A First Nations Continuing Care Policy Framework: An Intergenerational Perspective

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Transmittal

Attached please find the final version of the *First Nations Continuing Care Framework* developed in various drafts dated September 1998, December 1998, April 2002, May 2002 and October 2002. At the request of the AFN Social Development Secretariat this framework document was developed for the review of First Nation Continuing Care service representatives. This important issue has long been on the table and it is our vision that this framework will hopefully result in policy that will facilitate more effective and efficient programming for our precious resource – our children, our Elders and all First Nations individuals who require the services described herein.

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Note: The four main survey databases used to generate the statistics that appear in this Framework paper are the *Census of the Population* 1991 and 1996, the *Aboriginal Peoples Survey 1991*, the *Royal Commission on Aboriginal People's Report 1996*, and DIAND *Indian Register* Data and Demographics Data 1996

Limitations of the data are acknowledged as the Census undercounts for the "Aboriginal" population are a problem. This is because of incomplete enumeration of First Nation communities in both the 1991 and 1996 surveys. The 1996 Census does not include information on 77 First Nation reserves and settlements. In 1991, 78 reserves were not enumerated. Statistics Canada estimates that the size of the population effected by this problem might have been about 44,000. *Source: HRDC, In Unison 2000*

Further complicated is the fact that Aboriginal* population data is collected by Statistics Canada using definitions that include First Nation, Métis and Inuit populations. These data, therefore, are included in this document. Since there is limited data on need for continuing care these are provided to illustrate at least some of the need for First Nations and Inuit in Canada. For the purposes of the balance of this document First Nation will be used to encompass all such populations unless noted otherwise.

Purpose of the Document

The purpose of this document is to set out a framework of values, principles and guidelines for a continuing care program continuum of services and entitlements. Our goal is to provide direction for future activities related to program and policy development.

Continuing Care Defined

For the purposes of this framework the "*National Consultation on Continuing Care Needs in First Nation Communities*" (1994) definition for *continuing care* will be used herein: it is "a system of service delivery encompassing a range of insured, extended and uninsured health and social services *for all age groups*, addressing the holistic health, social and personal care needs of individuals who do not have, or have lost, some capacity for self-care. These *integrated services* are designed to improve individual functioning and provide culturally sensitive support and care in the community, where possible."

Adult Care, as a component of continuing care, is an integrated group of services designed to support and enhance the dignity and independence of persons with disabilities (mental or physical) and/or elderly adults to assist them to remain in their own community and thereby avoid dependency for as long as possible. These services may include such supports as meal preparation and house cleaning, adult day-care, foster care, and on-reserve institutional care in personal care homes, all designed to enhance the individual's functioning in their own community.

Background

According to the *United Nations International Plan of Action on Aging* para.25 (i)

> **"Ageing is a life-long process and should be recognized as such. Preparation of the entire population for the later stages of life *should be an integral part of social policies* and encompass physical, psychological, culture, religious, spiritual, economic, health and other factors."**

The concept of a society for all ages lends itself to the ideal of a society that accommodates itself to all. The society for all ages is a holistic concept of two dimensions: *lifelong and society-wide*. Moving towards a society for all ages will require policies that simultaneously facilitate individual development into late life, and strengthen enabling environments of family, neighborhood (community) and society at large.

The conceptual framework for a society for all ages was developed and introduced to Member States at the 54th session of the General Assembly of the United Nations in October 1992. Its key component maintains that investment in ageing can help to create a mutually enriching multigenerational society.

Individual development through the different stages of the life cycle requires both individual initiative and an enabling environment that is a process of interaction between the individual and society which can be mutually beneficial. At the individual level, this implies a combination of individual independence, while striving towards self-development through life-long education, upgrading of skills and healthy lifestyles. Society, therefore, must accord equal importance to the challenges of **each** stage of the life cycle.

Traditional self-preserving and society-preserving human characteristics are being challenged by current demographic trends and resulting societal changes. These are giving rise to a need for new intergenerational exchanges in the family, local community and (national) society, including the areas of care-giving, income security and cultural definition.

The family is the first and most intimate level of multi- generational relationship, where all tend to invest in one another and share in the fruits of that investment. This has been termed the "first resource and last resort" for its members. Families, however, are experiencing demographic, cultural and socio-economic changes with implications for intra-familial relationships, including care-giving. The changes both challenge and bring opportunities to multi- generational relationships (Source: UN/Division for Social Policy and Development).

Communities can facilitate multi-generational relationships, both within neighborhoods and between special interest groups. Though undergoing change, the neighborhood community is usually age-integrated, making interactions between its younger and older members a matter of daily routine. Communities of special interest, such as organizations of Elders or youth, can establish new relationships in addressing community concerns such as safety, environmental protection, cultural enrichment, income-generation and others. Communities can also facilitate communications between younger and older members as a matter of daily routine. At the national level, many developed countries are currently revising multi-generational exchanges, including the provision of social insurance and pensions, underscoring the importance for countries to develop their own appropriate national-level exchanges between the generations to ensure multi-generational consensus within society.

In the United Nations a/Res/47/5 *Proclamation on Ageing* the General Assembly states:

> "Noting the unprecedented ageing of populations taking place throughout the world; ..... "
>
> "Conscious that the ageing of the world's population represents an unparalleled, but urgent, policy and programme challenge to Governments, non-governmental organizations and private groups to ensure that the needs of the aged and their human resource potential are adequately addressed....."
>
> "Aware that a revolutionary change in the demographic structure of societies requires a fundamental change in the way in which societies organize their affairs,..."
>
> "Recognizing that ageing is a life-long process and that preparation for old age **must begin in childhood and continue throughout the life cycle;....."**
>
> "**Recognizing further that with increasing age some individuals will need comprehensive community and family care**, ..."

Urges the international community:

> "To provide the immense human and material resources now urgently needed for adjustments to humanity's coming of age, which can be understood as a demographic phenomenon, but also as a social, economic and cultural one of great promise; ....."

Also urges the support of national initiatives on ageing in the context of national cultures and conditions, so that:

> "Families are supported in providing care and all family members are encouraged to cooperate in caregiving; ....."
>
> "Local authorities cooperate with older persons, businesses, civic associations and others in exploring new ways of maintaining age integration in family and community; ..."

In summary, this framework holds as its basic principle that our children, our Elders, and all First Nations community members have the right to access adequate food, water, shelter, clothing and health care through the provision of income, family and community support and self-help (*excerpt from the United Nations Principles for Older Persons).*

- They should also be able to live in environments that are safe and adaptable to personal preferences and changing capacities...
- They should be able to reside at home for as long as possible
- They should also be able to have access to health care to help them to maintain or regain the optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness ....
- They should benefit from family and community care and protection in accordance with each society's system of cultural values...
- They should have access to social and legal services to enhance their autonomy, protection and care....
- They should be able to utilize appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment...
- They should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives (excerpted from the United Nations Principles for Older Persons).

A First Nations Inter-Generational Perspective

In First Nation societies Elders are viewed as older members of the community who are seen as counselors, guides and resources for the ones still finding their way along life's path. They play a critical role in the retention, renewal and celebration of First Nation language, culture and tradition. As a result they must be treasured and treated with dignity and care as they age.

Traditional societies were founded on reciprocal relationships. *Respect and responsibility* – to one's self, the community and the Creator. These are fundamental values that held our societies together. They were the bond that transformed a collection of people into a community. *People cared for each other*. Everyone had a role.

> *The Elders were there as a man and a woman to guide the society using the accumulated wisdom from a long life. The youth presented the hope and*

aspirations of a culture who learned by sense and imitation. The woman held the central and most honored role as the bearer of life and man held the envious role of the protector, to preserve and maintain the continuity of the family unit (RCAP vol. 4 p. 135). Daily activities, ceremonies, rituals and traditions strengthened these roles and fostered a strong sense of community and family.

Today First Nation communities no longer see a place where everyone has a role. Traditions have been eroded, and the values that once bound society and families together have been lost or abandoned. There is no harmony; the circle has been broken. Instead there is unemployment, welfare, poverty, substance abuse, violence within families, economic instability, suicide and disability.

The majority of First Nation continuing care programs serve Elders, however, they are not the only individuals who receive services. There are also First Nation persons with disabilities or chronic diseases, representing all ages who are served by these programs. Continuing care programming, therefore, must provide adequate resources to address this reality. This framework is based on this premise.

The Demand for First Nations Continuing Care

There is a critical need for quality and adequately resourced continuing care services. The demand for institutional care and related continuing care services for First Nations will grow rapidly over the next several decades due to increases in the number of First Nation members aged 55 and older over the next 25 years. The 55-64 year age group will increase by 236% and 65+ age group by 229% in this period. Life expectancy of First Nations males will increase from 59.2 to about 72 years by 2010 and from 65.9 to 79 years for First Nations females. There will be *57,000 more* First Nations members aged 65 and older in 2021.

This trend is consistent with the world's current demographic revolution, by the way, which is predicted to continue well into the coming centuries. One out of every ten persons in the world is now 60 years or above; by 2050, one out of five will be 60 years or older; and by 2150, one out of three persons will be 60 years or older (source: the U.N. Gateway to Social Policy and Development). The older population itself is also ageing. The oldest old (80 years or older) is the fastest growing segment of the older population. They currently make up 11 percent of the 60+ age group and will grow to 19 percent by 2050. The number of centenarians (aged 100 years or older) is projected to increase 15 fold from approximately 145,000 in 1999 to 2.2 million by 2050.

Increasing prevalence of chronic illness that limit independent living for First Nation community members will increase from 16% (1996) to 27% in 2016 for diabetes, for

example. Based on population and morbidity trends, it is probable that there will be a demand for approximately 2,000 to 2,250 Types 1 and 2 beds by 2011 and approximately 3,000 to 4,000 by 2021. Existing capacity is about *700 beds*. The demand for Levels/Types 3, 4 and 5 beds may be as high as 2,700 beds by 2011 and 4,500 beds by the year 2021.

In addition to chronic illness, in Canada, First Nation populations with disabilities resulting from injuries represent the highest rates of injured *than any other racial group in the country*. Canada is suffering an injury epidemic and in Aboriginal communities the epidemic is even more staggering.

In First Nation communities, injury is the leading cause of death for people under the age of 45 (Health Canada 2001). As well as being a major cause of death, injuries tend to kill at comparatively young ages. The biggest causes of injury death are motor vehicle accidents, suicide and accidental drug poisoning (2001). Injury death rates in First Nations communities are *far higher for men than for women*. First Nations people die from the *same types of injuries* as other Canadians *but the rates are much higher*. The age pattern is also similar in that in both cases, *people age 15-24 are at highest risk* (2001). Of those individuals who survive their injuries many are often permanently disabled and require home or institutional care for the rest of their lives. The staggering statistics are illustrated below in Table 1.0

Table 1.0
A Comparison of Injury Rates (Death per 100,000) by Cause and Age Group First Nations, 1989-1993

Age Group	Motor Vehicle	Suicide	Other	Fire	Drown-ing	Falls	Poison/OD	Fire-arms
Age 0-1Years	5.2	0	43	15.5	3.4	6.9	1.7	0
Age 1-14 Years	14.3	4.2	5.6	9.3	9.6	0.6	1.4	2
Age 15-24 Years	62.2	80.7	19.9	7.4	9.3	1.9	10.7	4
Age 25-44 Years	55.6	40.9	21.3	9.3	15.2	4.2	27.5	1.1
Age 45-64 Years	56.2	19	38.9	10.9	19	10.4	25.8	3.2
Age 65+ Years	50.5	12.8	42.7	16.8	7.8	56.9	12.9	1.3

* Death per 100,000 population
** Note: OD = overdose
Note: Other category = suffocation, exposure, homicide, industrial accident and aircraft

crash

Source: Health Canada Medical Services Branch In-house Statistics

According to the 1991 *Aboriginal People's Survey* 39% of the respondents reported that family violence was a concern in their community. Suicide rates in First Nation communities tend to be highest among youth aged 15-24 and to diminish gradually at older ages. Rates of *completed* suicide are typically *3 times higher* in First Nation males than females. However, *it is generally the case that far more women than men attempt suicide*. One major fallout of injuries is the resulting disabilities. According to the 1991 *Aboriginal People's Survey* 31 per cent of Aboriginal adults have some form of disability - this is twice the average of the general Canadian population.

Specific policies and social reform is required to address the *essential rights of people with disabilities resulting from injuries, to live a life of independence and dignity.* As users of continuing care services 100% of the target population for these services has a *disability* of one sort or another. According to the First Nation and Inuit Regional Health Survey, disability is defined as a *measure of difficulty in performing an activity in a manner or within the range considered normal for human beings*. This refers to *impairments* of *mobility, sensory and intellectually "deficit" or abnormalities of psychological, physiological or anatomical structure or function*. Thus impairments or "health problems" is something that presents difficulty for a person doing activities at home or in a community environment.

Disability may be considered a specific medical condition or a *disadvantage* in certain situations. Disabilities are considered on a continuum beginning with an underlying cause, which typically may be a *disease or trauma* (HRDC 1994). One in six Canadians and one in three Aboriginal people in Canada have a disability. The disability rate among young adults is almost three times higher for Aboriginal people than for non-Aboriginal people. Disabilities affecting mobility and agility are most common, but hearing and visual disabilities affecting a large portion of the Aboriginal population is also prevalent. Sixty-six per cent of Aboriginal adults with disabilities are affected by a mild disability; 22 per cent by a moderate disability; and 12 per cent by a severe disability.

The First Nations and Inuit Regional Health Survey (FNIRHS) (1997), found that approximately 50% of respondents aged 65 years or older had arthritis/rheumatism and high blood pressure and approximately 30% were affected by diabetes, heart and lung conditions. In addition, analysis of Department of Indian Affairs and Northern Development (DIAND) on reserve population statistics indicates an increasing number of elderly First Nations are returning to their home communities. As a result of these trends, the demand for all continuing care services is expected to increase sharply over the short and long-term.

The increasing demand for continuing care services is, in fact, consistent with general international, national and provincial trends. Over the last two decades, health care costs for the Canadian population have increased steadily and, in most provinces the health care budget represents the single largest expenditure. In response, most provinces have instituted various reform measures to control health care spending, including hospital closures and an increased emphasis on community and home-based programs and services. The following tables indicate the demand for continuing care from a First Nation perspective.

Table 1.1 indicates the population of First Nation people with disabilities by region from DIAND's *Indian Register*.

Table 1.1
Population of First Nation People with Disabilities by Region

Region	Population *	People with Disabilities**
Yukon	7,199	2,260
Northwest Territories	13,998	4,395
British Columbia	102,075	32,052
Alberta	76,419	23,999
Saskatchewan	94,953	23,815
Manitoba	95,113	29,865
Ontario	138,518	43,495
Quebec	58,640	18,415
NB-PEI	18,857	5,912
NS-NFLD/Labrador	20,834	6,542
TOTAL	626,606	190,748

*Note: *Population Source: Indian Register Population by Region INAC December 31, 1997*
***Disability Rate of 31.4% for Aboriginal People data source: Statistics Canada*

The disability rate as indicated above indicates a 31.4 percentage of the total registered First Nation population amounting to 190,748 individuals. The largest number of First Nation persons with disabilities are in Ontario (43,495), British Columbia (32,052) and Manitoba (29,495) followed by Saskatchewan (23,815), Alberta (23,999) and Quebec (18,415) respectively.

Table 1.2 indicates the total number of adults aged 15+ who responded to the disability question on the *Aboriginal Peoples Survey* (1991). The total *Aboriginal identity* respondents for Canada, the provinces and territories, who responded to

the question was 373,785 with 117,090 reporting a disability. The total respondents reporting a disability on and off reserve of *North American Indian identity* was 87,210.

Table 1.2
Total Number of Adults Aged 15+ who Responded to the Disability Question on the Aboriginal Peoples Survey 1991

# of Respondents	Total Aboriginal Identity: Canada , Provinces, Territories	Total North American Indian on and off reserve	Total North American Indian – on reserve	Total North American Indian – off reserve	Metis	Inuit
# of adults 15+ who responded to the disability question	373,785	277,650	100,400	177,210	81,650	18,805
# of adults who reported disability(ies)	117,090	87,210	33,155	54,055	26,030	5,445
Percentage	**31.3**	**31.4**	**33.0**	**30.5**	**31.8**	**28.9**

Source: APS Statistics Canada 1991 1-Disability 2- Housing

Table 1.3
Disability Rates among Aboriginal* adults who report Disability by Age Aboriginal People Survey 1991

Age Group	Total Aboriginal Identity: Canada , Provinces, Territories	Total North American Indian on and off reserve	Total North American Indian – on reserve	Total North American Indian – off reserve	Metis	Inuit
Total # who report a disability	117,090	87,210	33,155	54,055	26,030	5,445
15 + years (%)	31.3	31.4	33.0	30.5	31.9	29.0
15-24 (%)	21.7	21.7	21.7	21.7	21.9	21.0
25-34 (%)	23.6	23.7	23.3	23.9	23.1	23.2
35-54 (%)	25.5	35.4	35.5	35.3	37.2	33.3
55 yrs. plus (%)	66.5	66.4	70.1	63.3	68.1	62.5

Source: APS Statistics Canada 1991 1-Disability 2- Housing

As illustrated in Table 1.3 for the percentage of adults who report disability by age: **as age increases the incidence of disability also increases** in all Aboriginal population categories. For example, of the individuals reporting a disability at age 15-24 for the total Aboriginal population the rate was 21.7% compared to those age 55+ where the incidence of reported disability increased to 66.5%. This was the case across all population categories with the highest percentage reported by the Métis at 68.1% and *North American Indians* **on-reserve at 70.1%.**

Table 1.4
Number of Aboriginal* Adults Age 15+ who Report a Disability
By Nature of Disability
APS 1991

Nature of Disability	Total Aboriginal Identity: Canada , Provinces, Territories	Total North American Indian on and off reserve	Total North American Indian – on reserve	Total North American Indian – off reserve	Metis	Inuit
Mobility disability	52,430	39,735	15,520	24,215	11,505	1,940
%	44.8	45.6	46.8	44.7	44.1	35.6
Agility Disability	41,335	30,665	11,195	19,465	9,925	1,430
%	35.3	35.1	33.7	36.0	38.1	26.2
Seeing Disability	28,560	21,865	10,555	11,310	5,745	1,310
%	24.2	25.0	31.8	20.9	22.0	24.1
Hearing	41,135	30,450	12,820	17,625	8,735	2,395
%	35.1	34.9	38.6	14.1	33.5	43.9
Speaking Disability	15,080	11,475	4,500	6,975	3,365	525
%	12.8	13.1	13.6	12.9	12.9	9.6
Other Disability	42,530	31,990	12,245	19,750	9,140	1,980
%	36.3	36.6	36.9	36.5	35.1	36.3

Source: APS Statistics Canada 1991 1-Disability 2- Housing

Table 1.5
Persons with Disabilities Among the Adult (15+) Population Reporting Aboriginal* Identity for Canada, Provinces and Territories (APS 1991) by Level of Severity

Severity of Disability	Total Aboriginal Identity: Canada , Provinces, Territories	Total North American Indian on and off reserve	Total North American Indian – on reserve	Total North American Indian – off reserve	Metis	Inuit
Mild	77,005	57,090	21,415	36,675	16,930	4,055
%	65.8	65.5	64.5	67.8	65.0	74.5
Moderate	26,065	19,365	7,195	12,170	6,000	975
%	22.3	22.2	21.7	22.5	23.0	17.9
Severe	14,020	10,760	4,545	6,120	3,095	415
%	11.9	12.3	13.7	11.3	11.9	7.6

Source: APS Statistics Canada 1991 1-Disability 2- Housing

Table 1.6
Managing Everyday Activities Persons with Disabilities (age 15+) Population Reporting Aboriginal Identity (APS 1991)
N=117,000

Number of Adults who	Total Number of Adults who Need Help	Number of Adults Getting Help	Getting help from family member	Getting help from friend or neighbor	Getting help from someone else
Need help preparing meals	8,770	8,325	6,995	1,895	2,220
Shopping for groceries	17,775	16,755	14,795	4,905	3,145
Everyday housework	19,430	17,070	14,365	3,865	4,320
Heavy household chores	37,560	32,740	28,345	10,005	6,295
Personal Finances	11,865	10,485	8,805	1,970	1,810
Personal Care	5,350	4,895	3,690	810	1,695
Moving about within Residence	4,045	3,710	3,300	1,050	850

Source: APS Statistics Canada 1991 1-Disability 2- Housing

Table 1.7
Managing Everyday Activities Persons with Disabilities (age 15+) Population Reporting North American Indian Identity Living on and Off Reserves and Settlements (APS 1991) N=87,210

Number of Adults who	Total Number of Adults who Need Help	Number of Adults Getting Help	Getting help from family member	Getting help from friend or neighbor	Getting help from someone else
Need help preparing meals	6,920	6,565	5,730	1,565	1,625
Shopping for groceries	13,555	12,735	11,320	3,645	2,375
Everyday housework	14,920	13,200	11,090	3,035	3,425
Heavy household chores	28,015	24,525	21,270	7,535	4,615
Personal Finances	9,070	7,940	6,725	1,560	1,185
Personal Care	4,150	3,765	2,065	690	1,170
Moving about within Residence	3,145	2,885	2,600	780	655

Source: APS Statistics Canada 1991 1-Disability 2- Housing

Table 1.8
Managing Everyday Activities Persons with Disabilities (age 15+) Population Reporting North American Indian Identity Living on Reserves and Settlements (APS 1991) N=33,155

Number of Adults who	Total Number of Adults who Need Help	Number of Adults Getting Help	Getting help from family member	Getting help from friend or neighbor	Getting help from someone else
Need help preparing meals	3,020	2,765	2,475	755	780
Shopping for groceries	5,320	4,960	4,575	1,480	935
Everyday housework	6,725	6,045	5,180	1,480	1,865
Heavy household chores	10,815	9,385	8,380	3,050	1,870
Personal Finances	4,005	3,575	3,230	775	435
Personal Care	1,850	1,680	1,480	430	490
Moving about within Residence	1,540	1,440	1,340	430	325

Source: APS Statistics Canada 1991 1-Disability 2- Housing

Table 1.9

Specialized Features Required To Enter, Leave Or Move About Residence
An Aboriginal* Comparison
(Source: APS 1991)

Number of Adults who Require Specialized Features	Total Aboriginal Identity: Canada, Provinces, Territories	Total North American Indian on and off reserve	Total North American Indian – on reserve	Total North American Indian – off reserve	Metis	Inuit
Access ramps or ground level entrance	2,900	2,265	1,105	1,160	550	85
Widened doorways	1,120	820	375	445	285	-
Elevator or lift device	690	445	110	335	235	-
Total	3,425	2,725	1,310	1,420	600	105

Source: Aboriginal Peoples Survey Statistics Canada 1991

Table 1.10
Total Aboriginal Population Who Stated That They Had Difficulty Making Short Trips And That They Were Unable To Leave Their Residence
Source: APS 1991

Aboriginal Population as Compared to Canada's total Population	Difficulty Making Short Trips Under 80km or 50 km	%	Unable to Leave their Residence	%
Aboriginal	11,160	10%	3,255	29%
North American Indian	8,460	10%	2,550	30%
North American Indian on-reserve	3,275	10%	1,160	20%
North American Indian off-reserve	5,185	10%	1,390	27%
Metis	2,275	9%	580	25%
Inuit	600	11%	195	3%
Canada		12%		41%

Source: Aboriginal Peoples Survey Statistics Canada 1991

Table 1.11
Total Aboriginal Population Who Stated That They Required Travel

Adaptations to Leave Their Residence for short and long trips
Source: APS 1991

Travel Adaptations Required	Total Aboriginal Identity: Canada, Provinces, Territories	Total North American Indian on and off reserve	Total North American Indian – on reserve	Total North American Indian – off reserve	Metis	Inuit
Adults who require an attendant or companion on short trips	14,710	11,515	5,155	6,360	2,825	575
Adults who are unable to take long trips – 80km or 50 miles or more	14,085	10,325	4,040	6,285	3,180	715

Source: Aboriginal Peoples Survey Statistics Canada 1991

Table 1.12
Disability Rate by Age Group, Aboriginal People 1991

Age Group	Aboriginal People	Canada
15-34 yrs	23%	8%
35-54 yrs	36%	14%
55 yrs +	66%	53%

Source: In Unison/APS 1991 and HALS 1991

Research undertaken by the DIAND/Health Canada Joint Working Group on First Nations and Inuit Continuing Care found that in Saskatchewan, the home care budget as a percentage of the total provincial health budget had increased from 2.0% in 1991/92 to 4.2% in 1996/97. In Ontario, spending on home care programs also increased from $450 million in 1991/92 to $794 million in 1996/97 with a corresponding increase in utilization. This represents a 57% increase in expenditures in this six year period.[1] However, as we have seen illustrated in the tables previously these increases are **inadequate** to meet the needs of our First Nations community members who require continuing care services **now and in the future**. Because of jurisdictional issues, these home care increases were in many instances not even directed to First Nations, especially in Saskatchewan.

Increases in provincial home care and other community-based services were achieved by shifting existing resources from other health service sectors to community and home-based service sectors. The development of this community-based capacity to meet these changes in health care delivery is to support the goal of '*the right care, in the right place at the right time*'. All of the existing health care resources - facilities, personnel, programs and services - are being restructured to realize this goal. This is a transitional period for the health system, both on and off-reserve.

As a result of these significant provincial health care reforms there is significant pressure on First Nation systems to respond to this shift to home-based services. It needs to be noted that First Nations communities do not have resources to shift "from other health service sectors," as has been done by the provinces. Also, integration of resources that are i**nadequate** simply results in **ineffective** programs.

PROGRAM DESCRIPTIONS

DIAND Adult Care Program

The purpose of the DIAND adult care program (from a social/ mandate perspective) is to assist First Nations people with functional limitations (because of age, health problems or disability*), to maintain their independence, to maximize their level of functioning, and to live in conditions of health and safety*. There are three components to the Adult Care program:

- ***In-home care*** *- which provides homemaker services*

[1]National Framework - First Nations and Inuit Home Care (December, 1998)

- ***Foster care*** *- which provides supervision and care in a family setting*

- ***Institutional care*** *- which provides services in Types I and II institutions.*

This program was set out in a *1984 Memorandum of Understanding* between DIAND and Health Canada which established areas of responsibility for each department. Although DIAND provides funding for institutional care, in 1988 a moratorium was placed on new construction of on-reserve personal care homes, placing a greater emphasis on in-home care (Source: DIAND 2002 www.ainc-inac.gc.ca).

The Adult Care program primarily services the needs of First Nations Elders. In 1997-98 the program assisted approximately 700 First Nations people residing in institutions located on- and off-reserve and provided in-home care for about 5,100 individuals in their communities. The total budget for the DIAND Adult Care program was $30 million in its first year and is now $75 million with approximately $15 million for institutional care and $60 million for home care.

Adult care services are provided to registered First Nation individuals living on-reserve who have functional limitations because of age, health problems or disability and who require care. The program is administered by First Nations officers who assess the financial and social needs of the client (Source: http://www.ainc-inac.gc.ca/ps/acp_e.html).

Health Canada
First Nations and Inuit Home and Community Care Program

The purpose of the Health Canada FNIHCC program (from a health/medical mandate perspective) is *to provide home and community care services to people in the home. Home and community care services are provided to people based on needs identified through a client assessment to help people keep their independence in their own home and allow them to be close to their loved ones as long as possible. Services are provided in a holistic manner that looks at the person's physical, social, spiritual and emotional needs because each person is different and unique.*

Some of the essential elements of the home and community care program

- ***Client assessment*** *– through physical check ups, review of health histories, talking with family and doctor*

- ***Case management*** *– by ensuring that the care plan is right for the client*

- ***Home care nursing*** *– nursing care in the home or community by professional care givers and by teaching the family to help care for the*

client

- ***Personal care*** *– help with bathing, foot care and getting dressed*
- ***Home support*** *– help with light housekeeping, laundry and meal preparation*
- ***In-home respite services*** *– "care for the client while the family has a rest."* (Source: www.hc-sc.gc.ca)

According to Health Canada 667/697 communities were funded for Program developmental activities. Eighty six percent completed a program needs assessment, 79% submitted service delivery plans, 51% of the eligible communities had access to services impacting *282,057 First Nations and Inuit of all ages*. Also, according to Health Canada 34/35 of eligible Inuit communities are now in service delivery (Source: Health Canada 2002). The total budget for the First Nations and Inuit Home and Community Care Program was approximately $90 million in 2001-2002.

Eligible recipients for this program are:

- First Nations and Inuit of any age; and
- Who live on a First Nations reserve, Inuit settlement or First Nations community North of 60; and
- Who have undergone a formal assessment of their continuing care service needs and have been assessed to require one or more of the essential services; and
- Who have access to services which can be provided with reasonable safety to the client and caregiver, within established standards, policies and regulations for service practice

Source: http://www.hc-sc.gc.ca/fnihb/phcph/fnihccp/steering_committee/index.htm

Historical Overview of Activities

A variety of efforts have been made over the past several years to effect national policy regarding First Nations continuing care services. The following is a chronology of events:

- **In 1987**, an adult care inventory analysis was completed by DIAND. Due to lack of data to substantiate needs and the absence of a comprehensive program policy and authorities, DIAND declined to expand adult care activities at that time and instead proposed to develop a model for continuing care delivery with Health Canada (MSB/FNIHB).

- **In 1988**, a moratorium was imposed on the construction and operation of new on-reserve residential care facilities. DIAND did, however, increase the availability of homemaking resources.

- **In 1989** a joint Health Canada/DIAND adult care working group was established to support the development of a comprehensive community-based continuing care program. The Working Group 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."*

- **In 1991** as part of the National Strategy for *the Integration of Persons with Disabilities,* the following recommendations were made:

  - ➔ *Comprehensive continuing care services should be established which would include assessment, single source entry, case management and evaluation;*

  - ➔ *Health Canada (MSB/FNIHB) should be given the mandate and resources to provide home nursing care;*

  - ➔ *One federal department should take sole responsibility for the delivery of services in this area;*

  - ➔ *Case managed funding options should be developed which recognize regional and community diversity; and*

  - ➔ *Improved training and development programs and resources should be established*

- In its report *"National Summary: First Nations Continuing Care Services and Issues, **May 16, 1997**"* the DIAND/Health Canada Joint Working Group on First Nations Continuing Care noted that:

  - ➔ *A significant number of First Nations were providing basic housekeeping and homemaking services under band or Tribal Council administration. However, related services such as personal care, respite care, meals on wheels and volunteer services were not provided in most communities. Case management, comprehensive client needs assessments, liaison with acute care facilities and coordinated discharge planning were very underdeveloped*

in almost all regions. In some regions, the provinces were providing some home care services on-reserve.

➔ *In **1996,** there were approximately 15 on-reserve institutional care facilities across the country, serving approximately 300 clients. Despite the moratorium, some First Nations continued to develop personal care homes (PCHs) using other funding sources and arrangements. As a result of ongoing jurisdictional debates between the federal and provincial government, DIAND and Health Canada (MSB/FNIHB) do not have the capacity to license and monitor personal care institutions established on-reserve. Provincial authorities, who have the jurisdiction for the licensing and monitoring of on-reserve personal care facilities, will not, in most cases, accept the responsibility to do so.*

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

➔ *A limited number of home care nursing services are available, generally using funding under Building Healthy Communities Program, which gave Health Canada (MSB/FNIHB) the mandate for home nursing services. In some cases, these services include palliative care, case management and some aspects of personal care. Most regions agreed that existing services in this area are inadequate to meet current demand.*

➔ *Most regions were in agreement that, under the current continuing care directives and practices of DIAND and Health Canada (MSB/FNIHB), the majority of on-reserve First Nations clients do not have access to the same scope and quality of home care services as those offered by provincial programs.*

➔ *And most significantly, all regions agreed that current funding levels were inadequate to meet the current needs of on-reserve First Nations clients.*

♦ **In 1997** the Royal Commission on Aboriginal Peoples (RCAP) report was released. It provided volumes of information about the cultural, economic, education, health and social well being of Aboriginal people in Canada. This report included major sections on the great importance of a new Aboriginal health and healing strategy. It emphasized that to be effective the strategy must place a major emphasis on, not only the individual, but also on the *Aboriginal family and community systems*. The importance of an Aboriginal health strategy that is *grounded in a holistic approach, and supported by a human resource strategy*

which includes social housing and cultural renewal was also a major theme of the final RCAP report (Volume 3).

- **In January 1998** the federal government announced Gathering Strength - Canada's Aboriginal Action Plan which encompassed 4 principles: *Renewing the Partnership, Recognizing and Strengthening First Nations Governments, Equitable and Sustainable Fiscal Relationships and Supporting Stronger First Nations Communities And People.*

- **June 1998 to November 1998**, a Joint HC/DIAND/AFN/ITC working group was established to develop Phase I of the Continuing Care Framework. Also, in 1998 the First National Home Care conference was held in Halifax, Nova Scotia. At this conference many issues around service delivery, policy development, information gaps and resources requirements were highlighted and recommendations for change and action made. These issues were acknowledged by the Minister of Health in a speech he gave at the conference where he stated: *" I am responsible for the Medical Services Branch in my department and while we provide excellent services, we have a long way to go before we meet our responsibility of funding home and community care... in First Nations and Inuit communities."*

- **In 1999** the First Nation and Inuit Home and Community Care Program was announced and became fully operational in all regions within the next two years. It provides the nursing and personal care component of home care, building on DIAND's in-home support service. These services are provided mainly by RNs, LPNs and certified home health aides or personal care workers at the community level. The home health aides and personal care workers are supervised/supported by registered nurses.

- **Over 2000-2001** DIAND and Health Canada have continued to respond to Adult Care/Continuing Care issues through four streams of activity to:

  - ➔ Continue to work with Health Canada to identify and develop a national approach aimed at achieving a *single-window delivery system* that covers the full spectrum of care.

  - ➔ Participate in the joint working group on Continuing Care as it develops the Institutional Care framework, and oversee the conduct of research to help inform the development of the framework.

  - ➔ Participate as a member of *the Health Transition Fund Steering Committee* (sic) to ensure successful evaluation of the home care pilot projects

➔ Participate as a member of the National Joint Steering Committee, National Technical Advisory Committee (sic), in the planning and development of the First Nations and Inuit Home and Community Care Program. Source: http://www.hc-sc.gc.ca/fnihb/phcph/fnihccp/steering_committee/index.htm

Guiding Principles and Framework

The following guiding principles for continuing care form the basis for the development and implementation of this framework (source: *"A National Framework on Continuing Care Phase I (1998)."**

The Framework

The Vision

In recognition of the need for First Nations controlled and culturally appropriate, integrated continuing care services - continuing care services must be:

- *Appropriate to the unique health and social and cultural needs of First Nations defined communities.*
- *Facilitate First Nations control at a time and pace of their choosing.*
- *Contribute to capacity building of the First Nations.*
- *Promote sustainability.*
- *Recognize the on-going fiduciary relationships between the Crown and First Nations.*

Transparency and Trust

First Nations, Health Canada and DIAND will work together to create an atmosphere of trust, equity, cooperation, respect and transparency. Through a joint partnership approach this framework will guide options for the delivery of continuing care by First Nations.

Objectives

The development of this framework takes into consideration the principles of *Gathering Strength* as outlined below:

- ***Renewing the Partnership*** - through the establishment of mechanisms to recognize First Nations as governments and as partners working together with the federal government to jointly identify and address priorities, using initiatives such as the *Statement of Reconciliation,* renewed Treaty relationships, new mechanisms for decision-making, healing programs and other initiatives.

- ***Recognizing and Strengthening First Nations Governments*** - to support capacity development for implementing self-government with the legitimacy, powers and resources for effective governance over their members and territories.

- ***Equitable and Sustainable Fiscal Relationships*** - to support First Nations governments in developing fiscal autonomy and the financial capacity to support governance responsibilities and public services at levels reasonably comparable to the relevant local, regional or national standard.

- ***Supporting Stronger First Nations Communities and People*** - to support healthy sustainable communities, enhance economic development and increase individual and community self-reliance through initiatives such as developing an economic base, investing in Aboriginal training and education, investing in the well-being of children and families and addressing key health and disease concerns.

Guiding Principles

The following guiding principles for continuing care form the basis for the development and implementation of this framework (Source: A National Framework on Continuing Care Phase I (1998).

- ***Provision of care for the Elders and other vulnerable people****:* This is a fundamental value of First Nation people.

- ***Respect and maintenance of the trust and fiduciary relationship****:* Nothing in this framework will prejudice or jeopardize the trust and fiduciary relationship that exists between the Government of Canada and First Nations.

- ***Clear mandates and authorities for service components of continuing***

care: Within the various federal departments which hold responsibilities for service provision to First Nation people, greater inter-sectoral collaboration will occur.

- ***Quality assurance supported by clear standards of practice and care:*** All processes defined within the program framework will meet standards of practice, educational and training standards, occupational health and safety practices and care outcomes that meet quality control indicators defined by First Nations

- ***Community-based and community-paced planning:*** The planning and development of continuing care services will be responsive to the needs and priorities of communities.

- ***Care and/or service based on assessed need:*** An assessment process will be carried out with the client and family which will result in the development of a care plan that is delivered within a case management and/or coordinated environment. Clients and their families are involved in the decisions that influence their health care choices and maximizes the autonomy and independence of individuals.

- ***Single and/or coordinated point of entry:*** The organizational structure of continuing care is based on seamless access to services that are planned and delivered through a collaborative and integrated approach supported by team work.

- ***Continuing Care services are part of health and social system:*** Communities will be enabled to plan, develop services and set priorities for effective continuing care through additional resources, networking and building linkages with other programs and services.

- ***Equitable and effective services equivalent to those received by the general population:*** Ongoing evaluation and monitoring systems will be developed by the First Nation for continuing care. Systems developed will need to enable comparisons of equity, effectiveness and equivalency of continuing care services with those received by the general population.

- ***Supportive to family and community involvement:*** Client and family perspectives are valued by the staff providing services within this continuing care framework and are integrated into care plans. The ongoing and traditional role of the family and community will be enhanced not replaced by the continuing care services provided. Both services and the care

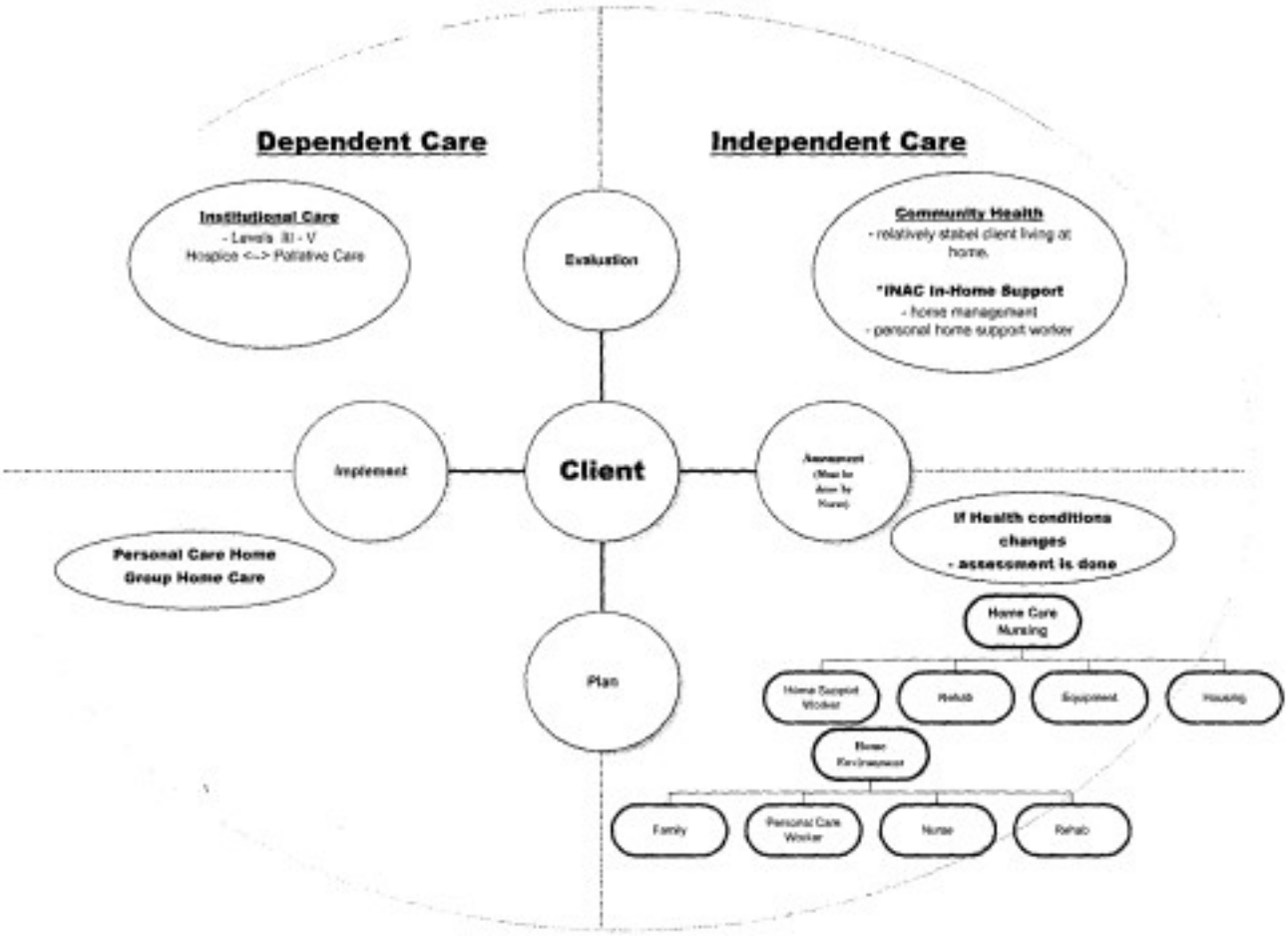
environment will be supportive to informal care givers, families and volunteers.

- ***Respects traditional and contemporary First Nation approaches to healing and wellness:*** Traditional and contemporary approaches as determined by the client, family and community will be valued and respected in the delivery of care and services.

- ***Recognizes and develops on-going need for capacity building:*** Human resource development that incorporates standards and scope of practice, quality care, ongoing training needs and occupational health and safety standards is essential to the development and delivery of a home care program that is effective and safe. Capacity building must also include the necessary infrastructure development to facilitate accessible care within a safe environment.

*Drafted by the Health Canada/DIAND/First Nations/Inuit Joint Working Group on the Development of a Continuing Care Framework December 1998.

THE FRAMEWORK VISION – GRAPHIC
An First Nations Continuum of Care



Services and Definitions Included in this Framework

The following definitions represent a range of services which may be included in a continuing care system based on the input of experts from across Canada.

Table 2.1
Core Community based, Residential Services and Other Services Definition Table

CORE COMMUNITY BASED SERVICES
Assessment and Case Management – constitutes a process of screening clients, conducting assessments, determining care needs, determining eligibility, making referrals to appropriate services, admitting clients into services(s) and providing for the ongoing monitoring of care requirements, including the revision of care plans and discharge planning. Assessors/case managers may also conduct financial assessments, act as client advocates in facilitating care provision and manage facility waiting lists.
Meal Programs are generally voluntary community services that deliver a nutritious, hot or frozen meal to the homebound client (meals-on-wheels) or bring the client to a congregate setting to have a meal (wheels-to-meals). The goal of meal programs is to supplement a client's diet by delivering an attractive nourishing meal to help maintain or improve health. Governments may pay for some of the costs of this program, e.g. cost of meals, transportation subsidy.
Home Support Services are provided to clients who require non-professional (lay) personal assistance with care needs or with essential housekeeping tasks. Personal care needs may include help with dressing, bathing, grooming and transferring, whereas housekeeping tasks might include activities such as cleaning, laundry, meal preparation, and other household tasks. Home Support workers may have post-secondary training to the same level as aids and care attendants and may provide similar types of personal care services. Specific nursing and rehabilitation tasks may also be delegated to homemakers. Home Support can also be provided as a respite service.
Home Care Nursing provides comprehensive nursing care to people in their homes, generally by registered or psychiatric nurses. A home care nursing program coordinates a continuum of nursing services designed to support clients of all ages to remain in their homes during an acute, chronic or terminal illness. This community based program provides nursing care in the client's own environment. Home care nursing encourages clients and their families to be responsible for, and to actively participate in their own care. Thus, teaching and self-care are promoted. Goals for home care nursing can be curative, rehabilitative, supportive or palliative.
Community Physiotherapy and Occupational Therapy provide direct assessment, treatment, consultative and preventative services to clients in their homes to monitor, rehabilitate or augment function or to relive pain. Therapists may also arrange for the necessary

equipment to manage the clients' physical disabilities and may train family members to assist clients. Community physiotherapy and occupational therapy programs also may provide consultative, follow-up, maintenance and educational services to clients, families, physicians, other health providers, hospitals and long term care facilities.

Adult Day Support provides personal assistance, supervision and an organized program of health, social, educational and recreational activities in a supportive group setting. Nursing, rehabilitation, and a range of other professional and ancillary services may be provided. The program is designed to maintain persons with physical and/or mental disabilities, or restore them to their optimum capacity for self-care. It can be used to provide respite care, training and informal support to family caregivers. Adult day support may be provided within a residential care facility or may be provided through organizations in the community.

Group Homes are homes or home-like residences which enable persons with physical and/or mental disabilities to increase their independence through a pooling of group resources. They must be able to participate in a cooperative living situation with other challenged individuals. This type of care is particularly suited for young adults with disabilities who are working, enrolled in an educational program, or attending a sheltered workshop. It may also be provided to senior and others who require an alternative to facility care.

CORE RESIDENTIAL SERVICES

Long Term Care Residential Facilities provide care for clients who can no longer live safely at home. Residential care services provide a safe, protective, supportive environment and assistance with activities of daily living for clients who cannot remain at home due to their need for medication supervision, 24-surveillance, assisted meal service, professional nursing care and/or supervision. Clients may have moderate to heavy care needs which can no longer be safely or consistently delivered in the community. They may suffer from a chronic disease, from a disability that reduced their independence and generally, can not be adequately cared for in their homes. In some cases all facility services, including chronic care, are provided in long term care facilities.

Chronic Care Units/Hospitals provide care to persons who, because of chronic illness and marked functional disability, require long term institutional care but do not require all of the resources of an acute, rehabilitation or psychiatric hospital. Twenty-four hour coverage by professional nursing staff and on-call physicians is provided, as well as, care by professional staff from a variety of other health and social specialties. Only people who have been properly assessed and who are under a physician's care are admitted to chronic care facilities. Care may be provided in designated chronic care units in acute care hospitals or in stand alone chronic care hospitals. Care requirements are typically 2.5 hours of professional nursing care per day or more.

Assessment and Treatment Centres and Day Hospitals provide short-term diagnostic, assessment and treatment services in a special unit within an acute care hospital or other health facility. These centres provide intensive short-term assessment services to ensure that persons with complex physical, mental and social needs are correctly assessed, diagnosed and treated.

The objective of the centres is to assist the client to achieve, regain and maintain an optimal level of functioning and independence. Centres may have beds for short-term inpatient assessment and treatment, a day hospital services and/or an outreach capability which permits staff to assist clients, who are in care facilities or in their homes, and their families.

OTHER SERVICES

Equipment and Supplies may be provided as required to maintain a person's health, eg. medical gasses or assisted-breathing apparatus, and to improve the opportunities for self-care and a better quality of life, e.g. wheelchairs, walkers, electronic aids, etc. Equipment may be loaned, purchased or donated.

Transportation Services may be provided to persons with disabilities and others with mobility related limitations to allow them to go shopping, keep appointments and attend social functions. Some vehicles are adapted for wheelchairs and other devices.

Respite Services may be provided to primary caregivers to provide them temporary relief or support by providing a substitute for the caregiver in the home or by providing alternate accommodation to client in a residential setting.

Palliative Care is an interdisciplinary service that provides active, compassionate care to the terminally ill in their home, a hospital, or other health care facility. Palliative care is provided to individuals, and their families, where it has been determined that treatment to prolong life is no longer the primary objective.

Congregate Living Residences are apartment complexes which offer amenities such as emergency response, social support and shared meals.

Quick Response Team or Quick Response Program is a health care program of services designed to prevent unnecessary hospital admission and to facilitate the earlier discharge home of clients who no longer require acute care treatment.

Sub-acute Care is to patients who have been in hospital and need extra time to recover before going home.

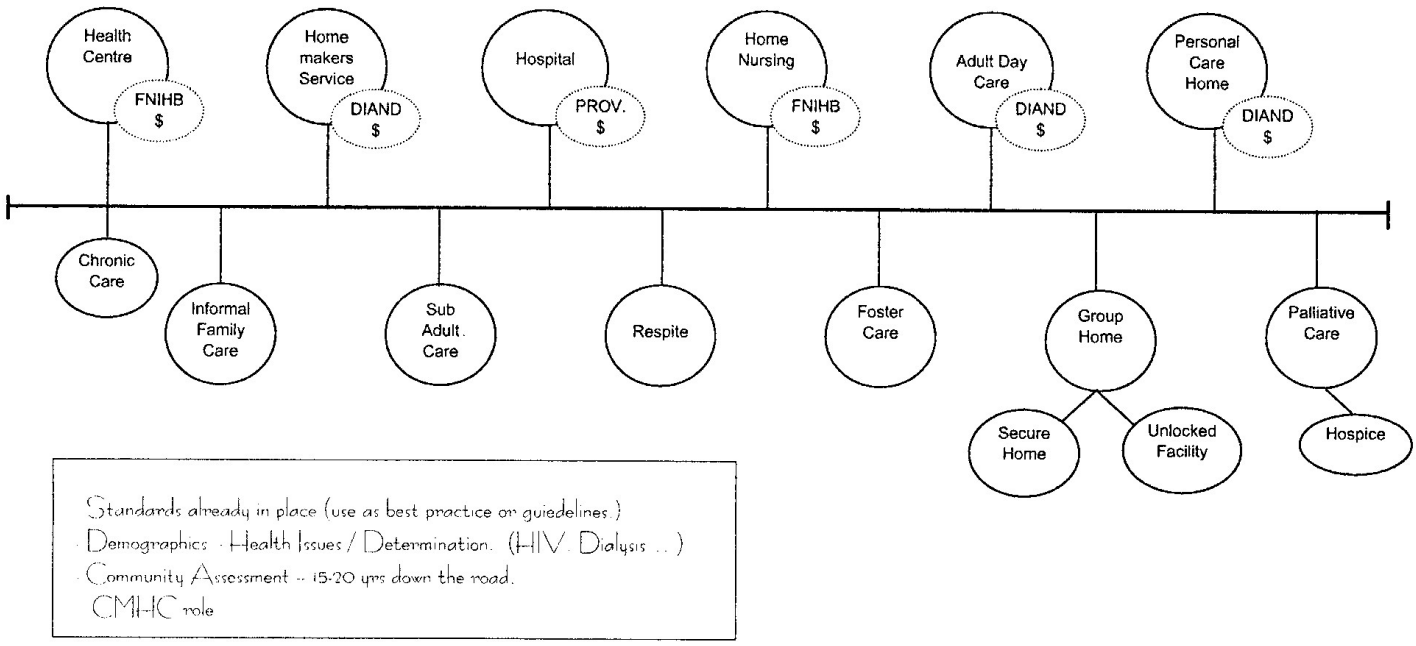
Home Maintenance and Repair is a support service which provides or arranges for an individual worker or company to undertake a home maintenance and repair job. The job may be undertaken on a regular basis or may be undertaken occasionally or one time only. Generally, the job is beyond the client's capability to undertake or arrange by themselves. Examples of ongoing jobs include property maintenance such as snow shoveling, yard maintenance and outside window washing. One time jobs include helping the client to arrange home repairs and renovations such as decorating, plumbing, electrical, new furnaces, roofs, masonry repairs and structural modifications for personal safety, barrier free access for positive quality life.

Source: Hollander and Walker, 1998, pp. 63-70

The following diagram illustrates a *First Nations Continuum of Care* graphically showing the kinds and levels of care an individual might require to meet their needs. The diagram also illustrates the source of funding for the various programs and services.

It is recognized that implementation of this framework will differ among First Nation communities. It is further recognized that it is important that the planning, development and implementation of continuing care services be based on a comprehensive assessment of client needs and community resources and the identification of appropriate programs and services that will meet those needs. This will ensure the most effective and cost-efficient use of resources and avoid duplication with other health or social services.

Schematic Diagram of a Continuum of Care: For First Nations Continuing Care



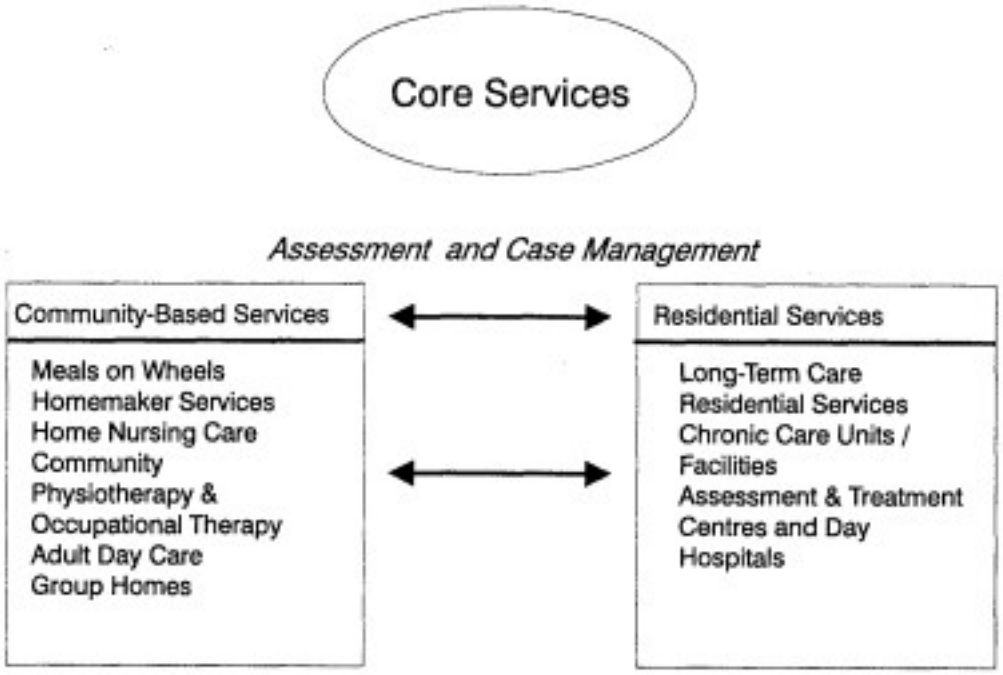
Description of the Elements of a First Nations Continuum of Care

Client Assessment	Client Care Plan	Implementation	Evaluation
The client is assessed to determine need for services. Assessment criteria includes: - General information about the client & entitlement data - Client personal data: address, phone number, marital status, etc. - Persons to notify in case of emergency - Client physician(s) information - Living arrangement: lives alone or with family - Client statement re: why they need help - Physical environment: assessment of cooking, water, toilet facilities, laundry, type of residence, etc. in terms of the kind of help required e.g. hauling water, wood, doing laundry or going to the Laundromat, etc. - Physical health: any health problems that limit normal activity e.g. diabetes, arthritis/ rheumatism, heart or circulatory problems, cancer,	**A Client care plan is determined and agreed to with the client and family based on assessment for services required which might include any of the following:** **Independent living** - light housework - heavy housework - laundry - preparation of hot meals - shopping - personal financial affairs help - bathing - care of hair - dressing and undressing - eating/feeding - sleeping - use or assistance with medications - telephone assistance **Specific independent living services options**: Community Health for the Client living at home – seen by CHN/CHR once a month INAC in-home support -home management personal home support worker Home Care nursing:	**The Client's care plan is implemented and reviewed periodically** **Independent Living:** Re: the **type of service frequency** for nursing, personal care and/or home management Re**: the type of service frequency** for meal preparation, respite care, etc. A contract for program care is agreed upon re: - What is presenting problems for the client - The goal desired and outcomes - Target dates - Met or unmet needs - Client-family-other responsibilities - Home care responsibilities - Signatures of the client and primary care giver - Date of re-assessment - Signature of care worker - Care check-list for personal care, homemaking tasks, time frames and shared responsibilities of the family	**The client's care plan is evaluated on regular intervals based on the original assessment criteria in both independent and dependent care settings based on the**: - General information about the client & entitlement data - Client personal data: address, phone number, marital status, etc. - Persons to notify in case of emergency - Client physician(s) information - Living arrangement: lives alone or with family - Client statement re: why they need help - Physical environment: assessment of cooking, water, toilet facilities, laundry, type of residence, etc. in terms of the kind of help required e.g. hauling water, wood, doing laundry or going to the Laundromat, etc. - Physical health: any health problems that limit normal activity e.g.

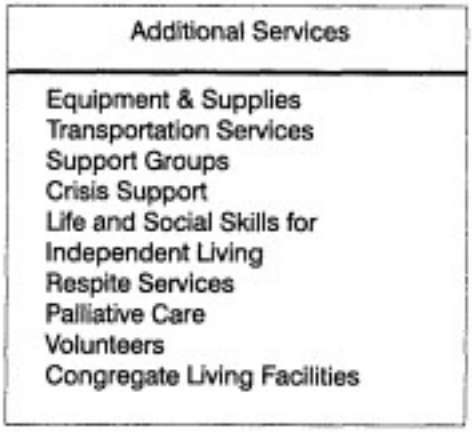
any operations, muscular/neurological disorders – stroke, epilepsy, accidents, injuries, etc. - Whether the client has been hospitalized lately & why - Current or recent medication information - List of allergies - Assessment of nutrition, elimination, respiration, skin and circulation, eyesight, hearing, oral/dental, mobility/physical abilities, aids used, social/emotional health - Other support workers utilized by the client - Family and friends who can help the client - Permission to share information - Service agreement - Case notes - An Assessment Summary re: environmental health, physical health, mental health, social/ spiritual health, referrals recommended by the assessor - Special considerations - Recommended services	Home support Rehabilitation Equipment Housing Home Environment: Family Personal Care Worker Nurse Rehabilitation If the client's condition changes a re-assessment is done and care plan changes are recommended **Dependent Living options:** - Personal Home Care - Group Home Care 24 hour supervised - Institutional Care Levels III-IV - Hospice - Palliative Care **Nursing data and care plan re:** - physical: weight, temperature, blood pressure, over all appearance, skin, eyes, extremities, etc. -activities of daily living: ambulation, rest/sleep patterns, level of activity -behavioral data -medication records, dosage, frequency, ordered by, date discontinued, comments - doctor's orders - progress notes	**Dependent living** in terms of 24 hour care within an institutional setting re: - Personal Home Care - Group Home Care 24 hour supervised - Institutional Care Levels III-IV - Hospice - Palliative Care **Contract for Nursing and/or care plan re:** - physical: weight, temperature, blood pressure, over all appearance, skin, eyes, extremities, etc. - activities of daily living: ambulation, rest/sleep patterns, level of activity and what the plan is to address - behavioral: client knowledge of their condition and treatment, their perception and adjustment to their illness, their mental status and the care plan that will address these - medication start date, dosage, frequency, ordered by, date discontinued, comments - doctor's orders - progress notes	diabetes, arthritis/ rheumatism, heart or circulatory problems, cancer, any operations, muscular/neurological disorders – stroke, epilepsy, accidents, injuries, etc. - Whether the client has been hospitalized lately & why - Current or recent medication information - List of allergies - Assessment of nutrition, elimination, respiration, skin and circulation, eyesight, hearing, oral/dental, mobility/physical abilities, aids used, social/emotional health - Other support workers utilized by the client - Family and friends who can help the client - Permission to share information - Service agreement - Case notes - An Assessment Summary re: environmental health, physical health, mental health, social/ spiritual health, referrals recommended by the assessor

			- Special considerations - Recommended services - Any new recommended services or comments from the assessor/evaluator

A. Core Elements of the Existing Continuing-Care System Canada

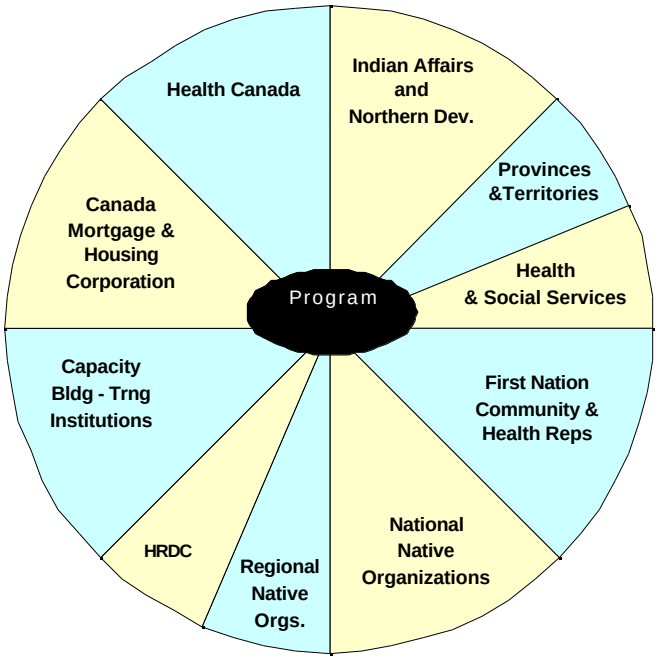


B. Possible Additional Services in the Continuing-Care System



Source : Angus et al 1995 adapted from Marcus J. Hollender, "The Cost- Effective of Continuing-Care Service in Canada" Queen's University of Ottawa Economic Projects. Working Papers No 94-06, University of Ottawa, Ottawa, 1996

Stakeholders



Partners in Change

This graphic illustrates the partners and stakeholders required to provide and fund the programs and services described within this framework. Collaboration and partnership is essential for the successful implementation of the program overall. This model builds on existing investments in health and social community based services **for all ages**. It is envisioned that the program will be integrated with other related services and training opportunities both inside and outside the community. The goal is for clients to have access to services in a manner that is *holistic and comprehensive* and which *maximizes both human and financial resource utilization*. A structured client assessment, coordinated care and a case managed approach are just some of the tools that will assist communities in realizing more effective, appropriate and timely access to care. Each community, or collation of communities, will achieve this goal of *seamless access* over a period of time and in a manner that supports the delivery of the program as developed by the community(ies). Evaluation, program reporting and data collection will incorporate all related programs to enable communities to more effectively determine the impact and the gaps of the continuing care continuum of services in their communities.

Roles of Partners/Stakeholders

Implementation of this framework will require a collaborative approach to planning, development and implementation with First Nations, Health Canada (HC), Human Resources Development Canada (HRDC), Canadian Housing and Mortgage Corporation (CMHC), and DIAND.

The roles and responsibilities of the **Federal Government** will be to:

- respect existing Treaty and Aboriginal rights and fiduciary relationships and negotiated self-government agreements;
- provide adequate funding resources to implement and maintain the program with all of the technical, specialized, professional, training, capital (to house program staff, as well as, build institutions), and evaluation financial supports to meet the demonstrated needs of First Nations;
- ensure that appropriate authorities have been secured for the implementation of inherent services;
- provide various technical, professional and capacity building supports which are negotiated and mutually agreed to by First Nations; and
- work in partnership with First Nations on the development and maintenance of appropriate First Nations adult, home and continuing care standards of practice.

The roles and responsibilities of **First Nations** will be to:

- plan and deliver training and services;
- monitor, evaluate and maintain the quality of services;
- maintain performance accountability to community members and the funding agents;
- ensure financial and program accountability for program funds;
- maintain liability and malpractice insurance, *delegation of responsibility;*
- negotiate with the Federal government, other governments or service

providers for various technical and professional supports which cannot be provided through the internal resources of the community; and

- work in partnership with the Federal government on the development and maintenance of appropriate First Nations standards of care and practice.

For **personal care homes**, program developments will need to occur in:

- Quality assurance to facilitate the implementation of accreditation processes when communities are ready to participate. To effect quality assurance, standards for occupational health, rights of clients, client record management, service provision, and other professional services, liability and program evaluation are just a few of the standard areas that will need to be developed for the delivery of this program. *A First Nations regulatory body will be established to do this "licensing" and monitoring, and thereby remove First Nation personal care homes from provincial jurisdiction.*

- Community-based planning and implementation procedures that require each community to develop a community health and social services plan that is built upon the community needs assessments that were carried out. *Many of these assessments identified the lack of resources in supportive housing/personal care homes as a major program gap.*

- Establishment of First Nation representation at the regional/national level where decisions and policies are developed that affect on-reserve personal care homes.

- Establishment of management infrastructures to support program delivery. This may include: a client record keeping system, staff activity records, program information system, administrative systems to hire and supervise staff and provide ongoing professional support and program direction.

- Capacity building that includes training, education, community development, peer support and networking to meet the needs in the area of program and professional consultation related to new and changing interventions.

- Development of program linkages and coordination to facilitate single source access to all continuing care services. These linkages will include referral and assessment protocols, collaborative discharge planning and case management teams. Linkages and coordination are meant to enhance existing services and programs and to avoid duplication.

- Comprehensive impact evaluations to enable the community/First Nation/Tribal Council to examine community satisfaction with the quality, accessibility and scope of adult care services; operational effectiveness of the services and to enable future goal and priority setting.

This framework recognizes that First Nations have the authority to provide health and social services to their members under the *inherent right to self-government*. It is also recognized that a clear statement of the federal mandate and authority for implementation will be required. This authority must fall within the following general guidelines:

- that it does not prejudice existing Treaty or Aboriginal rights;
- that participation is open to all First Nations communities, or combinations of communities, large enough to sustain a program;
- that participation is voluntary;
- that accountability to clients and community members is affirmed and maintained;
- that services implemented under the framework will operate within existing and emerging health and social legislation and regulations; and
- that the delivery of services under the framework will not duplicate existing services and not compromise or impede the delivery of mandatory public health and social services.

The transfer of authority for control and management of continuing care, including personal care homes, **shall be to First Nations.**

Financial authority for funding resources to support First Nations program services will be based on Treasury Board approval. **This approval must**:

- enable multi-year funding agreements;
- provide First Nations with the financial flexibility and discretion to allocate funds according to priorities and to retain unspent annual balances to enhance the ongoing adult care services; and
- ensure financial and program accountability through independent annual financial and performance audits.

To minimize duplicate report preparation and conflicting federal department policy issues, every effort should be made to include all adult care services under one funding agreement or other mutually satisfactory arrangements.

Another Perspective

As part of a society *of all ages*, First Nation Elders and persons with disabilities wish to be full and active members in society. It is their desire for society to accommodate *equally* the needs and aspirations of *all* age groups. Elders would also like to be appreciated for their life accomplishments and be respected for their continuing roles and contributions to family, friends, communities and society.

Dare that we forget that our Elders, and all other First Nation individuals, as a part of a **society of all ages**, are the reason for this framework. The following core values are offered as important in developing an implementation plan to affect change on behalf of our First Nation community members. They are:

Dignity

> *Being treated with respect, regardless of the situation, and having a sense of self-esteem e.g., having a sense of self-worth; being accepted as one is, regardless of age, health status, etc.; being appreciated for life accomplishments; being respected for continuing role and contributions to family, friends, community and society; being treated as a worthy human being and a full member of society.*

Programs must accommodate *the special needs* of First Nation individuals and community members so they can fully participate with dignity in the life of their community.

Independence

> *Being in control of one's life, being able to do as much for oneself as possible and making one's own choices e.g., decisions on daily matters; being responsible, to the extent possible and practical, for things that affect one; having freedom to make decisions about how one will live one's life; enjoying access to a support system that enables freedom of choice and self-determination.*

Programs must reflect the integration of safety, personal responsibility and educational awareness for First Nation individuals and community members to maintain

independence.

Participation

> *Getting involved, staying active and taking part in the community, being consulted and having one's views considered by government - e.g., being active in all facets of life (socially, economically, politically); having a meaningful role in daily affairs; enjoying what life has to offer; participating in available programs and services; and being involved and engaged in activities of daily living (decisions/initiatives in all spheres, not just those specifically oriented to Elders).*

Programs must support the development of a range of housing and care options for First Nation individuals and community members that eliminates barriers to independent living and encourages full participation in community life.

FAIRNESS

> *Having Elders' real needs, in all their diversity, considered equally to those of other Canadians e.g., having equitable access (socially, economically, politically) to available resources and services; not being discriminated against on the basis of age; and being treated and dealt with in a way that maximizes inclusion of Elders.*

Programs must ensure that if First Nation individuals and community members wish to be full and active members of First Nation society, health promotion efforts must strive to accommodate the needs and aspirations of ALL age groups.

Security

> *Having adequate income as one ages and having access to a safe and supportive living environment e.g., financial security to meet daily needs; physical security (including living conditions, sense of protection from crime, etc.); access to family and friends; sense of close personal and social bonds; and support.*

Programs must counter violence and fear of violence for *all age groups* and enhance security in First Nation communities. (Source: Health Canada, 1998).

First Nation Continuing Care Program Challenges
An Overview from an Implementation Point of View

Program Challenges Jurisdiction	Program Enhancement Requirements
Respect and maintenance of the trust and fiduciary relationship is required.	- Dialogue needs to be taken ***seriously*** by government.
Clarification of the roles and responsibilities of other levels of government (DIAND, HC and the provinces) in institutional care on-reserve is required.	- We need to get everyone in one room. - The government(s) need to be clear. - Inter-government Affairs needs First Nation representation - Inter-government Affairs determines our priorities for us re: money and jurisdiction – this is a big problem as they are not sensitive to our needs. - The key is to get the Federal Government to acknowledge their responsibility.
Updated and agreed upon definitions of levels of care e.g. Type I-V are required.	- We need a uniform system of categorizing the different levels of care. - The federal government's definition should supersede the provincial -currently they clash – the federal government needs to include Levels III – V. - We need to up funding to level V – the Federal Government shouldn't be able to off load to the province.
Integration of services – a continuum of services – (special development units, sub-acute, respite, palliative care, etc.) is required.	- We need one body for funding – there are too many stakeholders and jurisdictions. - We need clarification of jurisdictions – DIAND/provincial integration is needed because of multiple funding sources.
Addressing liability/risk for providers of institutional services is required.	- General liability for workers in Level I and II is covered only because of the licensing issue - this needs to be addressed. - To what level are we authorized based on licensing – e.g. for Level III-V the minimum is 2.5 hours for the liability cut off line and then the client becomes provincial liability. - There is a problem of PCH's assessing Level III-V clients lower to keep them at home. - The solution is a uniform definition of the levels of care and to include Level III-V. - The problem is Levels IV and V have to go off-reserve – the solution is to change the range available on-reserve -there was an agreement in place that

	addressed that in Saskatchewan. - The challenge for Level IV-V is that it is classified as medical by DIAND – their mandate is social. The solution is care should be holistic and the definitions be First Nation driven with resourcing that addresses the needs identified - The Challenge for HC/DIAND is to address jurisdiction and their roles and responsibilities. Authority is required to do this.
Licensing arrangements with the various provinces for on-reserve facilities is required.	- Licensing is a problem because of jurisdiction. First Nations have authority and jurisdiction to license. The government does not recognize this. - Staffing is part of liability. It is essential in terms of liability.
A broader definition of institutional care is required.	- A definition of institutional care Level I-V is required
Integration of reporting (DIAND, HC, Provinces) and flexibility of deadlines is required. There also needs to be clarification of report completion requirements	- What is the purpose for what is currently required to be reported by First Nations? It is administrative data only and it is not useful. It has to be sent in at certain times e.g. quarterly and it is a burden. - Names/ Band Number/DOB are now being requested by Health Canada. This is not acceptable. - A single reporting mechanism between INAC/HC would be more efficient - such as integration into one reporting mechanism. - Personal data is confidential in terms of client identifiers. Case numbers could be used instead to protect privacy and confidentiality. - We need to work with the province to clarify the reporting issue. - Reporting currently is a waste of time and effort. A pilot project is needed to address reporting and make it more user friendly and result in data that is useful.
Respect of regional diversity is required.	- Remote, small communities and cost of living needs to be addressed and respected. The cost of living needs to be higher e.g. in Oxford house, Manitoba which is very remote. The cost of pharmaceuticals at the provincial level are variable from region to region (from the Atlantic to the Pacific). Relationships effect service provision as well e.g. Level IV-V is not funded in Saskatchewan but *it is* funded in Manitoba. Wages for nurses also vary for on-reserve versus off-reserve and regionally.
First Nation sensitive evaluation mechanisms, with First Nation input on	- First Nations have a right to evaluate their own programs with their own criteria and tools. - Government evaluations are more cost savings oriented versus **quality** and needs/service or outcome

outcomes, are required.	oriented. - Special mechanisms are required for the evaluation of First Nation programs.
First Nation consultation and consensus on framework and program processes, planning and implementation are required.	Government needs to take us *seriously*.
Clear mandates and *authorities* for service components of continuing care is required.	See above
Training and Capacity	
Respect for traditional and contemporary First Nations approaches to healing and wellness are required.	- Acknowledgment and respect of the value of First Nation's traditional practices is required. The government believes they know how to take care us but they don't. This needs to change. Government needs to listen to First Nations who have the knowledge as to what works. They need to listen *and hear* what First Nations have to say - There needs to be more opportunities to facilitate First Nation traditional practices in terms of capacity. This needs to be more formally recognized - There needs to be more support and resources; and mentoring is required. - Licensing is an issue in terms of recognition of North American Herbal medicines. How do you label the *spiritual* aspect of a traditional medicine? - Respect, acknowledgment and trust in the fact that First Nation people know what is best for their communities is required. - Government needs to no longer be paternalistic and ethnocentric when it comes to First Nation knowledge.
Comparability of on-reserve services with other provincial services is required.	- More money is required to access services and for First Nations to provide/have their own services such as physiotherapy, occupational therapy, dietitian services on reserve, etc. - Provincial care homes have more flexibility and DIAND doesn't. - More access to training is required. - The same quality of services and equity as that of provincial service providers is needed by First Nations; especially in terms of wage parity. - Facilities and services must be equal to, or better than, the provinces. - There needs to be one national standard

	administered by one First Nation body or entity. There needs to be one national standard, one national monitoring model and one national licensing mechanism - all in one entity or body.
Good community infrastructure (housing, water, the ability to modify homes for persons with disabilities for example) to better provide services is required.	- Collaboration between *other* service providers such as housing, water, sewer, roads, etc. is required in terms of linkages and resourcing. - Modifications should be more easily accessible for First Nations. Chief and Council are faced with difficult decisions in prioritizing the needs of their communities. Capital dollars are required for infrastructure development and there needs to be specific moneys for modifications. - Capital requirements need to be reviewed and upgraded. Decision makers need to be trained to prioritize and keep membership informed. - Building codes for new construction should include universal design in order to be proactive.
Prevention is required.	- It is important for First Nation communities to understand and make prevention a priority for everyone – teachers, community members, children, Elders, hunters, etc. - There must be an ongoing education and prevention program for injury prevention, which needs adequate resourcing. Those communities who have transferred have more flexibility to do this then non-transferred. - Ongoing education prevention is a must.
Best practices need to be developed and shared.	- We need to look at, and identify what, exists already and share. It is more cost effective.
Licensing sources of funding for operation costs, accreditation costs infrastructure costs and programming is required.	See above
Training, tools, communication/responsibility are required.	See above
Recognition of the ongoing need for capacity building through training and other methodologies is required.	- We need First Nation individuals within the system to advocate for us. We must have control over the development of our own health systems. Political will is required to make this happen. - Inter-government agencies make decisions without our input. This is not good. - Cost containment is a government goal and this is a problem. Programming needs to be holistic. This is a stall tactic on the part of government.

Resourcing	
DIAND, HC, CMHC and the Provinces need to be partners and agree to funding arrangements	See above under licensing
Sources of funding for capital and operating costs of Personal Care Homes are required.	- The goal is 2,000 beds currently there are 500-700 beds covered by *DIAND*. Of the 13 homes funded 10 are in Manitoba. - We need to use statistics to justify need for at least 1,500 more beds nationally. - There needs to be a needs assessment conducted by First Nations. - Current PCH's continue to be funded after April 1, 2002 because of licensing. - Funding is currently by/per bed versus per client. - A new fiscal arrangement is required to cover: Level I and II in-home, Level IV-V provincial and Level III on-reserve. - We need to have First Nations involved in decision making e.g. what about the 80 bed facility being built in Winnipeg by DIAND? - Nothing is uniform currently - everything is piece meal. This needs to change. - Policies are required that are more uniform. We need 1,500 more beds. - Government is trying to choke First Nations out of business. - There needs to be political will and lobbying. A political strategy is required on continuing care. - What about First Nations that are small and remote? How will their needs be addressed? - A national needs assessment could establish criteria for the allocation of PCH's.
The type of funding for Adult Care (core versus non-core) needs clarification and is inadequate.	- This refers to transferred versus non-transferred First Nations. It boils down to crumbs in terms of resources. Adequate funding is required. - Fiduciary obligation and a uniform system Level I-V needs to be addressed. - Fiduciary funding needs to come from one-source directly to First Nations. - Band employment funds are limited in terms of employer contributions on the part of benefits, which are capped. - Funding is currently at 1997 levels and needs to catch up to the cost of living and to keep our people working on-reserve.
Comparability of on-reserve services with other provincial services	See above

is required to ensure equity of services.	
Out of province institutional care placements need resourcing.	- Saskatchewan clients came to Manitoba Personal care Homes and their per diems weren't covered after FY 2000. This is even though they were covered for about 5 years prior. This arrangement needs to be re-established since there are no PCH's in Saskatchewan. - Non-status individuals were covered on-reserve in Manitoba but cut due to licensing, jurisdiction and money. This needs to be addressed
Level of quality meeting and/or exceeding provincial standards is required through adequate resourcing.	See above
Accountability to membership is necessary.	See above
Funding for shared management structures are required.	See above
Equitable and effective services resourced to ensure equity to those received by the general population is required.	See above
Inadequate resourcing overall for the programs and services required based on need, changing demographic patterns of the population, and diversity in regions where services are being provided, is a significant problem.	See above
Management/Admin.	
Guidelines for the provision of the full-range of health services on-reserve (including needs assessment, training, etc.) are required.	- Whose rules are we adopting? We need a traditional approach to service delivery. - The core range of services required are addressed earlier in this document in terms of community based, core residential and other services are all listed and defined (see pg. 31-34) – this equals a "full range of services" - The universal right of Canadians is to a full range of

	services and this is NOT true in First Nation communities on-reserve - We need to tie in the United Nations Declaration of Rights of Persons with Disabilities, Indigenous Peoples, children, etc. - Mental health is a big issue and also is part of the range of services especially as part of group homes.
Determining of *client base* is required.	- The *client base* must include **ALL ages**. - Assessment must be based on need and not on someone else's criteria. Especially in the case of some residents who are under the age of 21 (10 years old in some cases). - Children are under care (foster), for example, and are the responsibility of Child and Family services (CFS). This is VERY high cost for CFS and needs to be covered under continuing care. Children under 18 have no special funding in the case of special needs and this must be addressed.
Integrated service delivery (single window) needs development	See above
Feasibility of partnering is required.	See above
Diversity of the policy framework to work for each region needs to be integral to all planning and implementation	See above
Integration of services is required for cost effectiveness and efficiency.	See above
Removing barriers for programs that may be competing or clashing, and building consensus, is required	See above
Planning support at the community level is required	- It is very important to develop long term community plans – 5 years minimum and that they be re-evaluated annually. - Training and staff planning, recruitment, retention is required. - Capital and budgeting is essential. - If there was a full continuum of care there would be full community support. - Involvement of community in planning initially, ongoing and in prioritization, is critical. Being involved in assessments for need and in evaluation e.g.

	quality of service surveys is also important.
Management support to follow through is required	- Good support is required from the Directors in terms of strong direction/leadership and supervision of staff. Chief and Council needs to be very supportive politically as well. - There needs to be tie back with planning, support e.g. education, housing, economic development, health care, Child and Family services, etc. Partnerships and collaborations for resources (human, physical and financial) based on working relationships and sharing is required. - We need to expand partnerships through terms of reference (s) and a guide for shops including governments
Quality assurance supported by clear standards of practice and care is required	See above
Community- based /community- paced planning is required	See above
Care and/or service based on assessed need – case management, monitoring, re-assessments, etc. is required	See above
Management must be supportive to family and community involvement.	See above

Next Steps

The critical challenges described in the previous table will determine the success, *or lack of success*, of the continuum of services described within this framework. To address these challenges it is recommended that key stakeholders such as DIAND, Health Canada, CMHC, HRDC and the provinces work together with First Nations towards the goal of **a seamless continuum of services** within the multitude of jurisdictions that exists between the various stakeholders. This can be attained in incremental stages. These stages include:

- ***Creation of a joint-steering committee*** *to include representatives from First Nations, HRDC, DIAND, CMHC, HC and the provinces.*

- ***Integration and coordination of services*** *with community based programs such as addictions, home nursing, housing and maintenance programs, adult care, existing physician and therapy services, etc.*

- *Development of* ***protocols and processes*** *with provincial service providers around on-site on-reserve assessment, referrals, discharge planning, access to therapy and institutional care.*

- ***Obtaining and/or changing authorities within specific federal departments*** *to address program and service gaps (e.g. the current lack of funding for Level III and IV individuals in personal care homes awaiting admission to provincial institutions due to lack of facilities on reserve).*

In the interim it is recommended Health Canada and DIAND at a minimum:

- *Continue to work with Health Canada to identify and develop a national approach aimed at achieving a single-window delivery system that covers the full spectrum of care.*

- *Participate in the joint working group on Continuing Care as it develops the Institutional Care framework, and oversee the conduct of research to help inform the development of the framework.*

- *Work with First Nations to ensure successful evaluation of the home care pilot projects.*

- *Participate with First Nations in the planning and development of the First Nations and Inuit Home and Continuing Care Program.*

Work Plan for Change

The following was developed for implementation in 2002 – 2003 and ongoing.

Jurisdiction:

Clarification of Role and Responsibilities of Government

Target for 2002-2003	Measure	Stakeholder
- Clarification of the roles and responsibilities of the Federal Government to First Nations is required. This is a big problem - Get all stakeholders in one room e.g. Ministers, Assistant Deputy Ministers and Director Generals to discuss mandates, policy, authorities and jurisdiction.	- Roles and responsibilities are determined beyond, for example, Memorandums of Understanding and Terms of Reference(s) and are brought forth and outlined. - There is a change in policy based on dialogues, needs assessments, research done to date.	TB PCO FN's HC HRDC CMHC DIAND CMHC Provinces

Gaps in Services Identified

Target for 2002-2003	Measure	Stakeholder
Gaps in services need to be identified and addressed.	What is there in terms of services and who is responsible will be determined.	FN's HC HRDC CMHC DIAND CMHC Provinces

Licensing

Target for 2002-2003	Measure	Stakeholder
Licensing needs to be addressed and it needs to be clear what has to be in place to be funded at the First Nation level	- Stop governments from off loading to one another e.g. from the Federal Government to the provinces. - A standard will be in place. - First Nations won't be held hostage.	FN's DIAND HC Provinces

National Standards

Target for 2002-2003	Measure	Stakeholder
- Establishment of national standards for the operation of Personal Care Homes is required. - Government needs to give First Nations time to develop their own national standards.	- National First Nation Standards for Care would be in place. - Training for First Nation caregivers and the whole spectrum of staff and management would be in place. - There would be a stop to deadlines that effect funding of current First Nation facilities.	FN's DIAND HC Provinces (support to FN's) CMHC HRDC

Address crisis issues

Target for 2002-2003	Measure	Stakeholder
- National Activities and meetings need to address crisis issues such as licensing before March 31, 2003.	- A national First Nations continuing care policy would be in place. - Policy would be in	FN's DIAND HC HRDC CMHC

- The MOU expires April 2003 in Saskatchewan; the impact is 80 residents would be evicted. This needs to be addressed.	place for: licensing, jurisdiction, resourcing, operational structure and capital.	

First Nations Continuing Care Framework

Target for 2002-2003	Measure	Stakeholder
The First Nations Continuing care framework is addressed ASAP/immediately by governments.	A First Nations continuing care policy would be in place.	FN's DIAND HC CMHC HRDC

Training and Capacity Building

Training

Target for 2002-2003	Measure	Stakeholder
- Training needs to be at a quality equal to mainstream. - Expectations and standards for training must be high. - Training must be accredited. - Training must be diploma and/or certified.	- Training is quality, First Nation specific and reciprocal to the outside world; - Training is accredited and given by acknowledged training schools. - Training is beyond the bare minimum.	FN's Training Institutions Universities Colleges

Adequate Resources

Target for 2002-2003	Measure	Stakeholder
- There are adequate resources for quality	There is an increase in the number of First	FN's Government

trainers to facilitate high end training and to ensure more First Nation people get into the health professions. - There is more PSE funding for bursaries (including Inuit).	Nation health care professionals e.g. nurses, doctors, etc.	Higher ed. learning institutions HRDC

Infrastructure

Target for 2002-2003	Measure	Stakeholder
- Facilities need to be in place for training and development. - Remote and isolated First Nations need to have *equal* access to infrastructure so they can provide training and capacity building	Infrastructure would be in place to facilitate training and capacity building.	FN's CMHC HRDC DIAND

Resourcing

Needs Identified and addressed

Target for 2002-2003	Measure	Stakeholder
Once roles and responsibilities have been clarified governments need to find the resources to address the needs identified.	Adequate resources and money would be in place to resource program needs based on assessments of need.	PCO TB FN's DIAND HC HRDC CMHC Province

Management

Planning and assessments

Target for 2002-2003	Measure	Stakeholder
- Planning and assessments are conducted to identify needs in collaboration with First Nation community and other stakeholders. Leadership needs to be a major part of this process	Plan and assessment of need equals a management plan.	FN's Governments DIAND HC HRDC CMHC Province

Leadership Support

Target for 2002-2003	Measure	Stakeholder
- Leadership needs to provide support to the process and commitment to the needs identified. - We need to educate leadership and define their role in supporting program management. - There needs to be respect that is mutual between leadership and front line workers.	- Chief and Council leadership provides support to program managers - There is respect for front line workers by leadership - There are clear lines of authority in place	FN Chief and Council Program Managers HR Planners

Governance

Target for 2002-2003	Measure	Stakeholder
- The impact of Governance re: separation of politics versus administration is a big issue. This needs to be addressed - We need to set priorities and transition time is needed for leadership. This needs to be seamless. - There needs to be fairness in program administration.	- There is a prioritized management plan in place. - There is a clear chain of command in place. - There are strong/ clear plans for priorities and codes of conduct. - There is a policy in place. - There is more respect within the chain of command.	FN's Leadership Community Program managers

Implementation Action Steps

The following action steps are recommended for the implementation of First Nations and Government as an integral and critical aspect of this framework:

- → Provide information at all upcoming key meetings e.g. the AFN Confederacy and Annual General Assembly; Assembly of Manitoba Chiefs Meeting; etc. to make presentations about work being done.

- → November 30 2002 is the Treasury Board submission date. This framework document must be submitted as part of it by government on behalf of First Nations.

- → Send the final First Nations Continuing Care Framework document to all First Nations.

- → Provide provincial and regional First Nation briefings through information sharing, communication and networking.

- → AFN meeting summaries will be provided and updates kept ongoing with sharing of information at all key levels.

- → Hold key meetings with government representatives that include, but are not limited to:

    - The Privy Council Office
    - Treasury Board
    - Health Canada
    - Department of Indian and Northern Affairs Canada
    - Human Resources Development Canada
    - Canada Mortgage and Housing Corporation
    - The Provinces

    → Assess the status of ongoing activities, continue work on the First Nations Continuing Care Framework activity plan and amend as required based on assessment of progress and status of implementation.

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Glossary of Adult Care Terminology

Accessible Care - Care that is available to the clients that is both physically and psychologically within their reach.

Accreditation is a structured approach to quality control and is provided by an organization which reviews a health delivery system against structured standards of care or service.

Acute Chronic Illness Care is home care nursing services provided to a client with a chronic disease or disability who is experiencing an acute illness, but has the potential for returning to a pre-illness level of functioning and self-care. The objective of the home care nursing is to control the symptoms and prevent the deterioration of the client. A chronic client who experiences an acute illness would be referred to the home nursing program for care during the acute episode and returned to the CWIS Chronic Care Program for ongoing monitoring.

Acute Home Care Nursing is nursing care provided for an illness or condition which requires care for a period of 8 weeks or less.

Acute Post Hospital Care is care provided to clients who are post-surgical or have had acute illness which has been diagnosed, treated and the client is stabilized and no longer requires acute or hospital services. The home care nursing service would monitor the client's condition and ensure that the required treatment is continued in a community setting.

Adult Day Program is a program of structured and supervised activities in a group setting for adults. Program delivery can occur in a community hall, personal care and or long term care facility. Persons benefiting from the program reside elsewhere.

Adult Foster Care is care and the provision of supervision in a family setting, other than the person's home.

Adult Health Clinic is an example of a home care service delivered in a central accessible location within or close to the person's community. These clinics can include direct services such as medication and general health monitoring, foot care, dental/mouth care and the administration of flu vaccines. A number of screening services can also be provided at these clinics

and often reflect the epidemiology of the community, for example blood and urine testing for early detection of renal disease. These clinics can act as a screening service, referral mechanism and resource centre for promotion of wellness through assessment, counselling and teaching of adults. (Paraphrase: Saskatchewan First Nations Home Care Program Guidelines, 1995)

Aides for Independent Living are items which are required to assist a physically challenged individual to function to their optimal level. These aides include: medical devices, medical equipment to enable safe mobilization, fixed household items to support transfer, for example: grab bars.

Assessment is a structured, dynamic process of continuous information gathering and knowledgeable judgments which attach meaning to the information being gathered. Assessment process can involve the client, family and other care givers and service providers.(Family Nursing: Theory and Assessment page 31).

Case Management ensures that all people receiving home care have their needs assessed, are involved in service planning, receive appropriate services, and then have their needs reassessed.

Children with Complex Medical Disorders are those persons under 18 years of age who are dependent and have special medical, learning, mental and social needs.

Chronic Illness Care - Continuous is home nursing services to clients with advanced chronic disease(s) or disabilities who cannot be maintained at home without ongoing home nursing care. The objective of this client is to maintain a chronically ill client at home and to reach their maximum level of functioning with ongoing home care nursing services.

Chronic Illness Care - Time Limited is home nursing care to those clients with early chronic disease/disability who will not return to their pre-illness level of functioning or self care and will eventually function without home nursing services. The home care nursing objective is to assist the client/family to control symptoms, prevent deterioration and support self care to reach a maximum level of physical and social functioning without continued home care nursing services and return to the CWIS Chronic program for ongoing monitoring.

Client-Centred Care - Care that is directly related to the need of the person/client that is responsive to the problems and concerns that they present.

Comprehensive Care - Care that is holistic and responsive to the total range of situations and problems that the client presents.

Disability - Following the approach suggested by the *World Health Organization*, people are considered to have a disability if they have a physical or mental condition or impairment that restricts them in their ability to do activities that are normal for their stage of development and in their cultural environment. For Canadian adults this might mean such things as personal care, working, traveling, shopping, using a telephone or doing daily tasks around the home. There have been two dominant ways of understanding disability over the past decades. The first locates disability in the individual and proposes medical or technical interventions to treat the disability or provide rehabilitation so that individuals can function "normally." The second locates disability in the social/cultural environment and argues that social arrangements make some forms of human differences into disability by failing to provide the necessary flexibility and resources (Source: HRDC www.hrdc-drhc.gc.ca)

Enriched Housing see Supportive and/or Enriched Housing.

Epidemiology is the study of the distribution of health and illness in a population.

Equity the services provided to or made available by First Nations and Inuit authorities will not be less than those provided to general Canadian population. That services provided will be at least 'equal to' in extent but not necessarily in 'exact form of service'.

Equivalency an understanding that Home and Community Care services provided to or made available by First Nations and Inuit authorities will be equal in value, measure and effect as that of those services received by the general Canadian population.

Evaluation is the gathering, analysing and reporting of information about a program, service or intervention for use in making decisions. (Page 2, Action-Oriented Evaluation in Organizations-Canadian Practices).

FNIRHS an acronym that represents First Nations and Inuit Regional Health Survey.

Group Home is a care environment provided to a group of about five or less persons. The supervision provided is similar to that of a personal care home. Persons live within the home/facility and provide for their own needs with the assistance of home makers with respect to laundry services, meal preparation, recreational activities, etc.

Health Promotion is a process of enabling people to increase control over and improve their health. (World Health Organization)

Holistic Approach is a conceptual perspective towards First Nations and Inuit health and social development which is considerate of each individual's, family's and community's spiritual, cultural, emotional, physical and social needs. (Paraphrase: Saskatchewan First Nations Home Care Program Guidelines, 1995)

Home Care Nursing is a service provided by a nurse currently registered with the provincial nurses association in the province in which they are practicing. Home care nursing can include: performing nursing assessments, treatments and procedures, personal care, teaching and supervising self-care to clients, family members and other care givers; teaching and supervising home health aides providing personal care and initiating referrals to other agencies. (Paraphrase: Saskatchewan First Nations Home Care Program Guidelines, 1995)

Home Health Aides/Personal Care Workers are trained and certified individuals who can provide both home support and personal care services including in-home meal preparation.

Home Maintenance and Minor Home Repairs is a service provided by a First Nation or Inuit public works infrastructure and is an important linkage to continuing care services to enable the client to remain in a safe home environment.

Home Management is a home-based service provided on assessed need of the client. Services provided may include: general household cleaning, menu planning, meal preparation, laundry, ironing, mending, changing linen, shopping, cutting/stacking wood, hauling water, friendly visiting and security checks.

Hospital Separations is a term used to describe numbers of patients who leave the hospital after admission, and includes both deaths and discharges.

Incident Report Form is a form which serves the functions of identifying at risk situations so corrective actions can be initiated, an education tool or training device to demonstrate prevention, a formal process to notify supervisor/manager of incident and to prepare for possible litigation or filing of claims.

Informal Care Giver is a person who provides supportive care to a person who would not otherwise be able to be maintained in the home environment. The caregiver is usually unpaid for his/her time.

Institutional Care is provided in a variety of private or public funded institutions whereby people are admitted, based on a formal assessment

process, and require care and services provided by a various certified/licensed service and care providers. Institutional care is provided in a number of settings that includes: personal care homes, long term institutions and extended care homes.

Levels of Care in Continuing Care: (**Note:** Description of levels of care was modified from those descriptions used in the province of British Columbia. Each region should use the definition of levels of care within their province/territory.)

Level l This level of care identifies a person who is independently mobile, with or without mechanical aids, requires minimal non-professional assistance with the activities of daily living including, but limited to, administration of medication, grooming, bathing, eating and toileting. A person recognized as Level l would not normally be admitted to a residential care facility.

Level ll This level of care identifies a person who is independently mobile with or without mechanical aids (walkers, wheelchairs etc.), requires moderate assistance with activities of daily living (as above) and requires a limited amount of daily professional nursing care and/or supervision.

Level lll Clients identified as requiring this level of care have heavier care requirements and need additional nursing and other support staff time and/or supervision. Care requirements for the function deficits identified as needing this level of care result from multiple medical diagnosed and/or moderate cognitive impairment.

Level lV Clients identified as needing this level of care remain independently mobile, with multiple diagnoses resulting in significant physical frailty, and/or severe cognitive impairment with behavioural problems, and require considerable assistance with all activities of daily living. Clients require a heavier level of care and considerably more nursing and other staff time than those at Level lll.

Level V This level of care recognizes the person with severe chronic disabilities which have resulted in physical frailty and/or cognitive impairment and require 24 hour a day professional nursing services and continuing medical supervision, but does not require acute care services. Clients at this level are usually not independently mobile, with or without, mechanical aids, and have a limited potential for rehabilitation and often require institutional care on permanent

basis.

Managed Care is care that incorporates an integrated and holistic service approach and can include case management, referrals and service linkages.

Meal Services is a home support service which provides meals to individuals to ensure their nutritional needs are met. Services can include: in-home meal preparation, meals on wheels and wheels to meals or congregate meals.

Mental Health Services is acute and supportive care provided to persons whose capacity for independent functioning is reduced due to a cognitive or emotional disorder.

Palliative Care is defined as the active, compassionate care of the terminally ill at a time when their disease is no longer responsive to treatment and/or intervention aimed at cure or prolongation of life. The focus of the service is on easing the pain, both physical and emotional, for the client and their family. Palliative care is comprised of pain and symptom control, counselling and bereavement services. It is a multi-disciplinary approach that encompasses the client, the family and the community. (Paraphrase: Saskatchewan First Nations Home Care Program Guidelines, 1995)

Personal Care is a home and/or community-based service provided on assessed need of the client, by a trained care provider. Services may include: assistance with the activities of daily living such as bathing, grooming, dressing, feeding, toileting and transferring; routine foot care; and supervision of activities to support daily living.

Personal Care Homes see Institutional Care.

Physical/Occupational Therapy Services are services which include the assessment of the client's functional ability to perform activities of daily living, followed by the planning and implementing and evaluation of the physical or occupational therapy treatments. The client, the caregiver, or the home health aide is taught to perform the therapy and monitoring as required when it can safely be done at home.

Prevention Care that is focused at all times on the comprehensive prevention of illnesses, whether they are the primary presenting illnesses, related illnesses, or other new and unrelated problems.

PTO is an acronym for Provincial/Territorial Organization (First Nations and/or Inuit).

Quality Assurance is an ongoing process that examines the efficiency, quality and effectiveness of a program or service. (Paraphrase: Saskatchewan First Nations Home Care Program Guidelines, 1995)

Quality Improvement Process These initiatives are a pro-active approach that seem to minimize the potential for future errors rather that focusing on the resolution of problems after they have occurred (Marelli, 1994)

Record Keeping is a process which may include: an assessment tool, a reassessment tool, a care plan and other documents to record care activities.

Rehabilitative Services are therapy services to assist a client to maintain or regain his or her highest level of functioning.

Respite Care is any combination of services provided expressly for the purpose of giving relief to the family or other care givers of a dependent person who lives at home. (Paraphrase: Saskatchewan First Nations Home Care Program Guidelines, 1995) Respite can include hourly and long term respite care for families with children with complex needs; palliative care; elder care and treatment after care.

In Home Respite is the service to provide relief to the caregiver in the home setting by scheduling a Home Health Aide to stay with the client for a period of time, or scheduling support at periodic intervals during the time the caregiver is away from the home. There is usually a limit to the time allowed for in-home respite so that one client does not take a disproportionate amount of time and leave other clients without services.

Institutional Respite is the service to provide relief to the caregiver in a setting other than the home. This can be through day or evening programs or several days of care in a long term care facility.

Second Level Home Care Services are a range of activities that often lend themselves to maintaining quality assurance, service coordination, staff training and development, staff support, program review and report writing. The continually changing caseloads, health needs and status of clients and care plans can result in a significant coordination and management resource requirement. The focus on needs based care and client outcomes is often best attained if the home care infrastructure has access to a second level of coordination and management.

Service Integration is a process that provides for greater continuity, comprehensiveness and flexibility in home care program delivery at the community and/or Tribal Council/PTO level.

Single Source of Entry is the concept that a person who requires continuing care of any kind enters into the system through one assessment process which determines the level and type and location of care that is most appropriate to meet the client's needs.

Supportive and/or Enriched Housing is a type of housing that has been developed or modified to meet the special needs of people and enables them to live independently while receiving support services that may include meal preparation, personal care, homemaking, nursing and therapy services. Examples of supportive/enriched housing are Elders lodges, independent living units.

Source unless noted otherwise: Health Canada First Nations and Inuit Home and Continuing Care http://www.hc-sc.gc.ca/fnihb/phcph/fnihccp/steering_committee/index.htm

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