# Planning research for greater community involvement and long-term benefit

**Special Working Group of the Cree Regional Child and Family Services Committee**

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*When the editors decided to print the report on the gestational diabetes intervention project, they asked the authors if someone in the region might be interested in writing a response to the article. The topic falls within the mandate of the Cree Regional Child and Family Services Committee that oversees children's policy, programming and planning for the region. A special working group was formed and, through discussions by fax and telephone, written comments and small meetings, the following response was prepared.*

Each year in Eeyou Istchee, the Cree region of northern Quebec, we notice that more pregnant women are being diagnosed with gestational diabetes[1] and more adults and teens are diagnosed with type 2 diabetes mellitus.[2] The rate of gestational diabetes among pregnant women is high because we have 890 people who have been diagnosed with type 2 diabetes. This is 11% of the population over the age of 15 years. These numbers in 2000 are 4 times as high as in 1989, and today type 2 diabetes is being diagnosed in younger age groups, including children. As is pointed out in the *Annual Diabetes Registry Update*[2,3] (May 2000), 94% of people with diabetes are overweight. The increase in diabetes and gestational diabetes in our community is matched by an increase in the number of people who are overweight and obese, along with a decrease in their level of physical activity. For the future of our people, we urgently need to understand how to reduce the number of new cases of diabetes and how to help pregnant women lower their risk of developing gestational diabetes.

This was the spirit behind and the context for the study reported by Katherine Gray-Donald and colleagues in this issue (page 1247).[4] It is also the reason why the study was strongly supported within the territory by the regional Cree Board of Health and Social Services of James Bay. Everyone benefited from having additional nutritionists in community clinics and from learning about gestational diabetes. The primary intervention involved several hours of contact between the non-Cree nutritionist, who was in the region for the first time, and each pregnant woman, whose first language was Cree. However, the pregnant women who were part of the intervention did not maintain a good weight, nor did they increase their level of physical activity.

How could better results have been obtained from this intervention? We have identified the following 3 areas where improvements could have been made: the method of intervention, the understanding of the changes in the Cree community and the need to involve local people.

In contrast to the one-on-one counselling used in the intervention described here, an earlier study on diabetes education recommended that group sessions would be more likely to build local support networks among patients and perhaps have a greater impact on their behaviour.[5] When we asked about this, several of the mothers who had been part of the gestational diabetes study said that they would have enjoyed participating in sessions with other pregnant women and knowing which other women were involved in the study.

New and younger mothers are not necessarily aware of their risk of gestational diabetes. In addition, they may not realize that having gestational diabetes will make them more likely to develop diabetes several years after their pregnancy. That is one reason why we would recommend teaching expectant mothers in group sessions. Not only would there be sharing of information and support among the pregnant women, but women from the community who have diabetes or who have had gestational diabetes could also be invited to sit in from time to time to help the pregnant women remain aware of the goal of preventing the onset of this condition.

When speaking in Cree, we are more comfortable if someone suggests ways to think of taking a different approach rather than telling us directly how to act. Elderly women and local midwives were not involved in the study, and we think that they would have used a more culturally appropriate approach for passing on advice and information through storytelling and oral education, having the women think of their diet by beginning to look at their roles as women and mothers, caregivers and providers. The food and activity messages would have been more integrated into the way the women were living and eating. Midwives and elderly women are a very important resource in the community that is often disregarded. There is an underlying respect for these women in the communities that outsiders would not notice or know about.

Group sessions would also have been a way to involve members of the women's extended families. Older women

from the community would have understood the difficulties facing a young pregnant women told to change her diet while living in an extended family household with an older relative, for example, a mother, mother-in-law or grandmother, who was in charge of the family kitchen and food purchasing. Within the group of pregnant women, access to traditional bush food and freedom of choice to buy food from the store and to decide what is cooked varied greatly from family to family.

People from the communities also suggested that had a local Cree person been involved, that person could have monitored the participating women more closely and helped to keep them interested in the project. Although the study hired a local contact in each community, we understand that they were used to set up appointments. The momentum of the study depended upon the nutritionists who were travelling between communities. To help people change, the momentum would need to come from the community.

We clearly need to promote physical activities that will appeal to girls and women. At present, recreation programs are responding to the interests of boys and men. We need instructors who can make the activities fun so that inactive girls and women become involved. We also need physical activities for women with gestational diabetes.

The gestational diabetes study mainly focused on the food consumption of each pregnant woman. However, the increased weight and the decreased activity of pregnant women are part of the large changes that have taken place in our communities in the last 3 decades.

Our ancient survival skills have changed with modern technology. Freezers have changed people's way of eating. In the past, wild meat had to be eaten when caught, usually through sharing it with others; now it can be frozen. Food is always at hand, which was not the case before, and processed, fast and junk foods have become easy alternatives. Before the 1970s, everyone knew what it was like to go hungry at times, and the best diet had the most fat.

Before, a woman was physically fit because of her important role and responsibilities as a carer and provider for her family. Being pregnant was not looked at as a disease. A pregnant woman worked as hard as she had done before becoming pregnant. She was not discouraged from her regular activities of chopping wood, hauling water and scrubbing wooden floors on her hands and knees. And, no one had a taxi or vehicle to carry the groceries home from the store. A pregnant woman was taught to have proper rest and to be up early in the morning and active. She was told that this would prevent the baby from becoming lazy and then she would not have difficulty during the delivery. She would also be advised to be careful and not to become too big. Then, there was more emphasis than today on looking after yourself. Now the young women say, "the clinic will do it."

Today, as housing is more available, young couples move away from their parents and lose the close contact with the oral education they would have received from their families. It is hard enough for the younger generation to understand what it was like when our people were living on the land, so we would not expect this understanding of a young nutritionist from the South.

When studies are considered in the future, recommendations from previous studies should guide their planning and design. Studies with a prevention or health promotion focus would benefit from intensive consultations with community health and social service personnel at the planning stage. This is especially the case when planning concerns how community members are to become involved in the study.

Within the region, managers need to ensure that their staff members participate in consultations about new projects as routine aspects of their work and not as special demands on their time. We have to make these kinds of consultations and responses part of what we do as a committee and as people involved in the health and social services field.

In conclusion, this was an important study for our region and through it we gained the services of 2 extra nutritionists and knowledge about gestational diabetes. However, we feel that this study might have had better results and, therefore, might have been of more benefit to the region had experienced local people been more involved, and had they been ready to be more involved, when the study was being planned.

*Competing interests:* None declared.

## References

1. Rodrigues S, Robinson E, Gray-Donald K. Prevalence of gestational diabetes mellitus among James Bay Cree women in northern Quebec. *CMAJ* 1999; 160:1293-7. Abstract available: www.cma.ca/cmaj/vol-160/issue-9/1293.htm
2. Cree Board of Health and Social Services of James Bay. *Annual diabetes registry update.* Chisasibi (QC): The Board; 2000.
3. Dannenbaum D, Verronneau M, Torrie J, Smeja H, Robinson E, Dumont C, et al. Comprehensive computerized diabetes registry. Serving the Cree of Eeyou Istchee (eastern James Bay). *Can Fam Physician* 1999;45:364-70.
4. Gray-Donald K, Robinson E, Collier A, David K, Renaud L, Rodrigues S. Intervening to reduce weight gain in pregnancy and gestational diabetes in Cree communities: an evaluation. *CMAJ* 163(10):1247-51. Available: www.cma.ca/cmaj/vol-163/issue-10/1247.htm
5. Lavallee C, Robinson E, Verronneau M. *Développement d'une intervention éducative destinée au patients cris diabétiques.* Montreal: Module du Nord quebecois, Unité de santé publique, Hôpital general de Montreal; 1994.

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