vol. XXIX, no 3, 1999.
- 7 D. H. Joseph et B. Patterson, "Risk taking and its influence on metabolic control: a study of adult clients with diabetes", Journal of Advanced Nursing, 19, 1993, p. 82.
- 8 K. Fecteau et B. Roy (dirs), Étude de besoins, centre de santé d'Unamen Shipu, 1999, page 125.
- 9 In total, 25 individual interviews were conducted, as well as 9 focus groups.
- 10 Much of the ensuing information came out of meetings with the case workers and professionals from the Montagnais Health Centre in Betsiamites. We are grateful to the health service workers and managers who made this highly informative meeting possible.
- 11 Chantal Leclerc, Working with groups: planning action and evaluation, Laval University, Faculty of Education, 1998, page 33.
- 12 Source: Nicole Medzalabanleth, Psychologist, Montagnais Health Centre, Betsiamites.
- 13 See: B. Roy, Évaluation quinquennale des services de santé montagnais de Natashquan (1994-1999), Groupe Recherche Focus, 1999 et K. Fecteau et B. Roy (dirs), Étude de besoins, centre de santé d'Unamen Shipu, Groupe Recherche Focus, 1999.
- 14 Chantal Leclerc, Intervenir auprès des groupes: la planification, l'action et l'évaluation, Université Laval, Faculté des sciences de l'éducation, 1998, page 48.
- 15 Chantal Leclerc, Intervenir auprès des groupes: la planification, l'action et l'évaluation, Université Laval, Faculté des sciences de l'éducation, 1998, page 49.
- 16 Frank Riessman, "The Helper Therapy Principle," Social Work, 10, 1965.
- 17 J.-M. Romeder, Self-help Groups in Canada: un aperçu d'entraide au Canada, Ottawa, Health Canada, Government of Canada, 1990.
- 18 N.Thiers, quoted in H. L. Hedrick et al., "Self-Help Groups: Empowerment through Policy and Partnerships", Self-Help: Concepts and Applications, The Charles Press Publishers, Philadelphia, 1992, p. 5.
- 19 D. Boisvert, F. Cossette et M. Poisson, Animation de groupes, Québec, Presses Interuniversitaires, 1998, page 19.
- 20 D. Boisvert, F. Cossette et M. Poisson, Animation de groupes, Québec, Presses Interuniversitaires, 1998, page 21.
- 21 Romeder, p. 29.
- 22 Romeder, p. 30.
- 23 Romeder, p. 31.
- 24 Romeder, p. 31.



- 25 J.-M. Romeder, p. 32
- 26 The following two paragraphs are taken from Chantal Leclerc,, *Intervenir auprès des groupes: la planification, l'action et l'Évaluation*, Université Laval, Faculté des sciences de l'éducation, 1998, pages 49, 50.
- 27 This paragraph is taken from Karen Hill, *Helping You: Helping Me; A Guide for Self-help Groups*, Canadian Council on Social Development, 1987, pages J-2 and J-3.
- 28 "This legend is presented by Duke Redbird in a film entitled *To Walk with Dignity*, produced by Tony Snowsil for TV Ontario. The legend is told by an old chief, played by Bernard Assiniwi in 1972. The action takes place during a meeting of the representatives of a native community with representatives of the Government of Canada. The latter wanted the Aboriginals to rally behind a single "leader" rather than confide the tasks to all the representatives. The Natives' answer is the legend give above. Bernard Assiniwi, *Windigo et la naissance du monde*. Hull, Éditions Vents d'Ouest, 1998, page 75.
- 29 Adapted with the permission of the Director of Health Services in Unamen Shipu, by: K. Fecteau et B. Roy (dirs), , *Étude de besoins*, centre de santé d'Unamen Shipu, Groupe Recherche Focus, 1999, pp. 59-63.
- 30 The WHO, in the Ottawa Charter for health promotion, defined this concept as: "The ability to identify and to fulfill ones aspirations, to satisfy ones needs and to modify or face ones environment. Health is therefore a resource for daily life and not an objective of life. Health is a positive concept, which focuses not only on social and individual resources, but also on physical capacity." World Health Organization, European Regional Office Ottawa Charter for health promotion, Copenhagen, quoted in Chandrakant P. Shah, *Médecine préventive et santé publique au Canada*, Québec, Les Presses de l'Université Laval, 1995, page 1.
- 31 F. Lacasse, "la conception de la santé chez les amérindiens montagnais", *Recherches amérindiennes au Québec*, vol. XII, no 1, page 28.
- 32 G. Paquet, *Santé et inégalités sociales: un problème de distance culturelle*, Québec, Institut Québécois de Recherche sur la Culture, document de recherche no. 21, page 67.
- 33 Adapted from de Chandrakant P. Shah, *Médecine préventive et santé publique au Canada*, Québec, Les Presses de l'Université Laval, 1995, page 16.
- 34 M.R. Richardson, "Des concepts pour l'étude des rapports sociaux de sexe dans le développement"; 242-257, dans M.-F. Labrecque, *L'égalité devant soi: sexes, rapports sociaux et développement international*, Ottawa, CRDI.
- 35 World Health Organization, European Regional Office Ottawa Charter for health promotion, Copenhagen, quoted in Chandrakant P. Shah, *Médecine préventive et santé publique au Canada*, Québec, Les Presses de l'Université Laval, 1995, 1995, page 2.
- 36 Atikamekw Health Services of Opitciwan, *Awacak – Users' Guide*, 1996.





[www.cssspnql.com](http://www.cssspnql.com)