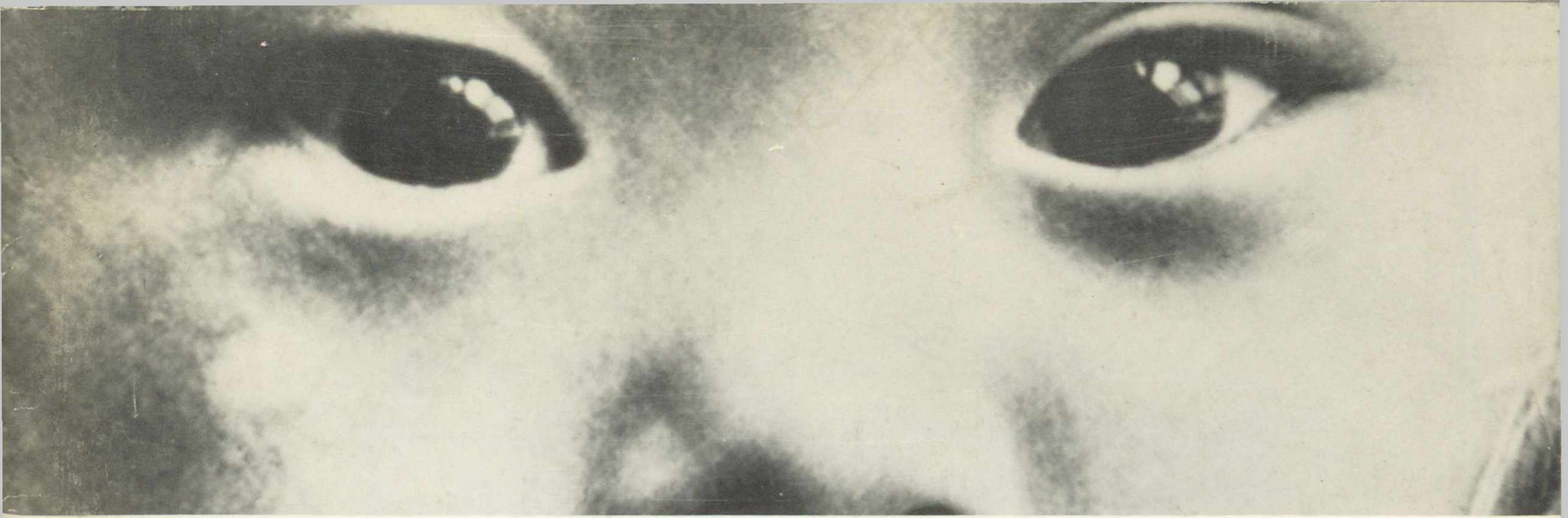

# FOLLOW-UP REPORT

## NATIVE POPULATION

CANADA
HOUSE OF COMMONS

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1980/83
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A125

DAVID SMITH
CHAIRMAN

DECEMBER 1981

# FOLLOW-UP REPORT
# NATIVE POPULATION

## SPECIAL COMMITTEE ON THE DISABLED AND THE HANDICAPPED

**FIRST SESSION, THIRTY-SECOND PARLIAMENT, 1980-81**

## FOURTH REPORT

The Fourth Report is available on audio-cassettes from:

**Richard Rumas**
**Clerk**
**Special Committee on the Disabled and the Handicapped**
**House of Commons**
**Ottawa, Ontario**
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**Native communities, and Native people living in Non-Native communities, suffer on a daily basis from living conditions which other Canadians experience only rarely. These adversities—political, economic, social and cultural in nature—greatly increase the probability of being disabled at some point in a person's lifetime. Although hard data is not available, it is generally felt by those who are knowledgeable about Native lifestyles, that the percentage of disabled persons is much higher among the Native population than it is among other groups of Canadians.**

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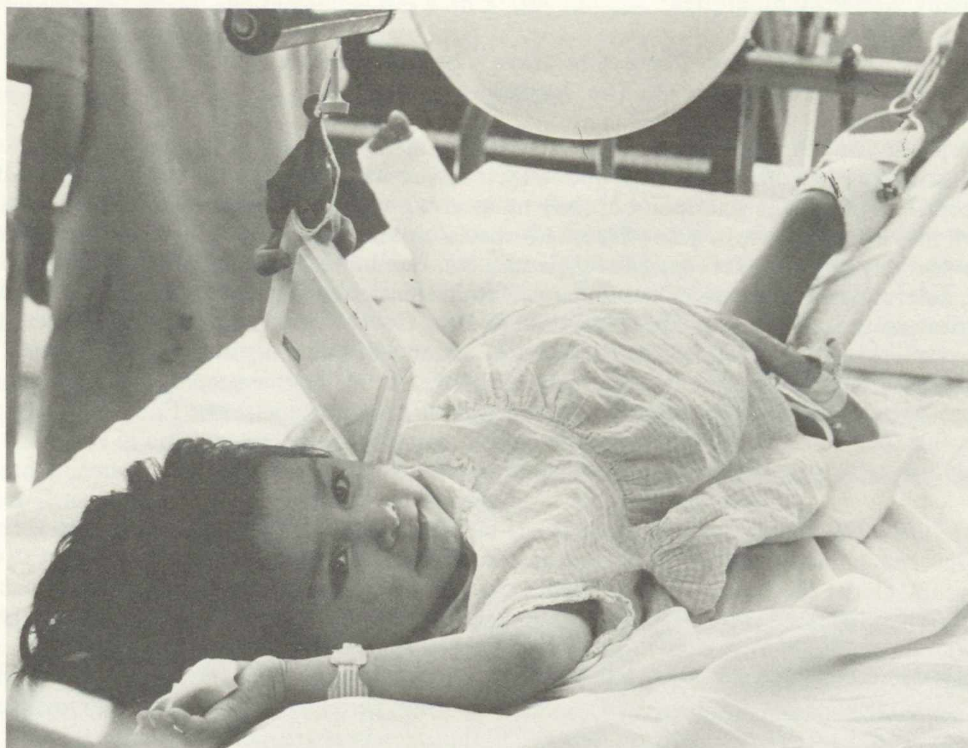
BACKGROUND

# WHY THIS FOLLOW-UP REPORT IS NEEDED:



In the report, OBSTACLES, which was released in February 1981, the needs and concerns of disabled Native persons constituted just one part of the Special Committee's examination of the effects of disability among all Canadians. Since February, however, the Committee has been made acutely aware that the Native population is a unique sector of the overall Canadian population. It is a sector which is frequently misunderstood by Non-Native Canadians, and one which is isolated from many of the resources which disabled Canadians who are not Native, can utilize on a regular basis. The needs of disabled Native people, therefore, require special consideration. This follow-up report focuses on the key areas of their lives where additional Federal Government action must be taken before many disabled Natives can be expected to help themselves.

### Major Government Initiatives On Behalf Of All Native People Have Not Necessarily Helped Those Who Are Disabled

During the past twenty-five years, the Federal Government has made significant efforts to increase the level of information, services and resources which can be utilized by Native people in general. Despite these commendable efforts, the results have fallen short of expectations. As a consequence, conditions have improved very little for those Native Canadians who are disabled. Frequently they find themselves competing with other members of their communities for limited financial and community resources.

### Many Of The Problems Of Disabled Native Persons Cannot Be Solved Until The Living Conditions For All Native Persons In A Community Are Improved

Native communities, and Native people living in Non-Native communities, suffer on a daily basis from living conditions which other Canadians experience only rarely. These adversities—political, economic, social and cultural in nature—greatly increase the probability of being disabled at some point in a person's lifetime. Although hard data is not available, it is generally felt by those who are knowledgeable about Native lifestyles, that the percentage of disabled persons is much higher among the Native population than it is among other groups of Canadians. The adverse living conditions which are a daily experience for many Native persons mean that it is practically impossible to deal

directly with the needs of disabled Native persons without first dealing with the general problems of poverty, unemployment, poor diet, poor health habits, and poor education, all of which are the normal fare for many Native communities.

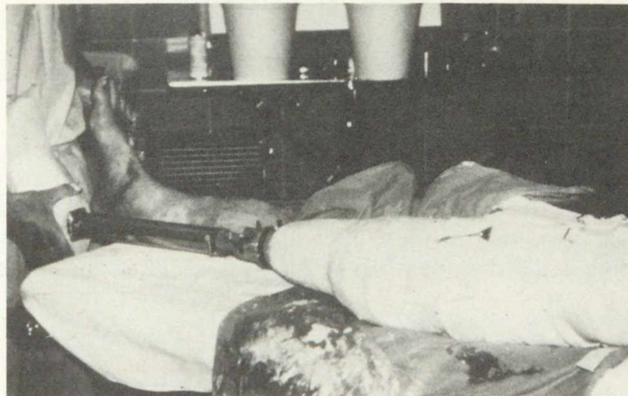
### Native Persons Are Divided Into Those Who Have A Special Relationship With The Federal Government And Those Who Rely On The Provinces

Native people in Canada may differ significantly among themselves in matters of origin, language, customs, institutions, wealth, leadership, and in their respective histories of association with Non-Native people. But from the standpoint of their relationship with the Federal Government, Native people, fall into two categories: those who have a special relationship with the Federal Government and those who rely upon the Provinces for their services. It is important to understand this distinction, because it determines, in large part, the scope and limitations of any attention that particular Native communities and individuals can expect from the Federal Government. As well, this relates to the recommendations made in the OBSTACLES report and in this follow-up document. In some instances, recommendations will call for actions which benefit all Native people, and other actions will apply only to those Native people who have a special relationship with the Federal Government.

### Special Relationship: Status Indians And Inuit

Two groups of Native people, numbering over 335,000 persons, have a special relationship with the Federal Government as a result of proclamations, treaties and Court decisions over the past two hundred years. Under the Indian Act, 315,000 *Status Indians* are registered by the Department of Indian Affairs and Northern Development. Their special relationship with the Federal Government is based on the Royal Proclamation of 1763, the British North America Act, and various treaties signed between individual bands and government officials. Over two-thirds of the Status Indian population occupy reserve lands in approximately 600 isolated locations throughout Canada, with most communities having fewer than 500 persons. Services to these reserves are delivered through local governments consisting of chiefs and band councils.

There are approximately 20,000 *Inuit* people residing in the Canadian north. Their special relationship with the Federal Government is based on a Supreme Court ruling in 1939 which gave them access to most of the Federal Government services provided to Status Indians. The Inuit have a tradition of strong community life, and a rich cultural heritage. Where they live within communities which also have Non-Inuit people, they participate actively in the political, economic and social affairs of the general community.



**"The adverse living conditions which are a daily experience for many Native persons mean that it is practically impossible to deal directly with the needs of disabled Native persons without first dealing with the general problems of poverty, unemployment, poor diet, poor health habits, and poor education."**

### No Special Relationship: Non-Status Indians And Metis

Over 1,000,000 Native persons are either *Non-Status Indians*, those not covered by special agreements, and *Metis*, who are of mixed blood, that is, descended from a marriage where at least one person was a Non-Status Indian. Although persons from both of these Native groups frequently have strong cultural, historical, and biological ties with Status Indians, they are almost entirely dependent upon provincial governments for services.

### Contentious Issues: Gaining, Retaining And Losing Status

There are contentious issues which underscore the difference between Status, Non-Status and Metis persons. A Status Indian who marries a Non-Status woman (either Indian or not) retains his status, and the woman gains status. Children born from such a marriage are considered Status Indians. But if a Status Indian woman marries a Non-Status man, she loses her status as do the children from such a marriage. In losing her status, the woman is ineligible for the special services which are provided by the Federal Government to Status Indians. These facts of differentiation are a source of difficulty both for the Native people involved and the Federal Government. That an Indian person gains, retains or loses status is a complex historical development. There is no easy path for improving the situation in the future, because improvement involves a fundamental review of the relationship between all Native people and the Federal Government. The Federal Government now is committed to reviewing criteria for status in order to end discrimination. Indian leaders would like to use this opportunity to review and amend the Indian Act in light of the movement for self determination. This is a process which has already begun, but which may take many more years of consultation.

**"If a Status Indian woman marries a Non-Status man, she loses her status as do the children from such a marriage. In losing her status, the woman is ineligible for the special services which are provided by the Federal Government to Status Indians."**

### Jurisdictional Disputes Between Governments

The Federal Government delivers services to Status Indians on reserves, and is willing to pay for services for the first year for those individuals who leave the reserve. In recent times, because of greatly increased migration of Status Indians from the reserves to urban centres, a dispute has developed between the Federal and Provincial Governments regarding the responsibility for delivering services to those individuals who are away from the reserve for more than a year. Some provinces, for their part, are reluctant or unwilling to foot the bill for a service that they consider to be the responsibility of the Federal Government. If the provinces do provide services to these individuals, they will frequently bill the Federal Government for having done so. This is a practice which in essence constitutes a double billing for a single service, since transfer payment arrangements between the Federal and Provincial Governments for social services are based on a population analysis which includes the Indian population. The dispute over this matter of service to Status Indians away from the reserve leaves the Indians themselves confused since they are frequently left without any services while the two Governments are arguing over ultimate responsibility.

### New Development: The Friendship Centres

Traditionally, the Federal Government has provided services to Inuit and to Status Indians living on lands exclusively reserved for them. With the increasing migration of Native people (including Inuit and Status Indians) to urban centres, however, the Government has supported the development of special referral or liaison facilities called Friendship Centres. These are described in detail in Recommendation #4 of this report. The Centres provide advice to Status and Non-Status persons, who are living in an urban centre or who are migrating, on matters of employment, housing, education, health and other community services that are available to them. These Friendship Centres are

growing in importance as a channel for improving services to *all* Native persons in urban centres, regardless of their status. Canadian society has changed dramatically over the past twenty-five years in respect to urbanization of the general population, which also includes Native people. The Friendship Centres represent a new kind of relationship which is developing between the Federal Government and Native people in a changing national society.

## Facts Of Life and Death For Native People in Comparison With The General Canadian Population

It is virtually impossible to develop reliable data on the living conditions and lifestyles of Native people because the information that does exist pertains only to Status Indians and Inuit. Little is known about the more than one million other Native people who consider themselves Non-Status Indians or Metis. Nevertheless, the information that is available gives some idea of the adversities which all Native people encounter in their reserves and communities, and in urban centres throughout Canada. Although the Federal Government, has done much during the past twenty years to provide resources needed to improve living conditions in Native communities and reserves, the following facts indicate that much improvement is still needed:

**Population Increase:** The Indian population is increasing rapidly. It has undergone a forty per cent increase during the past twenty years, and this has resulted in a greater demand for social services, education, housing and jobs.

**Birth Outside Marriage:** The proportion of Indian births outside of marriage is more than four times the national rate. The proportion of Indian children in care has risen steadily to more than five times the national rate.

**Education:** The number of Indian children who attend school until the end of secondary level is 20 per cent, compared with the national rate of 75 per cent.

**Language:** Almost one in every four Indian children who enters school speaks neither English nor French.

**Juvenile Delinquency:** The proportion of Indian juveniles who are considered delinquent is three times the national rate.

**Housing:** Although Indian housing conditions have improved over the past twenty years, nearly 19 per cent of on-reserve homes have two or more families living in them, affecting forty per cent of the total Status Indian families.

**Facilities:** In 1977, fewer than 40 percent of Indian houses had running water, sewage disposal or indoor plumbing facilities.

**Pollution:** At least twenty Indian communities, involving almost 10,000 persons have recently faced environmental hazards with industrial and resource development, including the dangers of mercury and fluoride poisoning.

**Income:** Although more Indians are working, and working more consistently than ten years ago, the average income is one-half to two-thirds that of the national average.

**Unemployment:** Indian unemployment is about 35 per cent of the working age population, and in some areas it reaches as high as 90 per cent.

**Prisoners:** Natives are over-represented in proportion to their population in Federal and Provincial penitentiaries. In Manitoba, Saskatchewan and the North, Native persons represent more than 40 per cent of the prison population.

**Death Rate:** The death rate for Indians, despite remarkable improvement over the past ten years, is two to four times the rate for Non-Indian people, depending on location.

**Death Causes:** Accidents, poisoning and violence account for over one-third of deaths in Indian and Inuit populations, as compared with 9 per cent for the Canadian population as a whole.

**Death From Fire:** Death from fire for Indians is seven times the rate for the rest of the Canadian population.

**Suicide:** Indian deaths due to suicide are almost three times the national rate, and are especially high in the 15 to 24 year old age group.

## Native People Share A Cultural Heritage Which Is Incomprehensible To Most Non-Native People in Canada

Perhaps the key problem which exists in the relationship between Native people and other Canadians has been the inability of Native people to explain and the inability of Non-Native people to comprehend the nature, scope and importance of Native cultures. There is no easy way to articulate this problem, and the Members of the Special Committee are in no position to offer solutions, other than to say that a great gap in communication exists in the best of circumstances. It is important for Federal officials to keep this fact in mind in all dealings with Native communities and individuals. The gap in communication is the result of two totally different ways of looking at life, both of which are incredibly rich in unconscious values, customs, and patterns of sentiment, thought, language and action. Native and Non-Native people in Canada have lived for three centuries in an uneasy relationship based on two totally different ways of organizing and strengthening human relationships, two different ways in proving one's individual worth, two different ways of identifying and solving problems which affect a whole community, and two totally different ways of reaching group decisions.

**"Native and Non-Native people in Canada have lived for three centuries in an uneasy relationship based on two totally different ways of organizing and strengthening human relationships, two different ways of proving one's individual worth, two different ways of identifying and solving problems which affect a whole community."**

## Native Cultures Survive And Thrive Despite Being Misunderstood And Exploited By Non-Native Canadians

The history of the encounters between Native cultures and the technologically-based consumer culture in Canada has been seen by the Non-Native people as essentially one of a superior civilization bringing enlightenment to an inferior one. The heritage and customs of Native people have been viewed as either barbaric or silly depending upon the era; but seldom have they been seen as integral parts of a unified approach to life which, despite strong outside pressure, makes considerable sense when judged by Native values. This attitude of superiority can be seen in an article from the book "CANADA IN THE GREAT WAR", written by a senior official of the Indian Affairs department in 1919, but which expresses sentiments that many Non-Native Canadians hold today:

> *"The return of the Indian soldiers from the front will doubtless bring about great changes in the reserves. These men who have been broadened by contact with the outside world and its affairs, who have mingled with the men of other races, and who have witnessed the many wonders and advantages of civilization, will not be content to return to their old Indian mode of life. Each one of them will be a missionary of the spirit of progress, and their people cannot long fail to respond to their vigorous influence. Thus the war will have hastened that day, the millenium of those engaged in Indian work, when all the quaint old customs, the weird and picturesque ceremonies, the sun dance and the potlatch and even the musical and peotic native languages shall be as obsolete as the buffalo and the tomahawk, and the last teepee of the Northern wilds gives place to a model farm-house. In other words, the Indian shall become one with his neighbour in his speech, life and habits, thus conforming to that world-wide tendency towards universal standardization which would appear to be the essential underlying purport of all modern social evolution."*

It is interesting to speculate on what "wonders and advantages of civilization" the Indian soldiers were exposed to on the front lines of World War I battlefields. More interesting, however, is the fact that the "quaint old customs" have not disappeared. In many Indian and other Native communities throughout Canada, cultures are experiencing a period of renewal, especially among young people. A culture survives and grows because it meets the deepest needs of the people. If only for this reason, that Native cultures are renewing themselves in the face of three centuries of misunderstanding and, in some cases, exploitation by the Non-Native population, the customs and heritage of Native people are worthy of respect. Very few Non-Native people will ever experience or comprehend the essential power of Native culture, and the Special Committee is not recommending that there now be a massive

educational campaign to enlighten the Non-Native population on these matters. What the Committee is recommending, however, is that the Federal Government in all of its dealing with Native communities, recognize that Native people and their leaders are fully capable of deciding for themselves what they need from outside of their own culture. What they choose or choose not to do within their own culture is a matter for respect and non-interference by Non-Native people.

### New Direction: Self-Determination And Community-Based Planning And Control

It must be emphasized that the Federal officials who work directly with Native people have recognized the need for Native communities to determine their own future development. The Federal Government recently introduced a policy which emphasizes community-based planning and control, involving the development of self-government and community self-reliance. This initiative fits well with the emerging movement of self-determination among all Native groups. Collaboration by community leaders and Federal officials should result in unique initiatives to address local needs and problems. The Federal role is to become less prescriptive and more supportive in promoting the transfer of control of these initiatives from government bureaucracies to Native community leaders.

**"A culture survives and grows because it meets the deepest needs of the people. If only for that reason, the customs and heritage of Native people are worthy of respect."**

* * * * *

# ONE

## DIRECT FEDERAL AUTHORITIES WHO IMPLEMENT RECOMMENDATIONS ON NATIVES TO CONSULT WITH NATIVE PEOPLE BEFORE ACTING.

In the OBSTACLES report the Special Committee set out 130 recommendations by which the Federal Government could improve the opportunities in Canada for disabled persons to help themselves. Of these recommendations, ten were specifically focused on the needs of disabled Native persons. The Members of the Special Committee now want to emphasize that the Federal departments which will act upon these recommendations— and the further recommendations that are contained in this follow-up report— should consult *fully* with Native representatives, and with each other before doing so.

**No Consultation:** Native persons in every part of Canada believe that for over a century they share the common experience of *not being consulted* about Federal Government policies and programs which have had a major, and sometimes devastating impact upon their communities.

**Fear and Mistrust:** It is hard to calculate the waste of money, professional skill, and goodwill that bureaucratic ignorance and indifference have caused, but it has been considerable. The Special Committee quickly discovered in its attempt to identify the needs and concerns of disabled Native persons, that the biggest obstacle which frequently prevents any useful contribution by the Federal Government in assisting these people, lies in the fear and mistrust that many of them have of bureaucratic attitudes and procedures.

**Consultation First:** The Committee recognizes that there are dedicated and skilled individuals in the public service whose actions and attitudes do not fit the description above. But the overall picture of Federal relations with the Native population reveals far too many instances of little or no consultation. At the base of attempts to help disabled persons in general, is the issue of self-determination. The Special Committee, therefore, is concerned that the Federal Government implement programs for disabled Native Canadians only after there has been consultation with representatives of Native communities, so that this principle of self-determination is given practical support.

There is also considerable evidence to show that the following Federal departments do not consult among themselves in a systematic fashion when implementing policies and programs which affect Native people:

- Department of Indian Affairs and Northern Development
- Canada Employment and Immigration Commission
- Department of the Secretary of State
- Treasury Board
- Public Service Commission
- Department of National Health and Welfare
- Department of Regional Economic Expansion
- Department of Justice

- Department of the Solicitor General
- Ministry of State for Social Development
- Canada Mortgage and Housing Corporation

**Wasted Effort:** The initiatives of one organization may frequently duplicate, complicate or undermine the efforts of another, without the officials of either being aware of the fact until it is too late. A phone survey established that senior officials in several departments did not know how their own budget or programs related to Native persons, even after they spent several days trying to find out this information. If this is true of other departments as well, then it is little wonder that officials do not consult across departmental lines. The net effect of this non-consultation is wasted money and effort on the Government side, and confusion and mistrust on the part of those Native persons whom the efforts are intended to help.

In the OBSTACLES report, for example, Recommendation 116 called for a study to determine the feasibility of a transfer of Indian health services from the Department of National Health and Welfare to the Department of Indian Affairs and Northern Development. This Recommendation was made because the Members of the Special Committee perceived that there was a lack of consultation and coordination between officials of the two departments in a matter of central concern to thousands of Indian people. This lack of consultation artificially separates the problems of health care from other problems such as poor housing, heating, sanitation and transportation which are direct contributors to a high incidence of disability in Indian communities. The Members are concerned not so much with how the Government delivers its health services as with the fact they be delivered in a way that addresses the realities, the often harsh realities, of life in these communities. If effective service means a transfer of a major responsibility from one department to another, then so be it. But, if the best results can be achieved simply by guaranteeing greater consultation and coordination within the present arrangement, then that will also be satisfactory.

**Co-ordination:** Some organization in the Government must now take responsibility to ensure that internal consultation and coordination take place not only in Ottawa but also in the field offices where direct contact between Native persons and the Federal Departments occurs. The Special Committee recommends that the Ministry of State for Social Development (MSSD) takes the initiative to put into place an organization which will ensure that no policy or program affecting Native people will be implemented without first going through a process of interdepartmental consultation, as well as a process of consultation with Native representatives. This organization may take the shape of a systematic committee structure which provides information between agencies and prevents duplication of services. As part of its responsibility, MSSD should also undertake an interdepartmental study of programs and services provided by the Federal Government to disabled Native people. In addition to reducing duplication and redundancy, this study will also be a first step toward identifying deficiencies of service.

**Departmental Strategy on Consultation:** As part of their responsibility, the departments should prepare in writing their policy and strategy on consultation, so that both Government officials and Native representatives will understand, if not agree, on how consultation is to be achieved on all issues. Any additional costs to the Government for carrying out these responsibilities will be more than offset by the subsequent savings which will result from the increased efficiency and effectiveness of coordinated activities.

**Necessary Interpretation:** The Committee feels that it is essential that as many Native persons as possible understand the recommendations in the OBSTACLES report and in this document. It recommends, therefore, that the Federal Government provide funds to ensure that translations and interpretations in Native languages can occur. The National Indian Brotherhood, the Native Council of Canada, and Inuit Tapirisat of Canada, have already indicated their willingness to coordinate and promote this exercise. Financial arrangements should be made through the Department of Secretary of State to ensure that the necessary interpretation occurs.

* * * * *

# CONSIDERATIONS FOR CONSULTATION BETWEEN GOVERNMENT OFFICIALS AND NATIVE REPRESENTATIVES.

One of the fundamental problems which prevents effective consultation from occurring between Federal officials and Native leaders lies in the tendency of the officials to design a consultation process based largely on internal bureaucratic needs. This tendency ignores the unique features of Native culture, social institutions, and living conditions. The various Native associations agree that this deficiency must be remedied before useful programs or policies can be developed and delivered to disabled Native persons.

Delbert Riley, President of the National Indian Brotherhood, says the following about consultation: "You must understand that for over a hundred years, the Federal Government has developed programs in which Indian people have had very little say. The government still deals with Indians almost on a crisis basis. There never seems to be enough real planning and understanding. Over time, Indian leaders have been conditioned and even moulded to react strongly to government decisions since they are seldom involved meaningfully in the discussions leading to those decisions.

"Now the government thinks that it will reverse this situation by some magical decree from Ottawa. They call it consultation. It seems that the Indian people are supposed to fall into line and comply with pre-determined guidelines and conditions. But consultation is much more than rules and organizational structures. Consultation is first of all an attitude that is based upon trust and respect between individuals. For Indians, it must occur within a forum which respects the social and political institutions as well as the reality of life on the reserves. When the Federal Government finally realizes that Indian people know the meaning of consultation and how to get things done, then we will have taken a significant step in achieving control over our own affairs."

Michael Amarook, as President of Inuit Tapirisat of Canada, made a similar case before Justice Emmett Hall's Commission on Health Services Review. Arguing for the fundamental principle of community responsibility, he stated:

> "Give us control over our own lives, let us stop being forced to be dependent on decisions made by others whom we rarely see and who are strangers to us."

Louis Bruyere, President of the Native Council of Canada, notes:

> "There is among us leadership and commitment, but little recognition from the government side. This must alter before significant changes can occur in the lifestyle of Native people. When it changes, then the Native people can tell government services how to best deal with the problems of the Handicapped and Disabled.
>
> "We are not sure whether it is a question of dollars so much as a question of co-operation and collaboration with the people in designing and delivering programs. This has been too long absent in the administration of government programs, whether federal or provincial... It is a sad fact that a once very proud people have become dependent on the non-Native population for all the wrong reasons."

In consideration of testimony received from Native leaders, and based upon its own investigations, the Special Committee recommends: in all matters related to the design, development and delivery of services to disabled Native people, that the Federal officials involved use the following guidelines in consulting with Native representatives:

- **Consultation Structure:** The process of consultation must take the form that is understandable and comfortable to those who will be affected by the resulting policies and programs, namely, the Native representatives and their communities. There are many textbook models for consultation which may be effective within Federal bureaucracies, but which are incomprehensible to Native representatives. On the other hand, the Native communities have developed their own effective structures for identifying problems and implementing solutions. Federal officials are advised to take advantage of the consultation process which is most likely to encourage the active and positive participation of the Native representatives—and which will meet with the understanding and approval of their communities.

- **Consensus Time:** Native people live by a different time sense than do bureaucrats in Ottawa. Such considerations as "fiscal year" and "project deadline" have little meaning for a people who depend almost entirely upon consensus for major community decisions. Federal officials must realize that Native participation in a consultation process is meaningless if the time needed for reaching consensus at the community level is not planned for and protected from the outset.
- **Early Involvement:** Native persons should be consulted at the earliest possible stage of developing policies and programs. Ideally, they should be involved from the start, and consistently throughout. In a given situation, they should know what steps are going to be taken to produce policy or program changes, that is the action plan which government officials are using to organize their own internal efforts.
- **Community Priorities:** The priority for shaping policies and programs should be based first upon what is most important in the eyes of the Native people. The needs for bureaucratic efficiency and standardization come second. In the final analysis, the community needs must prevail, because people in the community will be most affected by the policies and programs.
- **Resource Attitude:** The Federal Government has enormous resources of money, personnel and technology. It is important that these be viewed strictly as resources, and as nothing more. Too often, programs and policies have been determined by the bureaucratic need to utilize these resources, regardless of whether their utilization would solve any problems. There are too many instances of government officials rushing at the end of the fiscal year to use up their budgets, and with little sense of priority or discrimination. This suggests that bureaucracies are often self-sustaining and more involved in self-perpetuation rather than in effective problem-solving. This results invariably in useless programs whose predictable failures tend to discredit legitimate, well planned initiatives.
- **Local Reality:** Ottawa is far removed from the actual places where policies and programs for Native people are implemented. Federal bureaucrats who have not travelled to and lived for a time in Native communities have little or no appreciation for the realities which can support, limit or prevent the implementation of programs. Unless Federal officials are willing to take account of their ignorance on this score, and are willing to rely on the experience and expertise of those who actually live in the Native communities, then no program, no matter how conceptually sound, has much chance for practical success.

# TWO

## DIRECT THE DEPARTMENT OF SUPPLY AND SERVICES TO DEVELOP SPECIAL INFORMATION PACKAGES FOR DISABLED PERSONS, AS WELL AS NATIVE PERSONS.

Self-help on the part of disabled persons is impossible without accessibility to information about the services, facilities, programs and other forms of assistance that can be available to them at the community level. This lack of information is a problem faced by all disabled persons, but especially those who are Native Canadians. The Native population in general suffers from a lack of information about the world outside of their communities. They are isolated geographically, culturally, and very often linguistically.

**Short-Range Need:** In the OBSTACLES report, the Special Committee recommended that a Canadian Information Centre for Disabled Persons be established through the cooperation of Federal, provincial and private organizations. Action is now being taken on this recommendation. On a long-range basis, this centre is crucial, but in the meantime, another project should be initiated which will solve some of the short-range information needs of Native and Non-Native disabled persons throughout Canada. The Committee recommends that a special information package be compiled by the Federal government in consultation with representatives of disabled persons and Native communities, and which will provide disabled persons with information noted above.

**Special Task Force:** The Department of Supply and Services has within it a special Task Force on Services to the Public which has two purposes:

- Bringing government closer to the Canadian public.
- Making the government more responsive to individual needs.

In carrying out these purposes, the Task Force has created and published an Index of Federal Government Programs and Services, which features a detailed cross-referencing system. It is recognized within the Federal Government, that the Task Force and its Index has filled a major gap in bringing together information on access to the Federal Government and its services.

**Compile And Publish:** In view of this existing service the Special Committee recommends that the Task Force on Services to the Public be given the responsibility of compiling and publishing an information package on services and programs for disabled persons. In carrying this out, the members of the Task Force should do the following:

- Consult with provincial and private sector organizations which also provide programs and services to disabled persons.
- Consult with representatives of disabled persons and their organizations, to ensure that the basic information needs are clearly outlined and approved by people who will be using the information.
- Consult with representatives of Native organizations to ensure that the special needs of disabled Native persons are taken into account.

**Good Start:** Currently, the Bureau on Rehabilitation at the Department of National Health and Welfare is preparing an inventory and directory of information related to the needs of disabled persons in Canada. The inventory deals specifically with Federal programs and services, while the directory identifies provincial and non-governmental sources where disabled persons can receive

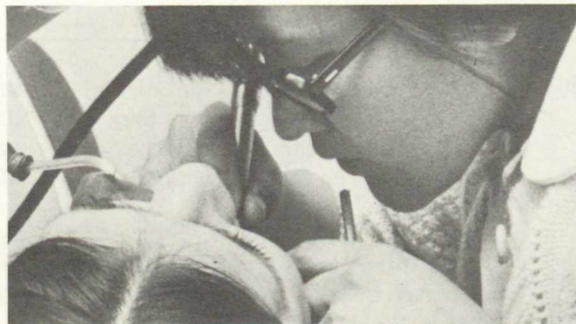
information and assistance. This is a good start and all information that is organized by the Bureau on Rehabilitation should also be incorporated in the information packages which are being called for by this recommendation.

**Basis for Centre:** In the long-run the publication and distribution of this information may prove to be a cornerstone of the Canadian Information Centre For Disabled Persons. As soon as the Centre is established, then the responsibility for up-dating the directory of services and programs can pass from the Task Force to the officials of that new organization. In the meantime, the Special Committee sees the Task Force On Services To The Public as the appropriate organization to provide this essential information.

**Distribution:** The Department of Supply and Services has fourteen walk-in information centres and eight other mobile units which can provide information on Government services to disabled Native persons in major population centres across Canada. These Service Bureaus have been set up to help all Canadians gain access to Federal programs and information. They are equipped and designed to accommodate the needs of the disabled and other disadvantaged groups. Specially trained staff provide face-to-face responses to queries about the complete range of Federal programs. The Special Committee recommends that the information packages referred to above be distributed through these Service Bureaus, at least until a distribution method can be developed which will reach disabled persons at their community level.

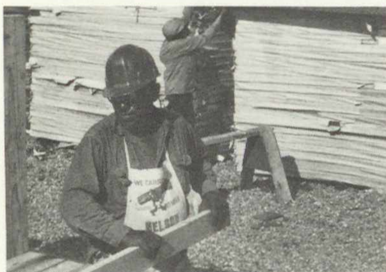
* * * * *

# THREE



## PROVIDE RESOURCES TO THE "JOINT COUNCIL", TO IMPROVE IMPLEMENTATION OF POLICIES TO HIRE NATIVE PERSONS IN THE FEDERAL SERVICE.

In the OBSTACLES report, released last February, the Special Committee clearly established that increasing employment opportunities should be the central strategy by which disabled persons can help themselves. Among those disabled persons who are Native Canadians, this need for more jobs is even greater because the entire Native population faces high unemployment. Before the special needs of disabled persons can even be addressed in this matter, attention must first be focused on increasing employment for all Native persons. The Federal Government has already recognized this objective in principle; the time has now come to back up words with actions, especially as they relate to increased employment opportunities within the Federal public service itself.



**Federal Policy:** On November 15, 1978, Treasury Board and the Public Service Commission jointly issued a policy statement intended to increase the participation of Indian, Metis, Non-Status Indian and Inuit people in the Federal public service. That policy was developed with the assistance of several Federal departments, as well as the National Indian Brotherhood, the Inuit Tapirisat of Canada, and the Native Council of Canada. Among the actions that the policy statement calls for are the following:

- **Identify positions:** Federal departments with program responsibilities for Native people were to identify staff positions which related to the delivery of services to Native people. At the time, this applied to approximately 60 organizations. The long-term intent was to staff the identified positions with qualified Native people. Each department was to devise an action plan on a tight time schedule, so that the goals of increasing the quantitative and qualitative employment status of Native persons would be achieved. In other words, hire more Native persons in general, and ensure that more of those who are hired are promoted to management positions. If the intent of this policy was to develop a participation rate that is consistent with the percentage of Native people within the general Canadian population, then 12,000 Native persons should be employed eventually throughout the Federal public service.
- **Special Responsibility:** The Office of Native Employment, which was established in 1971 within the Public Service Commission, was given special responsibility to facilitate this activity and ensure that the intent of the policy was understood and acted upon within the entire public service.
- **Joint Council:** Following the release of the policy statement, the Government formally established a Joint Council to advise on the best way to implement the policy initiatives. This Council was comprised of senior representatives of Treasury Board and the Public Service Commission, and also from five associations which represent Native persons in Canada: The National Indian

Brotherhood, the Native Council of Canada, Inuit Tapirisat of Canada, the Native Women's Association of Canada and the National Association of Friendship Centres.

**Implications:** The Special Committee understands the wording of this policy and the creation of the Joint Council to mean three things when it comes to actual implementation.

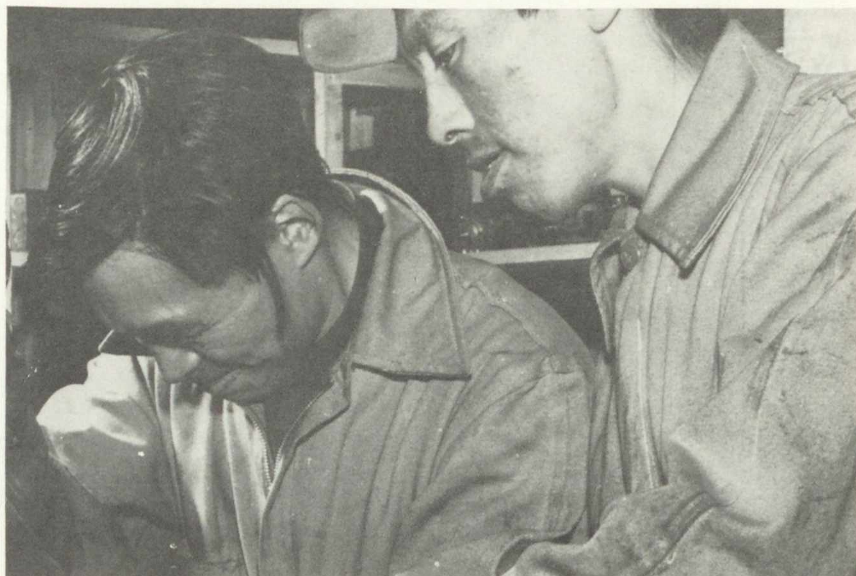
- **Significant Increase:** That there should now be evidence within the Federal public service of a significant increase during the past three years in the possibility of hiring Native persons, and that significant progress should have been made by now toward a target of 12,000 persons.
- **Significant Resources:** That the Office of Native Employment would have been given significant financial and personnel resources to carry out the mandate that is stated above.
- **Significant Consultation:** That Native representatives on the Joint Council would become integral participants in the implementation of programs which increase the employment possibilities for Native persons.

Such has not been the case.

**Little Action:** Regardless of what discussions may have taken place concerning these matters over the past three years, there has been very little improvement in either the quantitative or qualitative employment status of Native persons. As far as quantity goes, there has been only a net increase of 500 persons, bringing the present total to 3,000. There are approximately 300,000 public servants working for the Federal Government, and approximately 10%, or 30,000 of these leave each year as a result of retirement or resignation. That means that of the possible 90,000 replacements over the past three years, only 500 positions have been found for Native Canadians.

**Little Influence:** Regarding the increased quality of employment, that is, the promotion of Native persons to management positions within the public service, the following figures speak for themselves: There are at present 5,000 public servants who are considered to be in senior executive positions. Of these, only sixteen are Native Canadians. Given the importance of managerial power and status to influence and implement policy in any area of the Government, it is small wonder that Native Canadians have such little success in determining the policies which affect them.

**Shift Responsibility to Treasury Board:** The Special Committee has also ascertained that the Office of Native Employment has received very little support or emphasis. During the time since the policy statement was released, the Office has had sufficient resources to call for departmental actions plans, but has lacked the resources to pursue the overall employment policy aggressively. It is difficult for the Members to see how such an organization could possibly facilitate the significant actions which were called for in the policy statement. To this date, the action plans have resulted in several voluminous reports about good intentions, but not action. The Special Committee feels that of the sixty organizations which directly deal with the Native population, only three have shown exemplary activity in providing greater employment opportunities for Native persons. They are the National Archives, the Royal Canadian Mounted Police, and the Department of Public Works. The Committee Members also perceive that Treasury Board has not been as influential as its mandate allows in this whole initiative. The Members recommend, therefore, that the Treasury Board take over the analysis of departmental action plans. This will do two things: One, it will ensure a more effective use of Federal funds in the whole effort to increase the hiring of Native persons, and two, it will free the office of Native Employment to pursue



practical programs to train and place Native persons in Federal jobs as soon as these jobs become available.

**Eighteen Month Refusal:** The Members of the Special Committee have also ascertained that the Native representatives on the Joint Council, mentioned above, were not provided with either practical resources or expertise necessary to give useful advice to the Government on how to implement employment programs. By and large, these were Native leaders who did not live in Ottawa, who were not familiar with the hiring policies and procedures of the Federal public service, and who could not afford to research and determine the recommendations for effecting policies which were the responsibility of the Federal Government. The Government, in response to this complaint, encouraged the five associations to submit a proposal which would state what kind of resources would be required. The associations agreed among themselves that their mandate could best be carried out by a working group of hired specialists who understood the matters involved in Federal hiring practices, and that for this, each association would require $40,000 to pay for salaries and administration. The Government considered this proposal for eighteen months and then refused it.

**Key Issues:** The five associations, notwithstanding the lack of Federal support in this matter, have met to identify the key issues which should be considered by the Joint Council. The Native representatives feel that three issues must be fully explored before any significant improvement can occur in the hiring of Native persons within the public service.

- **Closed Competitions:** Many departments in the Federal service staff their units through closed competitions. In other words, the news of job openings is transmitted only to employees who are already working within the department. Persons outside of the departments, including Native persons, have no way of knowing about the possibility of jobs. The associations feel that closed competitions constitute a legal way of discriminating against Native Canadians. This may not be the intent, but it certainly is the result. The associations recognize that open competitions are more costly and time consuming, but they feel that if the whole issue is explored, other alternatives can be found.
- **Selection Standards:** The associations suspect that there may be a number of artificial barriers to the employment of Native people. These would include educational factors which are unrealistic given the role that Native public servants will play in the delivery of services to their own Native communities. The associations feel that standards should be weighted so that proven ability, credibility with the Native communities, and communication skills balance some of the educational factors. They recognize that if a Native public servant wishes to move elsewhere in the public service, to departments that are not directly related to the delivery of services to Native Canadians, then he or she must meet the qualifications that pertain for that position. The point to be emphasized here is that many Native candidates, who would work directly with programs related to Native communities, are being judged by criteria based on the educational requirements needed for public servants who are working with the Non-Native Canadian population.
- **Orientation Programs:** The associations feel strongly that many managers in the public service refuse to hire or promote Native persons because they are influenced by public attitudes which depict Native persons as unfit for employment in the Government. They feel that such problems were also encountered at earlier times by Francophone Canadians and by women. Extensive orientation for all public servants whose work relates to the Native field is required to reverse the biases and prejudices which are reinforced by these attitudes. A co-operative approach between Native and Non-Native people is essential to develop the content and design of such an orientation program.
- **Policy Implementation:** The Special Committee recommends that the Federal Government now provide the Joint Council with the financial and personnel resources that it needs to do the job for which it was established. This will be a first step in creating greater job opportunities for Native persons throughout the Government. The Joint Council is key to providing the input which represents the interests of Native persons in Canada.

# FOUR

## DIRECT SECRETARY OF STATE TO ESTABLISH PILOT PROJECTS TO IMPROVE CAPACITY OF FRIENDSHIP CENTRES TO ASSIST DISABLED NATIVE PERSONS.

At present, there are approximately eighty Friendship Centres in urban centres across Canada. If these facilities were given additional funds by the Federal Government, they would be able to provide valuable referral services to disabled Native persons. To varying degrees, Friendship Centres perform the following functions:

- **Meeting Places:** The Friendship Centres all have meeting rooms which can be used by Native persons for both formal and informal gatherings.
- **Lodging:** Housing and lodging services, either directly or on a referral basis. The Centre in Vancouver, for example, is a large dormitory facility set up along the lines of a YMCA. In smaller Centres, there are hostel services provided, or staff members help individuals to find accommodation in the community. Along with this service, many Centres also provide meals on an inexpensive basis.
- **Workshops:** The Centres design, develop and put on workshops for the Native and Non-Native population in the community so that people can gain a better understanding of each other's culture and traditions.
- **Reinforcement**: A complete program of activities designed to increase and reinforce the awareness that Native persons have of their heritage. The objective here is to strengthen the sense of identity that Native persons have as they are going through the process of integrating into a Non-Native community.
- **Social:** A year-round program of pow-wows, dances, bingos, fairs, dinners and parades involving many members of the Native population.
- **Recreation:** A wide range of sporting events including athletic tournaments, sports meets with other community groups,—and other activities such as walk-a-thons and fitness programs.
- **Community Involvement:** Participation with other community organizations to promote greater integration of Native people into community life.
- **Counselling:** Staff members and volunteers provide counselling in the areas of employment, family living, alcoholism, other health-related matters, legal rights and education.
- **Referral:** The Centres make referral to support services in the community. These relate to such needs as employment, medical aid, rehabilitation, social assistance and welfare, legal aid, education, and financial assistance.
- **Interaction:** The Community Interaction Program. This program, operated by the Centres, funds projects in the community which foster interaction between the Native and Non-Native population. An example of this is the Ontario Task Force On Native People In The Urban Setting, a joint Native-Provincial venture committed to improving the quality of life for Natives.
- **Transportation:** Staff members and volunteers provide transportation for those who cannot otherwise travel to health centres, and other support service facilities in the community. This service is also provided on voting days.

- **Fund-Raising:** The Centres raise money to support their own activities, as well as for activities in the community at large. For example, many centres hold walk-a-thons to raise money for the Cancer Society.

**Self-Governed:** The Friendship Centres are run by elected Boards of Directors which are comprised of Native and Non-Native persons. Not only do they direct the policies and programs of the Centres, but they play a key role in building bridges to other community services and programs. In Regina, for example, the President of the Board of Directors of the Friendship Centre also sits on the City Planning Board.

**Yearly Justification:** The Friendship Centre program began in 1958, with the first facility established in Winnipeg. Not all Centres provide the complete range of services listed above, but many more would do so if they had the finances to hire, train and keep skilled staff members. At present, the Friendship Centres receive $4.9 million from the Department of the Secretary of State to be used as core funding. That means the funds cannot be used to finance their program activities. The programs that do exist are financed from other sources, such as private enterprise, foundations and provincial governments. This other funding during the present year amounts to $18.5 million. All of this additional revenue must be justified anew each year, in order to continue in subsequent years.

**Overworked, Underpaid:** Under the existing budgetary limits, the 300 full-time staff members in Centres across Canada are badly overworked and underpaid. One reason for this situation is that the expectations of Native and Non-native members of the community for service from the staff members is very high; frequently it is unrealistic. A survey was conducted in the summer of 1981, by an independent management consulting firm. This survey of 17 Friendship Centres revealed that the work of full-time staff members averaged 72 hours per week, with weekly salaries between $190 and $300. Aside from salary, there was no other compensation, such as holiday pay, sick pay or training allowances. This latter is a critical lack since the extension of programs can be done at present time only through the up-grading of existing staff members.

The 1981 survey also indicated that if the Federal Government were to take over the administration of these Centres, and operate them with Government staff members to provide the same scope and quality of services, the cost of running the Friendship Centre program would exceed 200% of the present budget and cost Secretary of State 5 times its current financial commitment.

**No Failures:** One other thing should be pointed out about the funding that the Centres receive. Over the past ten years, the Federal Government has provided the program with $5 million for capital expenditures. The administrators and staff of the Centres have parleyed that original investment into assets now worth $15 million. During the period, no Centre has failed financially.

**Disabled Left Out:** This is the backdrop against which the needs of disabled Native persons must be considered. While disabled persons can be included as part of the client group receiving services from Friendship Centres, the specific needs of disabled persons do not receive any special attention. Program funding is stretched so thin, and staff members are so completely occupied with other activities, that there exists no leeway under present economic conditions for extending programs to cover the special needs of disabled persons.

**The Recommendation:** The Special Committee recommends, after considering the potential of these Cen-

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tres to provide special services to disabled persons, that the Department of the Secretary of State develop, through the National Association of Friendship Centres a pilot project with the following objectives:

- **Referral:** Establish a referral program aimed specifically at satisfying the needs of disabled Native persons. The funding of this referral program should include additional staff and educational resources.

- **Education:** Improve the capacity of Friendship Centre staff and board members to understand the concerns of disabled persons and advocate on their behalf. This may require a special training program, as well as general information campaigns focusing on the problems and concerns of disabled persons.

- **Accessibility:** Improve accessibility to the Centres and their facilities for disabled persons. In some instances, facilities now exist on the second floors of buildings which have no elevators, making it impossible for many disabled persons to reach them.

**Permanent Service:** Little is known about the unique needs of disabled Native people. National figures on frequency and types of disabling conditions are lacking. Everyday experience indicates that disability is a much bigger problem among these people than among other Canadians. New services and assistance are badly needed, but without proper data, it is difficult to deliver help in an effective manner. The purpose of establishing the pilot project, therefore, would be to identify the ways in which disabled persons would take advantage of special services, and the frequency with which this happens. If the pilot project proves that the services are well utilized, then immediate steps should be taken to transform this temporary pilot program into a permanent one, applicable to all Friendship Centres.

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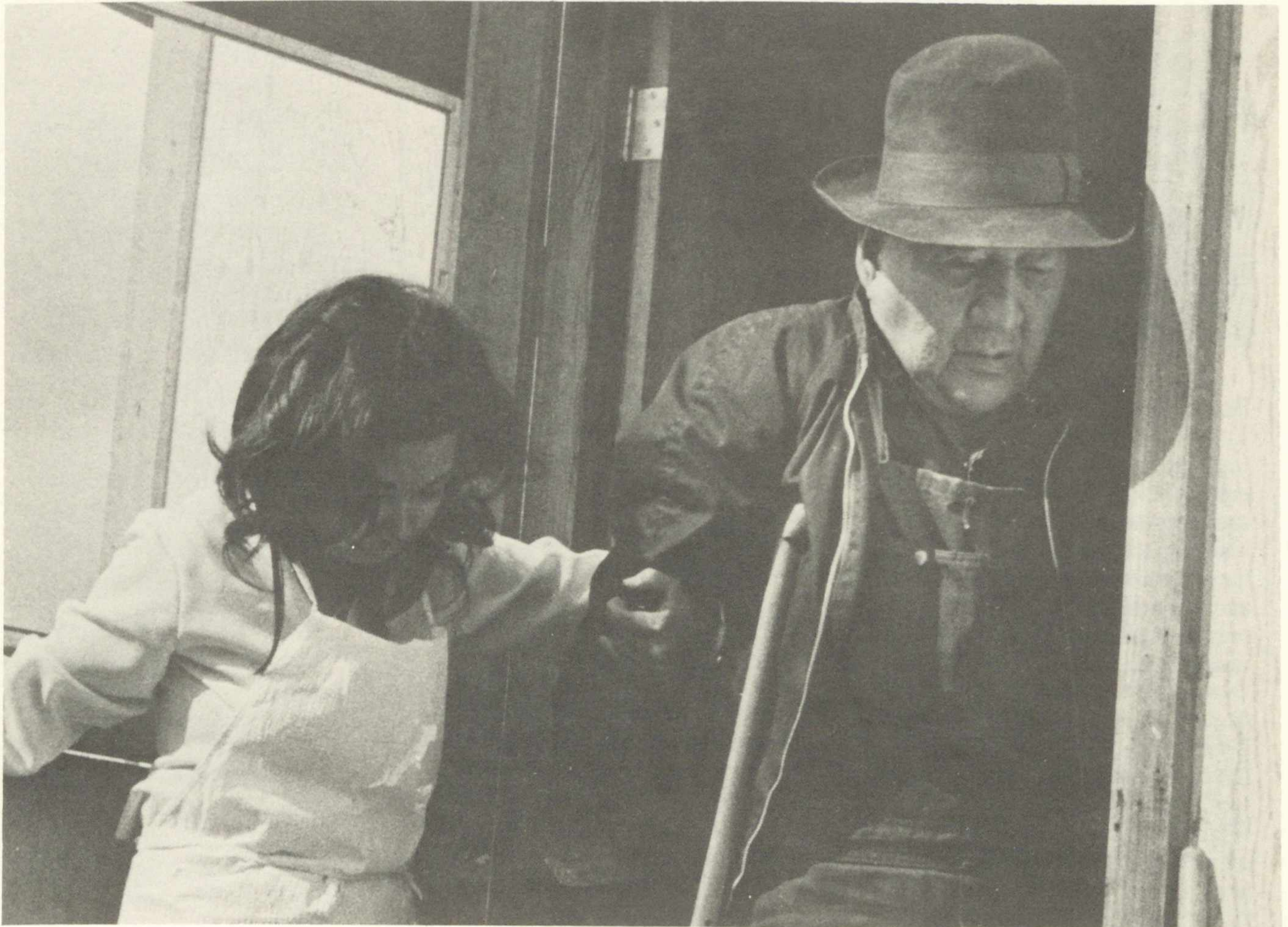


# FIVE

## INCLUDE THE NEEDS OF DISABLED PERSONS AS A MAJOR AGENDA ITEM IN THE UPCOMING NATIONAL CONFERENCE ON NATIVE HEALTH.

The Minister of National Health and Welfare has agreed to convene a National Conference on Native Health, and plans are already in motion to hold this conference in 1982. The Special Committee is concerned that the agenda of this conference include the needs of disabled Native persons as a central focus. There are three reasons for this:

**Inevitable Connection:** There is enough evidence to demonstrate the direct relationship between poor health conditions and the widespread incidence of disability among Native people. In fact, it is estimated that in some Native communities, more than 40% of the population lives with a disability of some kind. Therefore, in talking about health problems and solutions, the conference must inevitably discuss the needs of disabled Native persons.

**Cost Evaluation:** The key to major progress in eliminating the incidence of disability among Native persons lies in increasing the effectiveness of preventive health services in Native communities. The Federal Government is presently going through a period of cost evaluation of its health care programs for Native people. The Special Committee is worried that this evaluation will favour the curative side of health care over the preventive, because it is easier to measure the cost effectiveness of care given to disabilities which do occur than of care which prevents them from happening. By making the needs of disabled Native persons a central agenda item, the importance of preventive health care will be underscored at the conference.

**Wholistic Approach:** The natural tendency of traditional western medicine is to treat the health field as something separate from social, economic, political and cultural considerations. Yet within Native communities, it is obvious to anyone who has visited or lived within them, that the high incidence of health and disability problems, are direct consequences of these other factors.

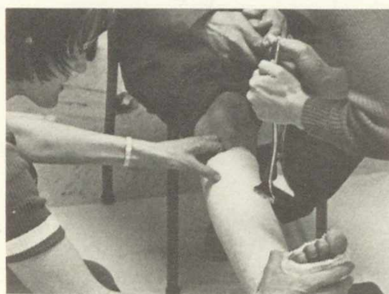
Therefore, the analysis of Native health issues must start from an attitude which incorporates a wholistic view of community conditions. The Special Committee feels that by focussing on the needs of persons who are disabled, the conference will be able to maintain an understanding of health issues which takes into account an individual's relationship with all aspects of daily community life, and how these either support or undermine healthy lifestyles.

**Representation:** With these considerations in mind, the Committee recommends that the official participation in the conference should be extended to representatives of Native people who can speak knowledgeably about all aspects of community life, including housing, employment, education, transportation and recreation—as well as about matters related strictly to health services.

# SIX

## DIRECT CANADA EMPLOYMENT AND IMMIGRATION COMMISSION TO DEVELOP AND PROMOTE SPECIALIZED PARAPROFESSIONAL TRAINING PROGRAMS FOR NATIVE PERSONS.

Under the present scheme of delivering Federally-sponsored health services to Native communities, there is a serious lack of trained personnel who can concentrate their efforts on the early detection and prevention of disabilities. This usually means that a disability can reach a serious stage before the disabled person is likely to receive medical treatment.



**Poor Situation:** In Northern Canada, for example, *otitis media* is a widespread and persistent problem for Native people. This middle-ear infection, which sometimes afflicts 80% of the individuals in a community at some time during their lives, often results in damage to the ear drum and consequent hearing impairment. At present, there are not enough trained medical personnel to concentrate on a systematic screening process to detect *otitis media* in an individual at an early stage. As a consequence, detection and treatment are hit and miss.

**Excellent, But:** There is a high turnover of public health nurses who are trained to deal with *otitis media*. Even in the best of situations, their ranks are understaffed, given the need that exists for their services in all areas of medical care. These nurses are dedicated and do excellent work. They make considerable efforts, often beyond the call of duty, to deal with the problems of disabled Native persons. But they are not members of Native communities, so their commitment to any location tends to be short term. The problems of disabilities, however, such as those caused by *otitis media*, and the programs for prevention, require a long-range continuity of attention and service.

**Further Problems:** A disability such as that caused by *otitis media* has more than medical implications. The Special Committee received the following testimony from representatives of the Government of the Yukon:

> "It is generally accepted that there is a higher incidence of middle ear infections in the Yukon and the Northwest Territories. Permanent or intermittently mild to moderate hearing loss means that the young child is at a severe disadvantage in acquiring speech and language skills. The problem is compounded still further when the child does not speak English as a first language or is not exposed at home to the standard English patterns that he needs in order to benefit fully from formal education."

Imagine the educational opportunities which are lost because this preventable disability often goes untreated or undetected until it reaches advanced stages.

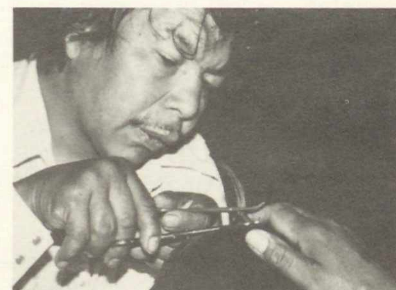
**Paraprofessional Training:** The Special Committee feels that this example clearly illustrates that the only long-term solution to problems such as *otitis media* lies in the active involvement of trained Native technicians who will deliver medical and health-related services to their own communities. In short, there is an urgent need for specialized paraprofessional training for Native per-

sons who can provide continual and consistent health care programs.

**Existing Resources:** Federal Government policies and programs already exist within the Canada Employment and Immigration Commission which, with minor adaptations, would quickly provide the practical structure for these health auxillary training programs. There also exists a Community Health Representative Program (Recommendation 12) which would immediately supply qualified Native candidates for specialized technical training. Other Federal departments, such as National Health and Welfare and Indian Affairs and Northern Development, have the expertise to help design the curricula and to provide technical assistance for the programs. The various Native organizations are eager at this time to participate in the designing of the paraprofessional roles and duties so that they relate directly and effectively to conditions and needs within Native communities.

**Flexible Program:** The Community Health Representative (CHR) program in the United States now sees more than 50% of its representatives go on for the kinds of specialized training that is being called for in this recommendation. In Canada, the CHR program, although national in scope, provides the kind of flexibility which will permit individual representatives to be trained to meet the unique needs of a specific community. At the same time, because it is a well-established national enterprise, the CHR program will ensure that standards of basic health education are met before the individual candidate enters the paraprofessional program.

**CEIC's Role:** The Canada Employment and Immigration Commission has played a major role in the development of the Community Health Representative program across the country by underwriting the training costs. The Committee feels that the Commission now has two agencies within it which can provide the expertise needed to co-ordinate the development of more specialized paraprofessional training programs:



- **The Manpower Training Branch** administers all CEIC training programs, including a special one called Training Opportunities For Natives Initiative (TONI). This Branch negotiates with provincial governments over the design and content of special training programs, and purchases these programs from the educational institutions which are operated in the provinces. Furthermore, there are a number of colleges in Canada which now provide special programs for Native students in

several social and professional disciplines. These institutions should be encouraged to tailor their programs to meet the unique needs of Native paraprofessional training. Certainly the Native organizations already involved in post-secondary educational activity could bring useful experience to the initiatives proposed by this recommendation.

- **The Native Employment Division** is a small unit which provides functional guidelines and advice to all levels of management within CEIC on the employment-related needs of Native people, and on the delivery of programs to Native communities.

**A Stronger Mandate:** The Committee therefore recommends that the Government direct CEIC to increase both the mandate and the resources of the Native Employment Division to reflect the findings of the recently released Dodge Task Force, which identified the Native population as a key contributor to the growth of Canada's labour force over the next ten years.

The Native Employment Division must be able to influence C.E.I.C.'s operations at field levels as well as the policy level in Ottawa.

There are other important issues which this recommendation addresses. As the Honourable Lloyd Axworthy, Minister of Employment and Immigration points out in his recent departmental statement on consultation:

> "Special attention will have to be paid to other groups of Canadians who have historically found it difficult to secure employment. These include Native people and the disabled, who are also waiting to participate in labour markets.
>
> Native people have for a long time been endeavouring to adjust to the disappearance of their traditional economic base. Many have been successful. Many others are still faced with serious problems in obtaining and retaining rewarding forms of employment. These problems must be solved. And it would be a tragedy if, in a region likely to experience high labour demand throughout the decade, we failed to find means to accommodating, and using in an increasingly effective way, a burgeoning and energetic young labour force already coming into place in that same region... We must take into account the economic aspirations of all Native workers when formulating new policies and programs..."

By expanding the role and responsibilities of the Native Employment Division, all of the concerns noted above will receive attention.

**Synopsis:** Together, the Manpower Training Branch and the upgraded Native Employment Division, in cooperation with other Government departments and representatives of educational institutions should undertake the development of paraprofessional training programs. The entire process should include the direct participation of Native representatives.

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**"Native people have for a long time been endeavouring to adjust to the disappearance of their traditional economic base. Many have been successful. Many others are still faced with serious problems in obtaining and retaining rewarding forms of employment. These problems must be solved."**

# MARY KOGEAHLOOK

**Yellowknife, N.W.T.**

## "Today, I have grade three, and I am very happy."

When I was nineteen years old, in 1953, I got polio. At that time I did not speak English, and I did not understand very much about what happens outside of Gjoa Haven. I was sent to the hospital in Inuvik, and there a nurse taught me to say, "I am fine, thank you." I never forgot that, and when the doctor came to visit me, I was very excited. First he spoke and I said "I am fine, thank you." Then he said, "Oh, you speak English." And I did a turn-around. I decided then that it was very important to speak English.

So I went to school right at the hospital. Before I finished grade one, they put me in grade two. Then they said again that I was too smart, so they put me in grade three. Today, I have grade three, and I am very happy.

Today I live in Yellowknife, but before that I lived for seventeen years in Inuvik. I went to Inuvik from my own little community of Gjoa Haven. That was a long time ago.

For seventeen years, I stayed in Inuvik, in my own apartment, because I knew how to look after myself. After a lot of time, I started to get sick, I got pneumonia, and I went back to the hospital. I could not go back to my community because the people were still living in igloos. Only the Hudson's Bay manager had a house. In Inuvik, it was not bad, but there were very many stairs. It was not easy for me to go to the store, and I had to count on other people to help me.

The right answer came when I moved to Yellowknife about a year ago. Here, I live in an apartment on the seventh floor, but there is an elevator. There is no problem with the stairs at my apartment. My apartment is nice, and I live here very well. I can go to the store, and I can do things for myself. In fact, I do not need anyone to look after me or stay with me. Only once in a while the public health nurse comes to help when I call her.

I like it here better than a boarding home, because I am on my own. I never get lonely, because I have many friends, and I have my sewing. I also have my own kitchen, my own living room, and I don't need anyone to cook for me. I am independent.

Since I have been here, I have been very happy with my work. I know my English is not the best, but it is good enough. For the last summer, I worked at the Prince of Wales Northern Heritage Centre. I like that place, and maybe next summer I will do that again. Right now, I do not have a job, but I am keeping very busy. I like to sew and I like to go outside. Mostly I make Eskimo dolls to sell to friends and people I meet. You never know how many people want a doll until it is finished. So far I have sold all of mine, and have not had to sell them through the co-op, because I am independent.

Just this year, I went for a visit with my sisters at Gjoa Haven, and it was a different experience. Since I have learned English, I do not use my own language very much. So, many of the words I have forgotten. I had a hard time talking to the people in the community. Not only that, but I had a hard time recognizing my own people. I had been away a very long time and I forgot some of the names. But they remembered me, and they asked me lots of questions. That was a very special trip for me, because I paid for it with my own money. Everybody was very kind, the air-plane people and all the people who helped me to make the visit. I saved my money for many years so I could make this visit. I will never forget going back to see my sisters.

I also like to go outside because I really like the cold. This is not true for many people, but I have my parka and I don't like all the heat that you get inside. Outside makes me feel very good.

# RUBEN BURNS

**James Smith Reserve, Saskatchewan**

## "It's a constant struggle to avoid the seizures and show him that we love him."

Our son Roger, who is now twenty-five, came down with encephalitis when he was five years old. That's what you call sleeping sickness and it left him with serious brain damage. At first, he was in a coma for almost a month, and the doctors said there was no way that he would recover.

He was just playing outside and he keeled over. We had to rush him to the University Hospital in Saskatoon because we were living in Prince Albert at the time. So he was paralyzed, completely paralyzed for nearly two months. He didn't respond at all until the day that his grandfather visited him. He really loves his grandfather and I guess the voice of someone he loves snapped him out of his coma. That was the first time that he even opened his eyes.

The doctors told us that maybe if he went home where he could be with his family, it might help him overcome his paralysis. And they were right, because he became almost fully recovered once his brothers and sisters started talking with him. Since then, only his slight limp reminds us that he was completely paralyzed for two months.

But the big trouble was that he developed epilepsey about three years after this first sickness. He was about eight years old when this happened, and since then much of Roger's life has been miserable and unhappy. Sometimes he has as many as six or seven seizures in a day, and this has been going on for seventeen years. He has also developed a very bad temper, which makes him tempermental. He gets stubborn and wants to fight us on everything that we do. Not the other kids, though, but with my wife and me. You know, he's a very lovable guy, and I am not saying that we don't love him. But sometimes, it is just so hard to take, what with the seizures and the outbursts. We wonder what's going on in his mind.

For awhile things got so bad that we had to send him away to the Bosco School for boys in Regina. That's a Catholic School run by a Father Larry and he was just tremendous. It really wasn't the right thing for Roger, though, because it was a school for boys who were in trouble with the law. It was the only place where we could find help, even though Roger had never been bad or cruel. He just had this problem with his temper. Anyway, he ran away a number of times. Every time he went back he just got into fights with some of the tough kids in school. It was kind of sad but we didn't know what else to do.

When Roger ran away he would come all the way back to Prince Albert by himself. I don't know how he could do it because he had seizures along the way. I know he did because he would show up at home with his face all bruised. When he's outside and the seizures come he just falls face foreward on the concrete. That must have been what happened to him. We'd always feel so bad because we knew that no one would understand what was happening to him when we weren't around.

School doesn't do much for Roger because he can't take the pressure of being asked questions. It just brings on a seizure. He doesn't have patience in the classroom, either, so I guess he is kind of unteachable. I mean he hasn't learned how to read or write. But around the home, he is very good. He has learned how to take care of himself, and he's very clean and very tidy. Even at home, however, there are pressures that really bother him. It's hard to talk to him about his problem because he gets defensive and thinks we might put him away. It's a constant struggle to avoid the seizures and show him that we love him.

For my wife and me, and for all the other children, taking care of Roger has been rough at times. Our life revolves around the care and attention that he needs. I think that you have to be very strong people to put up with this and still love the sick person. Muriel and I really can't do anything without taking Roger along. Even if we stay in bed for an extra hour in the morning it will make him so nervous that he starts banging dishes in the kitchen, or have a seizure. Lately, he has started having seizures in his sleep, and that has never happened before. We have no idea what is going on, and we feel helpless about it.

Our biggest need is to get some relief from this situation. Even a couple of days when we can be by ourselves. That would take the pressure off. I know that he won't like being separated from us, and it will cause him problems, but we also have our needs. It's funny, because if you met him, you would not think that there was anything wrong with him. He has a real nice personality, when he isn't under pressure, and everyone in the family loves him when the seizures aren't causing problems.

**"When he's outside and the seizures come he just falls face foreward on the concrete. We'd always feel so bad because we knew that no one would understand what was happening to him when we weren't around."**

We worry a lot about what is going to happen to Roger if something happens to us. We don't make that much money, but we are taking care of him right now. Muriel and I have worked most of our lives, and we have been able to raise ten children. We are a very close and warm family after all these years, so I guess we have done a lot of things right in spite of the problems.

But what will happen to him after we are gone? I know that his brothers and sisters will do their best for him, especially his older sister, but they have their own lives to lead.

We haven't received much satisfaction from the medical professionals as far as telling us what the problem is. We know that there is some kind of chemical imbalance in his brain, but no one knows much about it. Maybe there is some kind of prescription or operation that will cure the problem. One thing we won't do, however, is put him into an operation which could cost his life. Even with his problem, we want him alive and with us, rather than risking his death.

We need some help to relieve us from this responsibility, and so do a lot of other parents in the same kind of situation. I know about that, especially because of my work with Indians. I love my people across Canada, and I know that we haven't always had the services that are needed. There's always so much talk about services, and I suppose that things are better now. In the early days we were all alone with our problem and that's really rough. There are still a lot of people who are looking after these kinds of problems on their own. So many ailments and just live with them without looking for special services.

We didn't know where to turn for help with Roger, and often there really hasn't been any help there. I hope that in the future some service will be provided for people like us and like Roger. We've become strong because of him, and we know that we can keep going, but some assistance once in a while would sure help.

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# BARBARA SMITH

**Yellowknife, N.W.T.**

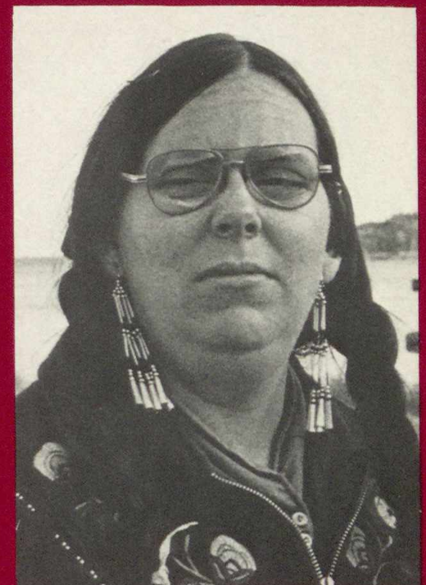
## "If you've grown up all your life surrounded by beautiful trees, water and blue skies then are plunked down in a noisy, crowded, dirty city, it's pretty scary."

I am not a status Indian but a Metis. I was born in the United States. I have four healthy sons but I am a single parent now because my husband died. After his death I moved up to Canada with my children to work for a real good friend of mine, an eye doctor. I came to Canada because I wanted to live in or near the bush. I wanted to be among Native people who still practiced their traditional way of life so my children could grow up understanding the old ways.

After what I had heard about Canada while still in the States I was surprised to find there is discrimination here too. It wasn't like in the States, but more subtle. For example, a lot of people I knew were willing to give me furniture or food or clothing but they never would come over to share a cup of coffee or visit. I finally realized that I was their charity case for that time. It wasn't very long, however, before I found lots of friends among the Native people. That's one of the beautiful things about the North. The people here didn't see me as a blind person. They saw me as a friend and someone who could help in the community. I don't think I'm exaggerating about that.

I am termed legally blind. That means I have just enough vision to keep from bumping into things. This has been the case since I was born. I feel right now like I have two disabilities; one because I'm blind and the other because I am a Native. The reason for this is the problems I face in getting services that I need. If you live in a big urban center or have lots of money, you can get most of the services that you need, but most Indian people live in rural areas and here the services are just not available. An additional problem is that most Native people don't even know what is available. No one has bothered to tell them and they don't like to leave their small communities to go to big centers like Calgary or Edmonton for training. If you've grown up all your life surrounded by beautiful trees, water and blue skies then are plunked down in a noisy, crowded, dirty city, it's pretty scary. Even people who are perfectly normal, in terms of health, don't want to go out to Edmonton by themselves. You see, in the small settlements people are very close. Extended families are real important and a child grows up with a real sense of belonging. If he has problems, say with his mother drinking, there is always an auntie or a grandma to go to. At least this is the way it used to be. Now it is changing somewhat as there is more white contact in the North.

The attitude in most Native communities toward disabled people is good. They feel a great community responsibility to take care of a disabled person. This is good in the sense that a disabled person grows up feeling like he belongs and is not an outcast. It is bad in a way because the community will always take care of him and there is no need to try new things or to try to achieve a better life for himself. A disabled person needs to know what is available in the way of services, but he also has the right to live in his own lifestyle, and at present that is not possible. If a person does not wish to



go out to a big urban center like Edmonton or Winnipeg he just does not get service. What is needed are more programs that go into the communities. You have to be practical. The instructors and people who design programs for the disabled have to be willing to change. The blind need to be able to function in their own communities, not in Edmonton. To give you an example, the mobility program that C.N.I.B. puts on teaches a person how to use a white cane in an urban setting like Calgary. But such training is useless to a person who wishes to return to his home community here in the Northwest Territories where there are usually no paved streets, but there are low-hanging branches, deep snow, and big rocks. Here a walking staff is much more useful than a white cane.

When I was young I always wanted to learn to use an axe but I was never allowed to for fear I would cut myself. If a C.N.I.B. instructor had come to my community when I was young, maybe I could have learned how to do that. I know there are blind people that do use an axe but I was never taught. Instead I went away to school where I learned to function and do things important in a white society. The point that I'm trying to make is that it is hard to get services for Native disabled people that they really need where they really need them.

Look at the blind children in the schools here in the N.W.T. They sit in their classrooms day after day with nothing to do because the schools don't have any qualified staff to teach them and their parents refuse to send them out to Winnipeg to go to school. These parents love their children and they don't want to loose them. If they go away to learn how to function as a blind person in Winnipeg they will loose their Native identity and their sense of belonging to their community. On the other hand, they are not adjusted into the mainstream of Canadian society either. They are like half-people, neither Native nor Canadian.

I'd like to tell you about something else that bothers me. You have asked me if the C.N.I.B. or any other agency has helped me find a job. The answer is no, I never received much help from any of these agencies. They talked good but did little or nothing. The jobs I've had, I found myself or got through friends. When I got out of school I tried very hard to find a job. I looked everywhere but no one seemed to want to give me a chance. Even though I had a degree I couldn't find work, even maintenance work. When I applied I was told I wouldn't see well enough to clean. I had been taking care of a family since I was 12 years old when my mother became ill with cancer. But the boss wouldn't even give me a chance.

**"Do you know what I ended up doing? I became a bar maid and go-go dancer. I didn't need the qualification of sight for that. In fact, it was just the opposite —I had to be viewed. You know, put on display."**

I couldn't even get a job doing dumb things that nobody needs training for and are usually given to Natives without any problems. But because I was blind I wasn't even allowed to do the shitty jobs that are usually given to minority people. Do you know what I ended up doing? I became a bar maid and go-go dancer. I didn't need the qualification of sight for that. In fact, it was just the opposite—I had to be viewed. You know, put on display. At the time I was proud of what I was doing because I had found that job and I did it, and I didn't have to feel inferior about it either. Really, I'm not ashamed of what I did. I was a pretty good dancer and I know that I had my job and kept it because I was a good dancer, and for that reason only. When I took my glasses off to go up on stage it was one time when I felt people were not patronizing me. I would have liked a more respectable job as a cash register lady in the dime store or something else, and God knows that I tried hard enough to get that kind of a job. But when I got hungry enough I took whatever I could get and to hell with what people thought.

When you are blind it is hard to get a chance. Today there are many programs set up to help Native people. Some of these programs I can use because I am a Native, but oftentimes they don't meet my special needs as a blind Native. There are very few programs designed to meet the needs of handicapped Native people. I would definitely say it is harder being blind that it is being a Native.

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# LIONEL STONECHILD

**Saskatoon, Saskatchewan**

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## "If I miss one session, I will become very sick. If I miss two sessions, that's about five days, I might die."

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When you look at me you probably think that I'm about thirteen years old, but actually I'm eighteen. I have a kidney problem that has restrained my growth. It's funny because little kids who are thirteen years old think that I'm one of them, and they are always surprised that I talk like an older person.

I'm used to talking about my kidney problem because so many doctors and nurses have asked me to describe my symptoms. I go for treatment at St. Paul's Hospital here in Saskatoon, so I guess I'm part of the teaching course for a lot of new doctors. They come around to see me, so I have to tell them over and over again what's wrong with me, but I don't mind because most of them are enjoyable to talk to.

**"Up until awhile ago I was in pain most of the time. My bones ached all night so much I couldn't sleep."**

The kidneys don't take the poisons out of my system, so I have to be hooked up to a dialysis machine three times a week. This cleans all of my blood. If I miss one session, I will become very sick. And if I miss two sessions, that's about five days, I might die. So being on time and making the sessions is very important for me. I think about death sometimes, probably a lot more than other people my age. But the big thing is just to make sure that I make the sessions.

Getting to the hospital has been a big problem for me and my mother. There are just the three of us, my mother and I and my sister. We used to live in Fort Qu'Appelle and that meant we'd have to go to Regina by bus, and then take another bus ride to Saskatoon. It cost us so much money for bus tickets and hotels overnight in Saskatoon or Regina, that we finally had to move here. Another reason is that I had a kidney transplant. Too much pressure and strain.

My mother doesn't have much money and there's all of the regular expenses to think about as well. We live here now, but it's still a problem because of the taxi fare to and from the hospital. I think that each month it costs me almost $120 to take taxis, and my mother only gets about $600 total from the government.

She's a great mother and she's had a hard time. Just before I got sick she lost both my father and my grandmother on the same day. And she has to take care of the house, and my sister, and make sure that there is money for my transportation. She could have put me away somewhere but she didn't. My sister spent most of her time when she was little playing in hospital lobbies because of all the time that we had to spend there.

The doctors and nurses have been very good to me, and sometimes they will lend me money for taxis when we are short. The problem is with the government agencies. We are Status Indians, but when we moved away from the reserve, no government agency wanted to take responsibility for our expenses. Sometimes the money was only available for six months or a year and then we would have to look someplace else. When the trouble first started, my mother spent three or four weeks phoning various government offices before she could even find someone who would take responsibility for this kind of service.

Up until awhile ago I was in pain most of the time. My bones ached all night so that I couldn't sleep. The bed was too hard and I'd be up until three or four in the morning lying awake just thinking. So I have had a chance to think about a lot of things in my life.

There are a lot of problems connected with the kidney failure. For one thing, I haven't grown a lot, as I mentioned, so that all of my friends are a lot bigger than I am. Actually, most of my first friends are back in Fort Qu'Appelle, so I had to start all

over here. The kids in my class are nice, and some of them come to visit me. They had a benefit basketball game for me which meant that I could buy a waterbed to ease some of the pain that I feel at night.

The other problem is that my bones are so brittle that they break very easily. One time before I had my wheelchair, I was walking across the street in front of home and I fell down. I thought I had just a bruise, but actually I broke my leg. It was so painful and puffed up that I had to go to the hospital, and that's where I found out that it was broken. The doctors used to tell me to be very careful because any kind of bump or fall could break one of my bones.

During the past year, I have been taking medication which makes the bones stronger and more flexible. And with the waterbed now it means that I can sleep at night, so I feel a lot better than just a couple of years ago. The doctors tell me that they don't think that things are going to get any worse so that's something good to think about.

I really don't think that much about the future. It's probably smart for me just to think about one day at a time. I'm just one year behind in my high school in spite of all the time that I have missed because of being in the hospital. The teachers have been really helpful to make sure that I kept up with my studies. Things are a lot better now than they used to be. If we had more money for transportation, they would be even better.

**"The other problem is that my bones are so brittle that they break very easily. The doctors used to tell me to be very careful because any kind of bump or fall could break one of my bones."**

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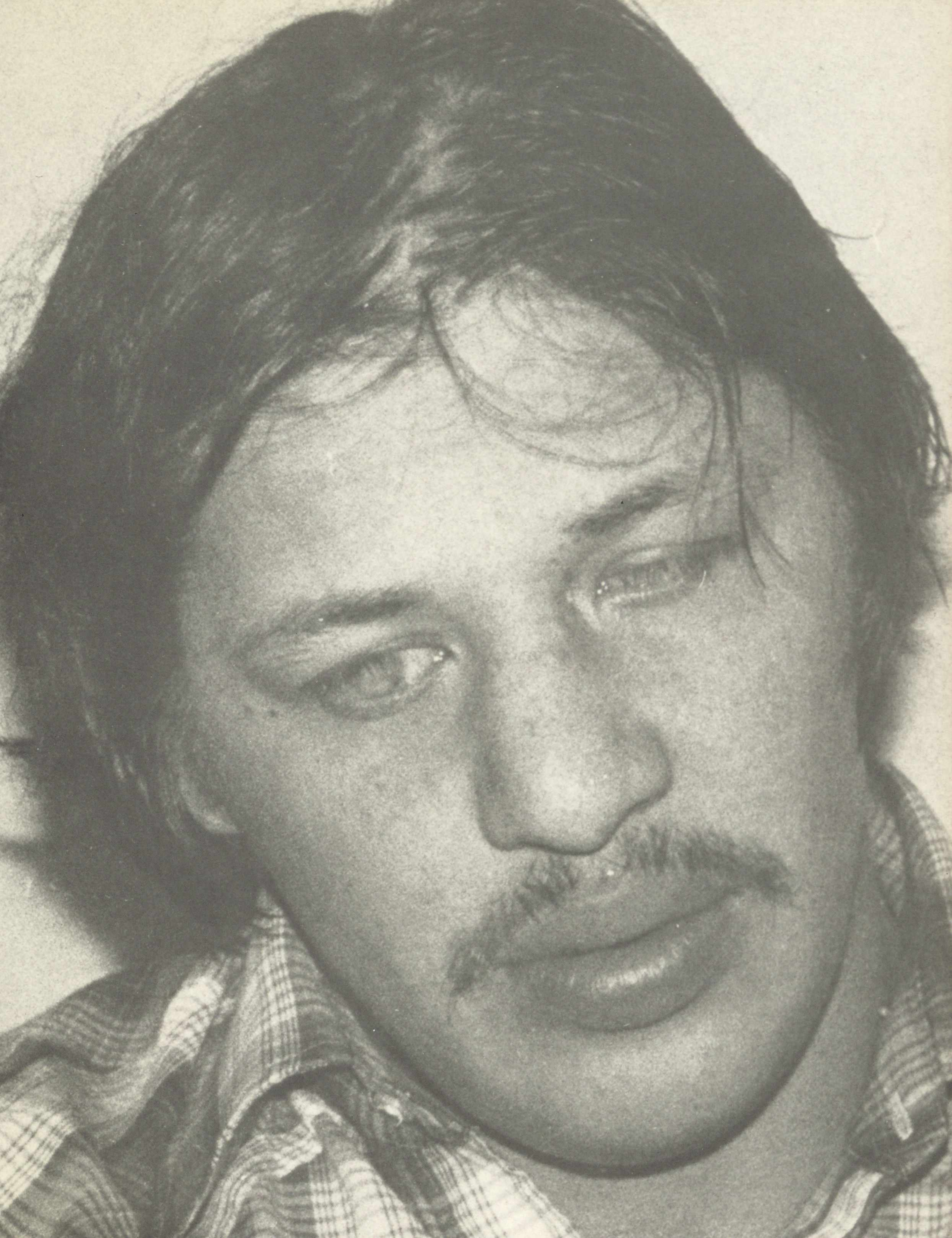


# DAVID GEHUE

**Shubenacadie, Nova Scotia**

## "I am blind, but I see all too well what's wrong with public attitudes. They're ignorant, not bad, just ignorant."

I lost my sight in 1974. My foster brother and I were wrestling. He meant to kick me in the chest but the heel of his foot caught me in the eyes. So that was that, an accident, retina detachment in both eyes. Blind.

Actually, my eyesight never was twenty-twenty. I spent about ten years in Halifax, going to the school for the blind, and in one sense, that was really hell. On Friday morning, I was at an Indian school, at home. And on Monday, I was in the big city. That's the first time I ever saw so many people, with all of those cars rushing everywhere. I thought I was going to some sort of prison. You know what I said to myself: "What the hell did I do? I didn't do anything," but there I was, nothing but a big bag of anger in a little boy.

No one ever explained that I was going to Halifax for my health. No one ever told me what it was going to be like, so I was scared. Everything was so different. I could not eat when I wanted to eat, and I couldn't play when I wanted to play. And I couldn't just be me. I lost my whole identity in that one move.

I wasn't alone, there were four other Indians. But they were from New Brunswick, wherever that was. I caused an awful lot of problems for myself and for everybody else. If somebody would have just sat me down and explained what was going on. Hell, I thought I never would be able to go home again. And there I was, stuck in a world that I didn't know how to handle.

I guess the school was pretty good. At least, they taught me some industrial arts, you know, canning and grass rope on chairs. I must have been a holy terror, because I was booted out three or four times. Finally, I made up my mind and said, "that's it, I'm going home where I belong."

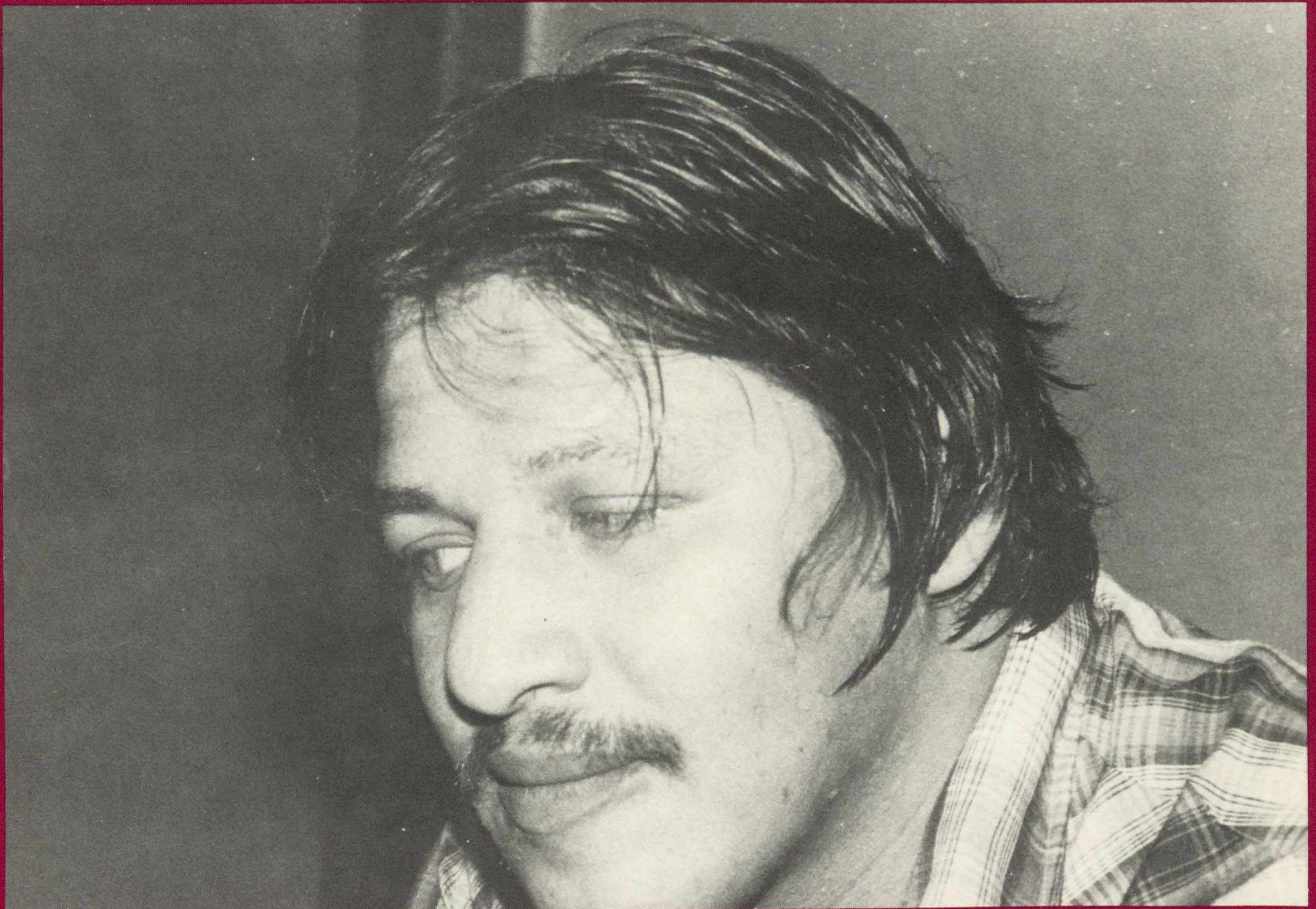
When I got here, I got into a public school and I still had some problems, but before I could sort them out, I had my accident and lost my sight completely. And I never went back to school.

You know, I don't blame anybody for the problems I've had. I'm sure there were good people around, but I guess I didn't meet them. When I was twelve years old, I started drinking. How do you like that changing your life? I seemed to drift a lot after that. I drank a lot more, and I suppose I messed up quite a bit. But people around here didn't give up on me. I got involved in lunch programs for the kids, in housing, just about everything.

I was pretty restless, and it was really tough to find a decent job. Most people think that blind people can't work. And so, I kicked around the country quite a bit. I even looked for David Gehue, whoever I am, in Alberta and Ontario, because I knew that something was missing.

My mom passed away in 1979, and I guess that really shocked me. I came home just to tell everyone that I was going to leave. And I left. I went to Princeton, Maine, and that's where I found God, and that's where I found David Gehue. I'm a lot more peaceful now, and I don't really care that I can't see you. I just care that I can do. I want to do things just like everybody else, because I know that I can. You know, I've been through hell on the alcohol trip, and I'd sure like to help other people avoid the mistakes that I made. Especially the kids.

Right now, I'm working, sometimes for pay, sometimes as a volunteer, to help kids get their shit together. If you don't grab them and give them something to cling to, then you're just inviting terrible problems for everyone.



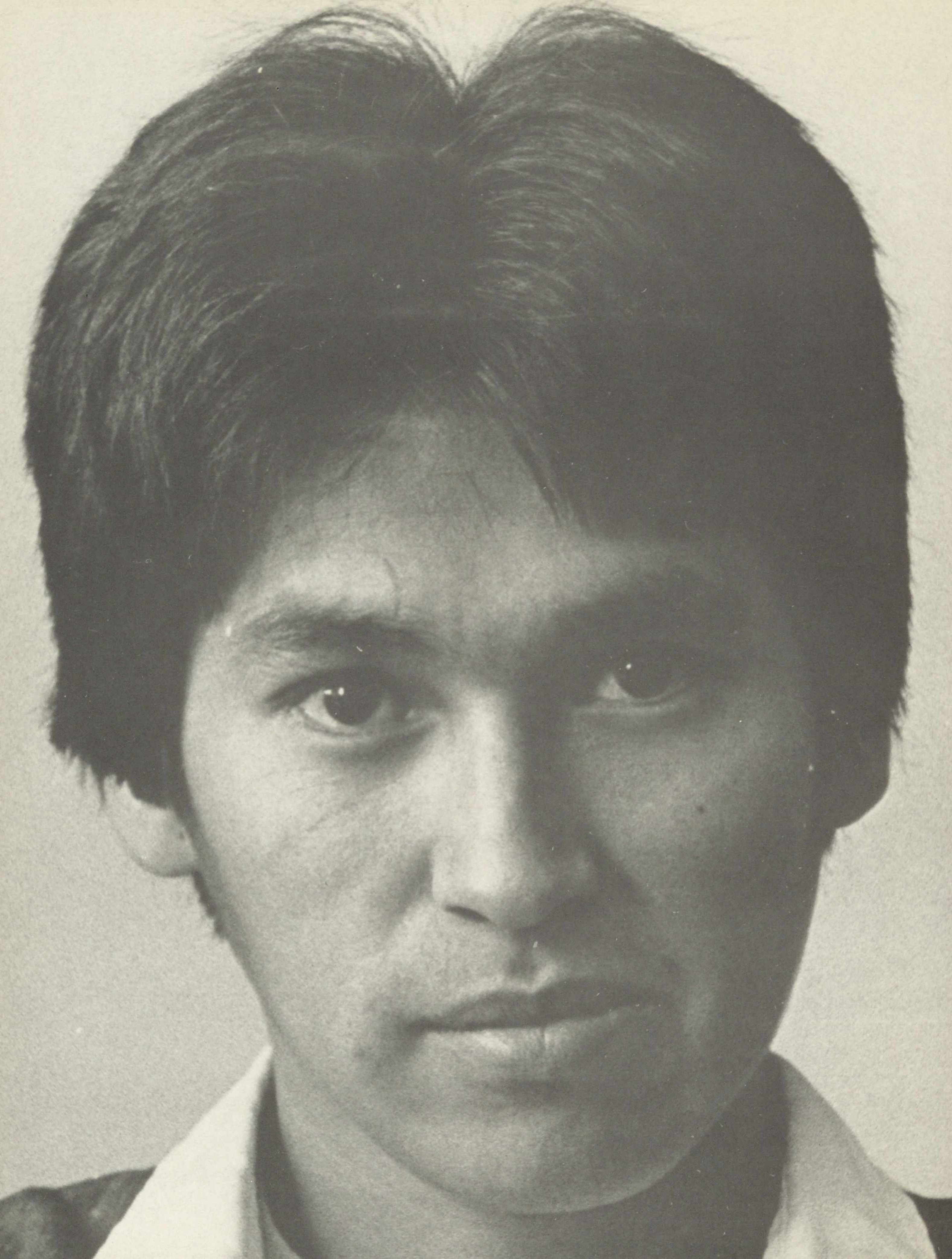
There are no schools and there are no certificates for the kind of work that I want to do. It's a demanding kind of job, which takes a special kind of person. The alcohol worker I'm talking about only lasts about three years. Then he gets burned out. If you love people, you'll do anything, anytime, over and over again. And when they slap you in the face, you're right back again. That's the kind of worker you have to be.

I don't think that I'm a disabled Indian anymore, because I know what I can do, and I know that I'm useful. But something should be said for my brothers across the country, who maybe haven't been as lucky as me. There's a great need for education, not only of the Indian people, but of the non-Indian people. We have to learn to accept one another as we are, not as we'd like each other to be.

You know, I have come home and the people here realize that, yes, he went out there and he has made it. And he's back home again. Isn't that wonderful. You see, I've got a lot more respect from them and from myself. They know I care, and I know they care.

One of the biggest problems, however, is the attitude of the public. I think the public puts disabled people in the background, because they honestly believe that they couldn't do anything. I am blind, and if I force someone to talk to me, they shout at me as if I was deaf. You want to talk about generalizations, okay, there's generalization. They probably expect me to hobble away on crutches, too.

I am blind, but I see all too well what's wrong with public attitudes. They're ingnorant, not bad, just ignorant. They need to be trained. You know, I stand on a corner, waiting to cross the street, and some good person just grabs me by the arm, rather than just offering help. But I'm not a rag doll, and I don't like to be dragged around. If you offer me an arm, I can move just as fast as you, and go wherever you want to go. It's ignorant not to be sensitive, and there's no excuse for it.



# ALLEN BOUVIER

**Yellowknife, N.W.T.**

## "You can say that I'm one of the lucky ones. I've been given a chance to do a useful job and I've been able to do it."

I was born in 1954, in Fort Providence. But when I was two, I contracted polio, and was sent out to Edmonton. I lived there for four years in the hospital, and the only people I knew were nurses and doctors. When they would take me out for walks, I would say "Hi, nurse" or "Hi, doctor" to complete strangers in the street. So they finally introduced me to the foster parent program, and I lived with these foster parents for three years and went to school.

In 1963, they wanted to send me back to my parents. In all that time, I saw my father only once. Just before I left Edmonton, he came to the hospital with TB, so I had a chance to see him.

I was kind of scared to go back home, because I didn't know much about Indians. I knew I was supposed to be one, but all I knew was what I saw on television. Little teepees, and things like that. I sure didn't see the Indians win very many things from the cowboys. So you can understand how scared I was to go back home.

Anyway, I ended up at home, and things weren't so bad. I got used to it, even walking to school on those cold winter days. I went to school at Fort Smith, N.W.T. for eleven years, but I only went home for one or two months a year. But I completed grade twelve, and I went to college down south for a year.

College was really worthwhile, because I got a job at the regional fire centre, working in forestry. And I've been there since 1974. In fact, a little while back, I took a break to train somebody else, and I applied to go into the renewable resources program.

Even though I was handicapped, people believed in me. And they knew I had knowledge and grim determination. I just graduated this year with my diploma, and I'm on my way to a new job with the Territorial Government as a fire Technician. Field trips were hard for me because of my disability, but determination got me through the program.

You can say that I'm one of the lucky ones. I've been given a chance to do a useful job and I've been able to do it. Sure there are some problems with the cane, but I make up for that in many other ways. There's a lot of work that I can do a lot better than other people. You'd be surprised.

I know that a lot of my friends who are Native run into lots of problems up here. There are problems with discrimination, and there are problems with jobs, and I guess there are lots of problems with families being separated. Anyway, all the fault isn't on one side. Lots of Natives are drunks and I don't think you can just blame everybody around for that. What I'm trying to say is that people's attitude will change on a person to person basis and you just have to keep working at that. I'm not a drunk just because I'm a Native, and you aren't mean just because you're white. For example, I'm an active player and member of the Northwest Territories Badminton Association. I may not win any trophies, but I can sure win friends by taking the opportunity and trying.

You know, you change as you get older, and I guess you get wiser, too. I know now that I could never live in Edmonton anymore. I was helped in Edmonton and I got a good start for somebody with polio, but look at what's going on in the cities today. And then come up here where it's nice and quiet. Where would you choose?

I suppose the only kind of recommendation I would like to make to the government people is that they try to move the services for disabled people closer to their homes. When people have to go to a foreign community, it's natural to adapt to the hospital there and never want to leave again. I was like that as a boy. Just consider all the beautiful things and wonderful experiences I would have missed out on if I had stayed down south.

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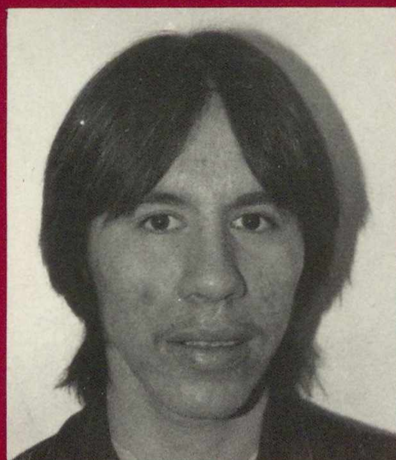
# FRANCIS McKAY

**The Pas, Manitoba**

## "You can't imagine unless you've had an experience like this the kind of fear that goes through your mind."



I'm twenty three right now, and about a year ago, I went to sleep one night and woke up a week-and-a-half later in a hospital, totally paralyzed. I don't know what happened to me, and no one else, not even the doctors who worked on me know why I have become paralyzed. I was in a traffic accident several months earlier and one doctor thinks that the paralysis might be the result of a delayed reaction to the accident. Another doctor thinks that I have some kind of virus in my spinal chord, but he's not sure. Nobody knows what the problem is.

When I woke up, I thought I had actually died and gone to heaven, or rather, hell, because it was a terrible experience. I was totally paralyzed except for my right thumb. You can't imagine unless you've had an experience like this the kind of fear that goes through your mind. There is just nothing you can do, and you don't know what's happened to you, or what is going to happen later on.

I thought about suicide several times, because it just didn't seem worth it to keep going on in this condition. And it would have been easy, suicide. It was so hard to breathe that all I needed to do was hold my breath for a couple of minutes. In the first couple of months, when I started going to therapy I would come back to my bed really depressed and ask myself why I was going on like this. I had to fight hard against the urge to commit suicide at that time.

There was this little kid in the therapy unit who really had an impact on me. He was paralyzed in this little wheelchair, and he would go up and down the aisle with a big grin on his face. I thought about myself and figured that if he could be happy, then I could too. That was an important turning point, looking back.

The other big factor in getting better was my sister, who really stuck with me during the four months that I was in the hospital. She came to see me every day and kept my spirits up by telling crummy jokes. Anything to keep my mind off the problem. I think that her support is a big reason why I'm so much better off now.

One day, we were talking and she suggested that I go on a marathon when I got out of the hospital. It was a crazy idea, but there was something about it that I liked. Anyway, it was something to think about besides my problem. It was a challenge that she was talking about, and I had a lot of energy even when I was paralyzed. So it didn't seem out of the question. When she explained it to my family, they all thought I was crazy. My family really had a hard time at first in dealing with my disability. With the exception of my sister, there was a four month period during which there was almost no communication about my problem.

**"I never had a real relationship with my father up until this time, and now there's a lot of warmth and communication."**

That's all changed now, however. Over the past six months, the attitude in the family has completely reversed itself, and the idea of the marathon has had a lot to do with it. It has opened up communication in the family, not only with me about my problem, but about a lot of other things. The illness has been a kind of trigger and the marathon became a positive topic that everybody could

talk about. It took them a couple of days, but everybody became excited about the marathon idea.

Even when we got into some heavy conversations, with some strong emotions my sister would bring the topic back to the marathon, and our spirits would pick up. So I guess it was not only important for me, but for every member of the family. We've dealt with a lot of things that hadn't been talked about for years. I never had a real relationship with my father up until this time, and now there's a lot of warmth and communication.

The planning for the marathon, or wheelchair-a-thon, took up a lot of our time and energy. We decided that I would wheel from The Pas to Winnipeg and back. That's a thousand miles roundtrip. There was so much to be done, organizing the route, getting sponsors, training, getting special equipment and, most important of all, enlisting the support of other disabled people and their sponsors. So it was a great exercise in management.

Our project was sponsored by the Pas Branch of the Manitoba League of the Physically Handicapped, right here in The Pas. And we received a great deal of assistance and financial support from hundreds of people along the route. It gave us a chance to focus attention where it is most important, on the communities of the North, where there are many other disabled people requiring the kind of attention and help that I received from my family and friends. I really hoped, as momentum for the marathon increased, that I could create an awarness in the minds of many Canadians that there are disabled people all over this country, and that they have simple needs that everyone can respond to.

I was able to cover the thousand miles this past summer in fifty-six days, and I used up seven sets of wheels and twenty-two pairs of gloves along the way. Some parts of the trip were really painful and exhausting, and there were many times when I would have to drive myself on by thinking, "Just another mile, just one more mile." There are hundreds of memories I can think of, and we received a great deal of publicity, especially from the United States. So far, the project has received $16,000 in pledges, and the money will go to the League for their work with disabled people.

Looking back, I'm happy for a lot of persons. I think that it was a challenge that has helped me to deal with my disability.

I'm also happy that the marathon has helped to focus public attention on the possibilities for improvement in the lives of disabled persons. When people get excited about doing something like the marathon, and they organize their efforts, there are very few things that can't be accomplished.

My life has changed a lot since my illness. I don't see many of my musician friends any more, but it's amazing how many old childhood friendships have started up again. There are people that I hadn't seen for ten years. My whole lifestyle and attitude toward life are much more positive. I'm only twenty-three, but I've already packed a lot of living into my life. I intend to pack a lot more into the years ahead.

**"When people get excited about doing something like the marathon, and they organize their efforts, there are very few things that can't be accomplished."**

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# CLIFFORD BONSPILLE

**Oka, Québec**

## "Here, I'm surrounded by friends, relatives and good people. A lot of people look out for me here."

I'm just in my early thirties and I know I have a lot of good years ahead of me. I've been having trouble with my kidneys for some time now. In fact, I've been going to Montreal for dialysis treatments twice a week. That's pretty rough because I have to hire a taxi from here to the village, and take the bus the rest of the way. Sometimes, on Saturday nights, the bus is crowded and there's no place to sit. So I just stand in line like everyone else. But after three hours on that dialysis machine, and all of that treatment, I'm usually very drowsy. I wonder how many people think I'm just another drunk Indian? People just don't take the time to learn about each other. That's the biggest reason why I don't like Montreal.

It's bad enough going there twice a week, and having to deal in French. But now, I'm faced with the possibility of having to stay there for a long time. The doctors have given me an ultimatum. I've got to have a kidney transplant. One good thing about that, however, is that at least I'll be able afterwards to get back out to work. I've been without a job these past four years. Before that, I worked for a treecutting company and I also operated pre-set machinery at an industrial factory. Now the doctors say I shouldn't work.

That makes it tough. It takes a lot of the human being out of me, and a lot of my dignity. I'm living on a fixed income and there's not much of that. Now I'm waiting until we can get a donor and the doctors can do the transplant. In the meantime. I don't do much of anything. Some people think I drink too much. I don't know. I spend a lot of time just sitting on the corner in the village.

It beats sitting in Montreal. Here, I'm surrounded by friends, relatives and good people. A lot of people look out for me here. Even though Montreal is closer to the hospital, it's very expensive and very unfriendly. There's corruption there, and I don't trust people with corruption in the city. You know, in the winter time, I have to move to Montreal because it's just about impossible to make my appointments for kidney dialysis from the village. I can't stand it for very long in the city, so I come back here for the week-end, every chance I get. There was a time when that was just wonderful. I'd come back and stay with my grandparents, and we would have a great time travelling back and forth on the bus, but it was worth it.

I suppose the Friendship Centre in Montreal is okay, but it's all French. And me, I do not speak much French. Hello, goodbye, a few little words here and there. They tried brainwashing me, but it didn't work. I guess I'm lost in this province, because I don't speak French and I've got my disability. But I'm not lost here.

I guess this reserve is very important for all of the Indians here, but I can see some problems. Our young people seem to be leaving to try out the big city. I know a lot of them want to come back when they find out that it was only a dream, but what have they got to come back to? Look at the housing around here. What we really need is apartment kinds of housing. Some kind of a small complex so that families are not so crowded. I actually think that a lot of people leave the reserve because it's too crowded, and then they end up getting in trouble with the law because they cannot handle the big city.

Actually, things would be a lot better for everybody if services that everybody takes for granted were closer to the reserve. Like myself, I spend a lot of money on transportation, taxis and busses. Sometimes, the welfare people pay for it, but a lot of times I do, too. I would sure be better if you could get some of those services closer to home.

**"I know in my head I'm an Indian, but it's not on a piece of paper. My mother was an Indian, but I was an illegitimate child."**

Look at my house, it's what you folks call a tarpaper shack, but I call it home. It's what my grandfather left for me. It doesn't have any running water. It has a sink, but no toilet, no electricity, and I cook on an old wood-burning stove. I gets pretty cold sometimes, right about now. I guess maybe I'll get some more insulation and fix it up.

This isn't one of the band houses, because you have to be a registered Indian to get one of them. I'm an Indian. I know in my head I'm an Indian, but it's not on a piece of paper. Everybody around here knows that I'm an Indian, and they all treat me like an Indian, but I'm not registered. It's a kind of technicality. My mother was an Indian, but I was an illegitimate child. My dad was an Indian, but he's never been identified. Anyway, there aren't any documents that say that I'm a registered Status Indian, so I don't have the social assistance and welfare system that the other people get here. I'm living on what you would call "white man's welfare".

Anyway, the key point is that I am living right where I like to be. And I don't have any big beefs. I think we have to pay attention to the young people and I think that we have to make life better for everybody here on the reserve. What I mean is that I'm not asking for special attention for me. But it would be nice to have that little orange card with a number on it. They call it an Indian Status Card given by the Department of Indian Affairs. It would help.

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# MARIE-THÉRÈSE JOSEPH

**Big Cove, New Brunswick**

## "All I need is just to walk. I will do anything to be able to walk again."

I can't remember very much about what happened before the car accident. It's hard on me, because I know one thing for sure. I almost got killed. And, oh! Jesus, I don't even know how to explain it. People tell me that I was drinking a lot, but I do not know. I think I had to forget Him, and you know who I am talking about. He owns me, He owns everybody. The Bible says God makes everything, and God owns everything. So God made me, and He owns me.

The accident was terrible. I was in the hospital for two years, just laying down mostly. My friends said that I was in a coma for six months, but I can't remember too much about that. Now I am home and I am just like a little kid learning all over again. I've got this walker. The Indian Affairs people gave it to me. So I do not need anything.

All I need is just to walk. I will do anything to be able to walk again. Sometimes, I get very tired, so I think I will take a knife and kill myself, but then I do not want to do that.

I don't have great troubles. I have good friends to help me. When I came home from the hospital, Frieda, the community health representative, was right there. She comes by and sees me all the time. Sometimes my family does not want to walk with me, because they are scared. The say that I am too fat and hard to lift up and down the stairs. But Frieda, she is right there.

So are Laura, and Mary, and Louise. It sure is great to have friends.

I know my friend down the road, Clarence. He worked on the railway for twenty-two years and now he is blind. He would be in a lot of trouble if he didn't have the homemaker coming in to help him. Just to show him where the knobs are on the stove, and how to get around his house. You see, Clarence is blind.

I know there are lots of other people with big problems. I hear about the poisoning from mercury and things like that. But I don't have any problems. All I need to do is walk.

When I get better and can walk, there is a doctor in the Moncton city hospital and he says, "Miss Therese Joseph, if you want to work, you have a job right here. It will be ready when you are done with this sickness." So, you see, my only problem is to walk.

All my friends believe that one day I will be able to walk. They make me feel good when it is cold and rainy outside. I'm not afraid to go away for the rehabilitation, and I will do all of my exercises so I can come back to my home. You know, it will be a little holiday from here, and at the same time, I will learn to walk. It might be better if I didn't have to go so far away, but I know it is worth it, just to be able to walk. I will do anything to walk.

## "The Bible says God makes everything, and God owns everything. So God made me, and He owns me."

# SEVEN

## CHANGE NNAAP PROGRAM INTO AN INITIATIVE WHICH RELATES TO THE CHEMICAL DEPENDENCY PROBLEMS OF INDIAN-INUIT PEOPLE.

The National Native Alcohol Abuse Program (NNAAP) was established in 1975 as a joint venture by the Department of Indian Affairs and Northern Development and the Department of National Health and Welfare as a response to the increasing problem of alcohol abuse in Indian and Inuit communities.

**Critical Problems:** All Native leaders agree that their most critical community problems result from alcohol abuse. Fully one-third of all deaths among Status Indians and Inuit are alcohol related, while over 60% of the Indian "children in care" arrive in that situation as a direct result of alcohol abuse. Total costs attributable to Indian and Inuit alcohol abuse approach $150 million per year. The social costs are inestimable. This is the harsh reality which so many Non-Native people cannot appreciate, and from which the disabled Indian and Inuit person cannot escape.

**Devastating Impact:** Alcohol abuse is only symptomatic of deeper problems in Indian and Inuit communities. The impact of modern Canadian society has been devastating. People have become dislocated from family and friends. Juvenile crime, child neglect, social tension and communicable diseases have become major social problems. Unfortunately, many Indian and Inuit people turn to alcohol as an escape from a grim future. Alcohol is a major and increasing cause of handicap and disability, especially among children who are born with fetal alcohol syndrome.

**Changes Needed:** The NNAAP program was designed to help communities counter the debilitating effects of alcohol abuse. Conceptually, the program is sound, but it requires major changes in its terms of reference, its organization and its administration in order to be more effective.

- **Confusion:** There is confusion at this time over who should receive support from this program and for what reasons. For example, even though it is called "Native" it does not include Non-Status Indians or Metis within its mandate; nor does it fund projects in the field of drug abuse, gas-sniffing, or glue-sniffing.
- **Complaints:** There have been complaints that the program is preoccupied with unrealistic evaluation criteria. In other words, the expectations on the part of Government officials have been very high, yet no reasonable yardstick has been developed to determine what would constitute a "success". This puts considerable pressure on the program organizers because they do not really know how it is that they are expected to justify further Government spending.
- **Inflexibility:** The program lacks flexibility in administration. For example, moneys are given out strictly on a single year basis— and are restricted to specific kinds of expenditures. This means that the local projects cannot be

planned over a number of years with any reasonable sense of security, and they are left without funds for essential facilities and staff members. This lack of flexibility undermines the development of long-term facilities and personnel which are essential to making the program effective. The time and talent of the staff are frequently used up in preparing applications for the next year's funding, or for seeking funds outside of the program.

- **Little Understanding:** Until recently, the program was controlled by a board in Ottawa which had little understanding for the special needs and initiatives on local levels. With the best will in the world, this board was not able to appreciate how unique the problems and opportunities are in each band or local community.

The Special Committee, recommends, therefore, that the terms of reference for this essential program be clarified and expanded in the following way:

- **Comprehensive:** The program should be called the Indian-Inuit Chemical Dependency Program, thereby stating for whom the services and funds are committed, and for what purposes. In addition to alcohol abuse this will allow the program to deal with the problems caused among Indian and Inuit bands and communities by the non-medical use of drugs, including glue and gas sniffing.
- **Additional Funding:** The program should receive additional moneys, twice the present amount, and should be established on an ongoing basis—so that local bands and communities can plan the development of their facilities and staff members over a number of years.
- **Decentralized:** The program should be decentralized in its administration at a pace and a direction determined by those Indian and Inuit people for whom it is intended. For example, The Cree Indians living in both Saskatchewan and Manitoba, may want to run their program in such a way that it includes bands in both provinces. But the Federal Government may prefer decentralization, when it comes, according to internal bureaucratic lines on a province or district basis. The Indian view should prevail as much as possible.
- **National Body:** A national body should be set up to serve the program as a board of review and appeal. Whenever conflicts develop at the local level, or when needs develop at the local level which call for initiatives that are beyond the terms of reference of the program, the board would be able to resolve the conflicts or represent Native community views at the national level.
- **Information Exchange:** The national body would also be responsible for improving the information exchange between the various projects across the country so that program failures and successes in one part of the country can contribute to the ongoing learning process within other projects.
- **Multi-Year:** Projects should be able to be funded on a multi-year basis, and include provisions for capital expenditures. What is the sense of renting a 16mm film projector for six months, when the same money would have purchased the machine outright?
- **Realistic Evaluation:** Project evaluation will be a key factor of the program. However, it should be done on a realistic basis that takes into account local difficulties and opportunities and resources. For example, in some bands or communities, the government structure may be such that the project can become fully operational in a very short period of time, while in other places it may take a year or several years simply to establish the foundation and staffing, before any effective program can commence.
- **Periodic:** The evaluation of the overall program should occur on a periodic basis, three to five years perhaps, and should include both empirical evidence as well as attitudinal surveys.

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# FIGHTING BACK AGAINST ALCOHOL ABUSE AND DRUG DEPENDENCY

Indian communities and leaders are creating their own programs to deal with the problems caused by alcoholism and other forms of chemical dependencies.

**Nechi:** The Nechi Institute On Alcohol And Drug Education in Alberta is an organization which designs, develops and markets training programs for persons, Native and Non-Native, who are recovering from drug and alcohol abuse. The Nechi program is funded by the Federal and Alberta Governments, as well as by private corporations including oil companies. But the Institute is entirely controlled and managed by Native persons. The programs focus on life skills which help the trainees to develop personal confidence. It also develops skills necessary for jobs in areas of retail sales such as waitresses, sales clerks and bank tellers. The success of the programs has led to working agreements between Nechi and private sector companies, and has prompted government departments in Alberta to send their own students through the training.

At present, Nechi uses one of the most sophisticated information programs in Canada in assisting its clients with drug and alcohol dependencies. The program is called the Native Alcohol Program Information System (NAPIS), and it was adapted from a similar program that was developed in the United States. Federal officials in Ottawa who have examined the system have judged it to be excellent both in design and operation. Nechi, however, has not been able to obtain funds to assist in the operation of NAPIS.

Nechi has also developed counsellor training programs for prisoners, through which the prisoners themselves become counsellors to other inmates in matters related to drug abuse.

Prison officials in Alberta have been highly complimentary of Nechi's efforts. Not only has the incidence of drug abuse been reduced, but prison officials believe that relationships between prisoners and guards are noticeably improved wherever this counselling program is in operation.

**Local Initiative:** While Nechi represents a sophisticated and comprehensive approach to the problems of alcohol and drug dependency, there is a great deal that can be done right at the community level and by the community members themselves. As Joanne Restoule, Chairperson of NNAAP (National Native Alcohol Abuse Program) points out:

> "Once the people on the reserves realize that they have the freedom to develop their own solutions to the problems caused by alcohol abuse, unique and even remarkable ways for coping will just bubble up, especially from the older generation. The elders have wisdom and experience on their side, and they really know how to get to the core of community problems. The Rediscovery Program in B.C. is just one example of how a community can deal with alcohol problems in a creative way."

**Rediscovery:** The Rediscovery Program has been operating for four years on the Queen Charlotte Islands, off the coast of British Columbia. The Program has been developed for troubled teenagers, most of whom have alcohol or drug problems. It consists of an intensive two week wilderness camp which focuses on Indian history, physical fitness, food gathering, and nature studies. Based at the ancient abandoned Haida Indian village of Kiusta, the program has proved so successful that the provincial correction service contracts for a certain number of spaces within the programs for Native teenagers under its care.

Projects like Rediscovery are the result of community commitment and action and therefore should receive support from a revised NNAAP program, as outlined in Recommendation 7.

# EIGHT

## DIRECT THE DEPARTMENT OF NATIONAL HEALTH AND WELFARE TO PROMOTE HEALTH AND SOCIAL SERVICE COMMITTEES AT THE BAND AND COMMUNITY LEVELS.

This recommendation is made to ensure that the needs of the disabled Indian and Inuit people are kept in the forefront of band and community planning as the process of self-determination develops across Canada.

**Self-Government:** Self-determination for band and local community governments is already receiving the full support of the various Federal Government departments which serve Indian and Inuit people. The Department of Indian Affairs and Northern Development has carried on a ten-year process of devolution which has called for the continual transfer of program control to Indian bands. Recently, this policy of devolution has moved up a step and has become a direct policy of encouraging self-government and community self-reliance.

**Exisiting Budget:** The Department of National Health and Welfare has received $3.6 million to support demonstration projects and special initiatives related to health and social service programs which are determined by Indian and Inuit bands and communities. The Special Committee recommends that these moneys be considered for the support of the committees described below.

**Existing Structure:** The institutions and community structures already exist in most bands and local communities to accommodate this important responsibility. Such existing representation should be used as fully as possible to avoid the development of a separate bureaucracy. In addition, the special health and social service committees should be open in membership not only to the band and community members, but also to those individuals such as local doctors, teachers, nurses and clergy who have a direct involvement in the health and social well-being of the communities. Of course the question of membership on these committees is something for each band or community to decide for itself. The committee members within each band or community will analyze their own needs and design their own programs as they see fit.

**Success At All Levels:** The concept of self-determination in local health matters was pioneered by a number of Indian tribes in the United States, and it resulted in the development of the National Indian Health Board. This Board eventually became advisory to the senior executives of Indian Health Services in the United States Government. In Canada, the Federation of Saskatchewan Indians (F.S.I.) started a campaign to motivate self-determination activities in health and social service areas. The campaign resulted in two major initiatives: The Task Force on Health and Social Services by the FSI is currently negotiating amendments to provincial legislation so that the concerns of off-reserve Indian children will be properly looked after. There is also a plan for a Saskatchewan Indian Alcohol Commission which proposes to take over responsibility for alcohol-related programs for Indians throughout the province. On a smaller, but equally significant scale, Everett Soupe of the Blood Band in southern Alberta is in the process of organizing a disabled Indian association which will bring their special concerns over housing, transportation, recreation and employment to the attention of the chief and council.

**Committee Roles:** Generally speaking, based on these experiences, the duties and activities of local health

and social service committees will probably include the following:

- **Participation:** Participation in the needs analysis, planning process and even in the administration of health and social services.
- **Advocacy:** Advocacy on behalf of specific groups, including disabled persons, within the band or community.
- **Information:** Development of information programs for band and community leaders, and the full community membership. This means identifying and explaining the needs and concerns of disabled persons.
- **Integration:** In all community planning, to participate and point out the necessary relationship between health issues and those of social services. For example, planning for housing and sanitation systems should be conducted with an eye to both health and social factors. The integration of these kinds of programs will reduce the risk of duplicate spending and wastage of resources.

**Other Support:** In addition to financial support from the Department of National Health and Welfare these committees should receive technical advice and assistance from Government officials. This could include training for the establishment of local programs, which will bring to band and community attention, the problems and needs of the disabled persons.

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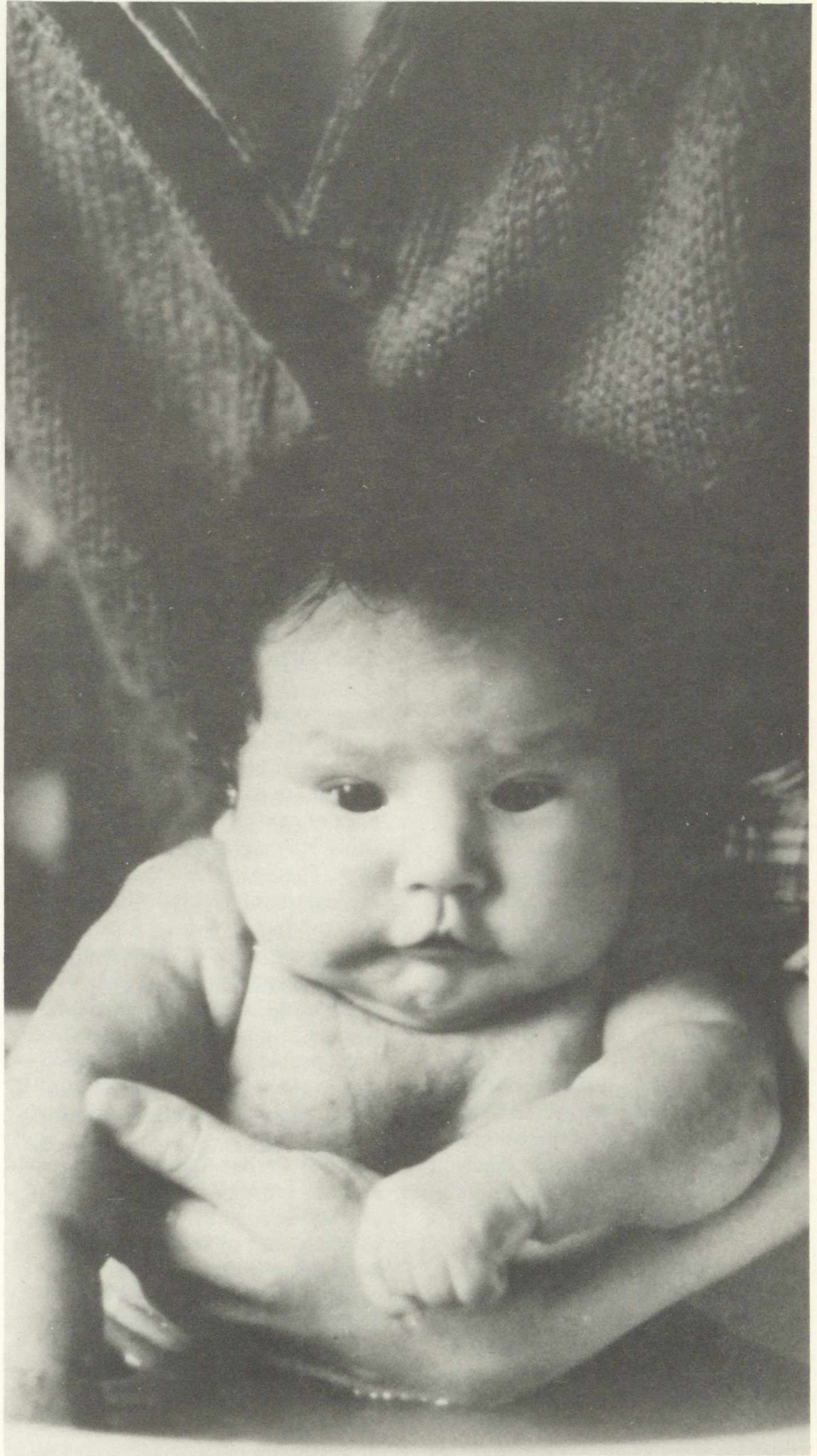


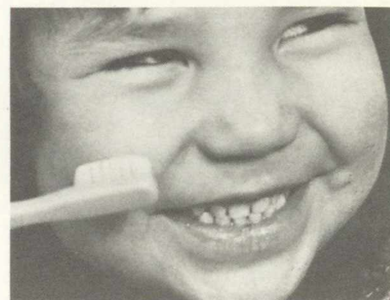
# NINE

## ESTABLISH HEALTH PROMOTION AND PREVENTION OF DISABILITIES AS PERMENANT PARTS OF CURRICULUM IN INDIAN-INUIT GRADE SCHOOLS.

Disability and the many causes of disability are such an immediate everyday reality in the lives of Indian-Inuit people, that the whole subject of disability and how to prevent it should be a major focus of education in Indian and Inuit schools, especially at the grade school level. The facts and figures which indicate the wide-spread existence of disabling injuries and illnesses clearly justify a special and major effort to make health promotion and the prevention of disabilities a central part of the curriculum in grade schools on reserves and Native communities across Canada. The earlier in life that Indian and Inuit children are informed of the special difficulties that they face, and the special dangers that they are subjected to on a daily basis, the better the chances will be that they can equip themselves with the knowledge and habits needed to avoid disability.

**Community Knowledge:** The least costly disability is the one which does not occur. Conventional health services which are provided to the Indian-Inuit people by professionals from outside the community tend to be curative in nature. They do very little to identify and to eliminate the causes of disability. The Indian and Inuit people often know best what the problems are which lead to disabilities among their families and friends. It is their experience and knowledge, therefore, which should be utilized in creating the curriculum of health promotion and prevention of disability. The assistance of advisors with specialized skills is secondary and complementary. The Special Committee recommends, therefore, that while financial and technical assistance for such a curriculum should be provided by Federal organizations, the form and content of the education itself should be determined by those Indian and Inuit people who are appointed within their bands and communities to carry out this responsibility.

**DIAND Responsibility:** The Department of Indian Affairs and Northern Development is responsible for the education of Indian and Inuit children. It directly administers a great number of the schools on Indian reserves and in Indian communities. The Department, therefore, should take the initiative in implementing this recommendation in collaboration with the health professionals who are employed by the Department of National Health and Welfare.



**Utilize Expertise:** The Department of National Health and Welfare, for its part, is already doing a great deal to promote healthy lifestyles, and to inform Indians and Inuit on ways of avoiding disabilities in their lives. However, at this point, little of this education is reaching children in the schools. The Special Committee, therefore, recommends that Government officials, professionals and any others that may be needed, should now assist Indian and Inuit representatives to design and implement the necessary curriculum for grade school children.

**Indians Point The Way:** Indians have recognized for a long time the

**"We need the opportunity to educate our people in the basics of healthy lifestyles. The greatest breakthrough in health care in our country today is the knowledge that human beings can be healthy, and can be responsible for their own health and their own lives."**

importance of prevention and health education. In a statement on Health Education, the National Indian Brotherhood made the following points:

> "The solution will come in educating people how to stay well and healthy and, therefore, how to prevent disease and disability. The solution will come with massive health education programs in our schools. We need the opportunity to educate our people in the basics of healthy lifestyles. The greatest breakthrough in health care in our country today is the knowledge that human beings can be healthy, and can be responsible for their own health and their own lives."

**American Experience:** There are several Indian reservations in the United States where the Indian people themselves control the school systems and where health promotion and the prevention of disability is a central part of the school curriculum:

- **Montana:** At the Rocky Boy Indian Reservation in Montana, an elected tribal health board three years ago established a special health education initiative in cooperation and consultation with university officials, state officials and health professionals from the private sector. A school curriculum was developed for kindergarten to Grade 8. Grades 9-12 will soon receive a curriculum presently under development. The curriculum emphasizes local values and culture, including the traditional sense of prevention as an integral part of health education. Indian staff members, with specialized training in health promotion, are currently training teachers in workshop situations so that this health curriculum will become an everyday part of each child's education.
- **Wyoming:** At the Wind River Reservation, in Wyoming, an elected health board decided to implement the School Health Curriculum Project, which is a national project developed by the Centre for Health Education in California. The latter is now in use in 2,000 schools in 29 states throughout the U.S., but not in Indian schools. The Wind River representatives implemented this project, with modifications, at four different locations throughout the reservation. The project enjoys significant community support and interest because it works. The Billings Area Office of the United States Indian Health Service, has fostered and encouraged the development of the project. They say that it has been one of the most effective methods of influencing attitudes and behaviour throughout the reservation—because the children carry the messages of good health home to their parents and friends.
- **South Dakota:** Recently, the Pine Ridge Reservation in South Dakota implemented the same program as that used in Wind River. Their own modifications emphasized intensive orientation of classroom teachers. The results have been similarly positive.

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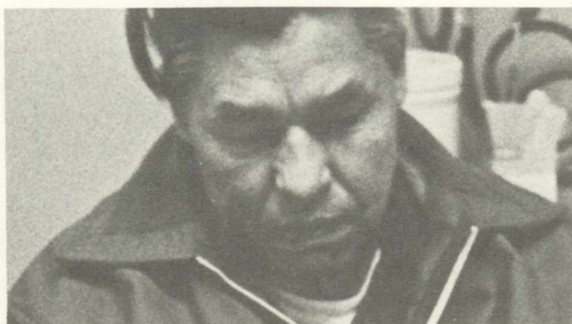
# TEN



## DIRECT DIAND TO LAUNCH AN INDEPENDENT INVESTIGATION INTO OUTSTANDING GRIEVANCES OF DISABLED INDIAN WAR VETERANS.

Indians have been involved in significant numbers, in both World Wars and the Korean War. They have never been required to serve in the armed forces, not even during times of conscription. Nevertheless, during the Second World War, over 3,000 Indians served overseas with the Canadian armed forces, and it is estimated that an equal number crossed into the United States to serve in the American armed forces.

**Benefits or Status:** Beginning with the experience of the returning Indian veterans from the First World War, there was a growing discontent over the treatment received from the Federal Government. Indian associations across the country note that Indian war veterans experienced difficulty in receiving the benefits due to them for having served in the wars. These difficulties continue today. According to the complaints, these difficulties take one of two forms: Either the veteran has been required to give up benefits as a Status Indian in order to receive veterans' benefits, or he has been forced to relinquish veterans' benefits in order to continue receiving benefits as a Status Indian.

The Special Committee received deputations from disabled Indian war veterans claiming mistreatment along the lines described above. The extent of the situation and the validity of their complaints have never been fully examined by the Federal Government.

**No Solution Yet:** There has been an undercurrent of discontent, going back to the First World War, regarding the benefits for Indian Veterans. Over the past sixty years, continual discussions have taken place on an informal basis within the Indian community, but no systematic attempt was made to resolve the issues. The controversy was brought into national focus by the death of Tommy Prince in Winnipeg in November 1977.

**Attention Focused by War Hero's Death:** Tommy Prince, the grandson of Peguis, a famous Saulteaux Indian chief, was one of Canada's most decorated soldiers, with distinguished service in both the Second World War and the Korean War. He received citations for conspicuous courage in action in Italy, Germany, France and South Korea. He served with the Royal Canadian Engineers, the 1st Canadian Parachute Battalion, the 1st Canadian Special Service Battalion (an elite unit of the famous "Devil's Brigade") and Princess Patricia's Canadian Light Infantry. He lived out his final days in a one-room hostel, alone and destitute. His only rewards for his war efforts were a chestful of medals and a small pension.

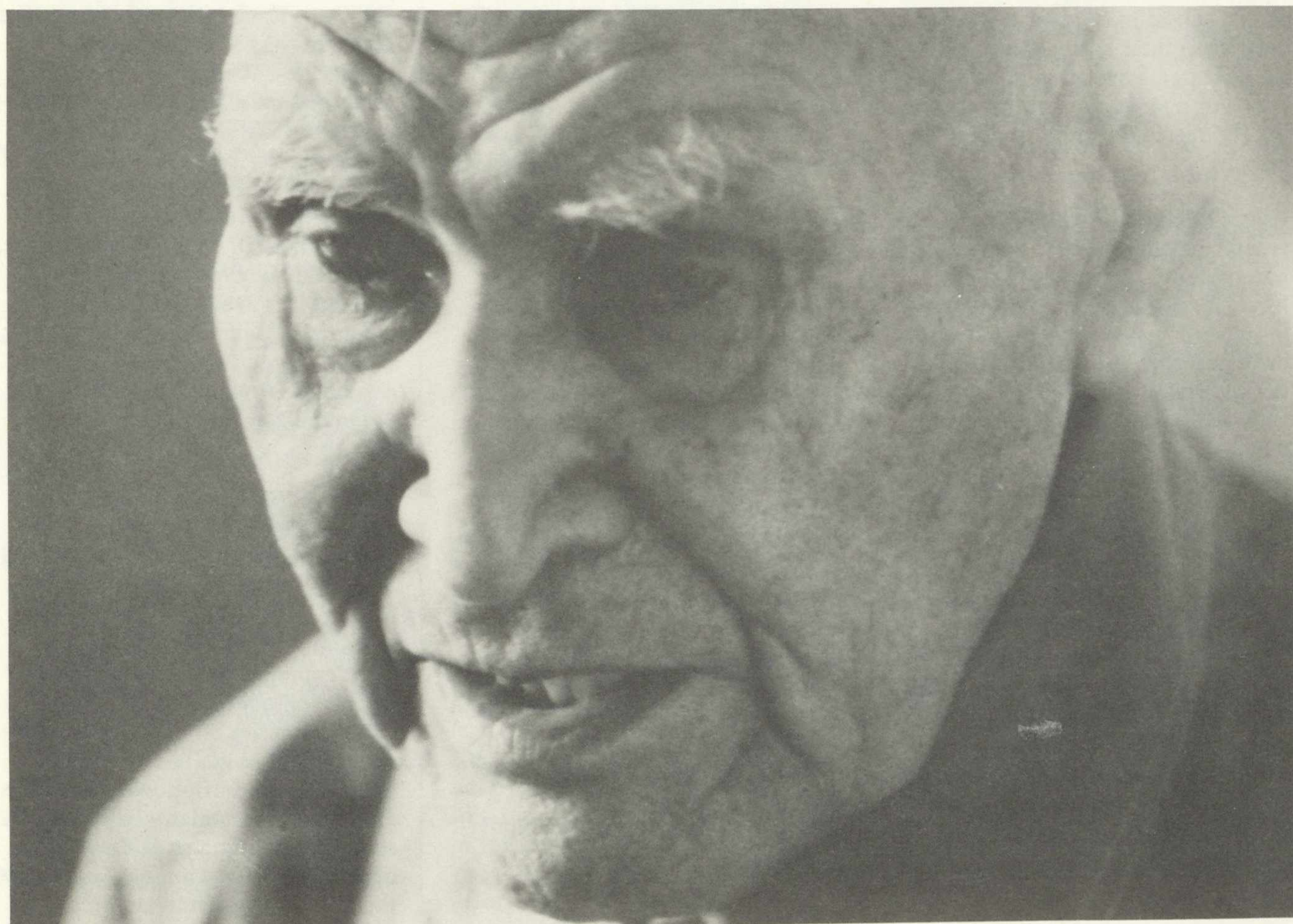
**Grass-roots Movement:** Following the death of Tommy Prince there was a renewed grassroots movement across Canada to come to grips with the whole issue of compensation to Indian Veterans. Discussions took place with the Federal ministers who were responsible for veterans and their benefits. In 1979, these local efforts led to the establishment of the National Indian Veterans Association in Ottawa. In that year, the Indian All Chiefs Conference gave an official mandate to this association to represent the concerns of Indian Veterans.

**Unavailable Files:** One of the big problems in resolving the complaints and clarifying the whole issue of

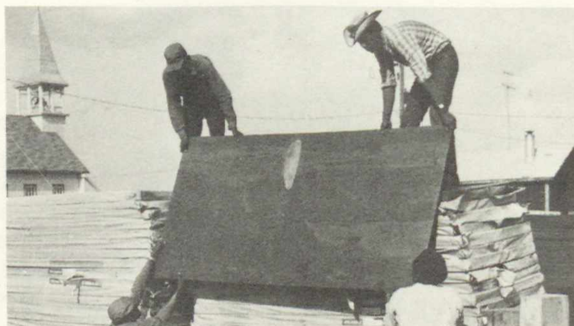
benefits for the Indian Veterans lies in the difficulty of determining what benefits have or have not been received. The National Indian Veterans Association has complied a list of 1729 men and women who have been identified as veterans with grievances. The association is seeking to obtain the files of these individuals on their behalf from the Department of Veterans Affairs, and from DIAND. So far they have had no success, since both of these Departments maintain that the files can be released only with the separate authorization of each individual.

**Independent Investigation:** The Special Committee, therefore, recommends that the Department of Indian Affairs and Northern Development, in collaboration with the Department of Veterans Affairs and the National Indian Veterans Association, launch an independent investigation into these complaints, so that the true facts of the situation can be brought to light. If the grievances are justified, steps to redress them should be taken immediately by the appropriate Federal officials. Steps should also be taken to ensure that such situations do not arise in the future.

**Authority to Examine:** The Members of the Committee recognize the importance of a specific examination of individual files. They therefore recommend that the independent investigator be given the authority to examine the files of all individuals who were veterans, and also those of their dependents to determine the full nature of benefits received or not. The Committee also recommends that the entire process of examination of veterans records, and the clarification of issues, take place with the direct consultation and involvement of officials from the National Indian Veterans Association. In this way, doubts about what has transpired between the Departments and the Indian Veterans over the past sixty years can be dispelled, and full information will be made available to everyone who has a need to know about these matters.



# ELEVEN



## DIRECT DIAND TO IMPROVE PROGRAMS WHICH PROVIDE MANAGEMENT TRAINING, INFORMATION AND TECHNICAL ASSISTANCE TO INDIAN-INUIT COMMUNITIES.

Ultimately, the problems that disabled Indian and Inuit persons face can be solved in significant ways only when their local governments are able to take on greater responsibility for community affairs, including the special needs of disabled persons.

**Information and Awareness:** For this greater responsibility to come about, however, two things are needed: First, there must be a great increase in the information available to these local governments about the technical and financial resources from private, public and voluntary sectors which can be used at the community level. Second, there must be a concerted effort to develop the awareness and skills of communities leaders so that they can identify and obtain the information and resources needed by their communities.

**Self-Government Skills:** The Federal Government, in statements from key departments that deal with Indian and Inuit communities, has firmly established a policy of self-government for these communities. Such a policy has meaning, however, only to the degree that the government is willing to provide the resources and the training to bring about self-governing skills on the part of Indian and Inuit leaders. The use and control of information at the local level is the very essence of these skills.

**Successful Role-Models:** The Federal Government has yet to come to grips with the issue of Native managers for Native affairs in any consistent or practical way. If the Native leaders must comply with Federal guidelines then these must be taught in such a way that they serve the interests of the community. Solutions will not come through legislation, nor can they be established on demand. To plug people in without developing their management skills, or to appoint individuals to senior posts purely on the basis of their political status only invites failure. It takes time and patience to develop successful role-models among the Indian and Inuit people, and the sooner the Federal Government faces this fact with a serious degree of commitment, the sooner self-determination will become a practical reality at the community level.

**Isolated Efforts:** In the past, the provision of information to Indian and Inuit leaders regarding essential resources has been looked upon within the Federal Government as something of a luxury. When it happened at all, it depended upon the extraordinary concern and efforts of concerned individuals. For example, in the mid-1970's, a regional director of DIAND, on his own initiative, produced an inventory of programs and services available to Indian communities in his western region. He did this in two consecutive job assignments, on his own time and without a specific budget for this service.

**Resource Inventory Guidebook:** More recently, an individual at the Department of National Health and Welfare, produced a comprehensive inventory of technical and financial assistance available to Indian and Inuit communities across Canada. This inventory informed the leaders of communities on how to get assistance, where to get it, and provided them with a description of the terms and conditions under which they could control the use of these resources. He was unable to promote the guidebook effectively because it

was practically impossible for a single individual, with no official mandate or budget, to reach almost 600 different communities from coast to coast. Nevertheless, where he was able to deliver the information, it met with an enthusiastic and practical response.

- **Communal Shower:** At Fort Good Hope, N.W.T. the people of the community were able to build a much-needed communal shower with funds from the Canada Mortgage and Housing Corporation, after learning about the availability of such assistance from the guidebook.

- **Food Guide:** The people of Pangnirtung, in the Eastern Arctic, successfully sought assistance from the Hudson's Bay Company in adatping Canada's Food Guide so that it relates to the living conditions of the North. Again, they learned how to approach Hudson's Bay with their request from information provided in the guidebook. The results were so successful that the concept is now spreading across the Arctic to other Inuit communities.

- **Management:** Similarily, the guidebook helped the organizers of the Nechi Alcohol Program in Alberta. They enlisted the support of the Canadian Executive Services Overseas, a voluntary group of retired businessmen, who offer managerial training and counselling services to community organizations. From the same program, a retired accountant offered his services to the Indian band of Lennox Island, P.E.I., to develop their alcohol abuse program. The guidebook proved its value once again.

- **Leaders Agree:** Indian leaders from provincial and territorial organizations across the country share the view of Bill Cramner, Chief of the Nimpkish at Alert Bay, B.C.:

"This community has been through hell when it comes to health care and control by the Indian people. I'm glad that the government is finally coming around. At least the bureaucrats in Ottawa seem to be on our side, but that isn't enough. You can't run a local government and solve local problems effectively if all you have is partial information and semi-skilled assistance. That in itself is a disability. If Indian Affairs, or some well-informed agency could simply help Indian leaders to become aware of all the resources that are available at the community level, and how to use them, then I'm sure we could do much more for our own disabled people. It's a question of knowing what's available and then going out and getting it."

**Recommendation:** Throughout its hearings, the Committee has been told repeatedly that the availability of information about resources and programs is a crucial element in any effort by disabled persons to help themselves. This need is even more deeply felt among Indian and Inuit people, who suffer from a general lack of information about outside resources, but especially about those which relate to disabled persons in their own communities. The Special Committee recommends, therefore, that the Department of Indian Affairs and Northern Development immediately begin work to provide a comprehensive inventory of services that can be made available by public, private and voluntary organizations to the leaders of Indian and Inuit communities. In this inventory, special emphasis should be given to services and assistance that relate to disabled persons. Further, the Department should develop a program which will train these leaders in the skills they will need to be able to identify and obtain the assistance they need for their communities. The development of both of these programs by DIAND should be done with the collaboration of Indian and Inuit organizations, and with the assistance and advice of Federal, provincial, private sector, and voluntary organizations who work directly with Indian and Inuit people.

# TWELVE

## DIRECT THE DEPARTMENT OF NATIONAL HEALTH AND WELFARE TO REINFORCE THE COMMUNITY HEALTH REPRESENTATIVE PROGRAM.

The CHR program began as the Community Health Worker Program at Norway House, Manitoba, in 1961. It was established to meet the need for some kind of linkage between health professionals and the members of Indian and Inuit communities. This was a unique, co-operative venture—the first of its kind in Canada—developed in consultation with Indian and Inuit leaders.

**Important Go-Between:** The need for a linkage resulted from the inability of health professionals, faced with the cultural and language barriers, to influence the patterns of daily living which caused disease and disability in Native communities. The Community Health Representatives are Indian and Inuit persons who have a basic grounding in the public health field and who have focused on preventative education among their people. Essentially, they have served as translators in all matters related to health between the professionals and the community members.

**Community Support:** From the outset of this program, these paramedical workers have had the support of their own communities, but they have frequently lacked recognition from the health professionals. One reason for this was the high turnover rate among the professionals, which meant that the CHRs continually has to reprove their worth as essential health workers. But over the years, as the program developed, it has been the CHRs who have represented the stable and continuous part of many health service programs in outlying communities. As a result, at this time, they are now seen as an integral link in the health care delivery system to communities throughout Canada.

**Vital Resource:** Cathie Bruyere, the Director of The Health Development Program at the National Indian Brotherhood recently stated:

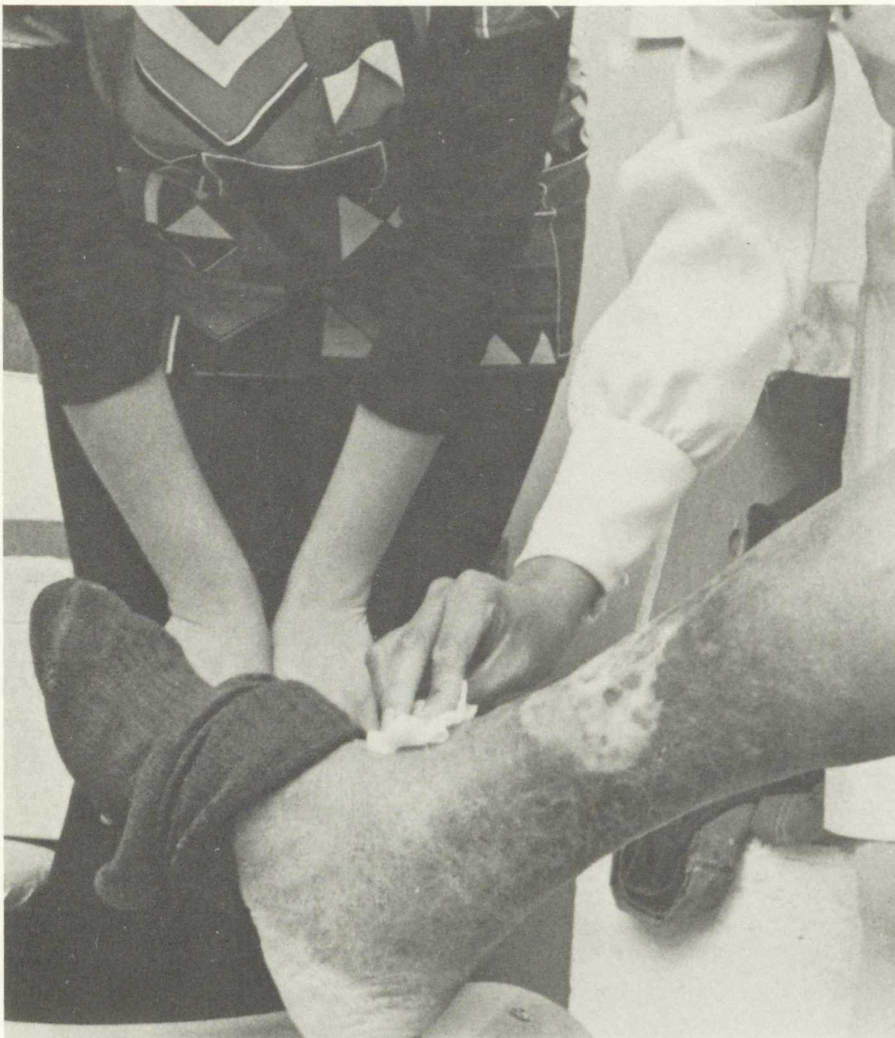
> "The Community Health Representative Program has been a great illustration of what can be achieved when Indian people become involved meaningfully in their own health care. Despite administrative problems, the program survives because it is based on sound principles of community development. There is room for improvement. The role of the CHR should be expanded so that the program keeps pace with the movement for Indian control of Indian affairs. CHRs should become specialists and be able to advise Indian governments, as well as the medical professionals, on the needs of Indian people, on the establishment of priorities, and on the recommended ways and means of providing new services. Regrettably, CHRs at this time are underpaid and frequently underemployed. And that results in a downgrading of their status within their own communities, as well as in the professional health community. They do not have a legitimate career path to follow in the health field, which makes them an undeveloped resource. I see them in the future specializing in many health categories including health administration, maternal and child health, mental health, and community health planning. The CHRs are a vital resource to their communities."

Her comments underline the intent of this recommendation:

- **Best Position:** CHRs already provide an essential service in the area of general health education, and they are in an ideal position within Indian and Inuit communities to identify and respond to the individual needs of disabled persons.

- **Historic Success:** At the present time, a national evaluation of the CHR program is being conducted jointly by Federal and Indian officials. This evaluation should take into account the historic success of the program, and the specific needs of disabled Indians and Inuit.

- **Career Opportunities:** Whatever shortcomings this evaluation may reveal, it is important to recognize the vital potential of this program. This recognition would best take the form of developing career opportunities for the CHRs, with specialization in such areas as environmental health, health education, mental health and even field nursing.



- **Emphasize Prevention:** In the meantime, in the curriculum and the recommended standards for certification of a CHR, special attention should be paid to the prevention of disabilities. A part of the CHR job should be to conduct surveys and primary care screening to identify those individuals who are prone to disabilities in their daily life.

- **Potential Candidates:** Incentives to attract more candidates into this program should include higher pay and an elevated profile for the program. As a way of introducing more potential candidates to careers in the health field, and at the same time to reinforce existing health education efforts, special student teaching projects could be developed to take advantage of major social functions such as pow wows, rodeos and treaty celebrations, all of which attract nearly the entire community population.

- **American Success:** In the United States, the CHR program has adopted all of these measures over the past ten years. In fact, over 50% of the CHRs in the United States now are trained specialists. They also play a critical role in ensuring the success of The Early Periodic Screening Program which was developed in collaboration with state and federal officials in an effort to prevent physical and mental disabilities in age groups from birth to 21. The CHRs administer this screening program on reservations.

For further discussion of the expansion of career opportunities for Community Health Representatives, see Recommendation 6 on paraprofessional training programs.

* * * * *

# WITNESSES

## OTTAWA

*Thursday, July 9, 1981*

**From the Inuit Tapirisat of Canada:**

Mr. Greg Thompson, Executive Assistant to the President.

**From the National Association of Friendship Centres:**

Mr. Bill Lee, National Executive Director;

Ms. Linda Jordan, National Facilitator.

**From the National Indian Veterans Association:**

Mr. Walter Dieter, President;

Mr. Robert Bird, Consultant;

Mr. John Dockstader, Executive Director;

Mr. Campbell Swanson, Secretary;

Mr. John Knockwood, Vice-President.

**From the National Indian Brotherhood:**

Mr. Sykes Powderface, Vice-President;

Miss Cathy Bruyère, Health Director;

Miss Joanne Restoule.

## GOOSE BAY—HAPPY VALLEY, LABRADOR

*Saturday, July 11, 1981*

Charles Fennimore, Canada Employment and Immigration Commission, Happy Valley—Goose Bay

Geraldine Fitzgerald, Supervisor of Instruction, District Vocational School, Happy Valley

Ernest Lyall, Community Council for People with Special Need

Dorothy Schwab, Occupational Therapist, Melville Hospital, Goose Bay

Suzanne O'Keefe, Social Worker, Department of Social Services, Government of Newfoundland and Labrador

Rosme Welti, Public Health Department

Regula Schule, Special Education Teacher

Hazel Williams, Survey on the Disabled, Department of Social Services, Government of Newfoundland and Labrador

Hilda Lycell, Labrador Inuit Association

Marguerite Hamel, Labrador Friendship Centre

Betti Broomfield

Beverly Massie, Manager of Social and Vocational Experience Program, Community Council for People with Special Need

Brian Massie, Community Council for People with Special Need

Maureen Fahey, Early Childhood Education Advisory Committee

Ann Brinston, Early Childhood Development Association

## NORTH WEST RIVER, LABRADOR

**(Sheshatshit)**

*Saturday, July 11, 1981*

Greg Penaschue, Band Chief

Michel Gabriel

Tony Jenkinson

Dr. Neil Hobbs

Dave and Dorothy Schwab

## FROBISHER BAY, N.W.T.

*Monday, July 13, 1981*

His Worship Bryan Pearson, Mayor of the Town of Frobisher Bay

Mr. Joseph P. Rizzotto, Secretary-Manager, Town of Frobisher Bay

Mr. David Hoe, Director of Social Services, Town of Frobisher Bay

Miss Gella Giroux, Director-Trainee of Social Services, Town of Frobisher Bay

Miss Kitty Minor, Regional Director of Social Services (Baffin Region), Government of the Northwest Territories

Simonie Alainga, Baffin Region Inuit Association

Mr. Ron Pumphrey, Baffin Region Inuit Association

Mary Padloo

Simonie Inga Metsima

Pitsialaq Arnaquq and Salomonie Arnaquq

Sammon Simonie

## FROBISHER BAY, N.W.T.

*Monday, July 13, 1981*

Ulurcaf Ainiarq

Joanasie Anirmeuq and Maliktuq Jaemesie

Harry Kilabuk

Qanirk Kilabuk

Peter Noah

Etituk Luralak

Oviloo Etituh

Nakushook Tikivik

Davidee Uluakkadlak

Lidia Charlie

Josie Peter

Jeager Lise Christensen

Shekuliaq Nakasook

Arnaquaksaq

Tommy Onalik

Jaemesie Padloo

Mattewsie Pootoolik

Attagoyooi David

Ezesiak Chickle

Aupaluk Eqevadloo

Peter Kilabak

Milurktituq Koarak

Abe Okpik

Nealee Qumaluk

Mr. Olaf Christensen

Miss Jan Lee, Physiotherapist, Frobisher Bay Hospital

Mr. Dennis Patterson, Minister of Education, Government of the Northwest Territories

Miss Jackie MacLaren, Mental Health Coordinator

*Interpreters:* English-Inuktituk

Gella Giroux
Simona Arnatiaq
Blandina Savard

## CHURCHILL, MANITOBA

*Tuesday, July 14, 1981*

His Excellency, The Very Reverend Omer Robidoux, Bishop of Churchill—Hudson Bay

Mr. John O'Connor, Councillor, Local Government District of Churchill

Mrs. Seegran Martin, Councillor, Local Government District of Churchill

Mrs. Elsie Forrest, Resident Administrator, Local Government District of Churchill

Ms. Florence Flynn, Director, Outreach Services

Mr. Donovan Attley, Alcohol Counsellor, Outreach Services

Ms. Vivian Cutler, Alcohol Counsellor, Outreach Services

Miss Linda Ponask, Community Health Worker, Outreach Services

Reverend Clark Day, Anglican Church

Mrs. Lily Wokes, Parks Canada

Mr. John Spence

Mr. Charlie Massan

# REGINA, SASKATCHEWAN

*Wednesday, July 15, 1981*

**From The Regina Friendship Centre:**

Mr. Al Robillard, Board of Directors

Chief Roland Crow, Board of Directors

Mr. Walter Stonechild, Board of Directors

Ms. Caroline Goodwill, Executive Director

**From The Federation of Saskatchewan Indians:**

Mr. Ken Sparvier, Executive Secretary

Mr. Ron Albert, Third Vice-President

Senator Edwin Pelletier

Chief Frank Marasty, Flying Dust Reserve, Meadow Lake

Mr. Walter Dieter

Mr. Aubrey Goforth, Executive Assistant to the Executive Secretary

**From The Association of Metis and Non-Status Indians of Saskatchewan (Southwest Area):**

Mr. Brian LaRocque

**From The Saskatchewan Human Rights Commission:**

Mr. Bill Fayan

**From the Regina Native Women's Association:**

Mrs. Isabelle Fayan

**Others**

Mr. Lionel Stonechild

Mrs. Isabelle MacNab

## STANDING BUFFALO RESERVE
## FORT QU'APPELLE, SASKATCHEWAN

*Wednesday, July 15, 1981*

Chief Melvin Isnana

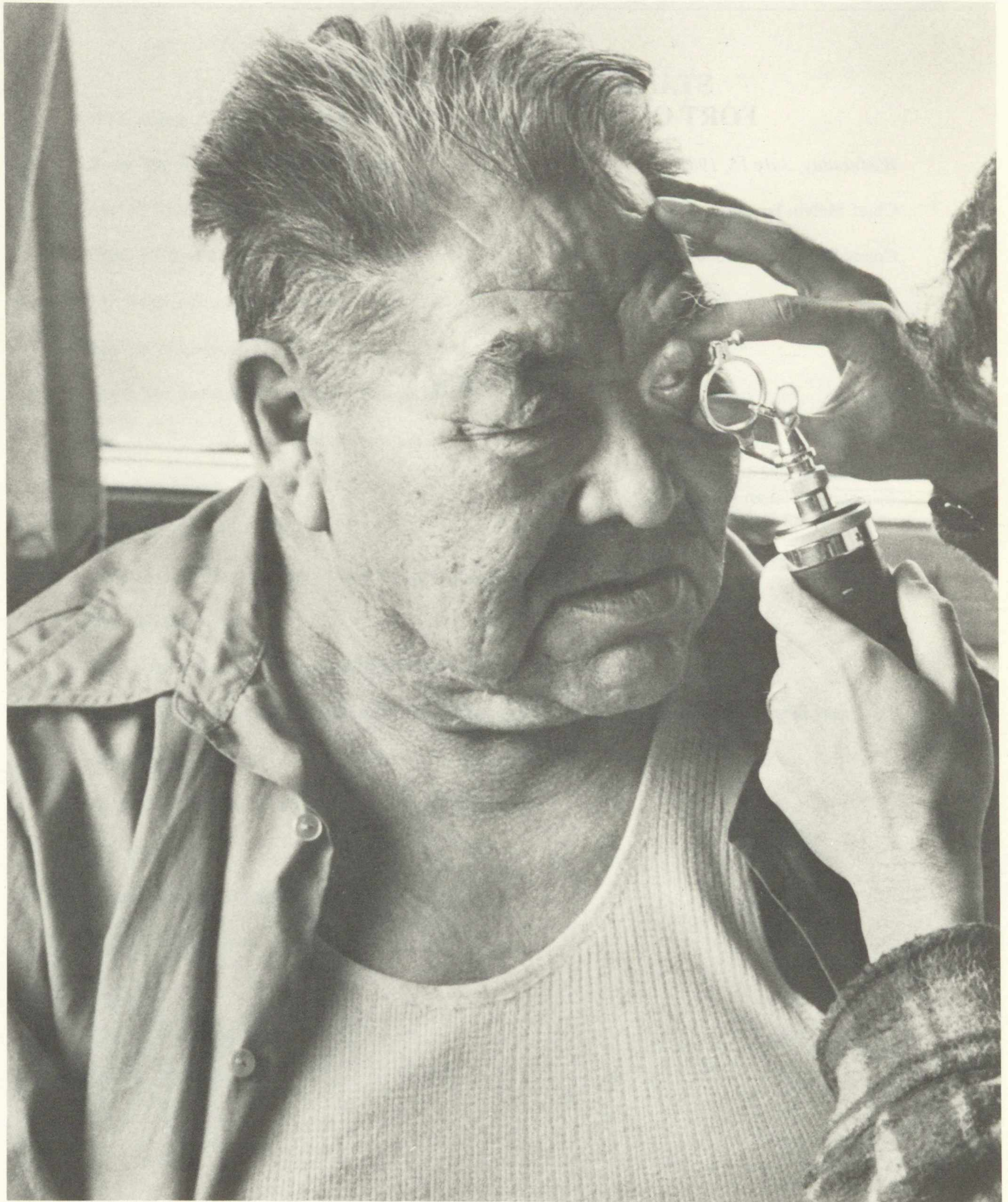
Councillor Wayne Goodwill

## OTTAWA

*Tuesday, October 20, 1981*

The Honourable John Munro,
Minister of Indian Affairs
and Northern Development

* * * * *



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Dave and Dorothy Schwab, North West River, Labrador

# PHOTO CREDITS

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# FOLLOW-UP REPORT

**NATIVE POPULATION**

DECEMBER 1981