FIRST NATIONS AND INUIT HOME AND COMMUNITY CARE PROGRAM (FNIHCCP)

Study 1, Implementation "Foundations for Success"

Summary Report: Executive Summary and Key Findings

December 2004

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NOTE TO READER

This study was prepared by Prairie Research Associates, Inc. (an independent research company) in collaboration with the FNIHCCP National Evaluation Advisory Group. Its findings do not represent the views of the Government of Canada.

This is the first of three studies that together will form the evaluation of the program. The next two studies will address the remaining questions in the Results-based Management and Accountability Framework for the First Nations and Inuit Home and Community Care program.

This is a technical report and as such, its findings are preliminary.

The final evaluation report is expected to be completed by 2006.

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EXECUTIVE SUMMARY

The federal government launched the First Nations and Inuit Home and Community Care Program (FNIHCCP) through the First Nations and Inuit Health Branch (FNIHB) of Health Canada in 1999. The purpose of the program was to address the growing need for home care and local care services in First Nations and Inuit communities. The overall vision of the program is:

> *The FNIHCCP Program will provide basic home and community care services that are comprehensive, culturally sensitive, accessible, effective and equitable to that of other Canadians and which respond to the unique health and social needs of First Nations and Inuit. The program is a coordinated system of home and community based health related services which enable people with disabilities, chronic or acute illnesses and the elderly to receive the care they need in their home communities.*

Discussions about a home and community care program for First Nations and Inuit began in the late 1990s. Several factors highlighted the need for such a program. Chronic and acute care needs among First Nations and Inuit populations were increasing. They also had a growing desire for culturally appropriate care in their own communities. Changes to health care delivery and an increasing focus on home-based care, led to increased demand for home and community care within First Nations and Inuit communities.

In 1998, Health Canada launched a pilot project for in-home care and community-based services in five First Nations and Inuit communities. The pilot project tested many program planning and implementation features that were later incorporated into the FNIHCCP.

A Joint Working Group with representatives from Health Canada, Indian and Northern Affairs Canada (INAC), and First Nations and Inuit developed the National Framework on Continuing Care. This framework identified key elements that became part of the FNIHCCP. The federal government announced the FNIHCCP as part of a significant investment in First Nations and Inuit initiatives in the February 1999 budget.

Although some home and community care services were available to some First Nations and Inuit before the FNIHCCP, these services were limited at best. The most significant gaps in service were the inability to provide full-time services or continuity of care, and the absence of professionals, trained personnel, case management and referral systems. Effective program coordination and administration was also lacking. The program was intended to respond to these gaps by providing First Nations and Inuit communities with services that are equivalent to those available to other Canadians.

At the end of the 2001-2002 fiscal year, an evaluation strategy was developed for the FNIHCCP. The strategy consists of three focused studies and an overall evaluation of outcomes achievement

and cost-effectiveness. Study 1 is primarily descriptive in nature and focuses on the implementation of the Program in communities across Canada.

How was the Implementation study done?

Several methods were used to study the FNIHCCP. These included a literature, document and national data review, a survey of second-level service providers, a series of key informant interviews, First Nations site visits and an Inuit-specific focus group. A study framework, based on the objectives for the program, was developed to guide the research.

How did program planning and development work? What were the challenges?

The FNIHCCP took a unique approach to program planning and development. First, it took a collaborative approach to program planning by involving all stakeholders in planning and development activities well before program funding was secured. The planning and development process involved the Health Canada national and regional offices. A National Steering Committee with representation from the Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK), Health Canada and INAC was established. Tribal Councils and provincial/territorial organizations, and individual First Nations and Inuit communities played a specific role in planning and development.

The FNIHCCP's structured approach to program planning and development was unique. In the past, FNIHB programs had distributed funds on the basis on proposals prepared and submitted by individual communities. However, the FNIHCCP required all communities to complete a multi-stage program planning process. This process included completion of a community needs assessment, followed by development of a service delivery plan, a training plan and a capital plan. The FNIHCCP, therefore, had considerably more complex and stringent requirements than had been typical of other programs delivered to First Nations and Inuit populations. Those involved in program planning spent much time and effort to inform communities about these requirements and to assist them during program planning.

Many communities met challenges during program planning. Fulfilling the planning requirements was difficult, particularly for small, remote, isolated and unaffiliated communities. These communities often lacked the internal expertise, resources and infrastructure to plan a home and community care program. The relatively short period of time available for program planning added to these difficulties. Some communities had a hard time completing planning activities in a timely fashion and consequently missed opportunities to access funds for training and capital development. As a result, many communities became disillusioned with the program's stated philosophy of "community-based, community-paced."

Training and staffing also presented significant challenges for many communities. Not only were the available funds not enough to meet communities' training needs but some were unable to

access training funds. Many communities had difficulties finding and keeping staff. Some program stakeholders questioned the logic of making communities carry out costly and time-consuming needs assessment and planning exercises when the funding allocation was determined using a population-based formula. Also, the program required that all communities implement certain essential services first. Many stakeholders at the community level observed that the needs assessments often identified more needs than communities were able to meet with the program funds. This process contributed to unrealistic expectations about what the program could accomplish, and created a need to manage these expectations at the community level. Finally, some communities faced political challenges during program planning, such as securing support and buy-in from the political leadership or gaining consensus among multiple communities.

For the most part, larger communities, affiliated communities, communities with significant health services and administrative capacity already in place, and transferred communities found the planning process easier. Although many faced challenges, there is widespread support at the community level for the concept of local communities planning their own home and community care programs. The perceived advantages of this approach include:

1. increased community autonomy, empowerment and responsibility
2. improved responsiveness to community needs due to input from community members
3. greater cultural relevance
4. greater legitimacy for and use of the program among community members
5. improved support from the political leadership.

How did program implementation work? What were the challenges?

A three-year start-up period was planned for the FNIHCCP. By the end of Phase 3 and the beginning of the 2002-2003 fiscal year, it was expected that the program would have been developed and implemented in all communities where there was an identified need for service. National office information shows that this goal has not been fully achieved, although much progress has been made. As of September 2003, most eligible communities (96%) were being funded by the program, while 78% of the eligible communities and 88% of the eligible population had access to full service delivery. The Northwest Territories, the Prairie provinces, Quebec and Nunavut have achieved the most extensive coverage, while Ontario, British Columbia, the Atlantic region and Yukon require additional time to fully implement the program.

As required by the FNIHCCP, all communities in full service delivery have all essential service elements in place. However, the level of essential services varies between communities. Larger communities that had services in place before the program were able to use funds to build on these services. In smaller and remote communities, however, providing even the essential services is challenging with the available funds. There is some indication that the essential service elements are not always those that respond best to the needs communities have identified.

The main ongoing gaps in services are palliative care, rehabilitative care, respite care and mental health services.

The FNIHCCP was based on the idea that local people would be trained to deliver services in their own communities. The program emphasized training in order to ensure safe and effective delivery of services. In the first two years, the program provided specific funding for training to assist communities to meet their requirements for trained or certified staff. Regions were expected to develop comprehensive training plans outlining how they intended to use their training funding. However, it appears that some regions did not complete planning, or did not do so in a timely manner, and therefore were unable to access training funds.

The FNIHCCP faced many challenges related to training. First, the need for training was higher than could be met by the available training budget. Second, many communities faced difficulties with hiring and keeping staff. Hiring personal support workers was difficult due to the relatively low wages, the need for trainees to leave communities for considerable periods of time for training and, in some cases, a limited pool of individuals with the necessary educational background. Hiring nursing staff was also hard, particularly for remote, isolated and northern communities. Many communities had difficulties with keeping staff, due mainly to a lack of wage parity with provincial home care or other services.

Other challenges included a lack of local training opportunities, the cost of sending staff out of the community for training and the need to tailor training to suit unique circumstances. There is widespread agreement that additional staff are required, along with additional or ongoing training, particularly in the areas of diabetes and foot care, computer skills, palliative care, case management, and general management skills. A critical question for the FNIHCCP is, therefore, whether training should be one of its ongoing responsibilities. Some program stakeholders argued that there are not enough funds to continuously train people. Others believe that the program cannot expect First Nations and Inuit communities to meet their requirements for trained personnel without providing the resources.

Despite these outstanding issues, the study found widespread support for the concept of training local people to deliver services. The advantages of this approach include:

1. familiarity with the local culture and language
2. ability to understand and meet the cultural needs of the community
3. improved trust on the part of clients
4. greater credibility for the program
5. economic benefits for communities due to the employment of local people
6. lower costs
7. greater self-sufficiency and independence for communities.

There are also some perceived disadvantages. These include difficulties recruiting local people and the need to manage work assignments to ensure that staff do not work for members of their own family to avoid the appearance of favouritism.

The FNIHCCP also provided funds for capital development in the first two years to help communities meet their basic start-up needs for equipment, supplies and infrastructure. The regions were expected to develop complete plans outlining how their capital funds would be used. Regions did this in different ways. Some tried to ensure that all communities received at least some capital funds or equipment/supplies. Others sent out funds on a "first-come, first-served" basis, which meant that some communities received no capital funds at all. It is clear that the start-up funds have assisted many communities to launch their home and community care programs and have met some basic needs, particularly for medical equipment and supplies. However, there is a greater need for capital than can be provided with the available funding.

How did program management work? What were the challenges?

The FNIHCCP management structure consists of four levels of program support (community, multi-community, regional/provincial/territorial, and national). At the community level, there appears to be a good understanding of the roles and responsibilities of local communities and the Health Canada regional offices in managing the program. However, the roles and responsibilities of the Health Canada national office, provincial/territorial organizations and Tribal Councils are less well understood. Clarification of these roles and responsibilities was a common suggestion for changes to program management. Many people also emphasized the need for ongoing efforts to improve communications among all parties. The relationship between the Health Canada regional and national offices was tense during the early stages of the program but has improved over time. Most importantly, program stakeholders emphasized the need for increased funding and resources for second- and third-level support, observing that the need for such support does not end once program implementation is complete. Finally, although program stakeholders did not identify this as an issue, it remains unclear which level of program support is responsible for the FNIHCCP's "program development functions." These responsibilities were identified during program planning but not assigned to any level of program support.

The FNIHCCP stressed data collection and reporting. Health Canada developed several tools to help regions and communities meet the program's reporting requirements. The current tool, the Electronic Service Delivery Reporting Template (e-SDRT), requires communities to report on about 12 pieces of information twice a year. While almost all communities are able to comply with the reporting requirements, data collection and reporting still present challenges.

The most significant challenge has been the unreliability of the reporting tools and the frequent changes that have been made to them. Early versions of the reporting tool did not work properly, presented computer compatibility issues, were time consuming and costly to complete, and took away from the ability of communities to provide direct client service. Program stakeholders were

not uniformly optimistic that these issues have been finally resolved. In addition, many communities lacked the necessary technology and skills to use the tool effectively. Communities without Internet connections cannot use the electronic reporting tools, while others are not computerized, lack adequate computer systems, or do not have staff with the necessary computer skills to use the tool. Other issues include the perception that Health Canada expects too much information to be collected, that irrelevant data are being collected, and that information is not being recorded consistently.

First Nations and Inuit communities have some doubts about Health Canada's use of the data that they provide. While communities believe it is important to provide regular reports to Health Canada, many are convinced that the data are not being used effectively, if at all. Program stakeholders believe that Health Canada should provide communities with regular reports to show that reporting is not merely a bureaucratic procedure, but produces real benefits for communities (something that Health Canada has said that it plans to do). In addition, some recommended making changes to the types of data being collected—for example, including outcome data to enable the program to evaluate the impact it is having at the community level or including information on non-client tasks. Others suggested improving the reporting capacity within communities, by funding a specific position with responsibility for data collection, by ensuring that all communities have access to adequate computer systems, or by providing additional computer training. Finally, several recommended integrating the FNIHCCP's reporting requirements with those of INAC's Adult Care Program to reduce the administrative burden on communities.

How effective is the program so far?

There is general agreement that the FNIHCCP has responded reasonably well to the identified home care needs of First Nations and Inuit communities. In many communities, there are now at least basic services in place. Previously, services of any kind were mostly unavailable. Positive outcomes from the FNIHCCP include the ability of communities to provide services to clients in their own homes, an improved quality of care and enhanced capacity to provide services, and improved quality of life and outcomes for clients. There is also general agreement that the FNIHCCP is merely a beginning or foundation, particularly for those communities that could implement only minimal services with their funding. The need for ongoing funding to sustain and expand the program and to respond to needs in areas such as palliative care, respite care and mental health services was emphasized.

The most important perceived strength of the FNIHCCP is its collaborative, consultative approach to program planning, development and implementation. This approach involved First Nations and Inuit directly in these activities and resulted in a strong sense of program ownership. The energy and commitment of staff at the community level was also singled out as a significant strength of the program and a key factor in its successful implementation.

Perceived weaknesses include:

1. the short time frame for planning and implementation
2. difficulties with the reporting system
3. a funding formula that is not needs-based and therefore provides inadequate funds to small and/or remote communities.

Among the most frequent suggestions for changes to the program, stakeholders mentioned ongoing funding for training and capital development, increased funding for second- and third-level support, improvements to the reporting system, increased or permanent funding, a revised (needs-based) funding formula, and improved communications among all program stakeholders.

A summary of the key findings:

The following observations, based on the findings from this study, are suggestions that the FNIHCCP may wish to consider to guide program development.

1. The FNIHCCP could take steps to assist eligible communities that are not currently in full service delivery to achieve the final stage of program implementation.

As of September 2003, 96% of eligible communities were being funded by the FNIHCCP, but only 78% of eligible communities and 88% of the eligible population had access to full service delivery. Some of the reasons why communities have not been able to fully access the program include:

- the existing resources and infrastructure at the community level
- the ability to access training funding
- the ability to hire and keep staff, the size of communities, and their
- degree of isolation or remoteness.

In the interests of equity, the program could help those communities that are not yet in full service delivery to reach the final stage of program implementation.

2. The FNIHCCP could determine whether support for training and capital development should be among its ongoing responsibilities.

The FNIHCCP provided funds in the first two years to help communities meet their basic start-up needs for training and capital development. The study suggests that the available funds were not enough to meet needs. In fact, some communities and even some regions were unable to access training and capital funds. In many communities, difficulties with hiring and keeping staff have created a need for continuous training. In light of the evident ongoing need in these areas, the

FNIHCCP could determine whether support for training and capital development should continue to be among its responsibilities.

3. The FNIHCCP could identify needs for training and capital development for those communities that have not received program funding for these areas.

As noted previously, some communities receive no program funding for training and capital development, which has delayed implementation of their home and community care program. Strategies could be developed to ensure that communities that received no training and capital funds receive at least some assistance in these areas. Strategies that could be considered range from allocating funds for this purpose in an upcoming year, to exploring partnerships with Human Resources and Skills Development Canada, or involving provincial/territorial organizations in the provision of training.

4. The FNIHCCP could review the responsibilities of the second and third levels of program support and determine whether these are realistic in the context of limited resources.

The FNIHCCP has a multi-level management structure consisting of four levels of program support. The study suggests that there are insufficient resources at the second (or multi-community) and third (or regional) levels of program support. Given the limited resources available to the FNIHCCP, the responsibilities of the second and third levels of program support could be reviewed to determine whether all of the functions assigned to these levels can be reasonably expected to be carried out.

5. The FNIHCCP could identify which level of program support is responsible for the "program development functions."

In addition to identifying specific roles and responsibilities associated with each of the four levels of program support, the FNIHCCP also identified several program development functions. With the apparent constraints on second- and third-level resources as described earlier, the FNIHCCP could identify which levels of program support are best positioned to fulfil the program development functions.

6. The FNIHCCP could clarify the management roles and responsibilities of the national Health Canada office, provincial/territorial organizations and Tribal Councils, and communicate this information to First Nations and Inuit communities.

The management roles and responsibilities of the regional Health Canada offices appear to be well understood by First Nations and Inuit communities. However, the roles and responsibilities of the national Health Canada office, provincial/territorial organizations and Tribal Councils are less clear. The FNIHCCP could take steps to communicate this information clearly to communities.

7. The FNIHCCP could provide annual reports to First Nations and Inuit communities on the data collected by the e-SDRT.

The FNIHCCP's reporting requirements have been a source of difficulties at the community level. Communities generally acknowledge the need to provide regular reports to Health Canada. However, technological problems, staff capacity and the perception that the data collected are irrelevant and are not used effectively have produced frustration and cynicism. Almost all program stakeholders who participated in this study emphasized the need for Health Canada to provide regular reports to communities on the data it requires them to submit to demonstrate that reporting has tangible benefits for communities.