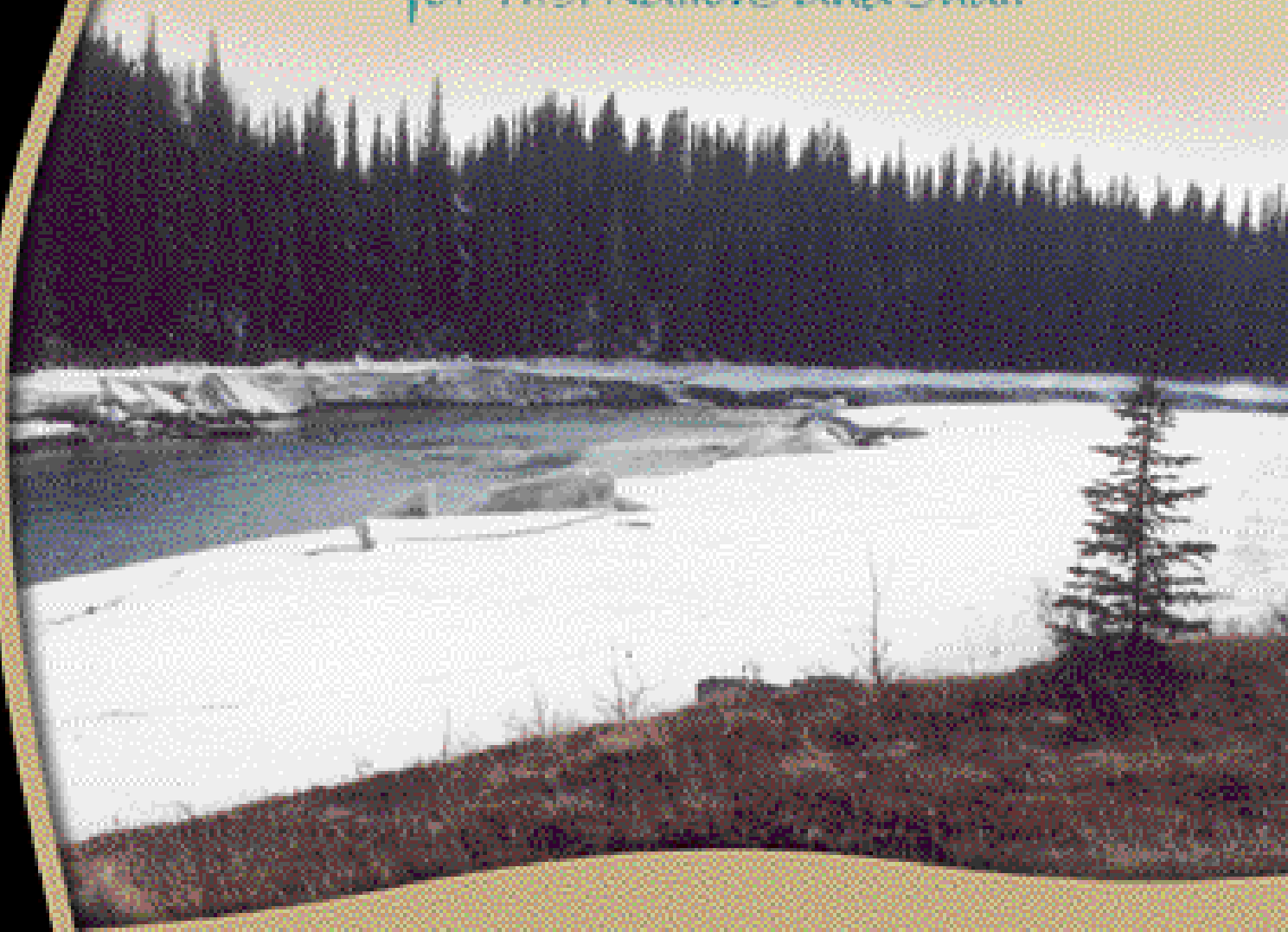
FINAL Report

Health Transition Fund Project NA1015:
Diabetes Community/Home Support Services for First Nations and Inuit



Health Canada Santé Canada

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This project was supported by a financial contribution from the Health Transition Fund, Health Canada. The views expressed herein do not necessarily represent the official policy of federal, provincial or territorial governments.

Cat. No. H35-4/12-2001E
ISBN: 0-662-30722-4

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EXECUTIVE SUMMARY

The increasing prevalence of diabetes has become a major health concern for Aboriginal people over the past decades. This increase has been accompanied by an escalating need for home and community care services and support for persons and families who are affected by diabetes.

The Diabetes Community/Home Support Services for First Nations and Inuit Pilot Project was carried out under the direction of the First Nations and Inuit Health Branch of Health Canada, and was overseen by a Project Steering Committee comprised of federal, provincial and First Nations and Inuit representatives. The Project was initiated in the Spring of 1999 and the evaluation took place in the Fall of 2000.

The expected outcomes from the Project, described in the Report, were:

- the development of sample service models;
- the identification of diabetes education and training, care and support needs for First Nations and Inuit communities;
- the validation of the First Nations and Inuit Home Care Framework and elements of the Aboriginal Diabetes Initiative; and
- the subsequent communication of this information to other communities planning diabetes services/home and community care services.

Major Findings of the Project

The analysis of the data gathered from the Project pointed to some common findings that may have relevance to other First Nations and Inuit communities who are planning diabetes community/home support services.

Identified Diabetes Service Needs

The needs assessments in each community had clearly identified gaps in three areas: diabetes education services; improved coordination of services; and care and treatment. The planning and development of services in each of the pilot sites focussed generally on these areas.

"The big picture is already showing us what is happening with in our people with diabetes. Sharing and learning through projects such as this one has given us a better understanding of diabetes."

Health Director -
Red Earth First Nation

Models of Home Care Diabetes Services

The four participating communities developed three unique models of home care diabetes services:

- contracted diabetes education service with community coordination, liaison and support;
- multi-disciplinary team approach with health and social support staff; and
- home care nurses with diabetes expertise in case management, diabetes education and care.

All of the models showed preliminary positive impacts for people with diabetes and for the community. The success of the services was not determined by the service model itself, but rather by how well the model fit with the needs of the community, the degree to which it had the support of the leadership and the dedication of appropriate human resources to the services.

Health Staff Diabetes Training and Education

Key health staff in each of the pilot communities identified the need for more diabetes education and training during the needs assessment. The learning acquired during the course of the Project was considered essential for the development of the diabetes services by professional and paraprofessional staff. Before the clients could receive education, the health staff needed to learn about diabetes and become confident in their ability to provide care and treatment.

"All staff involved need training in the care of diabetes. The home support workers have identified urgent care needs for their clients."

Rigolet Nurse

Once the nurses had accessed training and education, they were not only able to provide education and care for persons with diabetes and their families, but they also were able to provide education for the other health care staff.

Some of the nursing staff reported that they had made changes in the way they provided information as they had become more sensitive and skilled in client centred education and care. Others commented that they had an increased awareness of how difficult it is for their clients to make the eating and other lifestyle changes required for diabetes control.

Integration and Coordination

The pilot communities demonstrated that many of the identified service barriers can be fully or partially overcome through integration and coordination of services. To achieve this required first the allocation of human resources and focussed efforts to identify the barriers. The next step was the establishment of linkages and the utilization of a team approach. Communication processes were then formalized to ensure the team members were working with more complete and current client information such as client records and lab reports. Team work amongst all health service staff both within and outside the community was found to be crucial. Physicians, who were part of the team, found that their clients benefited from this approach.

Validation of the First Nations and Inuit Home Care Framework

The four pilot communities found that the First Nations and Inuit Home and Community Care Program clearly provided an infrastructure that supported the delivery of diabetes services for education, care and support. The elements of the Home and Community Care Program facilitated the improvement of care for persons with diabetes, especially in the areas of case management, linkages with other services and the establishment of home care nursing.

"The pilot project was good for our community - It has been a big turn around. People didn't used to talk about diabetes, now people are sharing ideas and asking for help from the health staff. Even elders are talking about the old days. We have workers we can trust to talk to and share ideas with."

Health Director - Red Earth First Nation

Validation of the Aboriginal Diabetes Strategy

The Aboriginal Diabetes Strategy Framework Document (Draft January 1999) was provided to the pilot communities to assist with their planning and development activities. The diabetes services, developed through the Project, are described in the context of the elements of the First Nations and Inuit Communities Program Framework of the Aboriginal Diabetes Initiative (ADI). These elements are care and treatment, prevention and promotion, and lifestyle supports. While the focus of the Project was care and treatment, preliminary effective impacts were shown through the Project in each of the elements identified in the ADI Framework. The diabetes home care services developed through the Project validated the Aboriginal Diabetes Strategy and the elements described in the ADI Framework.

Conclusion

The Project participants, including representatives from leadership, clients and staff were able to identify improvements in diabetes services through this Project. There was an increase in community awareness of diabetes, an increased skill and knowledge of health staff, and some clients had identified changes that they made in their self care and lifestyle to improve their diabetes management.

OVERVIEW OF THE PILOT PROJECT

(HOW THE PROJECT WAS DESIGNED)

In 1998, Health Canada partnered with First Nations and Inuit on a proposal to the Health Transition Fund (HTF) for a Pilot Project on "Diabetes Community/Home Support Services for First Nations and Inuit". The HTF provided short-term funding for projects designed to identify innovative and effective means of improving the health and the health care of Canadians in four priority areas: home care, integrated service delivery, pharmacare and primary care.

The goal of the Project was to identify ways to provide expanded diabetes support through home care services. The objectives for the Project, as outlined in the Project Charter[1] were:

- to identify the home/community care and support needs of people with diabetes and their families;
- to develop home care models of effective community based diabetes care, support and education;
- to develop approaches towards integration and coordination of services at the community, regional, provincial and federal levels;
- to identify the training and education needs of people with diabetes and their families and of health care staff; and
- to validate the First Nations and Inuit Home Care Framework and the elements of the Aboriginal Diabetes Initiative.

[1] The Project Charter guided the common undertaking of the Project by outlining the Project's purpose, objectives, how the Project would be carried out, and the role/responsibilities of key Project stakeholders.

Four pilot communities participated and were selected for their diversity in terms of culture, geography, governance structure and degree of isolation. The pilot communities were:

- **Sliammon First Nation** - a non-isolated Coast Salish community with 643 on-reserve members located on the west cost of the British Columbia mainland. It is 12 kilometres way from the city of Powell River. The community has a health centre and community health services. At the beginning of the Project, there were 26 persons or 4% of the community who had been diagnosed with diabetes.
- **Red Earth First Nation** - a semi-remote Swampy Cree community with 844 on-reserve members located in the marshlands in the north east of Saskatchewan. At the beginning of the Project, there were 91 persons or 10.8% of the total on-reserve population were diagnosed with diabetes. There is a community health centre on reserve that has biweekly physician visits. The nearest hospital is a one hour drive away. Travel to medical specialists takes 2.5 hours.
- **Wendake First Nation** - a non-isolated Huron-Wendat Community located near Quebec City with an on-reserve population of 1,188 persons. At the beginning of the Project, 4.4% of the on-reserve population was diagnosed with diabetes. Within the community there are several health services available including community health services, an Elders lodge and a private medical clinic.
- **Rigolet** - a remote isolated Inuit community with a population of 313 people. At the beginning of the Project, 16 people or 5.1% of the population had been diagnosed with diabetes. The community has a provincially funded nursing station. Community health services are provided through the Labrador Inuit Health Commission. The nearest physician and medical facility is a forty-five minute plane trip. A physician visits the community every four to six weeks.

Project Description

Each community first received orientation to the Project objectives and requirements, including receiving a copy of the Project Charter. Meetings were held with community staff periodically throughout the Project and monthly conference calls were held to maintain support and communication. Expert support was provided in the areas of program evaluation, diabetes education and home care.

The pilot communities were required to conduct several activities to meet the objectives of the Project. These included:

- carrying out a community needs assessment to identify the home and community care needs of the people with diabetes and their families;
- assessing the diabetes training needs of care providers;
- developing a home care and diabetes service delivery plan, including an implementation plan;
- developing a comprehensive program evaluation plan -- a program logic model and performance indicators for future evaluations;
- implementing the services; and
- participating in the Project evaluation.

The short time lines of the Project required a design that included specific ways to facilitate the completion of the Project activities. A number of tools were developed to assist the pilot communities though each phase of the Project.

Tools for Planning

- A Community Diabetes Needs Assessment Kit which included: a data collection tool to gather information about the heath status of the community; a chart audit form to collect baseline information on the health care status of persons with diabetes; a Learning Needs Self Assessment for health workers to determine their level of diabetes knowledge; and a key informants' consultation tool. The data collected by the pilot community staff was analysed and compiled by a project consultant.

Tools for Planning and Delivering Services

- A Diabetes Home Care Plan service delivery template was provided to assist the communities with the development plan for services.
- Monthly report forms were developed for the summary report as well as a report form for client services statistics.
- A client Diabetes Assessment Tool to facilitate client identified goal planning.

Tools for Program Evaluation

- A Self-Assessment Tool for evaluation was developed for the pilot team to describe both progress to date and plans for the future.
- A Client Survey tool was provided to capture clients' perception of and satisfaction with services provided by the project.
- A sample logic model and a sample logic model book were developed to assist the communities to develop their individualized models.

Project Evaluation (How the Information was Gathered)

The focus of the evaluation was to describe the planning and development of the program initiatives in the four pilot communities which may be helpful to other First Nations and Inuit communities who are designing diabetes services. This Report describes the results of the Project to date. A further evaluation in one to two years will permit determination of indicators for long term client outcomes.

Evaluation information was gathered in several ways. Throughout the Project, monthly summary and statistical reports were submitted. The project teams completed a comprehensive self-assessment describing the services developed to date and plans for the future. A client satisfaction survey was also conducted. Each community prepared an evaluation model (logic model) to be used for future evaluations. Lastly, the community-based pilot team, clients and leadership were interviewed by conference calls.

Limitations

The data reported from the communities should be considered preliminary and reflective of early changes that have the potential to lead to longer term positive outcomes. Several variables had influenced progress in each of the communities: the short project time lines and the extensive requirements; the complexity of diabetes; the varied learning needs of both health staff and community members and the length of time needed for change to happen. The data in this Report is qualitative in nature. The common themes have been validated by representatives from each of the pilot communities.

"As recommended, we established an evaluation committee composed of the members of the multidisciplinary team, the project coordinator, the psycho-social support worker, and a person with diabetes. We held three meetings to discuss and validate a background document on project self-assessment prepared by the project coordinator. This exercise was fruitful in a number of ways, proving to be: a helpful feedback exercise with respect to planned activities; a helpful exercise for reviewing the implementation of planned activities; a means of guiding future stages more effectively; a crucial part of the evaluation process."

Project Coordinator - Wendake First Nation

EVALUATION FINDINGS
(WHAT WE HAVE LEARNED)

The Project design guided the pilot communities through a comprehensive community-based process of needs assessment, planning and program delivery over an eighteen month period. Each community found unique ways to meet the identified needs and challenges. This section will report the actions taken to meet the needs and the impacts on people affected by diabetes and the communities by describing:

- the models of service delivery that were tested by the communities;
- the validation of the elements of the Aboriginal Diabetes Initiative;
- the education provided for health staff members;
- what we have learned about effective diabetes program planning and development within the context of the home and community care framework; and
- the barriers and challenges of program planning and delivery.

Models of Diabetes Service Delivery

One of the Project's objectives was to explore models of community-based diabetes service delivery in different geographical and cultural settings. Each of the pilot communities developed a model to suit their community and its distinct needs, and to fit within their existing organizational structure.

While the Project was designed for diabetes services within a Home and Community Care (HCC) Program, the essential services of the HCC Program were at different stages of development in each of the pilot communities at the initiation of the Project. Because of the short timeframe of the Project and the number of activities to be carried out, a decision was made to prioritize the development of diabetes services rather than have the pilot communities focus on the further development of their home and community essential services through the Project period.

All communities were able to increase the availability of diabetes services and expertise within the community. The delivery of services within the community was identified as a significant factor in the success and utilization of these services.

All project coordinators were nurses who knew and were trusted within their community. Two of the four pilot communities hired nurses who were working in the community and filled their former positions with new nursing staff. The other two pilot communities hired external nurses who were already familiar with their communities. The decision to hire nursing staff with considerable community knowledge and experience facilitated more efficient program planning and development in light of the short Project time lines. The pilot communities concluded that the selection of a nurse with a good knowledge of the community and an established trust relationship with community members was an important factor in the success of the Project.

All the models utilized a case management approach that followed persons with diabetes through the health care services to increase continuity of care and to facilitate care and treatment based on the Canadian Diabetes Association's Clinical Practice Guidelines (1998) (available to download at www.diabetes.ca).

Three distinct models of home care diabetes emerged in response to the needs identified in the needs assessment:

- **Contracted diabetes education service with community coordination**, **liaison and support.** One community increased coordination and capacity within the community through the nurse coordinator who focussed on the program development for persons with diabetes in the community. The project contracted with a Diabetes Education Team, consisting of a nurse and a dietitian, to come to the First Nation community two days per month. A trained home health aide was hired as a liaison between the health care givers and the persons with diabetes and their families. The aide did home visits for follow-up and support, interpreted for the visiting professionals and assisted with the organization of community diabetes events.

"The impact that we see resulting from this Project is that people are making positive changes which are being sustained. We used to see people only once a year, and they would be motivated to change, but with no support the changes were not long term… We are seeing the HbgA1c going down and that is something we haven't seen before."

Diabetes Nurse Educator - Sliammon First Nation
(Note: HbgA1c lab test is considered one of the best indicators of reduced risk of complications)

- **Multi-disciplinary team of health and social support staff.**
  All the nurses in the Health Centre fulfilled both the Community Health and Home Care Nurse roles. They provided coordination for a system of follow-up and linkages with care providers within and outside of the community. This community added dietitian and nursing time and utilized services of existing staff such as the psycho-social worker, the health consultant and a physician to meet the identified diabetes care needs.

"The multidisciplinary team approach is valued both by front-line workers and clients. Intervention support has increased and the coordination of follow-up services has improved. As a result, clients are better able to self-manage and are less dependent on service providers."

Project Team - Wendake First Nation

- **Home Care Nurses with diabetes expertise in coordination, education and care for persons with diabetes and their families.**
  Two of the communities expanded the roles and the capacity of their home care nursing staff to provide more comprehensive diabetes education and care. These communities built supportive team relationships with other health providers within and outside of the community to improve the continuity of care and to access expert support from diabetes teams in other centres.

Nurses are important at Red Earth - they come when we need them. Lots of people have diabetes and we need people to teach us - we don't want our children and grandchildren to have diabetes.

Client Survey - Red Earth First Nation

The models were developed and modified throughout the Project in response to client feedback and responses to services. No particular method or model emerged as superior. Positive impacts were evident from each one. It appears that flexibility and responsiveness to individual needs were the key to reaching the most people in the most effective manner.

"People are becoming more independent in their own care. They want to test their own blood sugars, exercise and make changes. They have become owners of their health and are looking after their own health. We are seeing clients setting their goals then coming back to us to set new goals.'

Home Care Nurse - Red Earth First Nation

Validation of the Aboriginal Diabetes Strategy

The needs assessment process gathered information regarding the need for diabetes services in each community. The communities then put together and implemented a plan to respond to these needs.

The following section summarizes the common themes of needs, the services developed and the early impacts of the services. The findings in this section are discussed from the perspective of the Aboriginal Diabetes Initiative First Nations On-Reserve and Inuit Program Framework elements.

Care and Treatment

Definition

"Services will begin to address the needs of First Nations and Inuit people already diagnosed with diabetes by providing them with direct services to help monitor their diabetes status, screen for and prevent further complications from developing, and provide diabetes education to clients to encourage self-management. Creative ways to remove service barriers should be examined and linkages be established to help ensure that the fullest continuum of care services may be realized."
(Aboriginal Diabetes Initiative First Nations On-Reserve and Inuit Program Framework)

"Clients receive much more intense follow up and support with this Project. People were only seen by health professional periodically. Now they are seen every few weeks."

Rigolet Pilot Team

Needs Identified

The community needs assessment identified the following concerns:

- **Direct Services and Diabetes Education**
  - few people in the First Nations/Inuit communities had the opportunity to receive diabetes education in the past year;
  - all communities identified the need for regular dietitian services;
  - only one community had a diabetes education team (nurse educator/dietitian) that visited the community; and
  - some communities already had a working relationship with the local diabetes education services while others did not have easy access to this service or had not established a relationship.
- **Screening for Complications**
  - in each community, 40-50 % of those with diabetes also had high blood pressure;
  - monitoring for possible complications was incomplete and could be related to several variables - physician practice, amount of documentation and/or clients not attending for follow-up appointments and/or tests;
  - many community members with diabetes were already demonstrating diabetes complications; and
  - the results of the Haemoglobin A1c testing were usually "sub-optimal" or "inadequate".

- **Removal of Service Barriers**
  - documentation about client health information such as lab work, was located in several places (local health centre, physicians' offices, diabetes programs, hospitals). There was minimal or no coordination of care and services using standards such as the Clinical Practice Guidelines.

Activities and Services Initiated

Four areas of activity and service will be described in terms of the categories of needs identified: direct services, screening for complications, diabetes education and removal of service barriers.

- **Direct Services**

  In all communities, dedicated staff had been made available for the diabetes service within Home and Community Care. This was the first time that staff resources with appropriate expertise had been allocated to a service specifically for people with diabetes. The model of staff allocation and service varied in each community and is described in detail in Section 2.1. Communities augmented their nursing services, but also added other staff with a diabetes focus.

  In the needs assessment, a common theme was the absence of follow-up care and coordination of care for people with diabetes. All communities implemented systems and processes to ensure the ongoing follow-up that is needed for this chronic condition.

- **Diabetes Education**

  Education about diabetes was provided to people with diabetes and their family members through a variety of methods and strategies, including:

  - diabetes workshops - sessions for persons with diabetes and families;
  - one-on-one - assessment/education/counselling with individuals who identified their own needs and set their own goals, with health care staff facilitating the process and supporting client-directed change;
  - development of teaching manuals and materials for clients who cannot read; and
  - Wellness clinics.

"Both clients and health district have expressed gratitude for the diabetes education available on reserve."

Home Care Nurse -
Red Earth First Nation

- **Screening for Complications**

  The chart audits, which were completed as part of the community needs assessments, compared the client data available in the charts against the Canadian Diabetes Association's Clinical Practice Guidelines (1998). All the sites are using the Guidelines to establish and continue regular screening programs for diabetes complications. Some examples include:

  - initiation of screening for all clients by the optometrist (no screening had been done previously);
  - blood glucose metres for all clients and ongoing regular testing by clients or their family members;
  - regular Haemoglobin A1c and other screening lab tests and monitoring of results on a long term basis (these results will also be part of future evaluations);

- communities receiving lab reports back from other health professionals so they are aware of results and can both communicate with clients and continue appropriate follow-up; and
- more referrals to follow-up abnormal test results.

- **Removal of Service Barriers and Promotion of the Continuum of Care**

  Prior to the initiation of the Project, all communities had identified a number of service barriers. While these were not totally eradicated, there were significant improvements toward their removal. The needs assessment identified several barriers to diabetes care and support which were present in the communities. The program plans for the communities were designed with the identified barriers in mind.

  - ***Lack of access to diabetes*** expertise within the community. All communities addressed this by either bringing diabetes expertise to the community or developing diabetes expertise within staff at the community level, or both.
  - ***Lack of coordination and follow-up care*** for persons with diabetes. This was addressed by improving case management and follow-up of persons with diabetes within the community. Linkages were established to share information between caregivers to improve the continuity of care. Clinical Practice Guidelines were utilized to standardize expectations for care of persons with diabetes.

- ***Transportation Issues.*** Difficulties with access to care and follow-up because of transportation and distance were addressed in several ways. It was partially dealt with by bringing expertise to the community and thereby reducing the need for off-reserve travel to services outside the community. For example, one community had their community health nurses trained to take blood for laboratory work.
- ***Culturally Inappropriate Diabetes Services.*** The pilot communities utilized various strategies to make the diabetes services more culturally appropriate. The following are a few examples:
    - the service delivery planning and identification of needs was a collaborative process with health staff and community members who guided the development of the services;
    - the development of more appropriate teaching aides, for example, materials were developed for persons who do not read and a workbook was developed to assist with teaching;
    - the utilization of persons who are familiar with the community members; and
    - teaming outside health professionals with a trained home health aide to provide cross cultural guidance and interpreting services.

Prior to the pilot project all communities identified service barriers. While these have not been totally eradicated, there have been significant improvements. One fundamental initiative to decrease the barriers has been the tremendous effort to build health teams working together and on behalf of clients and families with diabetes. These teams are both within the community and bringing in external partners and developing relationships that benefit people with diabetes.

The introduction of pilot and sometimes new staff members has meant the re-definition of roles, particularly between Home Care and Community Health Nurses. Some examples of the 'teaming' within communities included:

- Community Health Nurse and Home Care Nurse work closely as a team, sharing the workload and supporting each other's programs and working together on joint programs;
- the team took time to establish a vision and philosophy and this common understanding help to build the team; and
- placing the diabetes services within an existing community health program with all nursing staff becoming skilled in the full range of community health and diabetes skills and knowledge.

"People with diabetes regain a measure of control over their lives and are eager to self-manage their condition: they need the kind of support which this program can provide."

Multi-disciplinary Team - Wendake First Nation

The other aspect of 'teaming' has been to bring into the community services and health workers who are key partners in the diabetes program. The partners have included:

- physicians, dietitians and diabetes nurse educators. In addition, some professionals who were already coming to the community were included in the diabetes program in new ways. The involvement of physicians has been significant. The following are some examples of the new linkages with physicians:
  - the clients are now receiving care based on the Clinical Practice Guidelines from their physicians and results from the systematic follow-up by the nurses and the communication linkages developed; and
  - improved linkages to local doctor resulting in improved information sharing and changes in the clients' treatment plans to improve blood glucose or blood pressure control.

In some communities one identified barrier was the access to lab services to have blood drawn for ongoing diabetes monitoring. In some cases the health team is now able to obtain the blood specimens in the community and it is no longer necessary to travel for these tests.

"I've learned a lot. Very educational. I didn't know much about diabetes. After the first meeting I became interested. I have started exercising, and monitoring my blood sugars two or three times a day and recording them. I have changed the way I eat and read labels when I shop… I know what to do when my blood sugar is high or low. I've been doing really well. My sugar stays around 6 to 7. I have lost weight too… I've really changed my life and feel better. I enjoy life better."

Client from Sliammon First Nation

Impacts of Care and Treatment Services

Although the Project clearly resulted in a number of changes and additions in the services for persons with diabetes in all of the pilot communities, it will take a considerable length of time to see longer term impacts regarding reduced complications and sustained improvements in blood sugar and blood pressure control. Nonetheless in the short time of the Project, significant impacts were observed that indicated that the Project had moved care and treatment in the right direction to achieve the longer term outcomes.

As part of the evaluation, clients had the opportunity to provide input through a satisfaction survey. Clients reported not only changes in their self care practices, but also greater confidence in their abilities and belief that diabetes can be controlled. Three areas of improvement were evident in all the communities:

"Since the beginning of the Project, there have been decreases in the HgA1c lab results of several clients.'

Rigolet Project Coordinator

(Note: HgA1c is a blood test which is considered one of the best indicators of reduced risk of complications)

- more knowledge about food and its impact on blood sugar, and changes in eating habits with increased awareness of how foods eaten can influence blood sugar;
- more people had the capacity to monitor their blood sugar and are beginning to understand the meaning of the results. In some cases, this led to further change in treatment such as changes in oral medication or a willingness to start insulin therapy; and
- a general sense of "taking better care" of oneself and understanding of diabetes.

Some communities indicated that family members were also impacted by the Project. Family members gained a better understanding of diabetes and were able to provide more support to the person with diabetes.

Although it is much too early to assess the impact of the Project on rates of diabetes complications, health staff in the pilot communities noticed a trend in reduced Haemoglobin A1c results. This test represents the overall quality of diabetes control and the needs assessment indicated a high percentage of sub-optimal and inadequate results. Diabetes research has shown that any reduction in the Haemoglobin A1c reading can reduce the risk for diabetes complications.

Lifestyle Support Services

Definition

"Provides support to people living with diabetes and their families/care providers in coping with the consequences of having a chronic, potentially debilitating and life threatening disease. Lifestyle supports may enhance community capacity to provide holistic approaches to the realities of living with diabetes. Activities may include peer support groups, sharing circles, drop-in programs for people with diabetes and their family members, or youth programs. These activities may provide an opportunity to share feelings, and discuss issues, problems and solutions."
(Aboriginal Diabetes Initiative First Nations On-Reserve and Inuit Program Framework)

Needs Identified

In the community needs assessment, there was considerable variation in the identification of lifestyle supports for people with diabetes and their families. In all communities, it was noted that few people had received diabetes education within the past year. Diabetes education often includes lifestyle support through the education process itself, ongoing follow-up and community initiatives.

In the client assessments done during the Project, other issues affecting diabetes self care such as addictions, alcoholism or depression were identified.

Canadian standards for diabetes programs support attention to both the physical and psycho-social needs of people with diabetes. All the communities included lifestyle supports in their diabetes plan.

Activities and Services

In the program evaluation, all communities identified lifestyle supports being implemented. Again, these were all in the early developmental stages and it will take time for them to be accepted by community members and to become fully established. The following are some examples of the lifestyle supports:

- training of community members with diabetes to act as volunteer mentors for others with diabetes;
- health professionals providing more advocacy services on behalf of their clients;

- grocery store tours given by a health professional;
- cooking classes for men only;
- support groups;
- special luncheons for people with diabetes;
- walking clubs/programs - some include discussion as well as physical activity;
- referrals to the mental health therapist or psycho-social worker based in the community who help people adjust to the diagnosis and lifestyle changes; and
- beginning to develop closer working relationships between addiction services and the diabetes support services.

"Diabetes was scary for me… What the complications are. I wouldn't even talk about it. I was worried about what will happen to me. Now I have started to accept the idea about learning about diabetes."

person with diabetes -
Red Earth First Nation

"Now we want to do something for the students. Lots of letters to the school. A workshop was held with students, and the turn out was good. Promoting health in the schools is important. Students are living with parents who don't know what to do about their diabetes."

Health Director -
Red Earth First Nation

Impacts of Lifestyle Support services

Lifestyle support services had impacts on clients, family members and health professionals:

- people with diabetes were more willing to talk about the disease and to share ideas and information - both with health staff and with each other;
- some clients spoke about having a greater acceptance of the condition and greater willingness and motivation to deal with it positively and pro-actively;
- in one community, health staff observed that there seemed to be a decrease in the sense of isolation that may be felt by some people living with diabetes; and
- some health professionals indicated a greater understanding of the complexities of the condition and new respect for the challenges facing someone in living well with diabetes.

Promotion and Prevention

Definition

"Activities that target the entire population, to increase awareness of diabetes and its complications, promote healthy eating and active living, and encourage the integration of traditional methods and practices with western-based approaches. Diabetes revention and health promotion activities that focus on the need to educate youth will decrease the likelihood of the next generation suffering from diabetes."
(Aboriginal Diabetes Initiative First Nations On-Reserve and Inuit Program Framework)

Needs Assessment

While the awareness of diabetes as a serious community health issue varied considerably among the pilot communities, all community needs assessments mentioned the need for activities directed at the prevention of diabetes. In particular, the communities mentioned issues related to:

- access to healthy and affordable food choices; and
- opportunities to increase physical activity for everyone.

"…we want to meet with them before they are diabetic, those who are glucose intolerant, so we are now ready with this type of client also… We try to look for ways to get their interest rather than wait until they are sick. We want to involve them (people who are glucose intolerant or predisposed to diabetes) now, to work with them and their families."

Project Coordinator - Wendake First Nation

Activities and Services

Health promotion and prevention were not the major focus of this Project. All of the communities recognized the need to involve both leadership and membership in the assessment of needs and the planning of services in this area. Indeed, involvement in the assessment and planning processes often served to heighten awareness of the need for improved care, treatment and prevention. The need for more health promotion and prevention initiatives was more strongly identified in the evaluation than in the needs assessment.

All of the communities implemented specific activities to increase awareness about diabetes in the community. Examples of these activities included:

- displays in public locations that were changed on a regular basis (health centre, schools, store);
- regular newsletters;
- activities on Treaty Days;
- information and activities in the schools - talks on diabetes and prevention;
- involvement of family members in discussions about diabetes prevention for others in the family of the person already diagnosed; and
- screening clinics.

"The whole team has come to recognize and respect the time it takes to know clients, allow them their time (not pushing) and yet be supportive of their diabetes management.'

Home Care Nurse -
Sliammon First Nation

Impact of Promotion and Prevention

In the community evaluations, there were several examples of health promotion and prevention being impacted by the Project. This had a spin-off effect as health staff began to expand their efforts beyond those already diagnosed with diabetes.

- In one community, there was a demand for healthier food choices at community meetings. For example, at one meeting with donuts and snacks, organizers were asked about provision of healthier choices such as fruit.
- There is more interest in schools and some school programs have either started or expanded education about diabetes and prevention.
- Diabetes is no longer a taboo topic and is being talked about openly in the communities.
- Family members are seeking information, coming in for screening and asking about lifestyle changes for themselves.
- In one community, the health staff have been able to work with the local store and have used Canada's Food Guide as an education tool.
- Health staff are now planning extended prevention activities to focus on persons who have been identified as at risk of developing diabetes.

"Learning about the Stages of Change was very enlightening for me to learn about how to approach people and help them to identify their own goals. The hardest part for me was to hold back and give only the knowledge that they are requesting."

Home Care Nurse -
Red Earth First Nation

Health Staff Education about Diabetes

One of the Project objectives was to identify the education and training needed by community-based health care staff to provide improved services for persons with diabetes and their families. The knowledge and skills of health care staff clearly increased during the Project and this had a positive impact on their personal and professional practices.

Needs Identified

A common need identified in all pilot communities was increased diabetes education for all levels of community based health staff. The needs assessment package included one self-assessment tool for use by Registered Nurses and another for use by all other health staff members. In their self-assessment, the health staff identified most of the potential learning areas as important for learning. They also identified the need for up-to-date and consistent information to be given to clients.

Activities

The pilot team members took advantage of opportunities to access educational programs and workshops on diabetes throughout the Project. Workshops were accessed through the universities, diabetes education centers and regional conferences.

"The diabetes assessment tool to help identify gaps and facilitate goal setting and clients are reporting back that they have reached their goal and want to set new goals for themselves."

Home Care Nurse -
Red Earth First Nation

In addition to the workshops, community staff found that the working relationship with diabetes education teams developed during the pilot had a mentoring effect. It was a positive experience to work with diabetes education team members and to have them available to discuss client-related issues and concerns. The pilot staff were also able to access numerous written resources from these outside experts.

The specific activities to address the learning needs to health staff related to diabetes occurred in two ways: a 3.5 day workshop for Registered Nurses (two from each community) was provided through the Project to develop skills in the area of diabetes education, and at the local communities. As a result of this workshop, participants were able to:

- gain an understanding of the current principles for the care and treatment of diabetes;
- use and apply to their practice recognized standards of care and treatment (Canadian Diabetes Association Clinical Practice Guidelines);

"To become very comfortable and competent in diabetes management, staff members will need to actively participate in continuous learning: methods include obtaining subscriptions and reading magazines related to diabetes management, continue to participate in home visits with diabetes experts, and attend any information workshops and sessions available."

Home Care Nurse -
Sliammon First Nation

"At first I would just teach this and this. I just wanted to get it done and check things off. The (Diabetes) Workshop helped me realize that clients are only ready to learn depending on their own needs. The Stages of Change taught me that if people are not ready I can't just push material at them until they are ready. I have learned to respect people more. When I realize they are not ready to learn, I have learned to be more encouraging, be more supportive. It made me realize that you need to base everything on the clients needs."

Rigolet Home Care Nurse

- gain an understanding of the principles of diabetes education and one strategy to facilitate behavior change (Transtheoretical Model of Change/Stages of Change);
- use and apply a tool for client assessment developed specifically for the Project;
- obtain and try out practical tools for client education; and
- obtain materials and resources for further information and study.

As part of the community diabetes plan, the Registered Nurses who attended the above course provided education sessions for other health staff. Some examples included:

- eleven diabetes classes, each three hours long, held in the community for seven staff and three community members;
- ten in-service sessions for the Home Support Service Workers on diabetes management;
- twenty participants in diabetes workshops presented by the multi-disciplinary team; and
- Home Health Aide who worked closely with project nurse and diabetes educators, attended a three day workshop in the community.

Impacts of Health Staff Education about Diabetes

Health staff interviewed during the evaluation reported that the Project had increased their ability to deliver diabetes services to the members of their communities. Another significant impact was a change in the attitude and beliefs of the health care professionals who are working with the people with diabetes.

"Access to expert advice and creating professional clinical partnerships is also essential in providing quality care… The Certified Diabetes Nurse Educator provides expertise beyond the Home Care Nurse Coordinator's ability, and in some ways could be considered a mentor in diabetes management."

Sliammon First Nation
Project Coordinator

The understanding of health care providers was impacted by the Project in a number of ways:

- learning about diabetes is now more likely to be seen as a continuous and long- term process;
- the use of the Clinical Practice Guidelines has provided a tool and common standard for care amongst all the professionals;
- clients are seen as able to direct their own care and set their own goals while the professional is seen as a supportive resource and facilitator;
- high quality tools and processes can positively impact the care and treatment received by the people with diabetes;
- awareness that persons with diabetes can take charge of their health care and impact the course of the condition; and
- the effectiveness of the case management approach with a systematic follow-up by nurses can make a difference both to the clients but also to the care provided by physicians.

"I learned that people have to look at diabetes on a day to day basis. They have power to improve their quality of life by looking at nutrition, physical activity… and they can control it and also by reducing the stress. My motivation is now to help people to face the power of their lives and have better quality of life on a day to day basis."

Psycho-social worker - Wendake First Nation

"We are more confident in meeting with doctors because we now know what we are talking about. We use the guidelines as bottom line. When the doctors are not working with those guidelines, we ask them why. We are more confident with this type of follow up."

Project Coordinator -
Wendake First Nation

In conclusion, the education and training of front-line staff was one of the first and most critical steps in the creation of community-based diabetes services. This education served as a means to develop the vision for improved services and to develop new skills and knowledge which was then shared with other staff and community members.

Implementing diabetes services within a Home and Community Care Program will require a commitment to ongoing health staff education in both the technical aspects of diabetes care and treatment, and also the caring aspects of education and support for clients and their families.

Diabetes education and care skills need to be provided in a variety of ways, including formal and informal educational sessions, mentoring with diabetes education teams and written materials.

"The discussion of expectations of other team members and the establishment of roles and responsibilities needs to be done in the planning phase."

Project Coordinator - Red Earth First Nation

Program Planning and Development

Home and Community Care Framework and Diabetes Services

One of the objectives of the Project was to observe whether the framework developed to guide Health Canada's First Nation and Inuit Home and Community Care Program had relevance to the development of diabetes care and treatment services. Although priority was given to the development of the diabetes services, the diabetes program models which were developed through the Project fit within the framework for the First Nations and Inuit Home and Community Care Program.

Administrative Structure

The leadership of each pilot community decided how the funding and administration should be managed. In two of the communities, funding flowed through an organization which coordinates services to a number of communities (a Tribal Council and a Health Commission). The funding and administration in the other two communities was administered through the band government health services.

"The follow up with podiatrist and other specialists (are) according to (Clinical Practice) guidelines. This was not done before. It takes a nurse coordinator. The patients by themselves are really discouraged by the system of follow ups. It helps that the nurse supports them with this."

Health Consultant -
Wendake First Nation

Professional Supervision

Professional supervision was provided through a nursing supervisor at the Band, Tribal Council or Health Commission level. Advisory support from diabetes experts was accessed through diabetes education teams in nearby health districts or tertiary health organizations such as hospital diabetes teams or the Canadian Diabetes Association.

Client Assessment

The home support and home nursing services were, to some degree, based on the assessment of health needs by a Registered Nurse in all communities. There was a blurring of roles and responsibilities in relation to assessment and assignment of staff in communities where the home support services were under a different supervisory structure than the home care coordinators. Some communities have identified this as an area to be strengthen in the future.

"I learned that through a systematic follow up that nurses do make a great difference for the doctors in the community because people talk to the nurse – they don't talk as well to the doctors - they don't listen as well to the patient but nurses do. I saw the confidence that clients have for nurses. This will make a big difference and help the doctors – because doctors are very stressed over number of patients. Recording blood sugars with the nurse makes a big difference for doctors."

Health Consultant - Wendake First Nation

Home Care Nursing

All pilot communities added nursing staff to coordinate and develop the program. In three of the communities, the Home Care Nurse was the key provider of diabetes coordination, education and care. One pilot community added the diabetes coordination and follow-up duties to their Community Health Nurses who had a joint community health/home care job description.

The work description for the nurses involved in the Project differed from site to site and evolved as the Project progressed from a planning and development focus to service delivery. A close working relationship with the community health nurse(s) (and clinic nurses in the remote isolated site) was essential for the success of the Project. There was a need to redefine roles and responsibilities of the nurses in all the communities. In some communities, the chronic care monitoring and follow up of persons with diabetes became the responsibility of the diabetes home care nurse.

Acute home care nursing was available in all four communities. In one community it was accessed through the provincially funded services.

Personal Care

The personal care available was limited by lack of trained staff in some of the communities. The staff providing personal care generally received professional, but not day to day, supervision from the home care nurse.

Home Support Services

Adult care home support services existed in all communities. The self assessments identified the need to develop closer ties between the home support services and the Home and Community Care Program.

Case Management

A case management approach for the clients with diabetes was utilized in all of the pilot communities. Client services were coordinated to improve the continuity of care for clients receiving health care from a variety of providers.

Linkages

New linkages were developed to improve access to services and the communication with other health care professionals providing services to the clients. These linkages included service contracts and improved communication channels with local health districts, third-level hospital services, on-reserve health and social services and private healthcare providers. There was a reported increase in access to lab results and increased alignment of care with the Canadian Diabetes Association's Clinical Practice Guidelines (1998) in all communities.

"We proceeded in a respectful manner and clearly established that participation in the Project was voluntary, that nothing would happen without their consent, and that we were prepared to wait until they were ready or felt more confident about the program. This proved to be the best approach: the clients who participated are now promoting the services of the Centre."

Project Coordinator - Wendake First Nation

Supportive Infrastructure for Program Delivery

The communities were asked to identify the supportive structures that they needed in order to provide home care diabetes services. In addition to adequate staffing, education and training, the following were identified:

- educational tools and equipment for teaching;
- program policies and procedures;
- transportation for clients and staff;
- resource materials for clients and staff;
- professional supplies such as foot care instruments;
- clerical support;
- office space and office equipment;
- a budget for incentives and special projects related to diabetes;
- revision of the client charting system;
- new tools for client assessment and follow up; and
- new flow charts to track variables in follow-up care and service.

"If starting over again, I would probably assign the diabetes home care management to one nurse. I have found that because diabetes is a chronic condition, other 'urgent' situations often detract the Home Care Nurse Coordinator from being pro-active in diabetes outreach and management."

Sliammon First Nation - Project Coordinator

As the pilot communities developed and implemented their diabetes programs, there was a corresponding advancement of the essential elements of the Home and Community Care Program. Several areas, however, were identified for further enhancement. Those mentioned by the communities included; the need to coordinate the new Home and Community Care Program with the existing Adult In-Home Care Program funded through the Department of Indian Affairs and Northern Development (DIAND), and the need to form closer connections among diabetes services, nursing care, home support and personal care services. Other improvements mentioned included nursing services for clients other than persons with diabetes, and expansion of palliative care and respite services. All sites indicated plans in their self assessment to continue to strengthen the Home and Community Care Program.

"Following the loss of our professional nutritionist in July 1998, our clients were required to visit private clinics in order to access nutritional services. In some cases, this led to frustration and a loss of motivation. This Project accentuated the importance of making nutritional services available at the health centre. It is now generally recognized: these services will remain in place in the future."

Project Coordinator - Wendake First Nation

Integration and Coordination of Services

In response to the identified need for improvements in the continuity of care, the pilot communities made tremendous efforts to build strong unified health teams working on behalf of clients with diabetes and their families. These teams included both community health staff and external health professionals and resources. The introduction of new staff members associated with the Project also meant the re-definition of roles, particularly between Home Care and Community Health Nurses.

Some examples of "teaming" within communities included:

- Community Health Nurse and Home Care Nurse working closely as a team, sharing the workload and supporting each other's programs and working together on joint projects;
- establishing a vision and philosophy during the planning process that helped to strengthen the team; and
- placing the diabetes services within an existing community health program and all nursing staff became skilled in the full range of community health and diabetes skills and knowledge.

"Through its active involvement and interest in professional development, our nursing team has made slow but sure progress: we are confident in our knowledge and know our limits, as well as when and how to offer support to persons dealing with diabetes. We work as a team with the nursing staff, the nutritionist, the psycho-social support worker, the homemakers and our own colleagues."

Project Coordinator - Wendake First Nation

The other aspect of "teaming" was to bring external partners as resource people to community services and workers. These partners included physicians, dietitians, mental health professionals and diabetes nurse educators. Furthermore, some professionals who were already coming to the community were included in the diabetes program in new ways. The involvement of physicians was particularly significant. The following are some examples of these new linkages with physicians:

- in one community, clients received improved care based on the Clinical Practice Guidelines from their physicians, more systematic follow-up by the nurses and improved communication linkages between local nurses and off-reserve physicians; and
- in another, improved linkages to a local doctor resulted in improved information sharing and changes in the clients' treatment plans to improve blood glucose or blood pressure control.

Concentrated efforts to find ways to surmount the barriers to services led to the establishment of new means of delivery and new linkages with other service providers both within and outside the community. These innovations in the program planning resulted in effective initiatives to improve the services for persons with diabetes and their families in the four pilot communities.

"Take the time for public relations and involve all stakeholders to ensure that we are all working for the goal of quality client care. Good communication is a must."

Rigolet - Public Health Nurse

Challenges to Program Development

Every new initiative experiences barriers and challenges and the pilot teams dealt with many of the challenges by using a creative problem-solving approach. At the completion of the project, each community team was asked to look back at the challenges they encountered and describe some of the solutions they found effective. The following are challenges common to most of the pilot communities.

Client Involvement

All communities acknowledged the importance of involving people with diabetes in decision making regarding their own care. However, community project staff observed a hesitancy to commit to the Project and to participate in program activities. The health staff acknowledged that the introduction of a new project takes time and that it is important to work at the pace of the community and the individuals with diabetes. Trust is also a variable that requires time to establish. Good communication practices with clients are important in all aspects of the planning and implementation of diabetes services.

Knowledge of Diabetes

Initially, there was a lack of knowledge about diabetes and its care and management. Not only was the initial education important for the health staff, but continuing education and support was also found to be critical. In one community, the nurses felt that, prior to the Project, clients with diabetes did not see the nurses as a source of information and support. This changed as the nurses acquired knowledge and were able to share this with their clients.

Nutrition Support

The need for increased access to health professionals with nutrition expertise was identified by three of the communities as a significant gap in their services in the needs assessments.

"Within the Labrador Inuit Health Commission we have a wonderful Internet communication system that allows for daily communication with all staff. Therefore I have been taking advantage of it and I have been providing diabetes education with the Public Health Nursing staff. I plan to continue with this type of education when I have spare time."

Rigolet Diabetes Home Care Nurse

Human Resources

All communities recommended an increase in dedicated staff time to plan, implement, manage and monitor the new diabetes services. Combining the planning and management of the Home and Community Care Program with the new diabetes services was found to be too demanding.

Community and Leadership Involvement

At the beginning of the Project, there was a need to secure the involvement and commitment of key stakeholders. All communities acknowledged both the significance and the time required for this step. Key stakeholders included community leadership, other health agencies and personnel, community members and people with diabetes. The needs assessment and community involvement processes helped to build an awareness about diabetes and diabetes-related care and treatment. The needs assessment also permitted the project planners to tailor the program to the community. The fit between the program and the community was viewed as a critical factor for success.

"Seeing the transformation in knowledge (of the Home Care Nurse) made me want to take the training in diabetes education."

Senior Health Nurse
Red Earth First Nation

"I did not know we had so many people with diabetes. I was surprised with the number. It was the same with the Council. …We learned a lot (from the community needs assessment). Now we are able to address more what they need… It is going to be easier for me too re: my planning of programs, particularly around staff. I took the decision last week (to Council) regarding the nutritionist. Instead of having one nutritionist 3 days/week we will now have one nutritionist 5 days/week…"

Health Director
Wendake First Nation

Unexpected Project Impacts

There were some unexpected impacts identified through the Project evaluation that are worthy of mention. The Project had an effect beyond what was anticipated. These unexpected impacts included:

- Community based health care staff shared information they had learned from their diabetes educational sessions with family and friends, thereby raising the awareness of diabetes in the community.
- As other community nursing staff observed the increased skills and knowledge of the project staff, there was a desire to increase their own learning about diabetes.
- The increased knowledge about diabetes for one nurse opened opportunities for her to share information with other nurses in other communities.

"My whole perspective of how to help clients with diabetes has changed. I truly didn't understand how much support people need and how difficult it is for them to change their lifestyle. I have a new understanding of the importance ongoing support over time. I have a greater understanding of how to help people and that is even more important than knowing all the new and changing technical information."

Sliammon First Nation Home Care Nurse.

- The needs assessment results provided communities with the information to assist with longer term planning and to make the case to leadership for increased health staff.
- The success of this Project influenced decision-making for other programs for other communities. For example, one person who has experienced the positive impact of the diabetes services in his own life, has undertaken an advocacy and leadership role for improved diabetes services within an organisation which oversees health services to a large number of communities.
- A number of health care professionals have been influenced by this Project. In one case, members of a diabetes team visiting one community stated that they have learned to be more culturally sensitive when they provide services both in the community and within their own clinic setting. Another health team member stated that involvement with the diabetes pilot has changed his understanding of how to teach and motivate clients to take more control of their own health.

"We had to learn to trust ourselves and to believe in our ability to act as agents of change within the community and the health centre."

Project Coordinator - Wendake First Nation

- Nurses identified an increased understanding of the difficulties and fears faced by persons with diabetes and have become more sensitive in their approach and care.
- Nurses identified increased self confidence as their knowledge and skills have increased and some commented that they now see themselves as health educators rather than as technicians.

"Develop the common vision and philosophy and policies supported by administration and leadership (then revisit often and revise). Involve a community member who is respected as an advocate. Set goals and stick to them, do not divert."

Sliammon First Nation Pilot Team

Introduction to Program Logic Models

Program Logic Models can be used as a framework in both program planning and evaluation. A logic model can:

- provide a 'snap-shot' of a program by outlining the program activities, the direct outputs from the activities and the short and long term results;
- illustrate the links between the components of a program; and
- highlight the logic or reasons behind the planning and actions.

A logic model is client-centered. The completed model is a drawing that represents the logical relationships amongst each of the components. The development of the model is a dynamic process and as groups work through the model development process, they will:

- build a group vision and consensus; and
- become aware of potential issues in their program design and can work through these as part of the model building process.

"In my view, more days of training are needed in order to become skilled in designing a program evaluation logic model. Some of our forms will need to be revised in the coming years since it is highly unlikely that they comply with evaluation guidelines."

Wendake First Nation Project Coordinator

Future Evaluation Planning

An initial program evaluation plan was submitted with the service delivery plan for each pilot site. The communities were not given any tools or resources to assist them in program evaluation. It was jointly decided at the mid point of the Project to pilot a program logic model with performance indicators. It was hoped that this evaluation model would provide a tool for longer-term work by the pilot communities.

To assist the communities in using the fairly complex program logic model, the key members of the pilot teams were brought together for a workshop in which the information about logic models was presented. The objectives of the workshop were:

"Start with the community first, with information and posters. Build a team and involve people with diabetes then get the services in place. The key to success is to involve people who have diabetes. Get input and direction from them."

Pilot Team - Red Earth First Nation

- to develop an understanding of program logic models as an evaluation approach;
- to practice using all elements of logic models;
- to build a template program logic model; and
- to take home practical, user-friendly tools for discussion and application in their community to further develop and refine their own logic model.

A generic template for a home care diabetes logic model was developed at the workshop and individualized by the pilot team members from each community. The teams then went back to their communities to finish their models and to develop specific performance indicators.

Results to Date

Each of the communities developed a draft program logic model with performance indicators. In the final report evaluation, participants were asked to comment on the usefulness of this model for program evaluation and the support needs for its development.

All four communities stated that they found the logic model a useful tool in planning their long term program evaluation. One participant noted that this approach was helpful in understanding the rationale for nursing care and treatments and that it was also possible to backtrack from the indicator to find the gaps in services. Another community team member stated that the logic model assisted with the process of developing statistical records and the tools required to monitor the progress of the program. It was generally found to be a useful approach for evaluating both intermediate and long term outcomes and linking the program activities to the outcomes.

"It is essential to increase the staff to be able to commit time and effort to program planning. It takes additional time to build a comprehensive Home Care program that balances all service delivery."

Red Earth First Nation - Project Coordinator

"Before you start to work with the clients, you need to have a good understanding of the needs of the clients – not talking about statistics but to really know what each of the needs of clients, both community needs and individual needs perspective."

Health Director - Wendake First Nation

Some cautions however were noted by participants from the pilot communities. Most found that this model required extra support to familiarize the project teams with the concepts and to assist with the individual model development. It was felt that additional training days and one-to-one support would have been helpful in promoting confidence and skill required to effectively use this model. The communities also identified the need for more support regarding the development of performance indicators and tracking tools.

Conclusion

All communities were able to apply the workshop information and develop their own draft program logic model. However, resource materials and resource personnel were required to facilitate learning and use.

"The support of leadership is essential. In the Fall of 1999, we received moral and tangible support from the managerial team of the Huron Wendat Nation through the Council and Grand Chief Wellie Picard, …They participated in the needs assessment and agreed to speak to their families and urge them to take part in the program."

Wendake First Nation Project Team

GUIDANCE FOR PROGRAM PLANNING - WORDS OF WISDOM

For the eighteen months of the Project, project staff were dedicated to the planning and implementation of home care diabetes services in the four pilot communities. The frustrations and the triumphs, the successes and the failures of the project have all contributed to a substantial body of wisdom. This wisdom is offered to others who have an interest in developing similar services.

- To plan and develop a program of this magnitude requires additional staff who are dedicated solely to the Project. In particular, a project coordinator who has the appropriate professional training and who is familiar with and to the community is an important factor for success.
- To be effective, the services must be based on community needs.
- The involvement of community members in planning is key to ensuring the services will be responsive to the needs of the community.
- The support of leadership is essential. Their level of involvement is not as important as their recognition of the need and support for the program.

"Diabetes education training for all staff involved is essential. Every staff member was consulted during the needs assessment and now functions as a communicator who promotes the program at the community level."

Project Coordinator - Wendake First Nation

- The program and its services need a foundation of a vision and a philosophy for services which is supported by both leadership and community members.
- The involvement of all levels of health staff in diabetes education and program planning is important for success.
- Which ever model is used for the delivery of services, it is most important that the diabetes service has the flexibility to respond to the needs of the community and to each individual client and family.
- A team approach that includes different health care professionals from both the community and external agencies is essential. The roles and responsibilities of team members should be clearly identified to avoid overlap and enhance complimentary areas.
- Diabetes education and care can only be effective if they are client centred.
- Increased diabetes awareness of prevention and how it can be controlled needs to be communicated to the people.

"Encourage staff involvement in activities thus enabling staff to feel part of the Project and they may help you to reach your goals."

Rigolet Pilot Team

"Involve clients in all aspects of care and show them to make decisions about their care. Be thorough with care plan with client involvement."

Rigolet Public - Health Nurse

"Part of our success is that we are working with (community members) at their pace. Some people are very interested in systematic process but not interested in focus or support groups, some are only interested in nurse follow up or with nutritionist follow up and so we need to know what method that they feel works best for them."

Wendake First Nation - Project Coordinator

"I knew diabetics as an emergency physician. What I learned with the Project is diabetes is not a sickness. I only knew the complications. People can do a lot of things to prevent the complications and I was convinced myself and succeeded in convincing people who came to the workshops that they had a lot of power for their diabetes management."

Health Consultant -Wendake First Nation

"The support of Powell River health care providers and organizations has enabled us to incorporate a traditionally known hospital program into a community perspective. I believe this has created an awareness of the strengths and challenges both identities experience. This awareness has created creative, co-operative partnerships in which client needs and issues can be addressed at several different levels."

Sliammon First Nation
Project Coordinator

The last word on planning:

"Choose one good coordinator who is motivated, obtain the support of band council (without this you won't go far), have a good working team, do not be discouraged because with patience you will get to where you want to go."

Health Director - Wendake First Nation

APPENDIX A:

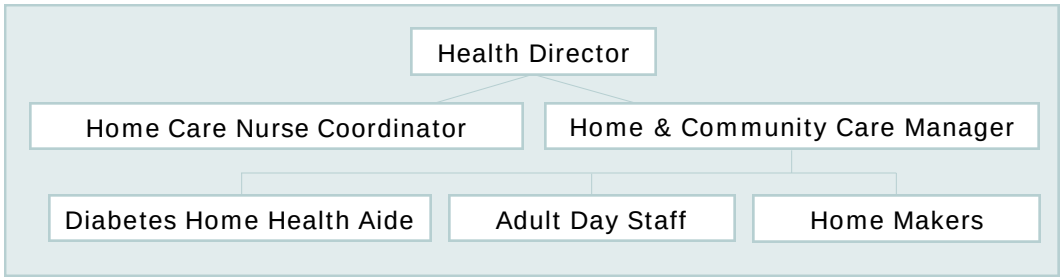
PROJECT PROGRAM MODELS

Sliammon First Nation
Diabetes Home Care Program Model

Sliamon First Nation developed a model with coordination and liaison services within the community and established linkages to diabetes expertise from the local health district. A community based team was formed to guide the project development. Two additional full time staff were hired, a home care nurse to co-ordinate the project and the diabetes services, a home health aide provides a liaison function and a diabetes team was contracted to provide diabetes expert support within the community.

Description of Model Diabetes Home Care Program - Sliammon First Nation

Management Structure



Project Staffing

- One nurse for program coordination and development, assessment and supervision of personal care.
- One trained home health aide to support the program through client follow-up and liaison.

Supervision

The Home Care Nurse Coordinator is provided with professional supervision from the intertribal authority and day to day supervision from the health director.

The home makers and personal care workers are supervised by the home and community care manager but receives professional supervision from the Home Care Nurse Coordinator for personal care and diabetes related tasks.

Diabetes Expert Support

Diabetes expertise is obtained from the contract with the Diabetes Day Program, Powell River.

Services

Client Assessment

Assessment of home care client needs is provided by the Home Care Nurse Coordinator. Before this Project this task was part of the Community Health Nurse's responsibilities.

Case Management

Sliammon First Nation identified the need for a strong team approach to diabetes care. The Home Care Nurse Coordinator coordinates the care for persons with diabetes and maintains close communication with the diabetes education team and the Diabetes Home Health Aide. It was further identified that regular home care team meetings are needed to consistently review the program and the policies within it and the management of client care.

Home Nursing

Acute home nursing care has been provided by off reserve health services from Powell River.

Personal Care

Personal care is provided by trained home health aides under the professional supervision of the Home Care Nurse Coordinator.

Home Support

Home support is provided through home makers from the (DIAND Adult Care) Home and Community Care Program.

Other Diabetes and Home Care Services Available

Diabetes Team from Powell River contracted two days per month.

A trained Home Health Aide who supports the diabetes program as "The eyes and ears of program" by maintaining very close contact with the clients. This position is considered to be essential to the success of the program. She has several areas of responsibility:

- to accompany diabetes educators (nurse and dietitian) on home visits to persons with diabetes;
- to follow up clients with additional visits each week. During these visits the client often ask for clarification of information;
- to inform community members of services encourages participation in diabetes initiatives; and
- to liaise between the health services and community members.

Integration and Linkages

Adult Care Program

Funding and staff for home care services are managed by the home and community care manager. Future plans have identified the need to establish closer linkages of support and supervision between the Home Care Nurse Coordinator and the aides who provide personal care and respite.

Community Health

The Home Care Nurse Coordinator and the Community Health Nurse work closely together. There has been some redefinition of roles through the Project.

Other Service Linkages

Contracted services for 2 days per month with Diabetes Day Program for diabetes education team to come to the community. The community visits were a combination of home visits for one to one counselling and group education.

Infrastructure Supplies and Equipment

Teaching Resources

- videos, educational pamphlets, educational games, food models, blood sugar models, various glucometers and test strips.

Treatment Supplies

- dressing supplies, blood pressure monitors (digital self monitoring kinds are very useful as they are user friendly for clients as well as the home health aides), portable digital scale (very, very useful), foot care equipment and lotions.

Other Support Needs

Equipment and/or funding to provide activities to promote exercise and active living would be very useful.

Promotional activities for the use of sugar free drinks and artificial sweeteners would also be of assistance to our clients.

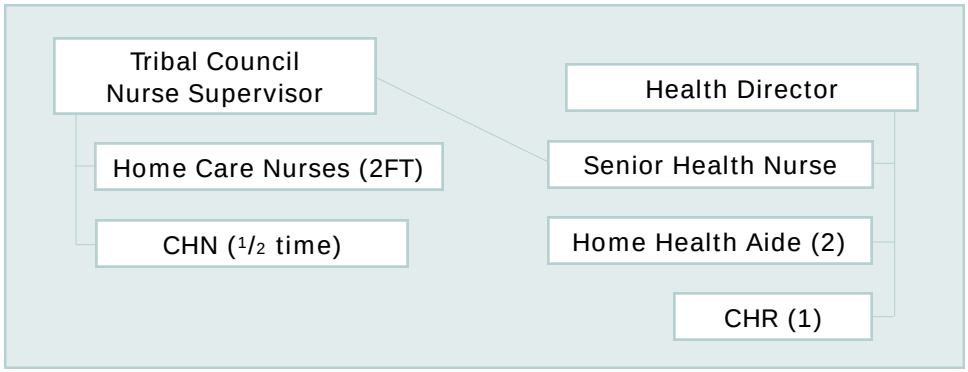
Resources available to provide luncheons, prizes for games – food coupons, samples of artificial sweeteners, sugar free drinks, etc.

Red Earth First Nation
Diabetes Home Care Program Model

Red Earth First Nation developed a program model which built capacity and expertise at the community level to increase access to diabetes services. Home Care nursing time was increased from one part time position to two full time nurses and the diabetes knowledge and skills were enhanced to support the program. The home care nurse(s) provide diabetes education and care and the coordination of other services for persons with diabetes.

Description of Model Diabetes Home Care Program - Red Earth First Nation

Management Structure



Supervision

The Senior Health Nurse supervises the Home Care Nurses. The home health aides report to the health director, but take some guidance from the home care nurses.

Project Staffing

Home care nursing time increased from two days per week to two full time home care nurse positions through this project. Home Health Aides also worked closely with the project team.

Diabetes Expert Support

Expert diabetes support is accessed from three different sources, the Tribal Council Diabetes team (Certified Diabetes Nurse Educator and Dietitian), the Nipawin Diabetes Team and the Diabetes Experts at the Tertiary Diabetes Centres in Saskatoon.

Services

Client Assessment

Home Care assessments are done to determine service needs and is done by the home care nurse. For persons with diabetes, a diabetes assessment is done through which a client establishes his/her own goals for self care. A diabetes assessment flow sheet was utilized for follow up care. An effective assessment protocol was developed.

Case Management

All persons with diabetes are assigned to the home care program. The home care nurses provide case management. Referrals are made as required for additional services.

Home Nursing

The full range of home care nursing services are available.

Home Care nurses provide case management, diabetes education one to one, teaching sessions, and treatment. All persons with diabetes are followed by the home care nurses.

Diabetes education starts with an assessment of the client's needs as identified by the client in a process guided by the home care nurse. The client sets his/her own goals. The nurse acts as a facilitator to assist the client to take control of his or her own health care through:

- individual goal setting; and
- ongoing follow up and support.

One of the home care nurses provides regular diabetes education mini classes.

Personal Care

Personal care is limited but will increase as home care workers are certified.

Home Support

Home support is provided by home health aides who are band employed. The processes are being considered to ensure the care given is based on a home care assessment by the home care nurse. The relationship between home care nurses and the home support staff is at this time not formalized.

Other Diabetes and Home Care Services Available

- A diabetes team of a certified diabetes nurse educator and dietician, employed by the Tribal Council, visit this community twice per year and are available for phone consultation. (This service was in place prior to the Project).
- Wellness clinics offered on doctors day to increase awareness and participation.
- Newsletters monthly - hand delivered to each home.

Integration and Linkages

Adult Care Program

The Adult Care (In-Home Component) Program is administered by the band and links with the nursing staff who are employed by the Tribal Council.

Mental Health, NNADAP and Recreation Director are referred to as needed.

Community Health

Information sharing on a regular basis informally and at regular staff meetings.

Clinics will be coordinated with CHN to assist with fall immunization program. Changes in nursing staff during the Project has necessitated redefinition of roles and responsibilities for all nurses.

Other Service Linkages

- Local physicians and pharmacist who visit the community twice weekly;
- North East Health District Diabetes Team;
- Physiotherapist and Occupational Therapist;
- Speech Therapist;
- Dietitian;
- Prince Albert Grand Council Diabetes Team - Dietitian service monthly;
- Saskatoon Tri-District Diabetes program as needed; and
- Diabetes Care Committee in Nipawin provides networking.

Infrastructure

Supplies and Equipment

The following supplies and equipment have been identified as required: (Office space, supplies (paper, pens, etc.);

- Computer with Internet access;
- Teaching tools equipment (overhead projector, TV and VCR); and
- Incentives for attendance to classes, workshops.

Other Support Needs

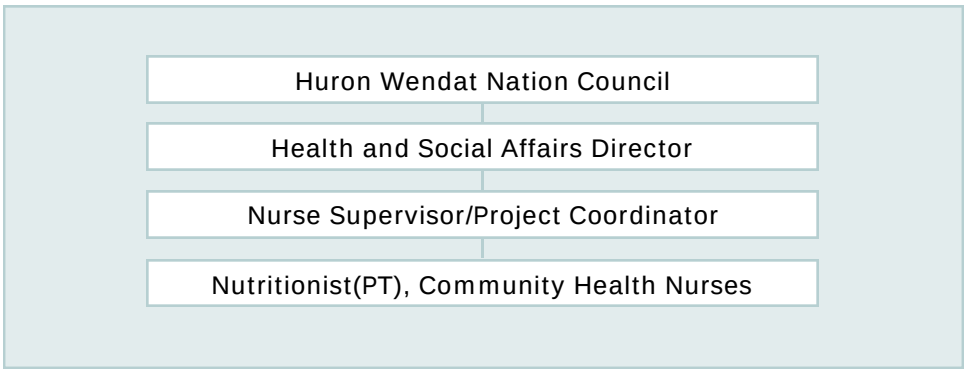
- Access to transportation for clients and staff.

Wendake First Nation
Diabetes Home Care Program Model

The Wendake First Nation pilot team has developed a unique model which has placed the home care diabetes services within the existing community health program and has added existing staff from other disciplines to round out the multi-disciplinary team. The concept is to have all nursing staff skilled with the full range of community health, home care and diabetes skills and knowledge. The nurses in effect become the case managers who coordinate care and provide services for persons with diabetes who enter the program. The program clientele are those persons with diabetes and their families who have been formally admitted to the program although it is open to all community members.

Description of Model Diabetes Home Care Program - Wendake First Nation

Management Structure



Supervision

The Project Coordinator manages the program and provides professional and day to day supervision of the nurse coordinators. For the Project another nurse has been hired to provide supervision of nursing care.

Diabetes Expert Support

Quebec City diabetes education centres. are used for education of staff and expertise on diabetes care.

Staffing

- Project coordinator (Nurse Supervisor);
- 4 FT Community Health Nurses already working - Systematic follow up added to work - one additional CHN hired Sept 2000;
- A part time nutritionist was hired in January 2000; and
- A psycho-social worker already working full time has taken training in diabetes and now provides support for persons with diabetes.

Services

Client Assessment

- Persons with diabetes are admitted though referral or from other medical professionals, or they can self refer. Requests for service are forwarded to the nurse or the psycho-social worker depending if the request is for nursing or home support.
- An initial screening is completed and forwarded to the nurse supervisor.
- A worker is assigned to visit the home for the initial assessment using the Levels of Care in Continuing care form (or a shortened form). A nurse does the assessment for primarily nursing clients, the psycho-social worker does the assessment for primarily home support services.
- A plan for care is then established, serviced implemented, then reviewed within three months.
- Clients are discharged when they no longer require service.

Case Management

A systematic client follow-up was developed through this program. The nurse is responsible for coordinating the follow-up services and to establish a communication network among various external and internal care providers. Her role is also to ensure client care is consistent with the clinical practice guidelines.

Home Nursing

If the request for services is primarily for nursing care, the nurse fills out the McGill data collection model to assist in determining the kind and level of care and services required.

Diabetes education and care is provided in part by the nurse coordinators.

Acute nursing care is provided as required.

Personal Care

Personal care is provided by trained health workers.

Home Support

Home Support services are administered through the social services. The services provided are based on assessed need of the individual clients.

Other Diabetes and Home Care Services Available

- Nutrition counselling service;
- In-home respite;
- Institutional respite available at on reserve continuing care facility;
- Mental health services;
- Transportation services;
- Palliative care is available when needed, however further staff training is required; and
- Physical rehabilitation services through agreements with provincial health system.

Integration and Linkages

Adult Care Program

The home support services are supervised by the social services. There is a collaborative relationship between the social services and the health services.

Community Health

Community health and home care are totally linked, as the same staff do both home care nursing and community health nursing. There is no separation in management or supervision.

Other Service Linkages

Linkages have been established with the physician who works on reserve, with the continuing care facility, and other expert diabetes services available in Quebec City.

Service agreements are in place for rehabilitative services, weekend and evening care from the provincial system.

Infrastructure

Supplies and Equipment
identified as needed for the Project

- Secretarial support;
- Program coordination time and human resources;
- Foot care equipment;
- Examination room for foot care and diabetes treatment, visiting specialists;
- Education tools and skills;
- Data collection tools; and
- Policies and procedures manual.

Training

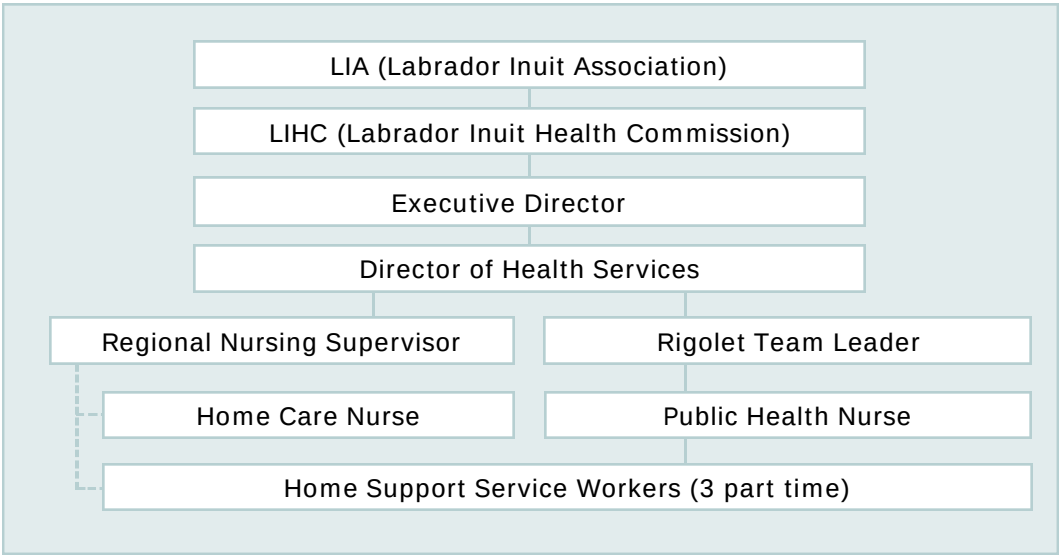
- Client assessment;
- Basic and advanced diabetes education; and
- Foot care.

Rigolet
Diabetes Home Care Program Model

Rigolet developed a model of diabetes home care which focussed on a team approach and development of diabetes expertise at the community level. The home care diabetes nurse focus is diabetes education and care for community members. She works closely with the public health nurse, the clinic nurses and physicians to enhance coordination of diabetes prevention, and treatment services for persons with diabetes and their families.

Description of Model Diabetes Home Care Program - Rigolet

Management Structure



There is a treatment centre in the community with treatment nurses who are employed and supervised by the Province, in addition to the home care nurse and the public health nurse who are employed by the Labrador Inuit Health Commission. A supportive working relationship exists between all health staff.

Supervision

The Team Leader provides day to day administration as needed for the nurses, and professional supervision is provided by the Regional Nursing Officer of the Labrador Inuit Health Commission. The Team Leader oversees health services at the community level.

Diabetes Expert Support

Contact with outside source who is a partner of the LIHC, (eg. Dietician) or direct call to specialists.

Staffing

Home Care Nurse with a diabetes focus was hired for this Project.

Services

Client Assessment

The home support needs are based on an assessment done by the public health nurse.

Case Management

All newly referred persons with diabetes are referred to the home care nurse and are seen within 24 hours for diabetes education and follow up.

All clients are followed by the home care nurse to ensure care is according the Clinical Practice Guidelines. This covers monitoring, education and treatment and screening for complications.

Home Nursing

- Clients are referred to the program from any source. Diagnosis of diabetes is made before the referral and permission is obtained for access to the health records and for follow up of other family members.
- A Diabetes Assessment is completed and discussed with client, then a care plan is agreed to by both parties. Referrals made as needed (ongoing).

- Blood Pressure (BP) checks are done on a regular basis. If BP high, client is followed on weekly basis for four weeks and if still high, referred for follow-up. With this information the physician makes changes in treatment according to the guidelines.
- Blood Glucose Monitoring - all persons with diabetes are taught the importance of blood sugar control and recording. 15 people now regularly testing and understand the results and the importance of staying within target range.
- Haemoglobin A1c - all clients have HbgA1c completed according to clinical practice guidelines.
- Retinopathy screening - all clients have been referred to optometrist for dilated pupil exam, and base line data is being collected.
- Foot Care - all clients have received education on self care of feet and are followed based on need.

Personal Care

Personal Care

Is provided by the home support service worker under the professional supervision of the home care nurse. The home support workers have been trained on the job for many skill transfers by the nurses.

Home Support

Is provided by home support workers based on the nursing assessment of client need.

Other Diabetes and Home Care Services

Dietician is now available in community four times per year.

Integration and Linkages

Adult Care Program

The home support workers provide client services based on the assessed need and are part of the health care team under the team leader. There are two different funding sources for these services through the Labrador Health Board and the Labrador Inuit Health Commission.

Community Health

The Public Health Nurse and the Home Care Nurse work closely as a team, sharing workload, and supporting each other's programs. The Public Health Nurse focuses on diabetes prevention and health promotion and some nutrition counselling. They worked together on joint diabetes initiatives.

Other Service Linkages

- Physicians and specialist to improve client care and share information.
- Optometrist for dilated pupil exams for persons with diabetes.
- Recreation director for walking programs and increase access to gym for students.
- Grocery stores to order in low fat and low sugar products and bring in frozen vegetables.
- Schools to introduce diabetes curriculum and to advocate for healthier school snacks.
- Anglican minister regarding assistance for those in need of help to buy nutritious foods.
- Linkages established with non-insured health benefits.
- Newfoundland/Labrador long term care program.

Infrastructure

Supplies and Equipment

Each community indicated supplies and equipment needed to develop their program. Rigolet reported the following needs:

- Transportation for nurse to do home visits;
- Office equipment;
- Resource materials (especially culture specific and in the local language); and
- Nursing supplies.

Other Support Needs

- Professional resources to support learning for professional staff;
- Home care policies;
- Venipuncture training; and
- Additional diabetes education opportunities.