THE AGED, DISABLED AND CHRONICALLY ILL IN THE NORTHWEST TERRITORIES: RESULTS OF A NEEDS ASSESSMENT SURVEY

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INTRODUCTION

In the context of the transfer of responsibilities from the Government of Canada to the territorial governments, with the official intent of passing control over health care into local hands, it is important to know just what responsibilities are being transferred, for what services, and for how many people. For instance, the lower life expectancies and higher mortality rates among Native infants, teenagers, and adults have been well documented in government, popular, and scientific literature, as have difficulties in Native utilization of health services (Grescoe 1977; Canada 1979; Badgley 1980; Jarvis and Boldt 1982; Spady et al. 1982; Shah and Farkas 1985; Postl 1986). The subject of disability among Native people in Canada has been less well documented. Indeed, the Canadian Health and Disability Survey (Canada 1986) did not indicate the ethnicity of its respondents and did not survey either residents of the Northwest Territories or residents of Indian reserves. This paper reports on a survey that ascertained the extent of disabling chronic disease and handicap among a population that is mainly Native: the inhabitants of the Northwest Territories.

METHODOLOGY

The Aged, Disabled, and Chronically Ill Assessment Project was performed by the Department of Health and the Department of Social Services of the Government of the Northwest

Territories (GNWT) in 1985-86. Because the population of the Northwest Territories is sparsely distributed, and detailed information was required for planning health services on a community by community basis, sample surveys were judged inaccurate, and a more complete data collection method was devised. The background and reasons for the methods adopted are reported elsewhere (McClelland and Miles 1987). In brief, given the difficulties in assuring that equivalent data were obtained from each region and given the many languages and cultural groups in the area, it was agreed that community-level surveys were needed to help the territorial government prepare for its assumption of responsibility for health care. The Executive Council of the Territorial Assembly approved funding to pay two Assessment Project Officers and related travel and project costs for the fiscal year 1985-86. Two project officers travelled to the various communities in the Northwest Territories from October 1985 to April 1986, to interview the aged, disabled, and chronically ill and their caregivers.

After obtaining general consent from the people concerned, the project officers used personal interviews, lists obtained from the community health nurses and social service workers, band or hamlet councils, and elders' committees to ensure that all the disabled and chronically ill were found. Use of multiple sources of information ensured that virtually every disabled and chronically ill person in the Northwest Territories was listed.

Information was collected on an assessment form already in use by the Northwest Territories Department of Health and Department of Social Services (GNWT n.d.). Ability to perform activities such as eating, dressing, bathing, cooking, cleaning, home maintenance, travel in community, and managing personal finances was covered. Information about medical-biological status was also collected, including eyesight, hearing, mobility, presence of diseases requiring medical or nursing care, ability to administer own medications, and mental status. In addition to the usual demographic data about age, sex, and ethnicity, information was collected on living situation and presence of family or other social

support. This resulted in a heterogeneous list of people whose impairments were physical (the largest group), sensory and mental.

Once the information about each of the aged, disabled, and chronically ill had been gathered, these people were classified according to a system already in use by the Departments of Health and Social Services. Each level in this system denotes a different amount of care required by the client and provided by another person. The higher the level, the more care required. Level four, for example, is assigned to people who require technically skilled nursing care such as would be available in a chronic care hospital. Only twelve such people were found; many of them lived in chronic care facilities in the Northwest Territories. Level three people are severely disabled and require twenty-four hours a day care, but that care can be provided by family members or by someone trained as an aide. Sixty-three people were at this level; some are in long stay beds in institutions, but many are being cared for in their home communities by family members with some homemaker support. Level two requires help with heavy work and a supervised or protected environment, and level one requires supervision and lighter help. "Future" was a category assigned to persons who did not require assistance at the time of the study but who had a condition which in the normal course of events was expected to require help from the Territorial Departments of Health and/or Social Services in the next five years.

To assist the GNWT in allocating resources to communities and regions, the number of disabled, expressed as a proportion of all the disabled found in the Northwest Territories, were calculated for each age group and each region. Although classification by level or care required, such as was used in this survey, provides only an approximate estimate of the amount of biophysical disability, the data reported here are not only very complete, they are the only data available for the Northwest Territories.

The results from the assessment survey were divided into three in order to give estimates of proportions of mildly,

moderately, and severely disabled for comparison with results from other surveys. Future and level one clients were assigned to the mildly disabled category, level two clients have a moderate degree of disability, and level three and four clients are considered severely disabled.

RESULTS

The study found 1077 disabled and chronically ill people. Half the people reporting disability at any level were 65 years or older, with the next largest number in the 15 to 64 age group. Only 113 (10.5%) were youngsters from birth to fourteen years. Overall, 272 people were assessed at level two, 411 at level one, and 319 were assigned to the "future" category (Table 1).

Classifications as mild, moderate, and severely disabled placed 67.8% of those clients found by the project in the mildly disabled, 25.2% in the moderately disabled, and 7% in the severely disabled categories (Table 2). A high proportion of working age adults have mild disability, while 17% of the youngsters who were found to have disability were assessed as severely disabled. The proportions of elderly disabled who fall into mild, moderate, and severe are 64%, 28.6%, and 7.5% respectively (Table 2).

Disability is unevenly distributed throughout the Northwest Territories (Table 3 and Table 4). Concentrations of disabled people were found in Fort Smith, Hay River, Yellowknife, Inuvik, and Chesterfield Inlet. Fort Smith region has 28 chronic care beds, Inuvik region has 16, and Keewatin region with St. Therese's Home in Chesterfield Inlet has 8 chronic care beds. Keewatin, a sparsely populated region, is notable for the very high proportion of its disabled who are classified as moderate and severe. Part of the explanation for this may be St. Therese's Home, which has cared for severely disabled Inuit children for many years. Most of its residents are now in their early twenties but are still severely handicapped, mentally and physically, and totally dependent. The chronic care beds in Hay River and Fort Smith region also accommodate patients from other communities, as do the newly created chronic care beds in Inuvik, but since these

TABLE 1

NORTHWEST TERRITORIES CHRONICALLY ILL AND DISABLED PERSONS BY AGE GROUP AND PROJECT CLASSIFICATION

Age Group	Level Four	Level Three	Level Two	Level One	Future Disab.	Total
Elderly (65+)	5(0.9)	36(6.6)	156(28.5)	212(38.7)	138(25.2)	547
Working Age (15-64)	4(1.0)	10(2.4)	88(21.1)	163(39.0)	152(36.4)	417
Youngsters (0-14)	3(2.6)	17(15.0)	28(24.8)	36(31.9)	29(25.7)	113

Note: Numbers in brackets represent percentage of disabled people in that age group.

TABLE 2

NORTHWEST TERRITORIES CHRONICALLY ILL AND DISABLED PERSONS BY AGE GROUP AND DEGREE OF DISABILITY

Age Group	Mild	Moderate	Severe	Total in Age Group
Elderly (65+)	350(63.9)	156(28.5)	41(7.5)	547
Working Age (15-64)	315(75.5)	88(21.1)	14(3.4)	417
Youngsters (0-14)	65(57.5)	28(24.8)	20(17.7)	113
Totals	730(67.8)	272(25.3)	75(7.0)	1077

Note: Numbers in brackets represent proportion of the disabled who are in that age group.

TABLE 3

NUMBER AND PERCENTAGE OF NORTHWEST TERRITORIES DISABLED BY REGION AND DEGREE OF DISABILITY

Region	Mild	Moderate	Severe	Region Total
Baffin	157(73.4)	42(19.6)	15(7.0)	214
Ft. Smith	257(66.0)	100(25.9)	29(7.5)	386
Inuvik	185(73.0)	52(20.6)	16(6.3)	253
Keewatin	71(49.3)	61(42.4)	12(8.3)	144
Kitikmeot	60(75.0)	17(21.2)	3(3.8)	80
All Regions	730(67.8)	272(25.3)	75(7.0)	1077

Note: Numbers in brackets represent proportion of all disabled in each region.

TABLE 4

NORTHWEST TERRITORIES DISABLED AS A PROPORTION OF REGIONAL POPULATIONS

Region	Regional Pop.*	Disabled and Chronically Ill		S.M.R. (%)**
		Observed	Expected***	
Baffin	8,302	214	1,046	20.4
Ft. Smith	22,386	386	2,865	13.5
Inuvik	7,483	253	958	26.4
Keewatin	4,327	144	553	26.0
Kitikmeot	3,243	80	415	19.3
All Regions	45,741	1.077	5,855	18.4

* Population estimates used in these calculations are based on 1981 Census Data.

** Standardized Morbidity Rate (Disability Rate).

***Calculated using the rates for Canada, Canadian Health and Disability Survey.

regions are more populous, the proportion of the disabled to the total population is less, and the impact on the total picture is more moderate.

A number of people confined to wheelchairs live in the communities of Keewatin. These people live at home and are cared for by their families with whatever formal community assistance, such as paid homemakers, and informal community assistance, such as family help, is available. Local housing associations provide ramps when requested, but most public buildings have no ramps to facilitate access, and the terrain and usual condition of the roads (no pavement anywhere) makes independent movement around the community difficult.

Deafness affects children and young adults, and concerns the educational authorities who must develop special education programs and equipment for them. It is widespread throughout the Inuit communities. Blindness particularly affects one Dene group located in the Fort Smith Region; negotiations are ongoing with the Canadian National Institute for the Blind about community-based training for these people.

Disabled people in the Northwest Territories have to surmount severe problems living in their home communities. The problems, which are routine for northerners, include lack of transportation other than by snowmobile or all terrain vehicle, rough ground and unpaved roads to traverse, buildings on pilings because of permafrost, and snow that can drift as high as the houses and pack so hard that steps and tunnels are cut into it to provide access to homes and public buildings. Long term care facilities are not available in the home communities of most residents. Home Care programs are available only in the larger of the Territories' 62 communities. Language and cultural differences make going to another community for care more difficult than it can be for disabled Canadians in the south.

DISCUSSION

As with any survey of disability and handicap, this study had difficulty separating the effects of environmental barriers and the

enabling effects of informal services from the measurement of disability as a biophysical state. Although we attempted to elicit information about the biophysical state, the propensity to report "a disability" was clearly affected by how much of a problem or "a handicap" the disability presented. A self-report measurement such as the Canadian Health and Disability Survey is also likely to encounter such difficulties. It is uncertain how much under- and over-reporting occurred in each survey, therefore all comparisons should be interpreted cautiously.

Because the Northwest Territories' population has a higher proportion of youngsters and a lower proportion of elderly than the population in Southern Canada, the groups balance out, leaving the proportion of mild, moderate, and severely disabled close to the proportions found in Canadians living outside institutions and off reserves in the provinces of Canada by the Canadian Health and Disability Survey (Canada 1986: 35).

At only 1077 out of an estimated total population of 52,064 (approximately 2%), the rate of chronic disease and disability in the Northwest Territories is strikingly low in contrast with the figures reported for the rest of Canada. Part of this appearance of health is due to the high number of youth, the least disabled group. With 547 of 1463 or 37.4% of elderly Natives reporting some degree of disability, the rate for the elderly is 97% of the rate which would be predicted if the Canadian rate is used. The number of adults reporting chronic disease or disability is very low, with a standardized morbidity rate of 14%. The number of youngsters with disability or chronic disease is only 9% of the number that are predicted when the rates for Canada are used (Table 5). It has been suggested that self reported measures applied to a total population or a sample will usually elicit higher prevalence of disability in the low impairment categories.

The Canada Health Survey (Canada 1981) reported long term disability, in terms of limitation of activity during the previous twelve months, at 12% of the population, with 2% being classified as severely disabled. If we assume that "severely disabled" means approximately the same regardless of the social and physical

TABLE 5

STANDARDIZED MORBIDITY RATES FOR NORTHWEST TERRITORIES*

Age Group	NWT Pop.**	Canada Rate***	Observed	Expected	S.M.R. %****
Elderly (65+)	1,463	37.4	547	564	97
Adults (14-64)	32,752	9.2	417	3,000	14
Youth	17,849	6.7	113	1,196	9

* Based on rates of disability for Canada, Canadian Health and Disability Survey.

** NWT Population projections for 1986, Bureau of Statistics, GNWT.

*** Calculated from Canadian Health and Disability Survey 1983-84, pages 21, 102. Expected rates are calculated using the indirect method.

****Standardized Morbidity (Disability) Ratio.

environment and the data used for estimate, our study shows severe disability is about as prevalent among this northern, mainly Native population, as it is in the rest of Canada.

The Canadian Health and Disability Survey reported on disability for adult Canadians living outside the Yukon and Northwest Territories, off Indian Reserves, and outside of the armed forces and institutions. It used a self-reporting interview method, and reported that rates varied from a low of 3.8% among those aged 15-24 to a high of 38.6% of those over 65 years of age (Canada 1986: 13). Since 547 or 37% of the estimated 1463 elderly in the Northwest Territories (GNWT 1986) were found to be disabled or chronically ill by the current study, the results appear comparable between the northern, mainly Native elderly and the elderly in the remainder of Canada.

Reasons for the very low prevalence of disability in the younger age groups are difficult to ascribe with confidence. The factors discussed above may contribute to some of the differences between the NWT population and the south. The Canadian Health and Disability Survey used a self-report method. In contrast, only some of the chronically ill and disabled people in the Northwest Territories could be interviewed. Unlike the rest of Canada, however, the nursing stations and the social service workers know everyone in the small communities, are responsible for delivering services to them, and can be expected to identify all community residents with disabilities. The multiple checks used by the officers should have ensured that everyone who had disabilities that seriously interfered with their normal activities were identified. It should be acknowledged that because the care providers were often the people who were asked about disability in their communities, they may have tended (consciously or unconsciously) to minimize the amount of mild disability acknowledged. On the other hand, since the formal resources to provide care in the community would presumably be increased if more disabled persons were found, there could be a countervailing tendency to inflate the numbers of disabled. We have no way to

assess these possibilities quantitatively; we can only rely on the multiple checking method used to enhance accuracy.

Payment records from the GNWT's Department of Health identify fewer than fifty Territorial residents being treated in southern Canada. With the move to scale down institutions and repatriate Natives, some Territorial residents who had been in residential facilities in the south returned to their northern communities during the study period. These people were listed with their home communities.

A factor that could contribute to the difference in disability rates, but whose magnitude is difficult to assess, is the difference in tendency to complain of or to report disability. Project officers noted that while informants in some communities reported all the people who were disabled, others tended to say "she (or he) is O.K." if the person was ever seen outside their home. Since traditional hunting, trapping, fishing and even cooking are still conducted outdoors in all seasons, the fact that someone is seen outdoors may not indicate that he or she is necessarily healthy. Especially with youngsters, families may make adaptations to a mild disability, accepting it and including the child in all family activities. Even severe disabilities are often managed at home when the alternative is removal of the child from the family for care in a distant institution. A project officer met an eleven year old girl, severely disabled with cerebral palsy, who was "trick or treating" at Halloween. She was being carried from house to house by her brother in a specially adapted amauti (Inuit garment which consists of a parka with a pouch at the back in which a child can be carried). Traditional Dene place high value on "being one's own boss" and "not bothering anybody." This may have combined with the environmental and social necessity to be active and to find ways to manage in spite of disability to make the Northwest Territories' Natives less likely to report any disability.

It is possible that northerners are more healthy than southerners. Certainly, the Northwest Territories has a high proportion of youngsters. These people, born after 1960, have had

access to nursing stations with public health programs, acute medical care and evacuation for serious medical problems and emergency care all their lives. Those who became ill or injured "on the land" where they did not have access to evacuation and medical care may have died. There might therefore be a smaller number of disabled people who have survived serious illness or accident. The so-called "chronic diseases of civilization," diabetes, ischemic heart disease, and cancer have only begun to be evident among the Native population in the Northwest Territories. Finally, the "healthy worker effect" (Monson 1986: 425) is evident. Only the physically fit can go to the north to work. Non-Natives, with the exception of the prospectors and traders who have made their lives in the north, generally return to the south when medical treatment or long term care is needed. These factors all contribute to a "healthy appearing" population.

In order to explore the distribution of disability further, the standardized disability rates for mild, moderate, and severe disability were calculated by the indirect method (Armitage 1971: 386). The rates for Canada, from the Canadian Health and Disability Survey, were used to calculate the "expected" rates. As Table 6 demonstrates, the standardized disability rates are higher than expected for the mildly disabled elderly; this probably reflects the fact that "chronic disease lists" were kept in nursing stations until 1985. People with diabetes, chronic obstructive pulmonary disease, and ischemic heart disease which, in the normal course of events, might be expected to cause a disability requiring care, were included in the "future" category. Since these chronic diseases usually appear around age 45 to 55, it would be interesting to subdivide the data for adults to see if this effect carries over into that age group. Unfortunately those data are not available. The close similarity between the observed and expected rates for moderate disability in elderly adults and the low rate for severe disability in elderly and working age adults (Table 6) lend support to the hypotheses advanced above to account for the strikingly low rates.

TABLE 6

STANDARDIZED DISABILITY (MORBIDITY) RATES FOR WORKING AGE AND ELDERLY ADULTS IN NORTHWEST TERRITORIES

Level of Disability

	Mild			Moderate			Severe		
Age Group	Exp.*	Obs.**	SMR%	Exp.	Obs.	SMR%	Exp.	Obs.	SMR%
Elderly (65+)	266	350	132	157	156	100	124	41	33
Working Age (15-64)	1729	315	18	617	88	14	283	14	5
Youngsters (0-14)	---- Not Available ----								

* Expected frequency figures are calculated based on the rates for Canada, Canadian Health and Disability Survey.

**Observed frequency.

The tendency of Natives to make up for a lack of formal community supports such as home care programs and facilities with informal supports such as help from family members, which was reported by Bienvenue and Havens (1986) for Natives dwelling on underserviced reserves in Manitoba, appears also to be present in the Northwest Territories. Repeatedly during the project, the project officers were told, "we take care of our elders." Not only elders but chronically ill and handicapped of all ages were living at home with assistance from extended kinship networks. Where wage labour was available, and where the care-givers were involved in the wage economy, demand for government assistance was increasing. Families with alcohol or other related problems of their own also required external support. Very few, however, wanted disabled or ill family members to be taken away from the community.

CONCLUSIONS

Despite the difficulties inherent in comparing a survey such as the one described here with self-report data such as the Canadian Health and Disability Survey, some tentative conclusions may be drawn. As far as we can tell by comparing community interview data with sample survey data, the prevalence of disability, particularly in the over sixty-five age group, appears to be about the same in the Northwest Territories as it is in the rest of Canada, although even the elders report more mild disability and less severe disability than the Canadian population. The regions which have larger proportions of Natives in their populations appear to have a higher prevalence of disability than the regions such as Fort Smith and Inuvik where non-Natives predominate. This discrepancy may be attributable to the tendency of non-Natives to return to the south when chronic disease or illness strikes. As more non-Natives become permanent residents of the Northwest Territories and as facilities for long term care improve in the north, this trend can be expected to reverse.

Because the survey results were "need" oriented rather than "biophysical impairment" oriented, all the results are linked to a judgement about need. In the case of this project, the assessment officers were chosen for their background in health care delivery, and all the judgements about need were made within a framework of knowledge about what the GNWT health and social service systems are expected to provide. The Territorial Departments of Health and Social Services are responsible to the elected members of the Territorial Assembly, who set the priorities. The articulation of expectations and of need is accomplished within the context of the emerging political awareness of the Territorial population.

Because of the "need" oriented nature of the data, the survey is especially suited to providing information for decision making about resource allocation. As an example, although the small numbers involved make imputations of causation impossible, clearly there are concentrations of severely disabled people in the Keewatin region. This should be taken into account in construction of facilities and development of programs. This survey was not intended, nor has it proven to be, the sole basis on which resource allocation decisions are made. The resources available, the organizational development of the communities, the priorities set by the local people themselves, and the energy devoted by local community members to documenting need and to obtaining resources from the government have all played a role in the determination of what programs were offered, where and when they were deployed.

A high degree of informal social support for disabled and chronically ill was found in the Northwest Territories. Although facilities and formal support for the care of disabled and chronically ill do exist, they are not available in the home communities of many of the Native population. Nursing stations, social services workers, band and hamlet councils already exist that could provide the administrative structure to deliver home care services to Native communities. These could be provided with additional staffing and utilized to provide a suitable mix of

formal and informal support for disabled and chronically ill to live and receive help in their home communities.

ACKNOWLEDGEMENTS

While the data were being collected for the project described in this paper, the author was employed as a Project Officer, Department of Health, Government of the Northwest Territories. The author wishes to thank Kue Young, Nelson McClelland, Margaret Marshall, Elaine Berthelet, Richard Stanwick and two anonymous reviewers for help with this paper.

REFERENCES

Armitage, P.
1971 Statistical Methods in Medical Research. Oxford: Blackwell.

Badgley, R.F.
1980 Social Policy and Indian Health Services in Canada. Anthropological Quarterly 46: 150-159.

Bienvenue, R.M. and Betty Havens
1986 Structural Inequalities, Informal Networks: A Comparison of Native and Non-Native Elderly Canadian Journal on Aging 5(4): 241-248.

Canada. National Health and Welfare
1979 Communique. Statement on Indian Health Policy. Ottawa: Supply and Services Canada.

Canada. National Health and Welfare and Statistics Canada
1981 The Health of Canadians. Report of the Canada Health Survey. Ottawa: Supply and Services.

Canada. Statistics Canada
1986 Report of the Canadian Health and Disability Survey, 1983-1984. Ottawa: Supply and Services.

Government of the Northwest Territories (GNWT)
n.d. Services to the Aged and Handicapped. Department of Health and Department of Social Services. Yellowknife: Government of the Northwest Territories.

Government of the Northwest Territories (GNWT)
1986 Bureau of Statistics Preliminary Projections May, 1986. Yellowknife: Government of the Northwest Territories.

Grescoe, P.
1977 The Tragedy of Native Health Care: A National Report. The Canadian Magazine 23, 30 April.

Jarvis, G.K. and M. Boldt
1982 Death Styles Among Canada's Indians. Social Science and Medicine 16: 1345-1352.

McClelland, N. and C. Miles
1987 1985/86 Assessment Project: Aged, Disabled and Chronically Ill Report (edited version). Yellowknife: Department of Health and Department of Social Services, Government of the Northwest Territories.

Monson, R.R.
1986 Observations on the Healthy Worker Effect. Journal of Occupational Medicine 28: 425-433.

Postl, B.
1986 Native Health Care -- A Continuing Concern (editorial). Canadian Journal of Public Health 77(4): 253-256.

Shah, C. and Carol Farkas
1985 The Health of Indians in Canadian Cities: A Challenge to the Health Care System. Canadian Medical Association Journal 133(1): 859-863.

Spady, D. W., F. C. Covill, C. W. Hobart, O. Schaefer, R.S. Tasker (eds).
1982 Between Two Worlds: The Report of the Northwest Territories Perinatal and Infant Mortality and Morbidity Study. Occasional Publication No. 16 Edmonton: Boreal Institute for Northern Studies.