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Corporate Services

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- Terms of Reference

Acronyms appearing in this report	
ADL	Activities of Daily Living
CFNFA	Canada First Nations Funding Agreement
CHST	Canadian Health and Social Transfer
CMHC	Canada Mortgage and Housing Corporation
DAEB	Departmental Audit and Evaluation Branch
EHCS	Extended Health Care Services
FNPCH	First Nations Personal Care Home
FNPCHN	First Nations Personal Care Home Network
F/P/T	Federal/Provincial /Territorial
FNIHCCP	First Nation and Inuit Home and Community Care Program
IHS	Insured Health Services
INAC	Indian and Northern Affairs Canada
JWG	Joint Working Group
LCSC	Local Community Service Centre
PCH	Personal Care Home
PRA	Prairie Research Associates Inc.
PWPCH	Pinaow Wachi Personal Care Home
RHA	Regional Health Authority
RMAF	Results-Based Management and Accountability Framework
SEPP	Socio-Economic Policy and Program Sector

Executive Summary

Background

Since the 1960's, the federal government has provided specialized social services to First Nations on reserve, to assist them in maintaining their independence. Indian and Northern Affairs Canada (INAC)'s Adult Care program was created in 1981-1982 and has been a program largely of historical precedent, evolving in each region in response to the demand for services and the varying availability of resources.

INAC's Adult Care program consists of social supports and services to First Nations individuals who are ordinarily residents on reserve, and are elderly, or have a disability due to illness or accident. The objectives of the Adult Care program are *"to assist First Nations with functional limitations (because of age, health problems or disability), to maintain their independence, maximize their level of functioning and live in conditions of health and safety."*[1]

The program has three components:

- In-home care, which provides homemaker services;
- Foster care, which provides supervision and care in a family setting; and
- Institutional care, which provides Types I and II services in institutions.

Type I is institutional care for individuals requiring only limited supervision and assistance with daily living activities for short periods of time each day, and Type II is extended care for individuals requiring some personal care on a 24-hour basis and who are under medical and nursing supervision. Both Type I and Type II care are non-medical in nature.

Purpose of the Evaluation

This evaluation examined the current situation of the services and institutions supported by INAC's Adult Care program. First Nations leaders perceive that gaps have emerged among the services available to First Nations on reserve. In 1988, INAC imposed restrictions on the construction and operation of institutional facilities on reserve until a new federal policy with appropriate authorities was developed. To support a new policy, scheduled for 2003, obtaining an objective assessment of Adult Care services available to First Nations communities is an important rationale for this evaluation.

[1] INAC. *Adult Care Program*. Available at http://www.ainc-inac.gc.ca/ps/acp_e.html

Methodology

Several data collection methods and multiple lines of evidence were used to respond to the evaluation issues underlying the study. Specifically, this evaluation employed the following:

- Administrative data and document review;
- Key informant interviews with First Nations, INAC, and Health Canada personnel;
- Adult Care client focus groups; and
- Case studies of on-reserve institutions.

Key Findings

Rationale and Relevance: With respect to the level and nature of the ongoing need for Adult Care services in First Nations communities, the evaluation found that:

- The Adult Care program currently plays an important role in providing care to First Nations;
- There is a clear rationale for maintaining Adult Care services in First Nations communities;
- First Nations communities face unique health and social problems, which create a greater challenge to meeting Adult Care needs.

Design and Delivery: With respect to the implementation of INAC's Adult Care program in First Nations communities, the evaluation found that:

- There is no clear division of roles and responsibilities among INAC, Health Canada, provincial governments, and First Nations for providing Adult Care on reserve;
- The separation of INAC and Health Canada services may impede the delivery of a full continuum of care;
- Levels and range of Adult Care services vary across regions and communities;
- First Nations have not been substantially involved in the design of Adult Care services;
- Monitoring and compliance activities are limited.

Success: With respect to the extent to which the Adult Care program has met its objectives, the evaluation found that:

- The lack of performance measurement for the Adult Care program creates difficulties in identifying outcomes and impacts;
- There is a need for personal care home/institutional spaces in First Nation communities;
- The potential for government to displace traditional community responsibility for caregiving may be an unintended outcome of the Adult Care program;
- First Nations culture and traditions are not necessarily reflected in quality Adult Care services.

Cost-effectiveness: With respect to the cost of INAC's Adult Care program, and the presence of alternatives to the current funding and service delivery configurations, the evaluation found that:

- The costs of Adult Care services cannot be accurately measured with existing data;
- The cost of First Nations Adult Care services cannot currently be compared to provincial services;
- Needs-based funding is an alternative to the per capita funding formulae for in-home and foster care;
- There are alternatives to INAC delivering the services offered under the Adult Care program, such as Health Canada delivering in-home care, and overseeing personal care homes.

Conclusions

1. INAC needs to clarify the roles and responsibilities for delivering Adult Care in First Nations communities through discussions with Health Canada, provincial/territorial governments, and First Nations. INAC and Health Canada might consider formally integrating the Adult Care program and the Home and Community Care program to reflect the informal integration that has already taken place in many First Nations communities.

2. INAC should develop a national policy for Adult Care services that provides standards for delivery while also recognizing varying regional and community needs.

3. INAC should continue to play a lead role in ensuring that the unique Adult Care needs of First Nations communities are met.

4. Monitoring of Adult Care services must be increased to ensure compliance with current (and future) standards and policies, and to determine the total cost of delivering those services.

5. INAC should develop a performance measurement strategy that can identify Adult Care program outcomes and impacts at the community level.

Section 1 - Introduction

Purpose of the Report

This report describes the evaluation of the INAC Adult Care program. The report includes a description of the methods used in the evaluation and a profile of the Adult Care program, and presents the findings of the research. Finally, the report presents the observations and conclusions supported by the evaluation findings.

Purpose of the Evaluation

This evaluation examined the current situation of the services and institutions supported by INAC's Adult Care program. The Adult Care program consists of three main components: in-home care, foster care, and institutional care. First Nations perceive that gaps have emerged among the services provided on reserve by INAC, the medical services provided by Health Canada in regional centres, and provincial home and Adult Care services. In 1988, INAC imposed restrictions on the construction and operation of institutional facilities on reserve until a new federal policy with appropriate authorities was developed. Obtaining an objective assessment of Adult Care services available to First Nations communities to support a new policy, scheduled for 2003, is an important rationale for this evaluation.

Evaluation Approach

The evaluation was managed by a senior evaluation manager in the Departmental Audit and Evaluation Branch (DAEB) of INAC in consultation with the Socio-Economic Policy and Program Sector (SEPP). INAC engaged Prairie Research Associates (PRA) Inc. to conduct the evaluation.

Evaluation Issues

The main objectives of the Adult Care program are to:

- Assist First Nations with functional limitations;
- Maintain their independence;
- Maximize their level of functioning; and
- Allow First Nations to live in conditions of health and safety.

This study addressed the extent to which these objectives were reached through a consideration of the evaluation issues of Rationale and Relevance, Design and Delivery, Success, and Cost-effectiveness. The specific evaluation questions associated with each of these issues are listed in the Terms of Reference. (see Annex)

Methodology

This evaluation used several data collection methods and multiple lines of evidence to respond to the evaluation issues underlying the study. Specifically, PRA employed the following four research methods:

- Administrative data and document review;
- Key informant interviews;
- Client focus groups; and
- Case studies of institutions.

These methods, and their application to this evaluation, are described in more detail in the sections below.

Administrative Data and Document Review

This component of the research gathered administrative and financial data to provide information on rationale and cost effectiveness for on-reserve Adult Care services in four regions:

- Atlantic Canada;
- Québec;
- Manitoba; and
- British Columbia.

The document review consisted largely of an analysis of documents dealing with the provision of health and social care to First Nations in Canada. These included provincial and federal studies, reports prepared by consultants and non-governmental organizations, as well as any other material identified as relevant by key informants during the course of the evaluation. Additional background information on INAC's Adult Care program was also obtained from selected communities and institutions (see Case Studies, below).

The financial data collected varied in completeness and format among providers and the four regions. The intent was not to complete a formal cost-effectiveness analysis but to offer a reasonable description of unit costs by provider and region for similar types of service. To this point, there is not sufficient documentation available to create a valid cost comparison with similar services in the provinces. In general, administrative and financial data do not support outcome measurement and cost-effectiveness assessment.

Key Informant Interviews

In consultation with DAEB and program staff, PRA prepared interview guides to address the evaluation issues with the key informants. All key informants received a letter from DAEB explaining the research and providing contact names at INAC, DAEB, and PRA. In a follow-up telephone call, PRA arranged interview times and identified the questions to be addressed, providing each key informant with the interview guide. Interviews of regional representatives (INAC, Health Canada, provincial) and social development workers were conducted in person when possible during the site visits; other interviews were conducted by telephone.

For each of the four regions, PRA conducted interviews with a range of people including those with direct knowledge of Adult Care operational issues and others who were able to provide context for both the program and other regional services for adults. Interviewees were drawn from the groups listed below; the number interviewed from each group appears in parentheses:

- Health Canada regional managers (4);
- INAC regional managers (9);
- Representatives of Health Canada HQ (2);
- INAC national headquarters managers (4);
- First Nations social development workers (5);
- Provincial Adult Care personnel (3);
- First Nations social/health care administrators/providers (12); and
- Joint Working Group (2).[2]

Client Focus Groups

PRA conducted six focus groups with clients to obtain information on Adult Care needs, service requirements, whether services adapt to needs, satisfaction with services, and the extent to which the objectives of the Program are being met. Institutional and program managers assisted us in identifying potential attendees for the focus groups in the following locations:

- ***Kitigan-Zibi First Nation, QC.*** The group consisted of two persons receiving in-home care services, and two caregivers.

- ***Kahnawake, QC.*** The group consisted of two residents of the Turtle Bay Elders' Lodge (an independent living facility providing some personal care), one in-home care recipient, and one home care worker.

- ***Fisher River Cree Nation, MB.*** Four in-home care recipients attended this group.

[2]The Joint Working Group (JWG) is composed of First Nations health and social personnel, INAC, and Health Canada members. While 9 persons interviewed for this evaluation are members of the Joint Working Group, 7 of them are already counted under the 'INAC Regional Managers' category.

- ***Norway House Cree Nation, MB.*** In this community, PRA visited six in-home care clients in their homes to obtain their input on the Adult Care program.
- ***North Thompson, BC.*** The group consisted of five residents of the Seniors Group Home (an independent living facility providing some personal care), and two home care workers.
- ***Cowichan First Nation, BC.*** The group consisted of one in-home care recipient, the daughter of an in-home care recipient, and the mother of an in-home care recipient.

Client focus groups were conducted in communities that were part of the institutional case studies component of the research, with one exception; an additional focus group was conducted in a third community in the British Columbia region.

Case Studies of Institutions

PRA conducted six case studies of care institutions selected in consultation with regional and headquarters INAC staff. INAC regional staff provided the names of key informants for each community participating in the case studies. As noted in the section above, the case studies were conducted in communities where PRA had conducted Adult Care client focus groups. The studies involved interviews with institutional administrators and community social/health workers, tours of the facilities, and a review of the available administrative and financial data. Table 1 (next page) presents a summary of the communities and institutions visited, and the personnel consulted for each case study.

Table 1: Institutional case studies		
Location	**Institution**	**Persons consulted**
Kitigan-Zibi First Nation, QC	Kiweda Group Home - Kiweda means "Our Home." The goal of the Home is to help keep seniors within the community and to assist them in maintaining their independence.	‣ Director of Health and Community Care Services ‣ Director of Kiweda Group Home ‣ Coordinator of home care services
Kahnawake, QC	Turtle Bay Elders' Lodge - Turtle Bay Elders' Lodge is an independent living centre for seniors, containing all the amenities to assist in their daily lives. The Lodge has 22 units, four of which are designated as extended care units.	‣ Manager of Home and Community Care Services ‣ Elders' Lodge Director of Operations ‣ Home Care Coordinator ‣ Nurse in charge of home care nursing
Fisher River Cree Nation, MB	The Ochekwi-Sipi Personal Care Home is a 32-bed facility primarily offering personal care for seniors in the community, meeting their hygiene, medical, and social needs. While the care home is intended to be for seniors, adult day care and respite care can be provided for community members.	‣ Administrator of the Personal Care Home ‣ Manager of Home Care
Norway House Cree Nation, MB	The Pinaow Wachi Personal Care Home (PWPCH) is a 26-bed long-term care facility that offers care primarily for Seniors and the disabled of Norway House. It also provides service to residents of as many as eight surrounding communities, including non-Status Indian and off-reserve residents.	‣ Administrator of the PWPCH ‣ CEO of Health Services ‣ Homemaker Supervisor
North Thompson Indian Band, BC	The Seniors Group Home consists of six units (22 - bedroom and 41 - bedroom), each equipped with full kitchen, bath, and private entrance. There is a common kitchen and dining area and common laundry facilities. Seniors who require additional services are provided home support, home care nursing, and homemaking through the Health Canada Home and Community Care Program (HCCP).	‣ Supervisor of Personal and Home Care ‣ Community Health Representative ‣ Home care supervisors
Cowichan First Nation, BC	The Elders Day Program assists seniors in staying healthier, remaining in their homes as long as possible, keeping them active in the community, and reducing the necessity for hospital stays by maintaining regular contact with social and health care providers.	‣ Supervisor of Personal and Home Care ‣ Elders' Nurse at the Tsewultun Health Centre

Section 2 - Profile and Background

INAC's Adult Care Program

Adult Care Program Background

Since the 1960s, as a matter of public policy, the federal government has undertaken to provide specialized social services to First Nations on reserve, in an effort to prevent undue hardship and suffering of people who required such services to maintain their independence in activities of daily living. The provinces have long taken the view that on-reserve services are a matter of federal responsibility.

INAC's Adult Care program itself has been in existence since 1981-1982 and has been a program largely of historical precedent, evolving in each region as demand for services and availability of resources changed.

In 1987, an inventory analysis of the existing Adult Care program was performed by INAC. However, because of a lack of information on needs and the lack of a comprehensive program policy and necessary authorities, INAC declined to expand Adult Care services at that time. Rather, a model for continuing care delivery with Health Canada was proposed.

In 1988, restrictions were imposed on the construction and operation of new on-reserve residential/institutional care facilities, because of escalating costs and INAC's unclear authorities in that area. INAC's involvement in non-medical residential/institutional care had originated with a 1984 Memorandum of Understanding with Health Canada, wherein INAC was listed as having responsibility for Types I & II care.

To offset the impact of the restrictions, INAC increased the availability of in-home support resources. Furthermore, in an effort to address these issues, a joint Health Canada/INAC Adult Care working group was established in 1989, to support the development of a comprehensive community-based continuing care program. The Joint Working Group (JWG) concluded that "significant gaps exist in the availability of community support programs in most communities" and "the lack of a specific authority for Adult Care services... has discouraged the development of a comprehensive federal policy framework (and contributed to) unclear departmental responsibilities, lack of a program structure, fragmented service development and inconsistent standards."

A joint Health Canada/INAC study entitled "National Summary: First Nations Continuing Care Services and Issues, May 16, 1997" again concluded that there were serious gaps in many of the services. These gaps included:

- Personal care, respite care, meals on wheels and volunteer services to complement the basic housekeeping and homemaking services existing under Band or Tribal Council administration; and

- Alternatives to institutional care, such as adult group homes, adult day care, adult foster care, and integrated residential-in-home care services.

The study concluded that the majority of on-reserve First Nations clients did not have access to the same scope and quality of home care services as those offered by provincial programs. Furthermore, regional funding levels were inadequate to meet the existing needs of on-reserve First Nations clients.

INAC's Adult Care program consists of social supports and services to First Nations individuals ordinarily residents on reserve, who are elderly, or have a disability due to illness or accident. The objectives of the Adult Care program are *"to assist First Nations with functional limitations (because of age, health problems or disability), to maintain their independence, maximize their level of functioning and live in conditions of health and safety."*[3]

Adult Care Program Components

The Adult Care program has three components:

- In-home care, which provides homemaker services;
- Foster care, which provides supervision and care in a family setting; and
- Institutional care, which provides Types I and II services in institutions.

Type I care is institutional care for individuals requiring only limited supervision and assistance with daily living activities for short periods of time each day, and Type II is extended care for individuals requiring some personal care on a 24-hour basis and those under medical and nursing supervision. Both types of care are non-medical in nature. Table 2 shows the availability of each of the three Adult Care program components in the regions considered for this evaluation. An 'x' in the cell means that the service is available.

Table 2: Adult Care program components available on reserve by INAC region (X = available)

Service	Atlantic				QC	MB	BC
	NF	PEI	NS	NB			
In-home (homemaker/personal) care	X	X	X	X	X	X	X
Foster care					X		X
Institutional care (Types I and II)			X		X	X	X

[3] INAC. *Adult Care Program*. Available at http://www.ainc-inac.gc.ca/ps/acp_e.html

Level of Services Available

The services available under the Adult Care program vary across the INAC regions and across First Nations communities. Among the four INAC regions considered for this evaluation, Québec and British Columbia offer three Adult Care program components – in-home, foster, and institutional care; Manitoba region offers only in-home and institutional care, with a number of institutions on reserve, while the Atlantic region offers only in-home and off-reserve institutional care. The range of services provided within each of the three types varies across regions and communities. In-home care can consist of as little as two hours per week for housekeeping assistance with laundry to 24-hour care for clients with higher needs who refuse to leave their homes. Levels of service available in institutions are technically limited to Type I and II, as noted above. However, some institutions provide services above this level in order to allow a resident to remain in the community.

It is important to note that individuals who require more extensive medical care (i.e., Types III, IV, and V) normally become the responsibility of provincial/territorial health authorities and will typically be cared for in medical facilities (hospitals), usually off reserve. However, the boundaries between Types I, II, III, and IV may blur in actual application.

Continuing Care in Canada

Legal Context

The *Canada Health Act*, passed in 1984, serves as the foundation for the public provision of health care and sets out two major categories of health services:

- *Insured Health Services* (IHS), traditional health/medical services, are defined as medically necessary hospital services, physician services, and surgical-dental services provided to insured persons.

- *Extended Health Care Services* (EHCS) include nursing homes or long-term residential care, home care, adult residential care, and ambulatory health care services.[4]

Provinces/territories have assumed responsibility for this last category of services, known variously as “continuing care,” “assisted living” or “independent living,” depending on the jurisdiction. Each jurisdiction has individually determined the type and level of services that they will provide. This contributes to variability among provinces in terms of regulations, user charges applied to clients, range and extent of services available, models of service delivery, and funding models.

[4] Hollander Analytical Services. (May 2000). *Technical Report 1: Incentives and Disincentives in Funding Continuing Care Services - Key Concepts, Literature and Findings for Canada*. p. 1-2.

Generally, however, provincial/territorial programs of continuing care are broadly similar in that they all offer a common base of services, including: client assessment; case coordination; case management; nursing services; and home support. There are also similar basic requirements for eligibility. Typically, the client must be a resident of the province/territory and undergo a comprehensive needs assessment to determine eligibility, and it must be determined that care cannot be provided by family and/or friends, that the home is safe and suitable for service delivery, and that the client consents to the care. A further similarity is that a minimum set of professional nursing services are provided without charge to clients.

Continuum of Care

Whether in the on-reserve or off-reserve context, it is useful to define the *continuum of care*. The continuum is a spectrum of health and social support services that address needs from routine to emergency and from episodic to chronic care. The idea behind the continuum of care is that patients receive appropriate levels of service in a timely fashion and that there are no "gaps" in the range of services available.

Along that continuum, there is a range of services, from light housekeeping assistance and companionship to support for in-home medical services (e.g., a nurse to manage medications and monitor the health status of the patient/client); to in-home medical procedures; and to long-term residential care. A basic philosophy that guides continuing care is to maintain the independence of clients.

The preference is to maintain the client in his/her home, both for social reasons and because it is usually less costly. At some point, however, the complexity and/or cost of bringing the care to the client rises to a level where it is more practical for the client to go to the care. All provinces/territories use various criteria to determine at what point clients/patients will be transferred to residential care, which, for many, can mean leaving their community in addition to leaving their own home. This is a traumatic experience for most people. Additionally, for the more extreme points of the continuum, the need to have access to hospitals and more advanced medical treatments means that residential care is usually located in larger regional centres and cities. At the farthest point of the continuum, terminally ill patients may elect to return to their homes at the very end of their lives. Table 3 shows the different services that the provinces provide off-reserve under the continuing care mandate. An "X" in the cell means that the service is provided.

Table 3: Off-reserve services provided by province							
Service	**Atlantic**				**QC**	**MB**	**BC**
	NF	**PEI**	**NS**	**NB**			
Homemaker/personal care	X	X	X	X	X	X	X
Self-managed care	X				X	X	X
Meal programs	X			X	X	X	X
Adult day support	X	X		X	X	X	X
Respite care	X	X	X	X	X	X	X
Group homes	X			X		X	X
Congregate living/Supportive housing					X	X	
Home nursing care	X	X	X	X	X	X	X
Assessment and case management	X	X	X	X	X	X	X
Assessment and treatment centres	X				X		X
Long-term care and chronic care	X	X	X	X	X	X	X
Sub-acute care							X
Palliative care	X	X	X	X	X	X	X
Community rehabilitation	X	X	X	X	X	X	X
Equipment and supplies	X		X	X	X	X	
Transportation services	X			X	X	X	
Quick response team			X		X	X	X
Home maintenance and repair	X						
Source: Hollander Analytical Services. Technical Report 5: An Overview of Continuing Care Services in Canada.							

Although generally similar, provincial/territorial practices vary when it comes to issues surrounding the regulatory status of home care programs, the charges to clients and how they are assessed, the range of professional services available (e.g., rehabilitation, oxygen therapy, etc.), the models of service delivery, and the level of funding.

The Home and Community Care Program

A key contributor to Adult Care on reserve is Health Canada's First Nations and Inuit Home and Community Care program, which *"provides basic home and community care services that are comprehensive, culturally sensitive, accessible, effective, equitable to other Canadians, and responsive to the unique health and social needs of First Nations and Inuit."*[5] Trained and

[5] http://www.hc-sc.gc.ca/fnihb/phcph/fnihccp

certified personal care/home health aide workers deliver the Health Canada program supported and supervised by registered nurses. This program was designed to complement the Adult Care program, and fill any gaps in the continuum of care, by providing services including nursing, personal care, and access to medical supplies and equipment.

INAC's Adult Care program is offered in the context of continuing care services across Canada. It is subject to the same demographic pressures, technical change, and economies as all continuing care services across Canada, but as shown in the next section, First Nations and the INAC program encounter some unique issues.

Section 3 - Evaluation Findings

This section presents the findings from the various data collection methods employed for the evaluation. Information is organized according to the evaluation issues of rationale and relevance, design and delivery, success, and cost-effectiveness and addresses the specific questions within each issue. Where responses or perceptions varied substantially by source, findings are presented according to the data source in order to reflect divergent opinions.

Rationale and Relevance

This section presents those findings that are applicable to the evaluation questions regarding whether there is an ongoing need for Adult Care services in First Nations communities, and whether First Nations needs are different from those of the general population. These questions are addressed in this section through a consideration of the factors that affect the level of need for Adult Care in First Nations, and the current and expected needs as identified by key informants and focus group participants.

Factors Influencing Adult Care Needs in First Nations Communities

While in some cases the care needs of First Nations are similar to those of the general population, there are also several unique factors affecting the demand/need for personal care and long-term extended institutional care for First Nations populations. These include:

- population demographic (the size and growth of the at-risk population between 45 and 64, and the population 65 years and over);
- morbidity and disability rates within the population;
- availability of a continuum of health care services; and
- the personal, social, and cultural preferences and expectations of the First Nations client.

Each of these four factors is discussed in more detail below.

The **population demographic** of First Nations is characterized by growth. Using the INAC Indian Registry System, by 2021, the total registered First Nations population will increase by 45.5 percent or by just over a quarter of a million people. During the same time, the First Nations population aged 65 years and over will increase by 228.7% or by 56,000 people. Another important age category is people between 45-64, since this cohort is susceptible to many of the chronic conditions and illnesses that require Adult Care services. This age cohort will increase by

124.5 percent (63,000), and the 55-64 age group will increase by 235.7 percent (70,000).[6] Key informants noted that these factors underline the current and future demand for Adult Care services for an aging population.

The **morbidity,** or prevalence of illness within a population, also drives the demand for Adult Care. *Prevalence* refers to the occurrence of a disease or condition within the entire population. Thus, one can speak of the prevalence of diabetes as 20 percent in the population over 50. The *incidence* is the rate per 1,000, and one expresses this as x cases per thousand. Chronic conditions are more numerous and more severe in aging populations, and this is *"particularly true of the Canadian First Nations population."*[7] This is due to the particular health issues facing the First Nations population, specifically those 65 years and older, and include:

- High incidence of diabetes and its associated complications including blindness, renal disease, and amputations;
- High incidence of cardiovascular disease, resulting from diabetes, poor nutrition, alcohol and drug abuse, inactivity, and smoking;
- Higher incidence of injuries than the general population (related to self-harm, alcohol and drug abuse, and other factors) resulting in higher morbidity and mortality;
- Social and emotional issues related to the impact of the residential school system, family breakdown, unemployment, and social stress;
- Reactivated tuberculosis caused by inadequate treatment in the past;
- A high incidence of lung disease such as chronic obstructive pulmonary disease; and
- An increasing incidence of Hepatitis C.

Compared to the general population, the First Nations populations also exhibits a generally higher health risk profile due to: the remoteness of many communities from full health and social services resources; family breakdown; and the loss of traditional family and community supports.[8] Most key informants confirmed the fact that these factors emphasize the need for an Adult Care program that meets the unique needs of First Nations populations.

Many key informants pointed out that attempting to address these needs will be a challenge. For example, the per capita funding formula can make it difficult for a small Band to provide a base level of service. There is also a common perception among key informants that most small communities will be unable to economically support a Personal Care Home (PCH); as one respondent noted, *"it will be hard to balance providing good service with economic and political*

[6] Adrian Gibbons and Associates Ltd. and JLS Associates. (September 1999). *First Nations Institutional Care: A Review of Critical Issues and Trends.* p. v.

[7] Ibid., p. 16.

[8] INAC. (October, 2001), Areas of Responsibility of Health Canada and Indian and Inuit Affairs for Health and Social Services to First Nations and Inuit Communities.

realities." Key informants also noted the lack of human resources, often resulting from the difficulty faced by small communities in attracting and retaining trained care providers and management personnel.

The role of the Adult Care program is important within the **continuum of care available** to First Nations populations. To reiterate, INAC's Adult Care program provides social support to the elderly or disabled in First Nations communities. The Adult Care program funds in-home homemaker services; adult foster care; and institutional care, which provides Types I and II services in institutions (whether on- or off-reserve).

Few other programs, regardless of origin,[9] contribute to the provision of Adult Care services in First Nations communities. The only other notable program is Health Canada's First Nations and Inuit Home and Community Care Program (FNIHCCP), which respondents consistently identified as an important contributor to the provision of Adult Care on First Nations reserves. Many key informants noted that the HCCP purposely complements INAC's Adult Care program by providing personal and home nursing care in First Nations communities. Respondents provided universally favourable comments on the HCCP. In most cases, it is the only other contributor to Adult Care in First Nations, since few provinces provide services on reserves.[10] Health Canada also maintains clinics and nursing stations in many First Nations communities to provide limited acute health care services.

Personal, social, and cultural needs are important for all continuing care programs. Evidence exists from key informants and the literature that First Nations have important cultural needs with respect to care services. Many key informants indicated that current care services are not culturally appropriate, and that it is more difficult for First Nations to leave their cultural milieu and community to obtain medical services only available off reserve. Some key informants also suggested that, among First Nations, there might be a greater resistance to institutionalization than among the general population.

A complete consensus does not exist on whether the needs of in First Nations communities differed from those of the general population (non-First Nations). Several in-home care clients stated that the needs are universal; *"We have the same diseases, and the same needs - there are no differences because we are First Nations."* Some also suggested that their needs might be better met on reserve simply because *"everyone knows each other. We know the people taking care of us, and we trust them."* Clients in one of the focus groups perceived that people on reserve receive more help than the general population. *"People in cities have to pay a lot if they want this kind of help."*

[9]Federal/provincial/territorial (F/P/T) governments, First Nations organizations, or other agencies.

[10]One exception to this is British Columbia, where limited services such as physiotherapy and occupational therapy may be offered on reserve by some RHAs.

Adult Care Needs in First Nations Communities

Key informants and focus group participants clearly expressed the importance of First Nations being able to receive the care they need while maintaining close ties to their culture and families. The literature supports the opinion of respondents[11] who referred to the negative social effects of moving First Nations to off-reserve facilities. Adverse effects include: loss of identity, social isolation, and culture shock; particularly for those from isolated communities. These adverse effects strongly encourage First Nations residents to remain in the community even in the face of receiving reduced care. Respondents said that this underlines the importance of keeping people (especially seniors) in their homes and communities, bringing them home from hospital earlier, or even being able to *"bring them home to die."* Obviously, the general desire to remain rooted in the community is increasing the need for services.

In-home care clients in the focus groups were more likely to concentrate on specific day-to-day assistance when offering their opinion on *"the kinds of things that people in this community need the most."* Responses were consistent across the focus groups, emphasizing the need for general assistance with daily household activities. General housekeeping tasks were the most commonly identified, such as laundry, cleaning, and cooking, and any "*heavy work.*" Other needs included transportation to appointments and errands and help with things like banking and paying bills. Participants also identified the social needs that many older and/or disabled people in the community have, such as companionship and *"someone to eat with once in a while."*

The needs identified by Health Canada and INAC key personnel tended to focus on policy and program level issues rather than client-specific daily needs. These key informants identified the following as the main Adult Care needs in First Nations communities:

- Care comparable to that available to the general population;
- Integrated (single window) operations among social and health services, including increased cooperation between INAC and Health Canada;
- Better training for Adult Care service providers;
- Better assessments of clients to ensure they receive appropriate services;
- In-home support; and
- More PCH spaces or beds.

The majority of respondents identified the last point, institutional care, as the most important need in First Nations communities. A related requirement identified by some key informants was increased funding to meet these needs. Of those key informants who offered an opinion on how these needs are identified, most indicated that community health and social services staff identify the Adult Care needs. Other responses included: identification of needs by INAC national personnel who travel to the communities, through INAC regional personnel, and at national meetings.

[11] The term "respondents" includes key informants and focus group participants.

While it may be clear for many respondents that additional PCH spaces are required, the real issues are location (on or off reserve) and size. Some key informants expressed the concern that PCH facilities can become "megaprojects," intended more for economic development than provision of care. Many respondents preferred small-scale personal care homes, which most believe can be supported and financially viable, while others spoke of the need for more of the "traditional" 20-30 bed facilities currently found in a number of First Nations communities. There is little consensus regarding what configuration of personal care spaces will best suit community needs.

Trends in Adult Care Needs

Table 4 shows the national total annual care days[12] and number of clients served under INAC's Adult Care program from 1997 to 2002. Data in the cells indicate care days / clients served.

Table 4: Total annual care days/clients served, 1997/98 - 2001/02 (INAC Adult Care Program)

Service	1997/1998	1998/1999	1999/2000	2000/2001	2001/2002
Foster care	23,965/71	33,647/144	47,188/130	32,986/101	19,763/86
In-home care	592,040/7,068	621,251/8,510	577,012/11,261	505,455/11,094	496,213/9,646
Institutional care	239,119/694	251,866/722	233,954/638	247,243/707	232,385/674

Source: INAC Data Operations

No clear trends in the number of care days being provided emerge from the table above. Nationally, the number of care days for foster care appears to peak in 1999-2000, while in-home care peaked in 1998-1999. The number of care days provided in institutions does not follow that general trend nationally but fluctuates over the five fiscal years.

The general opinion among key informants, that demand has been increasing and will continue to grow in the future, does not necessarily reflect the data in Table 4: *"our spending on Adult Care has doubled in the last four years;" "demand for in-home care and PCH spaces will quintuple in the next 10 years."* The perceived overall trend is a general increase in the demand for Adult Care services in First Nations communities; however, this trend also applies to the general population. Attempting to assign this rising trend simply to increasing population is not straightforward, and information from many key informants suggests the following factors for increasing demand (in addition to the core population and health dynamics cited above).

- People may have higher expectations for quality of life; given that all sectors of the population are healthier, and education and communication are increasing demand for services.

[12] One day billed equals one day of care. Regional care days may vary as some regions define a care day as 7.5 hours, while others may use 8.25 hours.

- With programs now being run by First Nations, additional care needs are coming to light. People may be more comfortable talking about their needs, and workers who live in the community are more aware of the needs.

- Provincial policies, such as early hospital discharge and closing long-term care facilities, create greater need for care on reserve. The moratorium on PCH construction may have alerted many residents to the issue.

Respondents from Health Canada naturally stressed medical and epidemiological factors in the demand for Adult Care services. They confirmed the core demographic (high birth rate) and general First Nations health risk trends as demand drivers. Additionally, they stressed increasingly complex health needs, such as diabetes and its complications (e.g., blindness and amputations), that will have to be served in First Nations communities. Some key informants from this Department also said that symptoms of diseases were becoming more pronounced, and some conditions were showing earlier onset. As one stated, *"people are sicker"* and *"getting sicker younger."* Other specific factors contributing to increased needs were high rates of attempted suicide and accidents in some communities, increasing demand for rehabilitation and palliative care, and increased awareness of the services available.

It must be stressed that while there is some objective evidence of Adult Care needs and trends in First Nations communities, there is still a critical lack of data from First Nations communities to reliably quantify specific needs and trends. Without such information, discussions of need are inevitably anecdotal.

Summary of Rationale and Relevance Issues

This research has identified the general demographic trend of an aging population (and the associated morbidity) as the main factor behind the perception that there is, and will continue to be, increased demand for Adult Care services in First Nations communities. Related to this is the fact that people are living longer.

This research also addressed the question of whether the Adult Care needs and challenges facing First Nations communities differed from those facing non-First Nations communities. The document review, client focus groups, and key informant interviews produced data that point to a number of specific challenges to providing service in First Nations communities. It should be noted that not all of these factors are unique to First Nations; in fact, many are shared by other rural and remote communities.

In summary, the responses to the two evaluation questions on rationale and relevance are as follows:

- *Are there clearly identified needs for Adult Care services?* Perceived needs for Adult Care are found in the opinions of key informants, focus group participants, and the literature. A preference exists for providing a continuum of care in as many communities

- as possible. Further, there is little doubt that the need for social and health care across the continuum will increase rapidly over the next decade, and it would be useful to have more detailed information on health incidence/prevalence to support planning services to meet these needs.

- *Are there service requirements unique to First Nations communities?* Whether these requirements are unique to First Nations communities is less certain. Aging clients wish to live in culturally familiar environments, which is why Adult Care and PCH services are often aligned with ethnic and religious groups. Therefore, the need for culturally appropriate services for First Nations is not in doubt. The question is one of finances and economics, and this must be determined at the community level. Larger communities will be able to develop services along a broader section of the continuum, while residents in smaller centres will need to rely more on families and friends. Once their needs increase, they may have to leave the community and move to a larger centre to maintain access to services at a higher level. One question for which there is no clear answer is whether Adult Care clients in First Nations communities have more or less access to family members than the general population. Greater access to family members would mean that movement away from the community could be delayed.

Design and Delivery

This section considers the implementation of INAC's Adult Care program, first examining the various roles and responsibilities for the delivery of the program. This is followed by a discussion of the degree of participation of First Nations community members in the design and delivery of the Adult Care program, as well as the main challenges to program delivery that have been experienced to date.

Division of Roles and Responsibilities in Delivering Adult Care

In general, a lack of clarity exists over the roles and responsibilities among the main funders/providers of Adult Care services on reserve. A range of possible explanations emerged in support of this perception.

a) Internal INAC Issues. Most key informants identified the lack of clear policies for the Adult Care program, at both the regional and national levels, as leading to a situation where the Adult care program is not being applied as intended in many communities. One key informant's statement is representative of this belief: *"the roles are not clear. We don't have a policy* S *we are just doing what we have been doing for years."* The authority and resources for this evaluation preclude identification of which communities exhibit variance from policy in delivering the Adult Care program, but the prevalence of opinion offers support that this is a problem. Many key informants said that, for example, provision of service without an assessment is a common practice, despite the program requirement for needs and means assessments.

A second and related internal issue cited by some is that the Adult Care program is "straying" into direct provision of health care in some cases. The case studies and key informant interviews suggest that this is particularly true for on-reserve personal care homes. Many key informants cautioned that INAC's proper role is as a funder of *social* programs on reserve. As one key informant noted, *"INAC should not be getting into any health-related area,* [INAC is] *not equipped for that."* Others explained that in the case of Adult Care, the line between social and health programs is becoming less clear.

b) First Nations Community Issues. Factors internal to First Nations communities may blur the lines of responsibility for providing care. Key informants told us that the community pressure to avoid sending community members to off-reserve facilities leads some First Nations to provide health care in Type II settings even if they cannot recover the cost from governments. Some spoke of *"turf wars"* between social and health personnel in First Nations communities as impeding the delineation of roles and responsibilities. This evaluation also found that some key informants in direct delivery have little interest in maintaining a distinction between social and health services. Direct service personnel are busy and pragmatic; as one key informant noted, they *"aren't really interested in debating jurisdictional issues; they just want to deliver services."*

c) INAC - Health Canada Issues. Those who worked in these departments indicated that communication needs to improve between the two federal departments. One comment illustrated this common observation: *"Health Canada and INAC don't talk to each other as well as they could. National-level issues are affecting services to First Nations."* Key informants were unanimous in their desire to clarify the Health Canada and INAC roles in delivering Adult Care and their belief that the two programs need to become more integrated if community needs are to be effectively met. These key informants also noted, however, that the *"blurring"* of Adult Care and HCCP is often resolved at the community level, since most First Nations already combine the funding from these two programs. Local level pragmatism *"solves"* the roles and responsibilities *"problem."*

d) Federal - Provincial Issues. Another common theme to emerge was the reported confusion, and occasional conflict, between federal and provincial governments over providing Adult Care on reserves. The three main issues of concern are jurisdiction, definitions of levels of care, and gaps in service. These issues are discussed in more detail in the sections below.

i) Jurisdiction

While provincial/territorial departments of health fund and provide off-reserve Adult Care, INAC funds on-reserve care. Sections 91 and 92 of *The Constitution Act* and historical patterns of program delivery have placed health and general welfare services primarily under provincial/territorial jurisdiction. The federal government provides these services on reserve as a matter of policy and not as a matter of statutory or legal obligation.

These jurisdictional boundaries may confuse delivery of a seamless continuum of service. A typical example might be a province that elects to construct Type III and IV facilities in a regional centre. Community members requiring service can elect to move or forego the service, or the community can elect to push the boundary and offer Type III and higher service in a PCH on reserve.

Increasing numbers of clients with Type III, IV, and V needs place First Nations in increasingly difficult situations. Either they keep the patient in their institution and do not provide needed services, they exceed INAC's policy authority and provide the services, or they transfer "the patient to an institution authorized to provide the required higher level of care," removing the patient from his or her family, community, and familiar cultural setting.

Based on key informant responses, in most cases the patient is not moved, and the PCH does its best to accommodate the client. In Manitoba, for example, federal Types III and IV care make up a considerable portion of care delivered to their residents; over 65 percent of residents in the First Nations Personal Care Home (FNPCH) in Manitoba receive level III and IV care.[13] As noted briefly above, the FNPCH does not receive additional funding for providing that higher level of care, and therefore must find ways to compensate for the lack of funding or not provide a full complement of service. Key informants reinforced the findings of the document review with respect to the fact that many FNPCHs are providing service above Type II.

Most provinces are not at all confused about their role S they refuse to provide any services in First Nations communities, according to respondents. Despite the fact that the provinces are responsible for health care for all provincial residents, *"they stop at the magic line that is the border of the reserve."* Many referred to an *"ongoing battle"* between the federal and provincial governments over responsibility for funding health care on reserve. A perception common to key informants is that the provinces are reluctant even to license PCHs on reserve because they fear that, under the Canadian Health and Social Transfer (CHST), they may become financially responsible for any services that go beyond social care and into health care.[14] Most key informants also believe that provincial governments are not eager to commit the human resources required to monitor and ensure that provincial standards are met in FNPCHs. In the words of one respondent, *"Nobody wants the responsibility for the financial and human resources required to meet the needs."* Another respondent stated, *"The provinces need to take responsibility. INAC is not looking to save money by pushing this onto the province. Health care money ultimately comes from the federal government; the province is just choosing not to spend it on First Nations."*

[13]Romanow, Bear and Associates. (November 2000). *Manitoba First Nations Personal Care Homes: Funding Analysis Draft Report.* p. 8.

[14]Under the *Canada Health Act*, provinces are constitutionally responsible for the administration and delivery of health care services to all residents of the province. The CHST transfers funds to the provinces for, among other things, health care.

Interviews conducted as part of case studies and other key informant interviews suggest that administrators of on-reserve PCHs, in at least one region, are willing to be licensed and monitored like off-reserve facilities: *"at the operational level, there is no reluctance to have the province come in and do it* S *they just want* someone *to do it. At the First Nations leadership level, they would like to see a First Nations monitoring body."*

ii) Definitions of Care Levels

Currently, there appears to be no agreed definition or common assessment tool among provinces/territories to classify patients. If a client cannot be unambiguously classified, problems emerge not only in assessing the service needs of patients, but also in determining responsibility for payments. Two sources that inform classifications of care at the federal level are:

- *Report of the Sub-Committee on Special Services in Hospitals: Guidelines for Establishing Standards for Adult Long Term Institutional Care*;
- *Report of the Working Party on Patient Care Classification to the Advisory Committee on Hospital Insurance and Diagnostic Services*.[15]

Provincial classification systems only roughly equate to these definitions. For example, in Manitoba, INAC Types I and II care are equivalent to Levels 1 through 3 within the provincial system. This issue is important because, as the Manitoba First Nations Personal Care Home Working Group stated:

> *as long as this confusion continues, it will be impossible to develop a reliable method of having funds flow between the various government departments with fiscal responsibility for the many levels and/or types of care provided by personal care homes.*

That being said, classifying patients in terms of needs remains complex. Many jurisdictions use rating scales related to the clients' capacity to perform simple activities of daily living (ADL), but there is room to improve the reliability and validity of disability rating systems.[16]

iii) Gaps in Service

These two issues of jurisdiction and definition of care levels merge to produce potential deficiencies in services provided on reserve. Disparities could emerge among the services funded on reserve by INAC, the medical services provided by Health Canada in regional centres, and

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[15]INAC. (October 2001). *Areas of Responsibility of Health Canada and Indian and Inuit Affairs for Health and Social Services to First Nations and Inuit Communities,* p. 23.

[16]A review of classification issues in measuring disability may be found in Altman, Barbara. "Disability definitions, models, classification schemes and applications", in Albrecht, Gary, L., Seelman, Katherine, D., and Bury, Michael (2001). *Handbook of Disability Studies.* Thousand Oaks, CA: Sage.

provincial services. This could be the most significant gap in the continuum of care for elderly and disabled people in First Nations and Inuit communities. In Manitoba, for example, the provincial health program includes dietetic services, rehabilitative services, and acute, chronic, long-term, palliative and extended care services. All these services are available to First Nations, but only if they are prepared to leave the reserve to access them. Once they are moved off reserve, there is no guarantee that the services will meet the cultural and linguistic needs of the client. It is worth mentioning that the development of new technology may help reduce the need to bring the patient to the care. Recent innovations such as home dialysis and tele-health may go a long way toward reducing the need to provide more complex medical care off reserve.

Even if a full range of service exists in the community, cultural or linguistic barriers may remain and make access to services more difficult. In Manitoba, for example, *"It is not uncommon to have Cree and Ojibway residents in a personal care home being cared for by staff who speak mostly English or Dakota."*[17] A report prepared by the Child and Family Services Research Group concludes that many existing services are culturally and linguistically inaccessible to Aboriginal seniors.[18]

Resolving Conflict over Roles and Responsibilities

Many key informants offered suggestions about resolving the confusion over roles and responsibilities. There is a perception that INAC should only be a funder of programs, allowing First Nations communities to design and deliver them. As one key informant noted, *"If we move beyond funding into project management, we don't have the capacity to do it. We are getting into a mixed bag and need to decide what business we are in."* With respect to INAC-Health Canada issues, many key informants commented that greater integration of the Adult Care Program and the HCCP is required in order to better define the responsibilities of each. They said that current planning efforts involve trying to find better ways to link the HCCP with the Adult Care program in First Nations and clarify which program is responsible for what areas. One key informant's comment reflected the commonly expressed opinion, *"We need to stop stove piping - there needs to be one continuum with all of the roles and responsibilities well defined, and a single set of reporting requirements."*

There is evidence that this is already occurring at the community level in some First Nations, but that increased regional- and national-level cooperation and integration is required. Key informants reported that efforts are under way to address this issue, including the creation of both regional and national committees to examine it. One key informant noted, *"There has been a lot of work done on a continuing care framework; we need to finish it and get the authorities to do it. Then we can get on with doing the job."*

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[17] Manitoba First Nations Personal Care Home Working Group. (October, 2001). *Reaching Provincial Parity: Providing Quality Personal Care Homes for First Nations Elders. Challenges and Recommendations, Part One*. p. 6.

[18] Child and Family Services Research Group. (May 2000). *Winnipeg Aboriginal Seniors: Needs Assessment and Service Recommendations*. p. 37.

However, good reasons exist for this blurring of social and health service delivery. A housekeeper who cleans and organizes a home produces a health outcome if the home is made safer and accidents are reduced. If that homemaker can also be trained to check medications, the need to send a higher cost professional may be eliminated. Therefore, efficiency may well drive the blurring of the distinctions between social care and health care. It is important to recognize that the efficient and effective way to organize a service may demand that roles and responsibilities be blurred, or more accurately, that no useful distinction between social and health services can be made, at least at the "*lower end*" of the care continuum.

Involvement of Community Members in Design and Delivery of Adult Care

Data from key informants suggest that, in general, First Nations community members have not been involved in developing Adult Care services.[19] Some respondents believe that input from First Nations was not solicited at all, while some noted that the national Joint Working Group has recently helped to obtain a First Nations perspective on Adult Care services. Most participants in the client focus group reported that they had not participated in the planning or delivery of services in the Adult Care program. Respondents in one group explained that this might be due to the fact that many people – especially seniors – are shy and *"would be uncomfortable"* participating. Members of these focus groups unanimously reported that more people should be involved in planning. Participants said that client and community involvement increases awareness of services, ensures that needs are being met *("because we are the ones who know what the needs are")*, and helps identify what people like and do not like about the care they are receiving.

Challenges to Design and Delivery

This research has identified a number of the challenges that have been faced in delivering the Adult Care program. The three main themes that emerged are described below.

a) Monitoring and Compliance. Many key informants reported a lack of compliance with guidelines for determining who receives service, particularly with respect to in-home care. It is apparent that in many communities, formal client evaluations and assessments are no longer required to be approved to receive care. Key informants in several regions reported that some communities grant in-home services to every person over a certain age, without any assessment of need. There were reports that there is often little monitoring of who is receiving service and whether the service is appropriate to their needs. There were also several reports of political interference in decisions regarding who would or would not receive care. As one key informant noted, *"In some cases, the program is being abused; we can't monitor whether the money is being used as intended."* In one of the communities visited for this evaluation, key informants noted that they developed a policy manual for their Adult Care services containing clear

[19] Exceptions to the overall lack of participation by community members were found in two communities, where clients reported taking part in meetings and a client survey.

standards for assessments and provision of service decisions. Key informants reported that the policy guidelines in the manual serve to *"depoliticize home care and make it respond to needs rather than wants."*

b) Lack of National Policy. Echoing the findings in the Roles and Responsibilities section above, substantial data obtained from key informants suggest that in the absence of a national policy for Adult Care, there is a lack of clear goals for the program and variations in the delivery of services. As one key informant noted, *"There is no manual, so it was 'here's the money, do the best you can with it."* Some observed that the Adult Care Program, particularly the in-home component, was not "designed" at all. One said, *"It wasn't designed – it evolved from having some temporary help around the house, to providing regular ongoing housekeeping services to elderly people."* Some key informants suggested that consultation with First Nations is required to develop a clear national policy for the delivery of Adult Care services.

c) First Nations Perception of the Program - Design and Delivery Issues. Several key informants reported complaints from community members about paying homemakers to provide help to the elderly. The concern appears to be that this practice weakens traditions of family care and creates an expectation of being paid to help others. Respondents referred to the common perception that since Adult Care funding is available from INAC, paying people does no harm. Key informants explained that it is challenging to explain to community members that *"there is only a certain amount, and if you get paid for visiting a sick relative, someone else won't get service."*

Other challenges reported by respondents include:

- General funding issues (*"if we want to keep people at home it will cost a lot"*);
- A lack of expertise and management capability at the community level;
- Dealing with increasing demand for service (*"we have to get ready for a lot more needs"*);
- Provinces' unwillingness to deliver care in First Nations communities (*"long-term care is up to the province, but they don't want to do it on reserve"*);
- *"Turf wars"* between health and social workers in the community that impede the integration of Adult Care and the HCCP; and
- Serving isolated communities.

d) Regional Challenges: Examples from Manitoba and British Columbia. More detailed information available for two of the jurisdictions (Manitoba and British Columbia) offers additional insight into the challenges faced in providing Adult Care in First Nations communities.

i) Manitoba

The Manitoba FNPCHN shares some of the same concerns cited above and also argues that provincial standards and guidelines do not address issues surrounding accountability, standards, and monitoring. The Network suggests the establishment of *"an appropriate licensing and monitoring regime to ensure that all on-reserve facilities are properly maintained and that they offer residents consistent quality care."*[20]

All the other issues raised by the Network revolve around funding, including:

- Capital funding shortages for building maintenance;
- Funding for professional support services, for example, dieticians, occupational and physical therapists;
- Funding for appropriate patient care levels;
- Escort and transportation costs;
- Staff hiring and retention;
- The need for more on-reserve beds;
- Transportation and freight costs; and
- A consistent and appropriate funding formula.

ii) British Columbia

A 1999 report concluded that there is *"poor continuing care services for Aboriginal peoples,* [and] *inadequate attention to the unique needs of rural and remote areas."*[21] In an attempt to address the needs of First Nations populations, the British Columbia Ministry of Health has adopted a policy that one person of Aboriginal descent must be a governor (board member) on each health authority. Aboriginal governors have encountered a range of problems attempting to raise issues concerning their constituents. The report concludes that there is an urgent need to improve the health status of Aboriginal people in British Columbia because they *"continue to be challenged by both the poorest health status among identified populations, and serious inequities in health when compared to other British Columbians."*[22]

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[20] Manitoba First Nations Personal Care Homes Network. (March 2001). *Reaching Provincial Parity: Providing Quality Personal Care Homes for First Nations Elders.*

[21] Steering Committee Report. (October 1999). *Community For Life: Review of Continuing Care Services in British Columbia.* p. 10.

[22] Provincial Aboriginal Health Services Strategy, available at http://www.healthplanning.gov.bc.ca/aboriginal/pahss.html , p. 1.

Summary of Design and Delivery Issues

In summary, the responses to the two evaluation questions on design and delivery are as follows:

- *Is there a clear and workable division of roles and responsibilities between funding departments?* A clear and workable division of roles and responsibilities between funding departments does not exist. In large measure, this reflects the inherent ambiguity of separating social and health services, and separating Type I and Type II from higher-level needs. The reason one speaks of a "continuum" is that segmentation is difficult. Many First Nations communities solve this ambiguity by pooling funding sources for social and health care and by stretching the definition of what can be offered as part of Type II personal care.

- *What are the levels of Adult Care services provided on reserve in each INAC region?* Describing the levels of Adult Care services provided on reserve in each INAC region is difficult if one wishes to move beyond the general descriptions offered in Section 1 of this report. In-home care is offered in all of the regions studied, but the specific services offered under this component of the Adult Care program vary widely by community. Foster care is offered in two of the regions considered (British Columbia and Québec) and is used to a significant extent in Québec (where it is used in 14 First Nations communities). Institutional care is offered in all four regions, but not always on reserve, and the number of PCHs varies widely among them. In order to obtain useful insights, levels of service available should be matched against needs as measured by a reliable and valid classification of disability (as a proxy of need). This would require integration of Health Canada, INAC, and provincial/territorial information, a development that is unlikely in the near future. Until that occurs, planning will be based on general trends, and levels of service will not necessarily be sensitive to local conditions.

Success

This section discusses the extent to which the Adult Care program has met its objectives, the outcomes and impacts of the program, and whether the services are adapted to the First Nations communities where they are offered. This is followed by a brief summary of the perceived strengths and weaknesses of the program.

Achievement of Objectives

The main objectives of the Adult Care program are to:

- Assist First Nations with functional limitations;
- Maintain their independence;
- Maximize their level of functioning; and
- Allow First Nations to live in conditions of health and safety.

Scant evidence exists to assess objectives achievement, and key informants reported that it is difficult to know if the Adult Care program is meeting its goals. The key factor identified as being responsible for this uncertainty is the lack of comprehensive performance data for this program. Key informants commonly raised the following issues:

- The fact that little information beyond basic financial data is collected;
- The fact that even basic reporting requirements are infrequently met; and
- The fact that no regular assessments or evaluations are conducted.

Most key informants believe that while INAC regional personnel might have some sense of what is working in the communities, little independent information is available to support assessment and planning. Selected comments illustrate this situation:

- *"It's hard to know if the objectives are being met. For the communities with multi-year funding agreements, we don't know what is going on."*

- *"I don't know how we would measure the success of the Adult Care program;we really only collect financial information."*

- *"We don't know if objectives are being met; we don't measure success. Some places report, others don't – we get minimal amounts of data. We need to get our act together and figure out what it is we need to collect."*

Health Canada respondents said that there is an evaluation plan and a Results-Based Management and Accountability Framework (RMAF) in place for the HCCP, and that INAC personnel participated in its development. They further noted that if INAC is developing an RMAF for the Adult Care program in the future, the two departments should collaborate on it. *"We should have a consistent logic model, and we want to have an integrated tool for communities to report to both Health Canada and INAC."*

Outcomes and Impacts of the Adult Care Program

Key informants believe that *"some people are getting some care;"* however, most were unable to identify specific outcomes beyond noting that seniors are receiving homemaking help and "basic services." Others said that at a minimum, more seniors are able to remain in their communities as a result of the Adult Care program. One key informant said that there was anecdotal evidence of people being able to stay in their homes and communities as a result of the services provided by the Adult Care program. The fact that so little data are available and the fact that INAC is "*a funder, not a service provider"* were identified as the reasons for the lack of specific knowledge of the outcomes and impacts of the Adult care program.

Key informants were more likely to offer opinions on the two outcomes they would like to see in the future: integration of services and the provision of more Adult Care services in First Nations communities.[23] These themes are discussed in more detail below.

a) Integration of services. Most key informants noted that some communities are already integrating resources and programs. An indirect effect of integration for some key informants is that it will improve measurement of objectives achievement. Others observed that the desired outcome is to provide a seamless approach to delivering Adult Care, *"Whether by marrying* [INAC Adult Care] *with the HCCP or otherwise."* That is, the specific configuration of funding and service delivery which is ultimately developed is seen to be less important than the service outcomes related to integration. As one key informant stated, *"As long as the client sees a seamless continuum, it doesn't matter how you do it."* Note that integration is not really an outcome but a redesign of service delivery leading to improvement in serving clients. The fact that so few key informants can speak of what the outcomes should be and how they might be measured indicates that the development of results-based management remains at an early stage.

b) Increased level of services. Most of the key informants consulted said that they would like to see more care services being delivered in First Nations communities in the future. The most common suggestion for achieving this outcome was to increase the number of PCHs on reserves. Several key informants suggested that provinces need to take responsibility for licensing and monitoring these on-reserve homes. The importance to the well-being of both clients and the community in general of maintaining people in their "natural environment" was cited as the most important reason for expanding the level of services available in First Nations communities. Respondents commonly noted that it is particularly important to develop services that will allow more seniors to stay in the community. Beyond simply keeping people in touch with their elders community members, they also identified the importance for the spirit of the community of not having to send people out of the community to receive outside services. As one key informant noted, "[keeping seniors in the community] *will have impacts on communities that come from caring for your own and being self-sufficient."* There is a related concern that even if needed services are not available in the community, residents will refuse to leave: *"People will stay* [in the community] *even if it means that they don't get the care they need. That's not a good thing."*

Some key informants commented on the viability of expanding institutional care in First Nations communities. Some thought that this approach was more of a policy issue than a financial one. As one key informant stated, *"If the political will is there, it could be viable. I don't see a huge financial impact on governments. There should be little difference in costs whether it's done on- or off-reserve."* Others maintained that long-term care on reserve is complicated with jurisdictional and political obstacles. *"We need to resolve the problem of long-term care for the community, but it has been under discussion since the moratorium."* The institutional case studies found evidence of small-scale group residences in First Nations communities that allowed

[23] In general, INAC personnel were more likely to concentrate on service-level issues, while respondents from Health Canada tended to discuss integration.

clients to live independently while having access to care services if required. Key informants at these facilities raised the potential for establishing similar homes with higher levels of care to serve the needs of communities that could not support a full-scale PCH.

Unintended Outcomes

Several key informants indicated that an unintended outcome of the Adult Care program was the potential for weakening the traditional family responsibility for care of seniors and increased dependence on government services. Some key informants reported that this is sometimes the case even where family members are able to provide the necessary care; "*in some cases, the need followed the service.*" That is, it appears that many seniors previously managed to stay in their homes with support from their family, but that *"when the services arrived, some people thought they replaced the family."* The main concern expressed is that the existence of the Adult Care Program could lead people in the community to believe that they are absolved of their responsibility to care for the elderly or disabled. Some key informants further reported that many clients initially receive care for a short-term condition, but they then develop an expectation that service will continue indefinitely. It is apparent that, once begun, it can be difficult for community workers to discontinue service to a client. One key informant's comment summarized this concern: *"There gets to be an expectation of services for life, and there can be political and family pressure to keep providing them."* Finally, some key informants stated that even in cases where family members continue to care for their relatives, there is now more likely to be an expectation of payment from the Adult Care Program for doing so.

A number of key informants identified the creation of employment for community members as an unintended positive outcome of the Adult Care Program. In several communities, there were reports not only of increased job opportunities, but also of a new incentive for community members to pursue training and to upgrade their skills. One key informant reported another unexpected outcome, that the Adult Care Program served to raise awareness of age and disability issues among community members and leadership. By keeping seniors and others with functional limitations visible in the community and *"more involved and participating"* in community life, the issues related to their needs and their care are kept in the forefront.

Services Adapted to First Nations Communities

a) Meeting Needs. Key informants provided qualified opinions on the issue of whether the Adult Care program is meeting the needs of First Nations communities. As noted in previous sections of this report, many key informants do not believe that the Adult Care program is fully meeting the needs of First Nations communities. They were most likely to identify insufficient funding to provide in-home care to all those who need it; a commonly held opinion is that the fixed per capita funding formula often means that *"there is just not enough to go around."* Some mentioned a lack of community institutional care for clients requiring services beyond Types I and II. Most others

indicated that they do not have sufficient information to offer an opinion on whether needs are being met, since needs vary so much among communities. A few respondents said that the Adult Care program is meeting needs to a certain extent, but responses were often qualified.

b) Culture and Traditions. This evaluation found that perceptions varied on the extent to which the services provided under the Adult Care program reflect First Nations culture and traditions. Among the INAC and Health Canada key informants, many stated that only First Nations community members could properly answer the question. Others believe that the services will naturally reflect First Nations culture and tradition because they are delivered by community members. Still others, reflecting the concerns above (unintended outcomes), believe that some INAC Adult Care services could actually run counter to First Nations traditions because they could serve to erode the families' responsibility for care.

Adult Care clients participating in the focus groups noted that the caregivers are all First Nations and community members, so they naturally share the same culture as their clients. With respect to cultural awareness, one client noted, *"Of course they understand it – they are from here and are First Nations themselves."* Most participants also pointed out that the services do not include any specific cultural or traditional aspects, nor did these clients report that they particularly want them to. Some focus group participants noted that their communities do not adhere to Aboriginal culture and traditions, but that they have strong Christian religious beliefs. One client pointed out that it would be good, especially for the seniors, if more of the care workers were able to speak the local language. Some participants added that the in-home care model could be viewed as reflecting First Nations culture in a more general way, protecting family and community ties by keeping seniors in their homes and in the community as long as possible.

c) Satisfaction with Services. The limited data obtained from Adult Care clients participating in the client focus groups indicate a high level of satisfaction with the services they are receiving. Most said that their lives were better as a result of having access to in-home care. The fact that they were able to remain in their homes, living independently and safely, was the main factor in their level of satisfaction. Only two issues were identified that had reduced some clients' level of satisfaction with their in-home care. First, some clients noted that care workers often arrived late and, therefore, did not work for the allotted amount of time. As one client noted, *"Many of us only get help for three hours a week, if she is an hour late, that's a big difference."* The other issue identified in one community was related to the fact that care workers were employed for six months and then laid off for six months in order to *"spread the employment around"* to more community members. Participants believe that this decreased the quality of the relationship and the trust that develops between caregivers and clients. Overall, however, clients rated the services highly:

- *"The program has made life much better; it makes it easier to stay at home safely."*
- *"The program has made my life better; I can't maintain my home by myself."*
- *"Without the program, we could not take care of ourselves; it gives us the help we need."*
- *"We can remain in our homes and maintain our independence."*
- *"The program makes it so people are not alone."*

Strengths and Weaknesses of the Adult Care Program

Key informants from INAC and Health Canada (both regional and HQ personnel) identified a number of perceived strengths and weaknesses of the Adult Care program. Most tended to mirror many of the findings presented in the preceding sections. The strengths and weaknesses reported by key informants are listed below with the frequency of response.

Strengths	N	Weaknesses	N
It offers services that people need	6	No national policy for objectives, roles, and standards	7
It is administered by First Nations, for their own people	4	Lack of financial resources/insufficient budget	6
There is flexibility in how to deliver the Program	3	Small communities can't get the whole range of services	4
It plays a necessary role in the continuum of care	2	Lack of PCH beds on reserve	3
Elder care has caught the attention of First Nations leadership	1	No process for monitoring and evaluation	3
It does a lot with limited resources	1	Federal-provincial jurisdictional issues	2
PCH administrators are very committed	1	Reporting requirements	1
Institutional care budget is based on need	1	Institutions on reserve not required to be licensed	1
Provides some employment in the community	1	Eligibility criteria not applied in all communities	1
		Adult care is more a health issue than a social issue	1

Summary of Success Issues

In summary, the responses to the three evaluation questions on success are as follows:

- *Are the Program's objectives met?* No one interviewed could attest to this. No outcome data exist and to meet objectives requires that outcomes are measured in relation to some standard of performance. The stated objectives of the Adult Care program are very broad and do not provide measurable standards. If one broadens the criteria and asks merely whether the Adult Care program provides resources to provide Adult Care on reserve, the response would probably be positive.

- *Do adults receive services adapted to their needs?* Whether adults receive care adapted to their needs is not clear since detailed information is lacking on services offered by community, matched with the needs of the clients. The fact that some communities are prepared to stretch Type II PCH services to include higher levels of care indicates a process of adapting services to meet the health needs of clients, while allowing them to stay in the community. At the same time, since these extra services cannot be cost recovered under the Adult Care program, the possibility exists that services may be trimmed in other areas, or the quality of service may deteriorate.

- *Are First Nations satisfied with the services?* From the qualitative evidence obtained from focus groups, the response is affirmative. Of course, this is not a rigorous client satisfaction reading. As well, the services are offered by a sole supplier, which limits clients' ability to make comparative assessments.

Cost-effectiveness

This section presents information related to the cost of INAC's Adult Care program. Some provincial Adult Care cost data are also presented in an attempt to place the INAC program in a regional context. Finally, the existence of alternatives to the current funding and service delivery configurations is discussed.

Costs of Providing Adult Care Services

It is important to note that the Adult Care program has little consistent information on the actual costs of providing Adult Care services. While information is available on the total amount of money INAC provides to First Nations for Adult Care services in the four regions, it is not clear precisely how the funds are allocated or whether funding is aligned with the actual cost of delivering the services included in the Adult Care program. That is, while this evaluation was able to ascertain what the Adult Care program is costing INAC, it is not clear what delivering the slate of Adult Care services costs. The reasons for this uncertainty are discussed in the sections below. Table 5 (next page) presents aggregate expenditure data for in-home, foster, and institutional care for the last five fiscal years.

Table 5: INAC Adult Care expenditures by region, 1997/98 - 2001/02					
Fiscal year	**1997/1998**	**1998/1999**	**1999/2000**	**2000/2001**	**2001/2002**
National					
Foster	$1,067,336	$1,175,460	$1,271,031	$1,205,708	$703,104
In-home	$32,337,287	$34,381,370	$42,255,417	$40,238,680	$39,414,494
Institutional	$17,517,744	$19,304,644	$22,647,704	$24,060,816	$27,315,164
Atlantic					
Foster	--	--	--	--	--
In-home	$2,719,118	$2,387,512	$2,395,354	$3,033,018	$3,073,739
Institutional	$951,852	$875,000	$1,232,370	$1,456,678	$1,566,873
Québec					
Foster	$231,083	$299,917	$276,533	$305,700	$269,276
In-home	$2,385,107	$4,280,881	$4,235,078	$5,035,459	$4,666,165
Institutional	$1,157,250	$3,147,834	$3,459,895	$3,986,272	$5,738,515
Manitoba					
Foster	$3,780	$2,000	$3,000	$2,000	--
In-home	$6,045,729	$5,720,319	$6,216,065	$6,247,298	$4,657,735
Institutional	$7,914,732	$6,980,547	$9,346,951	$9,859,355	$10,645,798
British Columbia					
Foster	--	$81,006	$158,528	$135,220	$139,781
In-home	$4,496,577	$5,141,705	$6,184,692	$6,290,864	$6,366,812
Institutional	$2,046,150	$2,403,847	$2,511,239	$2,673,358	$2,169,051
Source: Data from INAC Social Development Program					

No clear trends emerge from the Adult Care financial data in the table above. For in-home and foster care, total national spending appears to have peaked in 1999-2000; while national spending on institutional care climbed steadily over the five-year period. Regional expenditures are less consistent; in Québec for example, spending on institutional care increased significantly over five years, while in British Columbia, it remained relatively stable. Further complicating any attempt to identify trends is the fact that in some cases changes in expenditures are not directly related to changes in care days / number of clients. That is, in some regions, expenditures have risen while care days have declined, or vice versa. Many factors could be contributing to this situation; identifying them is not possible with the data available for this evaluation.

It is also important to note that the figures in the table above represent the INAC contribution to Adult Care services in First Nations communities. Some services offered under the Adult Care program might be subsidized by other funding sources, or the reverse might also be the case. Most communities combine funding from various sources, most notably the Health Canada HCCP, creating a budget that is used to meet a range of health and social needs defined at the community level. This is particularly true for communities with multi-year funding arrangements.

Adult Care by INAC Region (on reserve)

This section presents expenditure and service data, for the two most recent fiscal years, from each of the four INAC regions considered for this evaluation. The data presented in this section should be interpreted with caution, since fluctuations in Adult Care spending, number of clients served, and care days provided could result from a number of factors. As noted above, identifying these factors is not possible with the data available for this evaluation. The situation is further complicated by the fact that there are no data regarding the specific services being provided in First Nations communities.

a) Atlantic

Table 6: INAC Atlantic

Type of care	2000-2001		2001-2002	
	Expenditures	Care days/clients	Expenditures	Care days/clients
Foster care	--	--	--	--
In-home care	$3,033,018	44,638/245	$3,073,739	32,598/189
Institutional care	$1,456,678	12,783/30	$1,566,873	9,446/31

Source: INAC Atlantic Regional data

The bulk of services funded in the Atlantic region fall under in-home care; adult foster care is not offered. In Nova Scotia, the Confederacy of Mainland Micmacs (CMM), through the Adult Alternative Care Program, administers contracts for the care of the 26 First Nations clients living in special care facilities. The totals above for institutional care also include amounts paid for First Nations in provincial institutions. While total spending increased for both in-home and institutional care, the number of care days provided under in-home and institutional care decreased substantially from one fiscal year to the next. The number of clients receiving in-home care also dropped by approximately 25 percent.

b) Manitoba

Table 7: INAC Manitoba

Type of care	2000-2001		2001-2002	
	Expenditures	Care days/clients	Expenditures	Care days
Foster care	$2,000	--	--	--
In-home care	$6,247,298	113,253/1,051	$4,657,735	115,998/1,206
Institutional care	$9,859,355	71,604/201	$10,645,798	73,023/195

Source: Data from INAC Social Development Program & INAC Data Operations

This region funds in-home and institutional Adult Care; Manitoba does not offer a foster care program. Specific services offered vary by First Nations: *"Under the in-home care program, the First Nations provide a host of services that range from carrying in wood to 24-hour care for*

clients who refuse to move to a PCH." The table above shows that in-home care spending decreased substantially from 2000-2001 to 2001-2002, while the number of care days increased. Institutional care spending and number of care days provided both rose from one fiscal year to the next.

There is a total of 210 on-reserve PCH beds in Manitoba. In this region, FNPCHs are funded based on the "Klassen Formula,"[24] which was developed by Helmuth Klassen in 1993 and was designed to:

- *facilitate the equitable distribution of available funds to the FNPCH*
- *develop a financial base which supports the standards for FNPCH; and*
- *develop a system which supports the autonomy of the First Nations.*

It begins with the current provincial mean per diem, defined as *"the mean rate of payment per resident day paid by Manitoba Health for care in a proprietary personal care home for a given level of care."* It is then adjusted, or indexed, by taking into consideration the special needs of FNPCHs. These include such things as: economy of scale; service accessibility (remote/rural); transportation or freight charges; training and development; and other cost of living factors. This is calculated as a percentage and added to the provincial mean.

An addition is also made for a capital allowance per diem, calculated by noting the average amount per resident day, the mortgage (less Canada Mortgage and Housing Corporation (CMHC) subsidy), major building repairs or equipment replacement, and vans or other forms of transportation. This is then added to the residential charge, paid directly to the homes by the residents, and multiplied by the number of resident days. The total is the composite per diem or *"the net daily cost of operating a personal care home."* The funding agency portion is calculated by taking the adjusted mean and the capital allowance per diem and multiplying by the number of beds and the number of resident days.

c) Québec

Table 8: INAC Québec

Type of care	2000-2001		2001-2002	
	Expenditures	Care days/clients	Expenditures	Care days/clients
Foster care	$305,700	18,309/62	$269,276	8,946/59
In-home care	$5,035,459	64,035/600	$4,666,165	64,449/558
Institutional care	$3,986,272	37,530/133	$5,738,515	24,654/107

Source: INAC Québec Regional data

[24] Helmuth Klassen Consulting and Facilitating, Inc. (September 1993). *Funding Formula: First Nations Personal Care Homes*. p. 1.

Total spending for both foster and in-home care in the Québec region fell from 2000-2001 to 2001-2002. For foster care, the number of care days fell by approximately 50 percent, while the number of clients served remained relatively stable. For institutional care, the number of care days and number of clients both decreased, while expenditures increased.

Per diems paid by INAC for Types I and II institutional care in Québec are aligned with provincial rates and follow the provincial standards for client contribution. Key informants reported that in-home care funding is not in line with that of the province, since each Local Community Service Centre (LCSC) sets its own rates. Additionally, INAC region decentralizes the budget to agencies that have the flexibility to fix rates. Some Bands pay minimum wage for some services, but the wage is usually closer to $9.00 per hour to cover fringe benefits. Some Bands pay higher wages depending on the training of the employee. There is an INAC regional policy for in-home care, developed in consultation with First Nations, that is similar to those of the province.

d) British Columbia

Table 9: INAC British Columbia

Type of care	2000-2001		2001-2002	
	Expenditures	Care days/clients	Expenditures	Care days/clients
Foster care	$135,220	3,273/9	$139,781	2,589/7
In-home care	$6,290,864	60,253/3,343	$6,366,812	76,684/2,777
Institutional care	$2,673,358	15,791/43	$2,169,051	15,978/42

Source: INAC British Columbia Regional data

In British Columbia, INAC offers in-home, foster, and institutional care, although foster care is not widely used. Two on-reserve facilities are funded as institutions in this region. Expenditures for foster care rose slightly from 2000-2001 to 2001-2002, while the number of care days provided decreased. In-home care funding rose only slightly; however, the number of in-home care days rose substantially from one fiscal year to the next. Institutional care spending declined by approximately 20 percent, while the number of clients and care days for institutions remained relatively stable.

Expenditures by Province (off reserve)

The data in this section should be interpreted with caution, since provinces employ different data collection methods. In addition, the data are not comparable between provinces nor with INAC spending data, since the various jurisdictions and/or communities do not provide comparable slates of services.

a) Atlantic

Table 10: Provincial spending - New Brunswick (government contribution)				
Type of care	**2000-2001**		**2001-2002**	
	Expenditures	**Clients**	**Expenditures**	**Clients**
In-home care	not available	not available	$67,577,700	8831
Institutional care	not available	not available	$56,919,100	4063
Source: New Brunswick Long-term Care Services				

Long-term care services offered in New Brunswick include in-home care and adult residential care. In-home care services include homemakers, cleaning, cooking, personal care, and respite care. The services are intended to address long-term problems; clients must require services for at least three months to qualify. Two levels of care homes are funded under this program: Level 1 is intended for clients who have disabilities but retain most ability to function independently. Level 2 is intended to meet more severe needs and provides 24-hour supervision.

In the Atlantic region, off-reserve services vary. They all provide long-term and chronic care, palliative care, respite care, assessment and case management, homemaker/personal care, home care nursing, and community rehabilitation. In addition to those services, Newfoundland and Labrador provides assessment and treatment centres, meal programs, adult day support, group homes, equipment and supplies, transportation services, home maintenance and repair, and self-managed care. Prince Edward Island also offers adult day support. Nova Scotia's off-reserve services include equipment and supplies as well as a quick response team. Finally, New Brunswick offers meal programs, adult day support, group homes, equipment and supplies, and transportation services.

b) Manitoba

Table 11: Provincial spending - Manitoba				
Type of care	**2000-2001**		**2001-2002**	
	Expenditures	**Care days/clients**	**Expenditures**	**Care days/clients**
In-home care	$165,801,600	21,913 clients	$176,251,800	not available
Institutional care	$348,151,200	3,366,875 days	$376,191,900	not available
Source: Manitoba Health Annual Statistics (2000-2001); Manitoba Health Annual Report 2001-2002.				

Spending on in-home and institutional care increased from 2000-2001 to 2001-2002; client and care day information for the most recent year are not available. In-home and institutional care services are delivered under the Manitoba Home Care program. Its mandate is to provide home care services to persons who do not possess the resources to remain at home, and to place clients in long-term care facilities if and when *"home care services cannot maintain them at home safely*

and/or economically."[25] Of the four regions considered for this evaluation, Manitoba appears to provide the most extensive Adult Care services. These include long-term, chronic, palliative and respite care, assessment and case management, homemaker/personal care, home care nursing, community rehabilitation, meal programs, adult day support, group homes, equipment and supplies, transportation services, congregate living/supportive housing, quick response team, and self-managed care.

c) Québec

Table 12: Provincial spending - Québec

Type of care	2000-2001		2001-2002	
	Expenditures	Care days/clients	Expenditures	Care days/clients
In-home care	not available	not available	not available	not available
Foster care	$81,592,089	not avail. / 13,707	$74,720,750	not avail./13,012
Intermediate resources	not available	not available	$127,704,828	not avail./7,666
Institutional care	$1,994,060,783	14,342,267/40,204	not available	not available

Source: Ministère de la Santé et des Services Sociaux.

"Intermediate resources" include Types I and II services offered by providers under contract to the provincial government; "institutional care" refers to care provided in a long-term care home. Foster care expenditures do not include clients' contributions. Intermediate resources and institutional care expenditures include clients' contributions, which are approximately 55,000,000 per year. Other than a decrease in foster care spending from 2000-2001 to 2001-2002, the available data do not support the identification of any trends.

d) British Columbia

Table 13: Provincial spending - British Columbia

Type of care	2000-2001		2001-2002	
	Expenditures	Care days/clients	Expenditures	Care days/clients
Community	$412,499,656	7,053,089/39,083	$457,269,578	not available
Residential	$1,040,688,500	9,272,410/35,347	$1,082,497,239	not available

Source: Home and Community Care, Ministry of Health Services, British Columbia.

In British Columbia, "community care" includes home support, adult day care, home care nursing, and community rehabilitation. Residential care includes residential care facilities, extended care hospitals, private hospitals, group homes for the young disabled, and family care homes. Spending on both community and residential care increased from one fiscal year to the next. Data are not yet available on number of care days provided or number of clients served for 2001-2002.

[25] Manitoba Centre for Health Policy, (October 21). "*A Look at Home Care in Manitoba*."

Comparison of INAC and Provincial Expenditures

A general trend in home care expenditures is that they have increased substantially over the past two decades. In 1980, public spending on home care amounted to about $225 million (including spending by INAC), and the private sector was about $90 million. This rose to over $2.5 billion of public spending in 2000-2001 and just under $800 million in private spending.[26]

An important challenge exists in analysing the expenditures of INAC's Adult Care program in relation to the First Nations setting in each jurisdiction and in comparing First Nations spending with that of provinces. The services offered by INAC's Adult Care include in-home care (housekeeping), adult foster care, and institutional care. The portfolios of services offered by typical provincial home care programs differ from the portfolio of services offered by INAC Adult Care. The quality and quantity of services provided by each province will also be influenced by social, economic, demographic, and political factors. Additionally, what is actually provided varies by community and by jurisdiction, making it challenging to accurately describe the level and nature of services offered.

In one jurisdiction however (Manitoba), there are some existing data comparing costs of PCH (Levels 1 and 2) for on-reserve and off-reserve institutions. A November 2000 study found that *"funding rates are significantly higher* (for on-reserve PCH) *than for Personal Care Homes in Manitoba."*[27] Specifically, the study found that on reserve, the per diem rates were 41 percent to 62 percent higher than off reserve. This does not necessarily mean that the FNPCHs are not cost-effective; the study suggested several reasons for higher funding rates for on-reserve PCH:

- The high costs associated with remote/isolated/semi-isolated communities;
- Negligible levels of volunteerism on reserve;
- Low economies of scale on reserve (small facilities with high overheads); and
- Low levels of health infrastructure on reserve (resulting in few opportunities for partnership in training, cost-sharing, etc.)[28]

Another possible measure of relative costs is per capita spending, which in 2000-2001, ranged from under $50 per capita in Prince Edward Island to almost $200 per capita in New Brunswick. However, extreme caution is needed in using these numbers because these costs vary with the age/sex ratios in the populations and the range of services offered. For example, Prince Edward Island home care (which are services delivered to clients in their home) included *Group 1*, short-term care (up to 30 days) to assist a return to full functioning (after a hospital stay); *Group 2* intermediate care to persons requiring more time to return to full functioning; *Group 3*

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[26]Coyte, Peter, C. Home Care: Potentials and Problems, Presentation given at Diagnostics and Solutions: Building Consensus for Health Care Reform in Canada, http://www.hcerc.org

[27]Romanow, Bear and Associates. (November 2000). *Manitoba First Nations Personal Care Homes: Funding Analysis Draft Report.* p. 14.

[28]Ibid.

continuing care, which provides a range of support and is broadly similar to INAC's Adult Care Program, but likely includes Type III services and higher; and *Group 4* clients needing intensive care. Other provincial programs include a similar range of services that are not comparable to the INAC services.

It is difficult to compare INAC's Adult Care costs with provincial continuing care costs because the portfolio of services are grouped differently. One would need to have detailed budget breakdowns for the components of services to select a set of services in each of the four jurisdictions. This would require a high level of cooperation from the provincial departments, since this information is not publically available. Therefore, it can be misleading to present provincial home care expenditure data as a reference for INAC's Adult Care program. All that can be said is that both INAC and provincial services endeavour to meet similar Adult Care needs in the populations they serve, and that there are no striking differences between INAC per-day (or per-client expenditures) and provincial expenditures.

Alternatives to Current Funding and Service Delivery Configuration

The uncertainty regarding the actual cost (and nature) of the services provided under INAC's Adult Care program complicates any discussion of alternatives to the current funding and delivery configuration. A comprehensive assessment of actual need for specific services, based on standardized client assessments, is required to accurately determine necessary funding. In addition, close monitoring of actual expenditures for each service (from all funding sources) is required in order to quantify current spending and to determine who can most effectively and efficiently deliver the services. In some cases, this monitoring and assessment would require close cooperation of INAC, Health Canada, First Nations, and provinces/territories.

Interviews with First Nations health and social services personnel identified problems with the per capita funding method for in-home and foster care. They said that this method does not recognize the regional and community variation in care needs. This is a major factor in the common practice of combining INAC's Adult Care and HCCP's funding to allow better allocation of resources. One key informant noted that the ratio of social to health funding does not correspond to actual need. Approximately 75 percent of the community's combined social and health funding is from Health Canada for health services, with the other 25 percent from INAC for social care. This key informant stated that *"the needs are the reverse of that; there is a much greater need for homemaking services."*

Many key informants suggested that INAC should no longer be involved in the delivery of Adult Care services, especially in the absence of clear authorities and policies. This is mostly a result of concern over the fact that Adult Care service providers are often moving into providing health care services. In addition, there is a perception that the social care services provided under the Adult Care in-home component are also available through the Health Canada HCCP.

Summary of Cost-effectiveness Issues

In summary, the responses to the three evaluation questions on cost-effectiveness are as follows:

- *What are the costs of providing Adult Care services?* The full costs of providing Adult Care services to First Nations communities are not clear. Determination of total cost must take into account the fact that INAC's Adult Care funding and Health Canada's HCCP funding are combined at the community level to provide the range of services desired in the particular community.

- *How do these costs compare with similar services provided by other jurisdictions?* It is not possible to directly compare the cost of on-reserve Adult Care services with those provided by the provinces/territories. Provincial costs obtained for this evaluation normally include provision of a substantial number of services that are not available under the Adult Care program in First Nations communities. A very broad comparison of INAC and provincial Adult Care costs does not reveal any striking differences in per diem costs.

- *What are the alternatives to the current funding and/or service delivery configuration?* Any consideration of alternative funding arrangements will be contingent upon an accurate determination of Adult Care costs. Per capita funding formulae for in-home and foster care do not allow funding to be based on documented need, nor to respond to regional and local variation. There is a perception among most key informants that INAC should reconsider its involvement in the delivery of Adult Care.

Section 4 - Observations and Conclusions

This section presents the observations and conclusions that are supported by the findings presented in Section 3. The lack of key outcome and financial data limits the extent to which some questions can be addressed.

Rationale and Relevance

This section presents observations and conclusions regarding the level and nature of the ongoing need for Adult Care services in First Nations communities.

a) The Adult Care Program currently plays an important role in providing care to First Nations

INAC's Adult Care Program is one of the few programs dedicated to providing care to First Nations in their own communities. In combination with the Health Canada HCCP, it provides services that would not otherwise be available, allowing seniors and others with functional limitations to remain in their homes and communities. It is appreciated by clients and the community alike. These services could, however, be delivered by an alternate provider. The fact that a number of Adult Care services have moved into (or are approaching) health care, suggests that INAC might not be the most appropriate provider.

b) There is a clear rationale for maintaining Adult Care services in First Nations communities

A need exists for Adult Care services in First Nations communities, and the level of need will increase in the future. This demand is linked to the general demographic facts of the aging population and increased life expectancies. In the case of First Nations, however, this trend is coupled with the unique situation of First Nations with respect to particular social and health needs, geographic location, and economic situation. Again, there is no question that Adult Care services are needed; the question is who can most efficiently and effectively deliver them given that there is some question as to whether there is a clear rationale for separating social care from health care.

c) First Nations communities face unique challenges to meeting Adult Care needs

While most First Nations communities face the same general challenges and obstacles to supplying Adult Care as other small/rural/remote communities, certain challenges are unique to First Nations. These include health issues such as significantly higher rates of diabetes, heart disease and other illnesses; and social issues, such as the remoteness of many communities from full services and resources, family breakdown, and the loss of traditional family and community supports. These conditions occur at a younger age and with a higher incidence than the general

population. These factors confirm the need for Adult Care services that are specifically designed to meet the unique needs of First Nations communities. They also suggest the need to investigate new approaches to meeting social and health care needs.

Design and Delivery

a) There is no clear division of roles and responsibilities for providing Adult Care

Ambiguity surrounds the roles and responsibilities of the various parties involved in providing social and health services in First Nations communities. Indian and Northern Affairs Canada, Health Canada, First Nations, provincial governments, and provincial health authorities are all involved to varying degrees in funding and delivering care. This research has found that the confusion can result not only in some parties failing to provide the services for which they are technically and/or legally responsible, but also in services being provided by parties who do not have the authority (or the funding) to do so. This lack of clarity is also seen at the individual community level with respect to the roles and responsibilities of Indian and Northern Affairs Canada's Adult Care program and Health Canada's Home and Community Care Program.

At the same time, it is important to stress that the continuum of care compels the creation of an integrated service, which in turn requires that Indian and Northern Affairs Canada, Health Canada, and the provincial/territorial governments coordinate their funding and service delivery to a much greater extent. Related to this is the lack of policy for the delivery of the Adult Care program. An integrated and national policy can facilitate the communication of goals and objectives for the Adult Care program and provide guidance and support to the regional and community levels in attempting to achieve them.

b) Levels of service vary across regions and communities

Related to the point above, the level of Adult Care service provided to First Nations communities varies by Indian and Northern Affairs Canada region, by province, and by community. First, each Indian and Northern Affairs Canada region has considerable autonomy to administer the Adult Care program as it sees fit. While this flexibility is useful for responding to unique regional needs, it also results in varying levels of service across the country. Second, the level of provincial involvement (or non-involvement) in delivery and funding of care services varies too. This can result in gaps and overlap in Adult Care services.

c) First Nations have not been substantially involved in the design of Adult Care services

Prior to the formation of the Joint Working Group, there was little First Nations involvement in the design of the Adult Care program. Consistent participation in the Joint Working Group by federal and First Nations representatives should help to change this situation. At the community

level, there has also been little involvement by community members in the design of the services provided. It is clear that many clients would welcome an opportunity to have more input into the Adult Care Program in their community.

d) Monitoring and compliance activities are limited

There is little monitoring of how Adult Care funding is spent at the community level. In some regions, there is no policy manual for the Adult Care program; in regions that have a manual, it is apparent that non-compliance with the policy is often observed. In some communities, Adult Care services are provided without client assessments and sometimes only as a response to community and/or political pressure. The result can be insufficient resources to meet the legitimate needs of all community members. Home and Community Care Program manuals developed in some communities can provide a model for local Adult Care policies containing clear guidelines for program delivery.

Success

a) The lack of performance measurement for the Adult Care Program creates difficulties in measuring success

Virtually no formal data are collected by First Nations communities or by INAC that can be used to measure the extent to which the objectives of the Adult Care program are being achieved. Health Canada's experience with the development of performance measures, an evaluation process, and an RMAF for the HCCP could be useful in developing similar tools for INAC's Adult Care program in the future.

b) Outcomes and impacts of the Adult Care Program are unclear

In light of the lack of performance data, it follows that no quantifiable outcomes or impacts can be connected to the Adult Care program. However, it is clear that clients in the communities visited for this evaluation believe that the Adult Care program has had an important impact on their quality of life by helping them to more safely remain in their homes. There is sufficient anecdotal evidence and opinion to assume that the Adult Care program is filling a number of needs, particularly in communities with on-reserve PCHs.

c) There is a need for personal care spaces in First Nations communities

There appears to be a need for PCH beds (or similar alternative services) for First Nations , however it is neither economically feasible nor necessary to have a PCH in every First Nations community. There are, however, examples of small-scale group homes (in North Thompson First Nations, for example) that allow independent living while also providing care services to seniors. In collaboration with the Health Canada HCCP, such facilities could offer higher levels of care to people in small and medium-sized communities without the need to build a full-scale PCH.

d) There is concern about some impacts of the Adult Care Program

There is potential for the Adult Care program to affect social relations in First Nations communities. With respect to in-home care, for example, normalizing the idea of paying community members to help seniors with routine household tasks could be seen as contributing to the weakening of the traditional communal responsibility for elder care. There is also a sensitivity in many First Nations communities to programs that could actually reduce community self-sufficiency and create more dependence on government services. Looking at this issue another way, however, it is clear that if the Adult Care program supports the community in keeping their elders at home, that would be viewed by most as a positive outcome.

e) First Nations culture and traditions are not necessarily reflected in quality Adult Care services

The fact that care services are provided in the community by community members automatically brings an element of First Nations culture that is clearly important to the clients. Beyond that, however, there was little interest or concern from the clients with the more visible aspects of First Nations culture and tradition in the context of the services provided under the Adult Care program. It appears that client satisfaction is more a function of the punctuality of the caregivers and the technical quality of their work.

f) The separation of INAC and Health Canada services could impede the delivery of a full continuum of care

The fact that the Health Canada HCCP was purposely designed to complement INAC's Adult Care program, as well as the other available evidence, suggests that gaps and/or overlaps will not necessarily be created by the existence of two separate programs involved in the delivery of Adult Care services. There is, however, a need to ensure that untrained caregivers are not providing even "quasi-medical" services to in-home care clients. From the available data, it appears that most communities already combine funding for the two programs; combining management and delivery would be a logical next step.

Cost-effectiveness

a) The costs of Adult Care services cannot be accurately measured with existing data

The only reliable cost data available is the total INAC contribution to First Nations. The actual costs of the specific services included under INAC's Adult Care program are lost among the other social and health services provided in First Nations communities and among the various funding sources. Prior to reaching any conclusions regarding the costs (and cost-effectiveness) of the Adult Care program, the total cost of a full slate of services must be determined.

b) The cost of First Nations Adult Care services cannot currently be compared to provincial services

A high degree of cooperation from provincial/territorial governments would be required to determine the cost of a set of services comparable to those offered in First Nations communities. Portfolios of services are not equivalent, definitions of levels of care are not directly comparable, and data are not uniformly collected or organized. Future consideration of the comparability of Indian and Northern Affairs Canada and provincial/territorial Adult Care spending and services will require extensive consultation and partnership.

c) There are alternatives to the per capita funding formulas for in-home and foster care

There is sufficient evidence to conclude that the alternative of needs-based funding, if based on rigorous client assessments and comprehensive monitoring, would be preferable to the per capita funding method. Such formulas do not recognize the regional and community variation in the factors that affect the demand for social and health care. For example, differences in things such as age distribution, mortality and morbidity rates, and geographic location can all have significant effects on a community's Adult Care needs. There is also a strong rationale for involving the provinces/territories in discussions of funding alternatives for social and health care in First Nations communities.

d) There are alternatives to INAC delivering the services included under the Adult Care Program

The in-home component of the Adult Care program is clearly a valuable and needed service. However, Health Canada's HCCP currently includes a similar home support component. If a client is receiving homemaking services from INAC and home nursing from HCCP, it makes sense to combine the services so that they may be provided in a single visit. With respect to institutional care, it is clear that INAC-funded facilities sometimes go beyond Types I and II care and deliver health care. The potential exists for serious difficulties when INAC-funded PCHs are providing care beyond their authorities, and alternate arrangements should be considered. One possibility is for on-reserve PCHs to be accredited through a federal body (such as the Canadian Council on Health Services Accreditation) and operate under Health Canada oversight. An alternative approach would require increased provincial/territorial involvement in on-reserve care, where PCHs would be funded (at least partially), licensed, and monitored by the province or territory.

Conclusions

Based on the results of this evaluation, the following issues should be considered:

1. Indian and Northern Affairs Canada needs to clarify the roles and responsibilities for delivering Adult Care in First Nations communities through discussions with Health Canada, provincial/territorial governments, and First Nations. Indian and Northern Affairs Canada and Health Canada might consider formally integrating the Adult Care and Home and Community Care programs to reflect the informal integration that has already taken place in many First Nations communities.

2. Indian and Northern Affairs Canada should develop a national policy for Adult Care services that provides standards for delivery while also recognizing varying regional and community needs.

3. Indian and Northern Affairs Canada should continue to play a lead role in ensuring that the unique Adult Care needs of First Nations communities are met.

4. Monitoring of Adult Care services must be increased to ensure compliance with current (and future) standards and policies, and to determine the total cost of delivering those services.

5. INAC should develop a performance measurement strategy that can identify Adult Care program outcomes and impacts at the community level.

Terms of Reference

Terms of Reference

Evaluation of Adult Care Services

Purpose: The purpose of the evaluation is to support the policy development work which is expected to result in recommendations to Cabinet for a new framework for the delivery of social programs on reserve. The Adult Care Program is a part of this framework. The evaluation will also allow the department to have baseline information to assess and monitor the success of eventual changes to program design and/or delivery.

Background: Under welfare programs and services, INAC delivers the Adult Care program. The Adult Care program provides an enhanced form of social assistance to Indians ordinarily resident on-reserve who are elderly or have a disability and need special help with daily living due to limited functionality. These services include institutional care, in-home care and foster care.

The department funds Adult Care services which are comparable in nature and level of service to those provided by the provinces and territories for social services. It operates under a Memorandum of Understanding with Health Canada which outlines which costs are social support costs, and which ones are medical costs supported by Health Canada or the respective province. The majority of institutional placements are in off-reserve institutions due to the limited number of on-reserve institutions. INAC funds First Nations to deliver programs for Adult Care through the funding agreements, except where individuals are in institutional care off-reserve, where generally INAC reimburses costs invoiced by the institutions themselves.

The expenditures for Adult Care in 2000-2001 were $74.8 million. Expenditures on Adult Care almost doubled in the four years after 1991, but since 1995 have been rising at about 4% per year.

Institutional care costs are calculated by per diems based on provincial and territorial rates. The per diem is a combined rate for personal care, room and board and special needs services. In-home care pays for the cost of the home maker or care provider. Foster care costs are based on a per diem based on the level of special services required by the individual. Foster care is a service for those individuals who do not require constant medical care but cannot live on their own due to physical or mental problems.

In 1988, INAC opted to cease funding services provided through new on-reserve Adult Care facilities until a federal policy is put in place addressing the “general welfare” type costs that cover Adult Care and which are

authorized by Treasury Board; provincial licensing of on-reserve institutions; and responsibility for costs related to medical care for patients in unlicensed personal care homes. In many cases INAC has been left to cover these costs, despite having no mandate to do so.

There are significant gaps between the level of care provided on-reserve by DIAND, Health Canada and the provinces / territories and the services provided by the provinces or territories to communities in similar circumstances. First Nations have expressed their concern on this issue, and the need for a comprehensive review of the on-reserve needs for a continuum of care for the elderly and people with disabilities. DIAND and Health Canada have begun work on an Adult Care policy that is expected to result in recommendations for Cabinet consideration by March 2003.

Scope: The evaluation will be conducted at headquarters and the Quebec, Manitoba and British Columbia Regions.

The evaluation will assess the current situation of the services and institutions supported by the Adult Care Program in order to establish a baseline from which to assess and monitor the success of eventual changes to program design and/or delivery. It will also focus on clarifying the jurisdictional and service delivery issues between DIAND and Health Canada and to determine the gaps that exist in services between the level of service being provided by the federal government and that of the provinces.

Issues: The evaluation will address the following issues:

<u>Rationale and relevance</u>: Are there clearly identified needs for Adult Care services? Are there service requirements unique to First Nations communities?

<u>Success</u>: Are the program's objectives met? Do adults receive services adapted to their needs? Are First Nations satisfied with the services?

<u>Cost-effectiveness</u>: What are the costs of providing Adult Care services? How do these costs compare with similar services provided by other jurisdictions? What are the alternatives to the current funding and/or service delivery configuration?

<u>Design and delivery</u>: What are the levels of Adult Care Services provided in each region? Is there a clear and workable division of roles and responsibilities between funding departments?

Approach: The evaluation will use multiple lines of evidence. It is planned to use program file reviews of administrative and financial data, case studies of institutions, focus groups in communities, and interviews with program managers in regions, interviews with provincial management and an analysis of information gathered.

The evaluation will include a planning phase which will define the methodology. The evaluation will be managed by DAEB in consultation with program representatives.

Timeframe: The evaluation will begin in January 2002. A draft report will be available in August 2002.

Approved:

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Socio-Economic Policy and Programming
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