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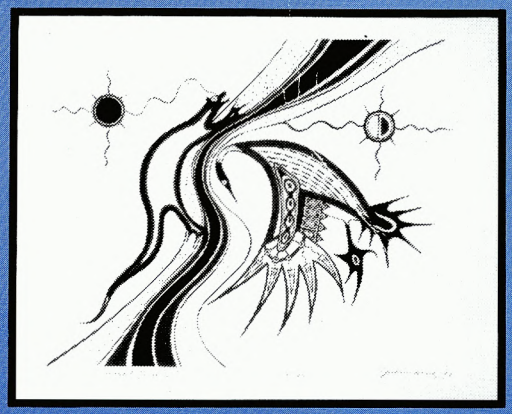

AN EVALUATION OF THE ADULT CARE PROGRAM AND ITS COMPONENT HEALTH AND HOME SUPPORT SERVICES FOR ELDERLY AND DISABLED INDIANS ON MANITOBA INDIAN RESERVES

March 21, 1986

Canada

Prepared for:

Indian and Northern Affairs Canada
First Nations Confederacy
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PROJECT STAFF

Project staff included: Dr. Ted Adam Harvey (Principal Investigator); Mr. David Groskind (Computer Programming and Analysis); and Ms. Marian Ficycz (Surveys and Data Analysis). Special recognition is due to Ms. Susan Rudnick, who was co-designer of the original study, responsible for initial consultation with Manitoba Indian Organizations in 1983, and who collaborated on re-design of the study in 1984. Other staff assisting with the study in the period 1983 to 1986 included: Ms. Caroline Hunt (Survey Design); Ms. Valorie Groskind (Health Consultant); Ms. Holly Bennett (Survey Design and Report); Ms. Sue Langton (Survey Design); Mr. Cameron Smith; Ms. Kristine Lewis; Ms. Vickie Goudanos; and Ms. Valerie Watson. Survey field staff included: Ms. Myrelene Ranville; Ms. Marguerite Partridge; Mr. Rodney Wood; Mr. Roy Redhead; Mr. Garnet Woodhouse; and Ms. Ann Thomas.

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Finally, we would like to thank those who facilitated the surveys, especially: Chiefs, Band staff and Health Service Professionals of the reserves studied; nurses of Medical Services Branch, Provincial Public Health Department and the Band nursing services which participated in the study; and the personal care homes and other Bands which participated in the study. We would also like to thank the 258 elderly and disabled Indians who agreed to be interviewed. Without their cooperation the study would not have been possible.

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EXECUTIVE SUMMARY

1. INTRODUCTION

This report is an evaluation of the Adult Care Program of Indian and Northern Affairs, and Medical Services Branch, Health & Welfare Canada, and its component services to elderly Indians and to other disabled Indian adults. The research was conducted in Manitoba, but has implications for Adult Care services across Canada.

1.1 Overview of Adult Care

Adult Care services encompass a wide range of institutional and home support services for elderly and disabled Indians on reserves. The program is intended to provide institutional or home support care to elderly Indians (age 65+), and disabled Indians ages 17 to 64, who are not able to care for themselves on their own. A stated goal of the program is to minimize institutionalization, and maintain individuals in their own homes for as long as possible.

The Adult Care Program on Manitoba reserves has the following main components: personal care homes (nursing home care); and home-support services, particularly homemaker services. As well, a variety of other services are part of the allowable Adult Care Program framework (home nursing care, meals-on-wheels, home repairs, and other services). These other formal home support services can be provided under the program but are actually provided on only a few of the 60 Manitoba reserves. The program is complex in its design, involving two Federal Departments, Indian and Northern Affairs Canada (INAC), and Medical Services Branch (MSB) of Health & Welfare Canada, along with Bands (in a delivery role), and the Province (selected involvements).

1.2 Main Evaluation Issues

The study was intended to examine several evaluation issues pertinent to program policy and delivery. These included:

- review of the *institutional care* and *home support services* provided to elderly and disabled adult reserve residents;
- assessment of Adult Care *needs* in Manitoba Indian communities;
- examination of the *appropriateness* (including cultural appropriateness) and *orientation* of both on and off-reserve institutional care and home support services provided to elderly and disabled reserve residents; and
- review of the adequacy of Adult Care assessments and professional resources to perform assessments.

2. METHODOLOGY

The study included several main surveys conducted on thirteen Manitoba Indian reserves. These included collection of related data from additional reserves, and a survey of eleven personal care homes (both Indian operated and non-Indian operated) which provided care to Manitoba Indians in 1985.

2.1 Sampling of Communities

The community survey component of the study was conducted on a sample of 13 reserves drawn from the total of 60 Manitoba reserves. These communities were randomly chosen to represent four main types of reserves: *reserves with and without personal care homes* (4 reserves with personal care homes and 9 reserves without personal care homes were studied); and *reserves in remote and non-remote areas* (11 non-remote, and 2 remote reserves).

The communities varied from very small reserves (Moose Lake, Brokenhead, Shamattawa) to very large reserves (Norway House, Oxford House, Peguis, Fort Alexander, and Sandy Bay), and included reserves in Northern and Southern Manitoba as well as the Interlake Area.

2.2 Surveys as the Main Data Source

The main survey was a personal interview survey of recipients of Adult Care services and individuals identified by Band staff as having current or potential unmet Adult Care needs. This survey was designed as a statistically representative survey of a random sample of over 250 such persons on the selected reserves. The survey was carried out through personal interviews, usually in the respondent's Native language, and involved use of a structured interview questionnaire. Community residents were randomly selected, to allow generalization to the broader sample of Manitoba's elderly and disabled Indians.

A second but very important survey gathered a variety of information including ratings by nurses of health conditions and health and social service needs of the same sample of elderly and disabled Indians included in the Community Needs Survey. Assessments included: ratings of functional ability; ratings of need for home support services, such as homemaker care, nursing care, home repairs, meals-on-wheels, etc.; and assessments of "best care" situations for elderly and disabled residents (from a health perspective).

The study also obtained information on Indian adults receiving nursing home care in personal care homes. This data was required to determine how the institutional component of the Adult Care Program has met or failed to meet the needs of Indian persons. This survey included 5 on-reserve personal care homes and 6 off-reserve personal care homes. Data on personal care homes and their patients were collected in the form of Patient Profiles for each Indian resident, and an Institutional Profile for each personal care home.

Finally, a survey of professionals and other key informants involved in Adult Care Programs was conducted. The survey included such key actors as: Nurses, CHR's (Community Health Representatives), the Chief (or his/her delegate), Band Managers, Welfare Administrators, Visiting Homemakers, Social Workers, Personal Care Home staff and NNADAP (National Native Alcohol and Drug Abuse Program) staff. The survey was conducted by means of personal interviews undertaken by trained interviewers, using a structured interview questionnaire.

2.3 Resulting Data Base

The resulting data base for the study included:

- Band assessments of functional capacity for 499 elderly and 133 disabled Manitoba Indian adults (obtained in sampling);
- structured interviews with 200 elderly and 58 disabled Indians living on Manitoba reserves (from the initial population list of 632 persons);
- 45 technical health assessments of 172 elderly and disabled Indians residing on Manitoba Indian reserves;
- technical health assessments for another 97 elderly and 24 disabled Indians from Manitoba reserves and residing in Indian operated and non-Indian operated personal care homes in Manitoba;
- assessments of community needs for Adult Care from over 60 health and social service professionals and community leaders involved in Adult Care services to 13 Bands; and
- assessments of community needs for Adult Care services from Band staff (Band Profiles) and Nurses, for an additional 24 Bands.

Data was therefore obtained for a substantial portion of Manitoba's elderly Indians living on-reserve, not in personal care homes, and for all elderly Indians in personal care homes.

Data reliability was assessed as good to excellent, on the basis of standard tests of indicator reliability and on the basis of agreement of data drawn from divergent sources (see Appendix B).

3. CONCLUSIONS

The study points to a number of major conclusions about the Adult Care Program and its operation in Manitoba. Some of these suggest major problems in program design, and to significant differences in range and level of services provided to elderly and disabled Indians as compared to services provided to other Manitobans. (References to sections of the report from which conclusions are drawn are provided in parentheses.)

3.1 Unmet Needs Are Extensive

The study identified extensive needs for home care services. These needs were strongly evidenced in reports of elderly and disabled Indians interviewed, and were also validated by Technical Health Needs Assessments provided by Medical Services Branch (MSB), Provincial and Band nurses. Most importantly, study results indicated:

- Need for **extension of home support services to a large proportion of elderly and disabled Indians in need of care.** Nurses' assessments indicated that some 40% of elderly Indians in need of home support received no home support services (Section 3.8.2), and that some 80% of disabled Indians in need of home support received no home support services (Section 4.3.2); and

- Need for **provision of a full range of home support services not now available to elderly and disabled Indians**, including home nursing care, meals-on-wheels, and respite care for families (Section 3.6.3).

The **need for emphasis on home support as compared to institutional care was underlined strongly by the views of elderly and disabled Indians surveyed in the study.** More than 80% of the elderly Indians surveyed and approximately 80% of the disabled surveyed indicated that their first preference was for care at home, rather than care in personal care homes or other institutions (Section 3.7.2).

3.2 Program Impacts are Appropriate But Imbalanced

Study results pointed towards important positive effects of existing services where these are provided:

- Most elderly and disabled Indians who received home support-type help reported that the help they received from Bands (mainly homemaker services), was the type of help they needed with everyday activities they could not do by themselves (Section 3.2.3); and

- o Available evidence seemed to support the view that on-reserve personal care homes provide more culturally appropriate care with better maintenance of family linkages than off-reserve institutions (Section 5.3.2).

Overall, however, the accomplishments of both of these program components were overshadowed by unmet needs (as noted above), and imbalances in actual program outputs, particularly:

- o Lack of the continuum of services conceptualized for the program (Section 2.3) (i.e. the range of appropriate service outlined for example in the INAC-MSB Memorandum of Agreement, 1984); and

- o Over-emphasis on institutional (personal care home) care as compared to in-home care (Section 2.3.1).

3.3 Cost-Ineffectiveness Results from Program Imbalance

Because institutional care is more readily available and home support unavailable relative to need, there is pressure to shift persons in need into **unnecessary and inappropriate institutional care.** Since institutional care is much more expensive, the result is cost-ineffective allocation of resources (Section 3.7.1 and Section 4.4.1). Considering as well, the fact that institutional care is inappropriate for many elderly and disabled Indians, it becomes clear that unnecessary institutional placement should be eliminated.

3.4 Lack of Adequate Housing Provides a Major Obstacle to Effective Care

Nurses' reports indicated that more than 75% of elderly and disabled Indians resided in inadequate housing (Section 3.8.2). This factor is critically important to Adult Care, since **effective home care for the elderly and disabled cannot be obtained in poor, ill-heated housing.** This is recognized by the emerging Adult Care Program design, which identifies home repairs as an important component of effective Adult Care, but there is no evidence to date of resources being mobilized to deal with this problem.

This lack of adequate housing appears to be a major factor in the pressure by Bands for more personal care homes. It is also apparent that many elderly and disabled Indians are now receiving institutional care not because of personal disability, but simply because they have no other place to go (Section 3.7.1 and Section 4.4.1).

These effects of poor housing are, of course, contrary to basic objectives of the program, and reflect serious program design issues. As well, the contrast between the housing situation of elderly and disabled Indians and the range of housing alternatives available to non-Indian Manitobans is striking indeed, and reflects the large gap between range and quality of services available to Manitoba Indians and those offered to other Manitobans. **Much of this problem could be remedied through adjustments in housing programs at the INAC (and Band) level to facilitate construction of senior citizens' housing units on reserves.**

3.5 Standards are Needed for the On-Reserve Institutional Component (Mainly Personal Care Homes)

The Personal Care Home Component represents an important part of the continuum of Adult Care services, but standards are needed for Indian-operated personal care homes (see Section 5.5.3). An operational review of the five on-reserve homes (or at least the four unlicensed homes) should be initiated immediately, in association with a steering committee formed by INAC in consultation with the Manitoba Indian Organizations, and the personal care homes themselves.

This review could be conducted with assistance from the Province (INAC would need to second or borrow Provincial Staff), or by a private consultant or practitioner, or a committee of representatives from licensed nursing homes (preferably with experience with Indian patients). Considering the dangers of institutional health care (e.g. the recent epidemic in one Ontario nursing home), **this is a severe responsibility, in the absence of licensing, and one that should not be neglected any longer.**

There is also a need to review the hostel care provided on three reserves. This type of care is allowable under Adult Care, but is not currently funded under Adult Care in Manitoba Region. Since such care should be more economical than personal care home care, this warrants examination.

3.6 Alternative Care Models Are Needed

There is a **need for new program models which provide for a more complete continuum of service** on reserves, including home nursing, more extensive homehelp and homemaker services, meals-on-wheels, and related services. (See Section 3.8.2 for related discussion.) Alternative care models also need to integrate this wider range of services.

New program initiatives in Manitoba may or may not include new personal care homes, but in communities where they do, care should be taken to assure that personal care homes provide support for an integrated Adult Care Program, and/or Adult Day Care -- a program where services are arranged to complement each other. Similarly, home care programs should be designed for delivery in conjunction with adult day care programs, where these can be provided. As well, adult day care programs could be coordinated with housing initiatives: where facilities suited for a day care program are to be constructed, these might ideally be co-located with senior citizen housing units.

3.7 Clarification of Program Mandate is Urgently Required

Overall, problems with Adult Care appear to stem from **lack of a clear program mandate and lack of focused responsibility in a single Federal Department.** A number of major administrative problems appear to result: lack of program staff; problems in the information system; and problems in program implementation. (Sections 2.5, 2.7, and 2.8.)

The two Federal Departments have been unclear about responsibility for this program. To allow for effective program development, one Department, preferably the one with technical expertise relevant to the program (HWC), should take the lead Federal role (Section 2.1.2).

3.8 Issues Regarding The Province of Manitoba

Problems in delivery of a comprehensive Home Care Program are intensified by Manitoba's not being involved in Adult Care. This is a problem of particular note as regards the issue of standards and licensing of personal care homes, since the Province could efficiently assist INAC and Bands in this area. (Section 2.6). As well, some Bands might wish to access Provincial services, under Federal Provincial cost-sharing agreements, as can be done in Ontario and Quebec.

Lack of access to Provincial services is a major problem, since it restricts Bands' service provision options. Resolution of this problem, to allow Band access to Provincial services, would allow elderly and disabled Indians their due access (under appropriate Federal-Provincial cost-sharing) to the home care services which other Manitobans enjoy.

3.9 New Policy and Program Planning Mechanisms are Required

A number of problems in the Adult Care Program have gone unresolved over long time periods because of the **lack of a central steering body.** As well, effective treatment of program issues may have been hindered by the **lack of a mechanism for Indian participation** in this policy process. (Evaluator's conclusion, see Section 2.7, for discussion of INAC-MSB coordination.)

Accordingly, it appears that there is a **need for a new steering mechanism** for Adult Care, both Nationally and at the Regional level. A new steering body would have senior representation from major Indian Organizations, as well as INAC and HWC, and would be designed for possible eventual inclusion of the Province. As a policy-making group, it would introduce significant Indian input to the Adult Care policy process.

3.10 National Implications

Study results reveal an Adult Care Program which lacks a clear National mandate and structure for implementation; leaves significant needs of the elderly and disabled unmet; and has a number of contradictory impacts including indirect encouragement of cost-ineffective institutional care. The results, of course, apply most directly to Manitoba, since the study was done in Manitoba.

But since a number of these problems stem from a confused mandate and administrative structure at the National level, it seems probable that they are manifest in varying degrees in other Regions as well. Accordingly, extension of some aspects of the type of research reported here, to other Regions, may be desired as follow-up to this report.

4. RECOMMENDATIONS

Considerable change is essential in Adult Care services in Manitoba (and probably Nationally as well), if the important goals of the program -- to provide effective care for elderly and disabled Indians -- are to be achieved. Ultimately, these changes should include increased resources for Adult Care, in recognition of the extensive unmet need evidenced by this study, and significant changes in program delivery mechanisms.

4.1 Need for Increased Home Support Resources to Extend the Range of Services

Recommendation 1: Additional resources should be provided to meet urgent needs of elderly and disabled Indians which are being met only in part, at this time, particularly in the area of home care.

Rationale and Discussion: These needs are strongly evidenced in the Technical Health Needs Assessments completed for community residents by MSB and other nurses serving the 13 Bands studied. Particular attention should be given to expansion of the Homemaker Program and related home help (e.g. help with wood and water) since these are easily expanded within existing Band structures and delivery capability.

Recommendation 2: The Home Nursing Program now under review by INAC and MSB should be approved and initiated as soon as possible.

Rationale and Discussion: Addition of home nursing services to the actual range of Adult Care services will greatly improve home care services to elderly and disabled Indians, and meet critical needs which cannot be dealt with in the absence of this program.

Overall, creation of a genuine home care program centred on these services will not only meet important human needs of elderly and disabled Indians, but also contribute to more efficient use of resources, by reducing demand for institutional care.

4.2 Immediate Housing Initiatives

Recommendation 3: A Task Force should be established between INAC, Canada Mortgage and Housing Corporation, and National Indian Organizations to review the way in which housing programs currently serve elderly and disabled Indians. Its specific objectives would be:

(a) to identify obstacles to delivery of home repair services, senior citizens housing, and special purpose housing for the disabled;

(b) to identify interim funding for senior citizens housing on Manitoba reserves, particularly for reserves which are now considering personal care homes;

(c) to assess need for housing for the Adult Care target group in other Regions.

Rationale and Discussion: Study findings point to inadequate housing as a core problem: (1) as a factor preventing effective treatment (e.g. it is difficult to treat an ill, elderly person in a house which cannot be kept warm in the Winter); and (2) as a factor contributing to unnecessary and costly institutionalization.

4.3 Alternative Care Models and Relevant Professional Development Issues

Recommendation 4: A review and consultation process should be initiated, to identify ways in which additional Adult Care services could be added to the present range of services, within integrated program models. Specifically, this would include:

(a) identification of models for integrating personal care home facilities with home care services; models for integrated delivery of senior citizens' housing and adult day care; and models for integrated delivery of adult day care and personal care home care; and

(b) development of program design guidelines and training materials suitable for use by Band staff, to assist Band staff and Band Councils in evaluating alternative care models.

4.4 Consolidating Gains in the Institutional Component (Mainly Personal Care Homes)

Recommendation 5: An operational review should be undertaken for the on-reserve personal care homes which are not now licensed.

Rationale and Discussion: Such a review would consider issues such as adequacy of buildings and equipment, need for staff training, etc., and would be a useful first step in reducing the legal dangers attendant to running such a program without licensing or standards.

This review should be conducted under supervision of the special purpose body described in Section 6.2.7, Recommendation 12, with full participation of Manitoba Indian Organizations.

Recommendation 6: A separate review should be conducted of hostels now operating in Manitoba on three reserves.

Rationale and Discussion: Hostel care is a component of Adult Care, according to the Memorandum of Agreement between INAC and MSB. Yet hostels are not funded in Manitoba under Adult Care. Since hostel care is expected to be more economical than institutional care, this should be a concern in overall program development. This review should also be conducted under direction of the same group supervising the review of personal care homes.

4.5 Clarification of Program Mandate

Recommendation 7: A clear mandate for Adult Care should be obtained through a joint HWC-INAC submission to Cabinet, for authority and resources to fund and support a complete Adult Care Program.

Rationale and Discussion: Lack of "clear mandate" has been identified as a core problem for Adult Care, which contributes to a variety of specific problems, due to lack of direction, lack of staff and related gaps.

Recommendation 8: Main Responsibility for the Adult Care Program should be placed with MSB of Health and Welfare.

Rationale and Discussion: This would include responsibility for Type I and Type II institutional care (personal care homes), which is now under INAC. MSB has the appropriate technical skills to deal with the broad range of issues involved in this program, which INAC simply does not have. INAC's Adult Care responsibilities would then be mainly for social services and housing areas.

Recommendation 9: A review should be undertaken to assure that the Adult Care Program information system (and standards) are in place and working, so that accurate program information (units of service and costs) are provided.

Rationale and Discussion: This information is essential for well planned and effective application of increased resources to Adult Care needs.

4.6 Clarification of Provincial Roles and Option to Use Provincial Services

Recommendation 10: Possible roles for the Province in Adult Care must be clarified, particularly to explore the feasibility of Manitoba Indian Bands accessing relevant social services, under cost-sharing agreements similar to those now in existence in Ontario and Quebec.

Rationale and Discussion: In many cases, especially for smaller Bands, it may be more economical for Bands to access existing services on a contractual basis, than to develop their own services. Bands should have this option.

Clarification of possible changes in Provincial role should be examined, initially in the new policy and program mechanisms proposed (Recommendations 11 and 12 below).

4.7 Implementation Through New Policy and Program Planning Mechanism

Recommendation 11: At the National level, a Ministerial level task force should be appointed with senior representatives of INAC, HWC and key Indian Organizations, to follow-up on recommendations of this study, particularly:

(a) to monitor clarification of program mandate and Departmental responsibilities;

(b) to establish program goals and priorities;

(c) to monitor achievement of program goals;

(d) to undertake a review of the financial needs or means test in Adult Care and the desirability/ feasibility of eliminating it, either generally, or in Provinces where non-Indians are not required to complete a financial means test for similar services; and

(e) to consider the desirability of extending this type of research and other data gathering, to assess aspects of Adult Care in other Regions.

Recommendation 12: At the Regional (Manitoba) level, steps should be taken to shift responsibility for development of Adult Care policy and programs to a special purpose body comprised of INAC and MSB and Manitoba Indian Organizations (with majority Indian representation) solely concerned with Adult Care.

Rationale and Discussion: This body would have majority Indian representation, and be solely concerned with Adult Care. It would operate in a public environment, and eventually be supplied with staff sufficient to allow an effective program development role.

Its immediate role would focus on: (1) formulating its own terms of reference; and (2) follow-up on the recommendations of this report, particularly the proposed operational reviews of on-reserve personal care homes and hostels.

Taken together, implementation of these recommended changes could significantly increase the ability of the Adult Care Program to effectively meet the serious needs of elderly and disabled Indians.

1. STUDY BACKGROUND AND OBJECTIVES

1.1 Background

This report is an evaluation of the Adult Care Program of Indian and Northern Affairs Canada, and Medical Services Branch, Health & Welfare Canada, and its component services to elderly Indians and to other disabled Indian adults. The research was conducted in Manitoba, but has implications for Adult Care services across Canada.

1.1.1 Mandate of the Evaluation

Periodic evaluations of programs are undertaken on a regular basis by Indian and Northern Affairs (**hereafter INAC**),* under guidelines established by the Office of the Comptroller General of the Treasury Board of Canada. According to the Comptroller General's Guide on the Program Evaluation Function:

> *Program Evaluation* is the periodic, independent and objective review and assessment of a program to determine, in light of present circumstance, the adequacy of its objectives, its design and its results both intended and unintended. Evaluations will call into question the very existence of the program. Matters such as the rationale for the program, its impact on the public, and its cost effectiveness as compared with alternative means of program delivery are reviewed.**

Such evaluations are undertaken generally to deal with four basic program evaluation issues: rationale, impacts and achievements and alternative approaches, as shown in Display 1.1 (next page).

The evaluation is especially important for several reasons: (1) there is growing attention to the needs of the elderly in an aging society; (2) elderly Indians have a unique importance in Indian culture; (3) claims of growth in program costs and actual growth in numbers of institutions has, in recent years, been a concern for INAC; and (4) Indian organizations have expressed serious concerns about overall lack of services to meet the needs of elderly and disabled members of their communities.

As noted below, historical development of the study included an extension of the study plan to include an evaluation of needs for Adult Care on behalf of the three Manitoba Indian Organizations (First Nations Confederacy, Manitoba Keewatinowi Okimakanak, and Brotherhood of Indian Nations, hereafter referred to as FNC, MKO and BIN).

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*The Department is also referred to as The Department of Indian Affairs and Northern Development or DIAND.

***Guide on the Program Evaluation Function*, Office of the Comptroller General of Canada, Treasury Board, 1981.

DISPLAY 1.1
BASIC PROGRAM EVALUATION ISSUES*

Classes of Evaluation Issues	Basic Evaluation Questions
Program Rationale (Does the program make sense?)	o To what extent are the objectives and mandate of the program still relevant?
	o Are the activities and outputs of the program consistent with its mandate and plausibly linked to the attainment of the objectives and the intended impacts and effects?
Impacts and Effects (What has happened as a result of the program?)	o What impacts and effects, both intended and unintended, resulted from carrying out the program?
	o In what manner and to what extent does the program complement, duplicate, overlap or work at cross-purposes with other programs?
Objectives Achievement (Has the program achieved what was expected?)	o In what manner and to what extent were appropriate program objectives achieved as a result of the program?
Alternatives (Are there better ways of achieving the results?)	o Are there more cost-effective alternative programs which might achieve the objectives and intended impacts and effects?
	o Are there more cost-effective ways of delivering the existing program?

*Guide on the Program Evaluation Function, Office of the Comptroller General of Canada, Treasury Board, 1981.

1.1.2 Policy Context: December 1985

In late 1985, while this report was being completed, the two responsible Federal Departments, INAC and Medical Services Branch of Health & Welfare **(hereafter referred to as MSB)**, were giving consideration to a major change in Adult Care -- the introduction of a Continuing Care Program which would include an in-home nursing program. It is hoped that this evaluation will assist with that program decision.

1.1.3 Overview of Adult Care

Adult Care services encompass a wide range of institutional and home-support services for elderly and disabled Indians on reserves. A capsule overview of the program is provided here, with a complete program description provided in Section 2 of this report.

The Adult Care Program is intended to provide institutional or home support care to elderly Indians (age 65+) and disabled Indians ages 17 to 64, who are not able to care for themselves on their own. A stated goal of the program is to minimize institutionalization, and to maintain individuals in their own homes for as long as possible.*

The Adult Care Program on Manitoba reserves has the following main components: personal care homes (nursing home care); and home-support services, particularly homemaker services. As well, a variety of other services are part of the allowable Adult Care Program framework (home nursing care, meals-on-wheels, home repairs, and many other elements). These formal home support services can be provided under the program but are actually provided on only a few of the 60 Manitoba reserves.

The program is complex in its design, involving two Federal Departments, INAC and Medical Services Branch of Health & Welfare Canada, along with Bands (in a delivery role), and the Province (selected involvements). As well, components of the program model (see Display 2.2, pages 20-21 below) are linked to other programs in INAC (e.g. housing), and MSB (e.g. NNADAP).

1.1.4 History of the Evaluation

Preliminary Activities

Review of the Adult Care Program began in 1982, with an assessment study: An Evaluation Assessment of the Adult Care and Rehabilitation Services Program Component, 1982, Evaluation Branch, Corporate Policy, INAC. The purpose of the study was to identify basic issues for the subsequent evaluation, and to suggest evaluation approaches.

The study was initiated by the Evaluation Branch, Corporate Policy, INAC (Headquarters) in 1983, to assess the effectiveness of Adult Care services provided to elderly and disabled Indian persons on reserves in Canada. It complies with Treasury Board policy which requires that programs be evaluated with respect to their "effectiveness in achieving their objectives and the efficiency with which they are being administered" (Circular No. 1977-47 T.B. No. 751995).

The study was also conceived as a pilot study for a National Evaluation of Adult Care.

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*Adapted from: *Adult Care Program Review* (DRAFT), 1983, page 1. It should be noted that the *draft* program review documents are the only general documentation available on the program, and that no final, or official version of these reports has been completed by the Department.

The 1983 Study Plan: A Manitoba Pilot Study

Initially the study began as a pilot study of the Adult Care Program in Manitoba, to test methods for a National evaluation of Adult Care. In general, objectives of the evaluation were:

1. To determine if the program was meeting its various objectives, as regards health and social service needs of elderly and disabled Indians living on reserves;
2. To identify ways of improving the program, where improvements were found to be needed; and
3. To provide refinements to study design for a National evaluation.

An initial study research plan was prepared in Summer 1983, under direction of an evaluation committee formed by INAC and Health and Welfare Canada without Indian participation.

At this point a comprehensive study plan was completed, and preparations for the study field work begun.*

Manitoba Indian Organizations protested this management procedure, which they regarded as excluding them from the study process, in presentations made to the Minister. As a result, the study plan was suspended in September-October, 1983, pending creation of a joint INAC/Indian Organizations Steering Committee.

Negotiations between INAC and Manitoba Indian Organizations resulted in the achievement of full Indian participation in the study in 1984-85. Extensive consultation with health professionals serving Manitoba Indian communities followed. Several changes in study emphasis and design resulted, with a number of changes in study design, most importantly, inclusion of a major needs assessment component.*

Consultation Process and Redesign

The continuing work on this project in 1984-1985 involved extensive redesign of the project work plan in consultation with Manitoba Indian Organizations and selected professionals involved in health and social services on Manitoba Indian reserves. This portion of the work achieved key design shifts including: overall strengthening of the needs assessment component of the study; development of a formal survey for the needs assessment component; design adjustments to deal with handicapped/disabled persons; revision of sampling plans for reserves; and development of sampling plans for the community needs survey. This work built upon parts of the 1983 design study.**

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*See: *Planning Report, Evaluation of the Manitoba Adult Care Program*, SPR Associates Inc., September 1984, for details.

**See: *Planning Report, Evaluation of the Manitoba Adult Care Program*, SPR Associates Inc., August 1983.

The consultation included a one-day workshop which the consultants conducted with the Steering Committee, FNC, MKO,* and INAC staff and selected health and service professionals, to review study objectives, revise questionnaires, examine procedures, etc. The consultants prepared initial draft materials for this workshop, and subsequent revisions of materials, for review by the Steering Committee and workshop participants.

The consultation process resulted in preparation of a completely new study planning report and questionnaires.**

The 1984 Study Plan: Needs Assessment and Other Changes

It is noteworthy that the 1984 evaluation plan included several major shifts in emphasis from the 1983 study plan. The evaluation study included a much-expanded needs component, including data from structured interviews with a random sample of 250 elderly and disabled Indian persons.

Greater emphasis was also placed on services and needs of disabled Indian persons (offsetting the focus of the August, 1983 research plan on elderly Indian persons only). Home support-type care was also given greater emphasis in the revised study plan.

Conduct of the Study

Conduct of the study began in April 1985. Community surveys and related research activities for the study began in June 1985, and were completed in September-October 1985.

Ongoing consultation and liaison took place with an Evaluation Steering Committee. Committee membership included delegates from Manitoba Indian Organizations, and staff of INAC and MSB. Throughout the study implementation, valuable assistance was provided by staff of FNC, MKO and BIN, and extensive assistance was also provided by MSB. As well, review of the draft involved a two-day workshop with representatives of FNC, MKO, BIN, INAC and MSB, as well as other health and social services professionals involved in Adult Care. The overall chronology of the study is summarized in Display 1.2 (next page).

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*BIN was not included in the study until Spring 1985.

**See: *Planning Report, Evaluation of the Manitoba Adult Care Program*, SPR Associates Inc., September 1984, for details.

DISPLAY 1.2
CHRONOLOGY OF THE ADULT CARE STUDY

DATES	ACTIVITIES
March, 1982	Start of Evaluation Assessment.
October, 1982	Completion of Evaluation Assessment.
May, 1983	Initial pilot study begins.
September, 1983	Pilot study halted at request of Manitoba Indian Organizations.
January, 1984	INAC agrees to meet concerns of Manitoba Indian Organizations.
February, 1984	New Steering Committee established under the direction of Manitoba Indian Organizations.
April, 1984	Workshop on study design.
***	
September, 1984	Final study plan approved.
***	
April, 1985	Main study begins.
June, 1985	Hiring of interviewers begins; survey begins.
September, 1985	Main surveys (Community Resident and Key Informant) completed.
October, 1985	Nurses Survey and Personal Care Home Survey completed.
December, 1985	Workshop on study report.
January, 1986	Draft final report submitted.
March, 1986	Final report submitted.

*** Study "on hold" due to contract approval process.

1.2 Overview of the Study and Its Objectives

1.2.1 Main Evaluation Issues

The study was intended to examine several evaluation issues pertinent to program policy and delivery. These included:

- review of the *institutional care* and *home support services* provided to elderly and disabled adult reserve residents;
- assessment of Adult Care *needs* in Manitoba Indian communities;
- examination of the *appropriateness* (including cultural appropriateness) and *orientation* of both on and off-reserve institutional care and home support services provided to elderly and disabled reserve residents; and
- review of the *adequacy of Adult Care* assessments and professional resources to perform assessments.

1.2.2 The Evaluation in Broader Context

The study was also designed to provide information addressing the following concerns, which might identify ways of improving this program in the future:

- *The extent to which Adult Care may be deinstitutionalized* (paralleling the shift in service models found in care for the elderly in urban Canada in the 1970's); and
- *Issues of alternative care* in light of: (a) program feasibility, especially in light of the challenge of providing workable models for alternative care on smaller reserve communities; and (b) the need for Indian communities to develop and experiment with innovative alternative programs reflecting their own principles and unique cultural approaches.

1.2.3 Planning Concerns

Finally, this evaluation was to serve a variety of other objectives. For example, it was expected that study findings would aid in longer-term program planning and development; and it was anticipated that the study would provide a model for development of a National evaluation of Adult Care.

1.3 Methodology

The study included several main surveys conducted on thirteen Manitoba Indian reserves, collection of related data from additional reserves, and a survey of eleven personal care homes (both Indian operated and non-Indian operated) which provided care to Manitoba Indians in 1985.

1.3.1 Sampling of Communities

The community surveys component of the study was conducted on a sample of 13 reserves drawn from the total of 60 Manitoba reserves. These communities were randomly chosen to represent four main types of reserves:

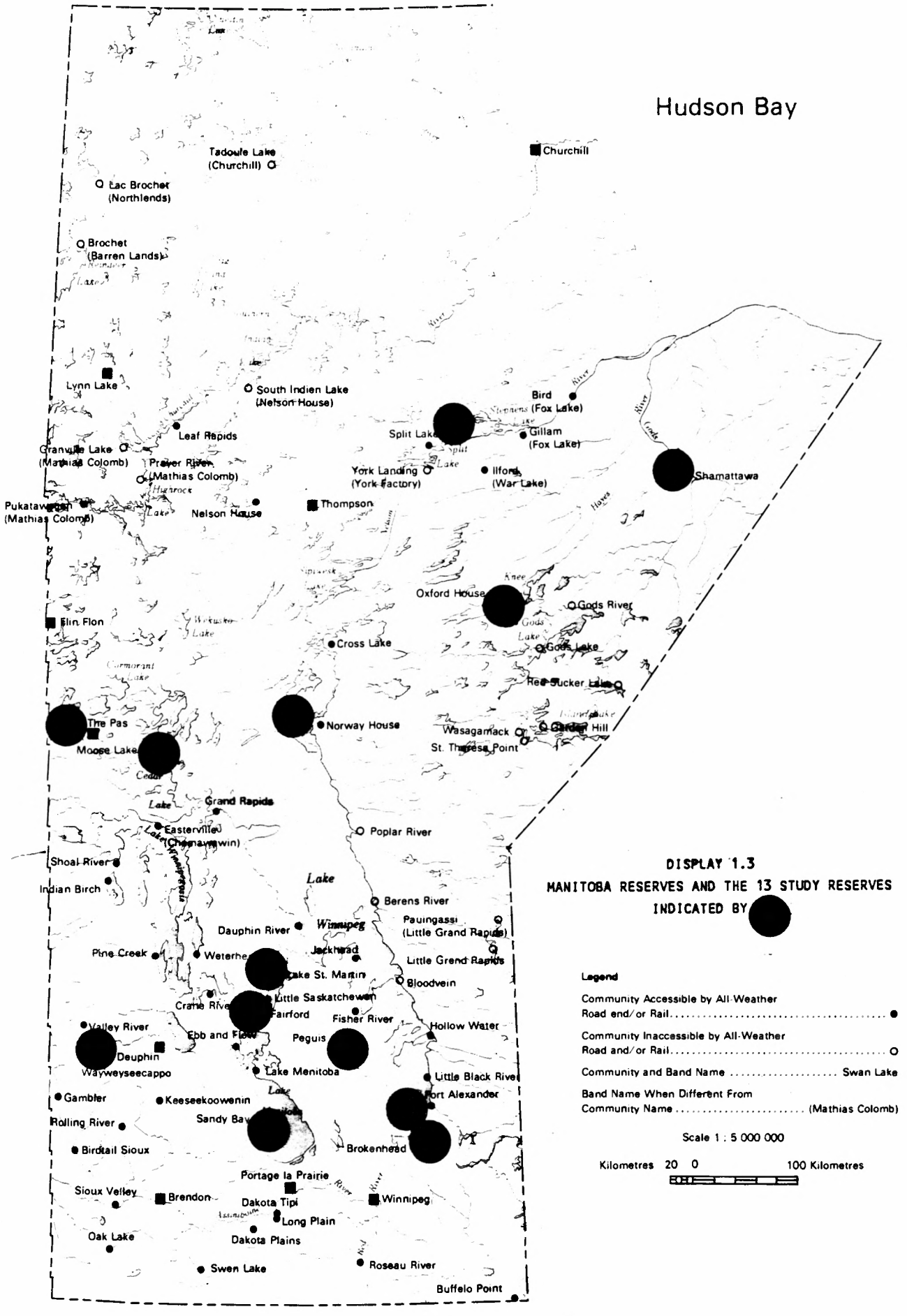
- *reserves with and without personal care homes* (4 reserves with personal care homes and 9 reserves without personal care homes were studied); and
- *reserves in remote and non-remote areas* (11 non-remote, and 2 remote reserves).

The communities varied from very small reserves (Moose Lake, Brokenhead, Shamattawa) to very large reserves (Norway House, Oxford House, Peguis, Fort Alexander, and Sandy Bay), and included reserves in Northern and Southern Manitoba as well as the Interlake Area. (Geographical distribution of the thirteen reserves is illustrated in Display 1.3, next page.) (See Appendix A, Part I for more details on sampling.)

1.3.2 Interviewer Training

Training for interviewers was extensive, covering a three and a half day training program, conducted in each of three separate regions.* These sessions dealt with details of study objectives, the Adult Care Program Model, survey procedure, interviewing practices, the interview questionnaires and their translation, needs of the elderly and related matters.

*Training sessions were held in: Winnipeg; Thompson; and at Peguis reserve.


Hudson Bay
Tadoule Lake (Churchill)
Churchill
Lac Brochet (Northlends)
Brochet (Barren Lands)
Lynn Lake
South Indien Lake (Nelson House)
Bird (Fox Lake)
Split Lake
Gillam (Fox Lake)
Leaf Rapids
Granville Lake (Mathias Colomb)
Prayer River (Mathias Colomb)
York Landing (York Factory)
Ilford (War Lake)
Shamattawa
Pukatawagan (Mathias Colomb)
Nelson House
Thompson
Oxford House
Gods River
Gods Lake
Sun Flon
Cross Lake
Red Sucker Lake
The Pas
Norway House
Wasagamack
Garden Hill
St. Theresa Point
Moose Lake
Grand Rapids
Easterville (Chemawawin)
Poplar River
Shoal River
Indian Birch
Lake
Berens River
Dauphin River
Winnipeg
Pauingassi (Little Grand Rapids)
Pine Creek
Jackhead
Little Grand Rapids
Bloodvein
Crane River
Fairford
Fisher River
Hollow Water
Valley River
Peguis
Dauphin
Waywayseecappo
Lake Manitoba
Little Black River
Fort Alexander
Gambler
Keeseekoowenin
Rolling River
Sandy Bay
Brokenhead
Birdtail Sioux
Portage la Prairie
Sioux Valley
Brendon
Dakota Tipi
Winnipeg
Long Plain
Oak Lake
Dakota Plains
Swan Lake
Roseau River
Buffalo Point
DISPLAY 1.3
MANITOBA RESERVES AND THE 13 STUDY RESERVES INDICATED BY
Legend
Community Accessible by All-Weather Road and/or Rail
Community Inaccessible by All-Weather Road and/or Rail
Community and Band Name ..... Swan Lake
Band Name When Different From Community Name ..... (Mathias Colomb)
Scale 1 : 5 000 000
Kilometres 20 0 100 Kilometres

1.3.3 Survey of a Random Sample of Elderly and Disabled Indians

The main survey was a personal interview survey of recipients of Adult Care services and individuals identified by Band staff as having current or potential unmet Adult Care needs. This survey was conducted for a random sample of over 250 such persons on the selected reserves*.

The survey was carried out through personal interviews, usually in the respondent's Native language, and involved use of a structured interview questionnaire.**

Sampling of Community Residents

Community residents were randomly selected, to allow generalization to the broader sample of Manitoba's elderly Indians. This was done by obtaining lists of elderly and disabled residents, for each of the 13 Bands, along with a rating*** by Band staff, of likely degree of need for Adult Care services. Those to be interviewed were randomly chosen within each rating group*** of need for Adult Care services.

It is noted that use of a scientifically selected sample, with known probabilities of selection, is a special strength of the study, assuring more objective information for all users of the survey results. (See Appendix A, Parts I and II, for more details.)

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*See: *Planning Report, Evaluation of the Manitoba Adult Care Program*, SPR Associates Inc., September 1984, for details on sampling procedure.

**See: *Planning Report, Evaluation of the Manitoba Adult Care Program*, SPR Associates Inc., September 1984, for details on questionnaires.

***Categories were: (1) **Independent/Mobile** (capable of living on their own, no problems with activities of daily living); (2) **Slightly dependent** (with need for only occasional assistance from family, Band or others with activities of daily living and tasks (for example, once or twice a week); (3) **Moderately dependent** (with physical or mental health problems requiring: assistance with some activities of daily living everyday). Approximately one half hour of nurse/nurse's aide/homemaker or family assistance time would be required per day; (4) **Fully dependent** (need, but do not have full-time, institutional-type care, or extremely intensive home care with assistance for nearly all major tasks); and (5) **Fully dependent, and now residing in an on-reserve institution.**

1.3.4 Survey of MSB and Other Nurses To Obtain Technical Health Assessments on Community Residents

This survey gathered a variety of information including ratings of health conditions and health and social service needs of the same sample of elderly and disabled Indians included in the Community Needs Survey.

Assessments included ratings of: functional ability; ratings of need for home support services, such as homemaker care, nursing care, home repairs, meals-on-wheels, etc.; and assessments of "best care" situations for elderly and disabled residents (from a health perspective).

The Nurses' Survey included detailed instructions on how to complete the Health Profiles, definitions and telephone assistance as needed from the study office.

1.3.5 Survey of Personal Care Homes With Indian Residents

This data was required to determine specifically how the institutional component of the Adult Care Program has met or failed to meet the needs of Indian persons. Therefore, the study included assessment of Indian patients in personal care homes. This included 5 on-reserve personal care homes and 6 off-reserve personal care homes.

Data on personal care homes and their patients were collected in the form of Patient Profiles for each Indian resident, and an Institutional Profile for each personal care home. These surveys were mailed to each institution, and completed by staff of each personal care home included in the study.

The Patient Profiles collected a variety of information, including information to allow detailed comparison of Technical Health Assessments of personal care home residents to Technical Health Assessments obtained for community residents.

1.3.6 Survey of Key Informants

Professionals and other key informants involved in Adult Care Programs were also surveyed. The survey included such key actors as: Nurses, CHR's (Community Health Representatives), the Chief (or his/her delegate), Band Managers, Welfare Administrators, Visiting Homemakers, Social Workers, Personal Care Home staff and NNADAP staff. The survey was conducted by means of personal interviews undertaken by trained interviewers, using a structured interview questionnaire.*

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*See: *Planning Report, Evaluation of the Manitoba Adult Care Program*, SPR Associates Inc., September 1984, for details on sampling procedure and questionnaires.

1.3.7 Band Profile

Each FNC/MKO/BIN Band was sent a brief form for profiling their reserve's Adult Care Program and needs.

Chiefs/Band Administrators or their delegates (usually health services or social services staff) used this profile to: provide selected statistical data on needs; identify services available on their reserves; identify satisfaction with various program aspects; and identify alternative approaches to Adult Care on Indian reserves.

1.3.8 Related Data

Other data were obtained from various sources including INAC Regional and National Offices (e.g. expenditures, caseloads, community profile data), Medical Services Branch of HWC (health statistics), and Manitoba Health Services Commission (data on Provincial programs).

1.3.9 Resulting Data Base for the Study and Data Quality

The resulting data base for the study included:

- Band assessments of functional capacity for 499 Manitoba elderly and 133 disabled Indian adults (obtained in sampling);
- structured interviews with 200 elderly and 58 disabled Indians living on Manitoba reserves (from the initial population list of 632 persons);
- technical health assessments of 172 elderly and 45 disabled Indians residing on Manitoba Indian reserves;
- technical health assessments for another 97 elderly and 24 disabled Indians from Manitoba reserves and residing in Indian operated and non-Indian operated personal care homes in Manitoba;
- assessments of community needs for Adult Care from over 60 health and social service professionals and community leaders involved in Adult Care services to 13 Bands; and
- assessments of community needs for Adult Care services from Band staff (Band Profiles), and Nurses, for an additional 24 Bands.

Data was therefore obtained for a substantial portion of Manitoba's elderly Indians living on-reserve, not in personal care homes, and for all elderly Manitoba Indians in personal care homes (see Display 1.4, below).

DISPLAY 1.4
POPULATION OF ELDERLY MANITOBA INDIANS (AGE 65+) ON-RESERVE AND IN PERSONAL CARE HOMES, COMPARED TO THE NUMBER FOR WHICH SURVEY DATA WAS OBTAINED

	ELDERLY INDIANS			
	On-Reserve, Not In Personal Care Homes	In Personal Care Homes	Total	% of Population
1. Estimated population of elderly Indians*	1,538	97	1,635	--
2. Band assessments of functional capacity obtained	499	--	499	30.5%
3. Personal interviews obtained	200	--	200	12.2%
4. Technical Health Assessments obtained	172	97	271	16.6%

*Estimated from: Population Projections of Registered Indians, 1982 to 1996, Indian and Northern Affairs Canada, 1985; and from: Social Development Program: On-Reserve Services to the Elderly and Handicapped, Social Development, Indian and Northern Affairs Canada, Winnipeg, January, 1985.

Because these data represent a substantial proportion of all elderly Indians on reserves (13% of population), and in personal care homes (100%), survey estimates are very reliable, with confidence intervals (see Glossary) of estimates predicted to fall within $\pm$ 3% to $\pm$ 6% accuracy, 19 times out of 20.

Personal interview data were also obtained for a sample of 58 disabled Indian adults not in personal care homes, and Technical Health Assessments were obtained for some 45 disabled adults living on reserves and for all 24 Manitoba disabled Indian adults now in personal care homes. The proportion of disabled Indians interviewed is estimated to be about 15% of the total disabled population.

1.3.10 Weighting of Survey Data

Throughout the report, statistical survey data have been weighted to represent the Manitoba population of elderly Indians living on reserves and not in personal care homes. This was done in computer runs using the "weight" function of the Statistical Package for the Social Sciences, appropriate weights being projected for a population of 1,538 Manitoba elderly Indians living on reserves and not in institutions. (The weighting scheme is outlined in detail in Appendix A, Section II.)

As a result, the study data presented show estimates *of actual numbers of elderly Indians in any given category* (these estimates being reliable to within plus or minus approximately 5%, 19 times out of 20). Weighted estimates are also provided for the disabled Indian population, but these must be regarded as more illustrative, because of the small sample size of disabled persons included in our survey.

1.3.10 Quality Control and Data Reliability

Special emphasis in the study was placed on the collection of reliable survey data, particularly through:

1. Emphasis on extensive and rigorous training of interviewers;
2. Strict control over sample selection;
3. Development of multi-item indicators wherever possible; and
4. Use of multiple data sources.

Data reliability was assessed as good to excellent, on the basis of standard tests of indicator reliability (Appendix B), particularly factor analysis (see Glossary, end of report), and on the basis of agreement of data drawn from divergent sources (see Appendix B).

1.4 Reading This Report

Reading Statistical Tables in the Report

Two features of the tables should be noted: First, the statistical presentation includes frequencies (actual estimated numbers of elderly or disabled persons falling into a given category) based on weighted* estimates to convey a picture that applies to the whole population of concern: all on-reserve elderly Indians and all other on-reserve disabled adults.

Second, percentages are included with each frequency, since these usually aid interpretation. Usually just "row" or just "column" percentages are presented, but sometimes both are provided, with an explanation.

Use of Other Statistics

The report also presents results of a number of other types of statistical analyses. Considerable qualitative information is provided, but most of the central information is statistical, to allow more accurate answers on key issues.

The reader should note that use is also made of the concepts of correlation and statistical significance, which are briefly explained here. When we say that two factors (e.g. housing and health) are correlated, we usually mean that they "go together", and this implies that a change in one will result in a change in the other. For example, in studies of social welfare, it is often argued that an improvement in sub-standard housing will generally result in an improvement in health. Correlations may therefore convey social and political truths, or raise social and political issues.

Two types of correlation statistics are used in this report: **Pearson's r** and **GAMMA**. Both vary from -1.0 (perfect negative relationship), to 0.0 (no relationship), to +1.0 (perfect positive relationship).

Statistical Significance is assessed for correlations and other statistical tests, to determine whether the results are scientifically reliable within certain limits. In this report, a correlation is considered to be "significant" at a scientific probability level (**P**) of .01 or less. This means that the relationship (or correlation) is unlikely to be a "chance" occurrence, and would be expected to occur 99 times out of 100 if the study method was repeated. Correlations discussed in this report which are not statistically significant are noted as "not significant".

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*See Section 1.3.10 for details on weighting procedure.

2. THE ADULT CARE PROGRAM

2.1 Introduction

The Adult Care Program is a combination of programs which have existed in INAC (e.g. Homemaker Program, Personal Care Home Program), and MSB (Nursing and related services), for some time.

2.1.1 Definition

"Adult Care" includes services and assistance to Indian adults (age 17 or older) who (due to age, physical or mental incapacity that is likely to continue) are unable to care for themselves and require third party care either in their own homes or through placement in an institution.*

The program has two main target groups:

- o elderly Indians (aged 65+); and
- o disabled Indian adults (aged 17 to 64).

2.1.2 Authority and Structure

The two Federal Departments (Health & Welfare Canada and INAC), do not have an official mandate for this program. Rather, monies are spent each year under Annual Appropriation Acts.** There are no staff at the INAC National office. Federal standards are reported to exist, but current standards could not be provided to the study team by either Federal or Regional INAC. Available documents indicate that, historically, INAC and HWC have not agreed on certain program issues. For example, INAC Review Documents note:

> Historically, the Federal government's division of responsibility for Adult Care was determined by whether the facility or services was under health or welfare auspices or the services provided was of a health or social services orientation. That delineation of responsibility was workable but contentious.***

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*Adapted from: *Adult Care Program Review* (DRAFT), 1983, page 1.

**See: *Review Paper: Adult Care Program* (DRAFT), June 1985, page 15.

***See: *Adult Care Program Review* (DRAFT), DIAND, 1983, page 4.

> An argument can be made that Federal responsibility for extended health care on behalf of status Indians should rest with the department having the appropriate expertise to deal with assessments and care standards. Since these are primarily the domain of health professionals, the Medical Services Branch should take the lead in extended health care, rather than DIAND. The Medical Services Branch has not accepted this interpretation.*

The evaluators have been advised that there is no INAC-MSB program planning group at the Regional level, with the two Federal Departments implementing their respective program activities independently.

2.1.3 Program Objectives and Principles**

The primary objectives of the Adult Care Program are to:

- Provide aged and incapacitated Indian people with a *range of assistance* and services including the *option to remain at home* and *in their own community* as long as possible;
- Ensure that assistance and services are significantly *related to the needs of individual adults* by having in place: processes and criteria for assessing care needs of the individual, as well as considering the emotional, social and psychological needs of the individual and family; and
- *Integrate Adult Care within the framework of existing Band programs* through the purchase of Provincial/territorial health and social services (emphasis added).

The fundamental principles which underlie and are an integral part of the current Adult Care policy are:***

- Indian adults have a *personal responsibility* for their own well-being to the limits of their financial means and physical capacity;

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*See: *Review Paper: Adult Care Program* (DRAFT), DIAND, June 1985, page 40.

**Adapted from: *Adult Care Program Review* (DRAFT), 1983, page 1.

****Adult Care Program Review* (DRAFT), DIAND, 1983, pages 1-2.

- Immediate *family members and Bands share responsibility* within their means and resources, for planning and providing care to incapacitated adults of their community;

- Indian adults have a right to assistance and services which *enable them to participate in and contribute to society* fully and for as long as their circumstances permit;

- *Concepts and definitions established in the Canada Assistance Plan* (requiring provision of assistance contingent upon a financial needs test) *are adhered to*;

- Services and assistance provided are *suitable to the physical, social and cultural needs* of Indian individuals; and

- (Subject to service delivery capacity and cost constraints), the Adult Care Program promotes *Indian participation in design and control of services*, and funds these activities through contribution agreements with Bands and Tribal Councils.

2.2 Components of the National Adult Care Program

Adult Care Program activities comprise a wide range of potentially available health and social services for adults. These services aim to maximize individual self-sufficiency by maintaining individual functioning where possible within the context of the family and community.

Four main program areas are identified by a 1984 Memorandum of Understanding between INAC and MSB: Home Support; Residential Care; Prevention; and Case Management. The memorandum notes that: "... the list of components is not to be considered as either exhaustive or obligatory. The availability of these components will vary depending on the resources of the individual, the Band and the responsible Department."* This reflects the fact that different program components have been more strongly developed in some regions and on certain reserves.

These health and social services are designed to provide assessment, treatment, rehabilitation and supportive care, in order to prevent or minimize disability of adults suffering from chronic physical, developmental, or emotional impairments. Services are provided to individuals, their families and their communities in a variety of settings, including the home.

**Memorandum of Understanding on Adult Care*, DIAND, and Medical Services Branch of Health and Welfare, June 11, 1984.

In principle, special emphasis is placed on encouraging adults to remain in their own home/community due to the lower cost of home support care as compared to institutional care, and due to contemporary professional views that home support care is a superior form of care for most elderly and disabled individuals.

Display 2.2 (next two pages), lists principal components of Adult Care identified by Medical Services Branch of Health and Welfare, and INAC, in 1984.

Taken together, the variety of services potentially available under Adult Care is consistent with the concept of a *continuum of care* for the elderly, which begins with minimal assistance in the home, and ends with institutional care for those who are unable to care for themselves at all (Display 2.1).

DISPLAY 2.1
NEED FOR ASSISTANCE IN RELATION TO A CONTINUUM OF CARE

Need for Assistance by the Elderly or Disabled Individual	Continuum of Care Required to Meet Needs
Fully independent, needs no help with usual activities of daily living.	No assistance or care.
Needs occasional assistance with heavy work, transportation.	Heavy cleaning, transportation.
Needs regular assistance with activities of daily living, and some supervision.	Home support services such as meals-on-wheels, homemakers etc.
Needs regular assistance with activities of daily living, some supervision and medical assistance.	Home support services and home nursing.
Needs supervision and care every day.	Residential Care: (e.g. hostel, group home, personal care home) (Type I care).
Needs supervison and care every day and some medical care.	Institutional Care: personal care home (Type II care).
Needs regular supervision and care incuding extensive medical care.	Institutional Care: Chronic Care Hospital.

It is significant that in addition to its care activities, *the Adult Care Program framework extends into other major INAC and MSB program areas,* most importantly: Housing (see Display 2.2, "Section 1.4. Personal Environment" -- which specifies renovations to bring homes to accepted standards); and Preventative health services and rehabilitation services related to nutrition, alcohol and general health.

DISPLAY 2.2
ADULT CARE PROGRAM COMPONENTS*

1. HOME SUPPORT

1.1 Health Care Services

1.1.1 Nursing and nurse supervised home nursing care**
1.1.2 Physiotherapist
1.1.3 Dietician
1.1.4 Chiropodist
1.1.5 Podiatrist
1.1.6 Medical Technician and Technologist
1.1.7 Assistant to any of the above
1.1.8 Speech Therapist
1.1.9 Community Health Representative (CHR)
1.1.10 Alcohol Counsellor (NNADAP)
1.1.11 Mental Health Worker

1.2 Ambulatory Care Services

1.2.1 Day Centres/Drop-in Centres:
i) capital
ii) O & M

1.3 Social Services

1.3.1 Homemakers assisting with the acitvities of daily living
1.3.2 Handyman services for home chores
1.3.3 Non-medical transportation
1.3.4 (Band and) INAC welfare worker services
1.3.5 Meals-on-Wheels and Wheels-to-Meals
1.3.6 Friendly visitors; security checks for the homebound; telephone reassurance

1.4 Personal Environment

1.4.1 Renovations to bring homes up to accepted standards
1.4.2 Adaptations to meet special needs
i) to homes
ii) to personal-use items e.g. transportation, clothing
1.4.3 Special appliances e.g. bath-tub lifts, elevators

* From: Memorandum of Understanding on Adult Care, DIAND, Medical Services Branch of Health & Welfare, June 11, 1984.

**Due to resource constraints as of 1983-85, MSB involvement is limited to patient assessment and urgent clinical procedures. The provision of further home nursing care services was noted to be contingent on the availability of additional financial and human resources.

DISPLAY 2.2 (CONT'D)
ADULT CARE PROGRAM COMPONENTS*

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2. RESIDENTIAL CARE

2.1 Private Homes (foster homes)

2.2 Group Homes (licensed or approved)

2.3 Institutions

2.3.1 Hostels
2.3.2 Homes for the Aged (type I care)
2.3.3 Nursing Homes (type II care)
i) user fees
ii) all other costs and services

3. PREVENTION

3.1 Health Education

3.2 Counselling Service

3.2.1 CHR
3.2.2 Nutritionist/Dietician
3.2.3 Alcohol Counsellor (NNDAP)
3.2.4 Mental Health Workers
3.2.5 Social Worker

4. CASE MANAGEMENT

4.1 Care Assessment

4.1.1 For Provincial programs/institutions
4.1.2 For Federally run or sponsored programs/institutions

4.2 Case Supervision (including referral, follow-up, record-keeping, service coordination)

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*From: Memorandum of Understanding on Adult Care, DIAND, Medical Services Branch of Health & Welfare, June 11, 1984.

2.3 The Program in Manitoba

While many services come under Adult Care, only two of them are implemented in a major way in Manitoba. These are: Institutional Care (personal care homes); and In-home Care (as provided by homemakers).

2.3.1 Institutional Care

To date, program emphasis in Manitoba has been focused mainly on Institutional Care (personal care homes).* Five Indian-operated personal care homes are now in operation on Manitoba reserves, and other proposals are under review. In addition, a number of elderly/disabled Indians are currently residing in non-reserve personal care homes throughout Manitoba. As well, several reserves have designed and established less institutional residences for elderly and disabled members of their communities (e.g. hostels),** but these are not funded at this time under Adult Care.

The Indian-operated personal care homes vary a great deal in size and other characteristics. These personal care homes are all operated by Bands or local Boards of Directors. Only one is Provincially licensed -- the other four being operated with no formal inspection or enforced standards. Generally they are much smaller, and have fewer professional resources than licensed personal care homes in Manitoba (see Section 5 of this report).

The establishment of these on-reserve personal care homes has greatly reduced the number of elderly and disabled Indians located in off-reserve institutions. More elderly and disabled Indians requiring institutional care have been able to remain in their home communities, or to find care in institutions with Indian-oriented programming (e.g. diet, cultural activities).

Geographic locations and other characteristics of the five Indian-operated personal care homes are noted on the map within Display 2.3 (next page).

2.3.2 Home Support Services

Development of home support services comprises a far lesser portion of resources, mainly under other program headings (e.g. Homemaker Services provided by Bands until 1985, out of social assistance funds). Some home nursing service is provided, but only when essential, and when nurses' workloads allow, since no program mandate exists for this service.

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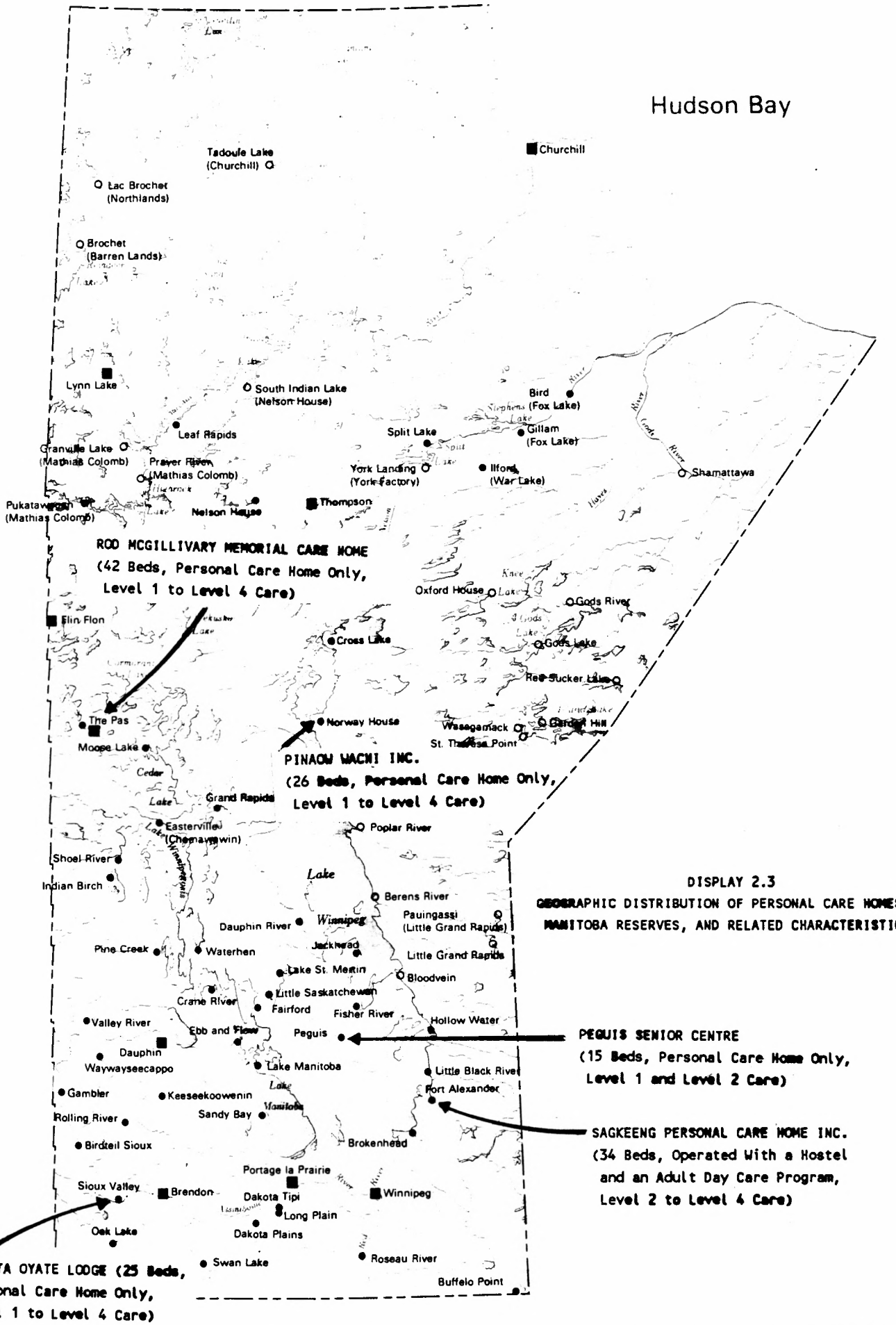
*Personal care home expenditures for Manitoba Adult Care were $3,620,200 in 1984-85. No In-Home care costs are separately identified for Manitoba, although certain support services are provided through the social assistance homemaker program. As for National figures (see below), no breakdown is provided of the MSB cost for home support services, and other major gaps in cost information exist.

**No information is available on hostels.



DISPLAY 2.3

GEOGRAPHIC DISTRIBUTION OF PERSONAL CARE HOMES ON MANITOBA RESERVES, AND RELATED CHARACTERISTICS

Therefore, a number of services which would represent an important part of a full continuum of care are not funded, and are simply not available on any scale. Services which are not generally available on reserves include: in-home nursing, meals-on-wheels, help with wood/water, adult day care, and non-medical transportation.

2.4 Costs and Cost Trends

Overall, the Adult Care Program has been modest in total expenditures,* relative to other INAC programs (in 1984-85 INAC spent $7,675,600 on residential care Nationally, and $4,449,000 on In-Home Care, for a total of $12,124,600).

Manitoba Indian Organizations have indicated that this may reflect unmet needs, rather than simply that Adult Care requirements are modest. Accordingly, a needs assessment was incorporated into the evaluation to provide an objective assessment of this issue.

Nationally, costs for Adult Care (INAC components*) are reported to have grown at a rapid rate since 1972-73. However, it is not possible to determine what proportion of these increased costs represents an actual increase in care provided.

In 1972-73 expenditures were reported to be $693,000, reportedly growing tenfold, to $7,557,000 in 1982-83, and $12,124,600 in 1984-85. But this growth reflects a number of effects other than expansion of service. Inflation is one factor, but more importantly, a significant portion of this increase represents accounting transfers (e.g. from MSB or the Province, to INAC). For example, INAC reports:

> o Increases in Adult Care Program expenditure since 1977-79 are due in part to an agreement with National Health and Welfare whereby Indian Affairs assumed financial responsibility for certain individuals in nursing homes.**
>
> o While the utilization of Adult Care services continues to increase, some of the increase in volume is primarily a statistical change resulting from reporting certain homemaker costs as Adult Care instead of social assistance.**

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*Note: Statistics on contributions by MSB for the health component of the program are apparently not available on a consistent basis. For example, the *Adult Care Program Review* (DRAFT), includes Types III to V Institutional Care, which are excluded from current definitions of Adult Care; and includes all of NNADAP expenditures. See: *Adult Care Program Review* (DRAFT), 1983, Annex "C", Tables III and IV.

**See: *Review Paper: Adult Care Program* (DRAFT), DIAND, June 1985, page 30.

> It should also be noted that while these costs include some mentally retarded Indian adults, the majority of adult retardates are not being financed by DIAND, though some Provinces have been pressing for payment. There is now a trend by Provinces toward returning as many of these individuals as possible to their home communities. DIAND is being asked to pick up the cost of care for these individuals.*

As well, MSB staff note that a significant proportion of elderly Indians institutionalized after 1976, are actually transfers from the Province, upon changes in Provincial chronic care policy.**

Thus, historical cost trends cannot confidently be assessed as indicative of actual expenditures for care of elderly and disabled Indians. In fact, the Adult Care information system does not provide adequate information to determine with certainty whether real total costs (by all Governments) for this type of service have grown, stayed the same, or declined in recent years.

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*See: *Review Paper: Adult Care Program* (DRAFT), DIAND, June 1985, page 29.

**Personal communication, MSB staff, at Analysis Workshop, December 18, 1985.

2.5 Management and Funding Responsibilities

2.5.1 Administration/Locus Within INAC

Adult Care is one of four program components included under the Social Development Directorate, Education and Social Development, Indian and Inuit Affairs Program. INAC is responsible for the social service aspect of Adult Care, and appears to play a "lead" role in relation to MSB (at least as far as identified expenditures indicate).

2.5.2 Division of Responsibilities

Division of responsibilities is rooted in the different mandates of the two Federal Departments involved. Generally speaking, MSB of the Department of National Health and Welfare has a mandate for provision of health services to Indians, and INAC has a mandate for the provision of social services.

INAC and MSB apparently have not agreed in the past as to whether one Department or the other should have the lead role. Neither appears to want to take primary responsibility. The argument has been made by INAC* that responsibility should rest with the Department having the necessary expertise (MSB), since the primary care needed is medical in nature. However, INAC reports that MSB has not agreed with this proposal.* (See Section 2.1.2 above.)

Division of Responsibility for the Institutional Component of Adult Care

There are five types of care approved by the Federal/Provincial Advisory Committee on Health Insurance** in November, 1973, and now used by National Health and Welfare for purposes of planning, development, administration and research. They are described briefly as follows:

Type I - Residential, ambulant or limited personal care (Manitoba Levels 1 and 2).

Type II - Intensive personal care with nursing supervision or nursing home care (Manitoba Levels 3 and 4).

Type III - Extended care in a chronic care unit or hospital.

Type IV - Special care for a stable disability in a rehabilitation centre or hospital.

Type V - Acute care of seriously or critically ill in a hospital.

**Policy Review*, 1985, pages 29 to 30.

***Report of the Working Party on Patient Care Classification to the Advisory Committee on Hospital Insurance and Diagnostic Services*, November 1973.

INAC is responsible mainly for Types I and II care which are included under Adult Care (generally provided in personal care homes in Manitoba). The Department of National Health and Welfare takes responsibility for payments for co-insured health services components of Types III, IV and V care, which are not included under Adult Care.

Under the Adult Care framework, INAC is responsible for non-institutional residential care such as foster homes, group homes etc., and MSB is generally responsible for prevention activities (e.g. health education, nutrition counselling). All parties may be involved in case management activities.

Division of Responsibilities for Home Support-Type Services

This division of responsibilities extends to the area of home support-type services, where health services in the home (nursing, medical specialists etc.) are generally funded and managed by MSB; and social services (such as homemakers, handyman services) are generally funded and managed by INAC (Band is usual delivery agent).

Although lack of resources is probably a main factor, INAC reviews have suggested that lack of clarity in division of responsibilities was a factor limiting home support care programs, at least up to 1983:

> ... The non-existent status of home health care on reserves is perhaps very much related to the fact that MSB and DIAND have not really come to terms with who should be responsible for extended health care...*

2.6 Provincial Role

The overall Provincial role in Adult Care in Manitoba is modest. It includes informal support and advice to four Indian-operated personal care homes, licensing of one Indian-operated personal care home, and direct nursing services to seven reserves provided through the Provincial Public Health Department.

Federal review documents state:

> ... The refusal of some Provinces (Manitoba and Alberta) to extend professional services by way of licensing and supervision of band-operated personal care homes will retard the development of community-based adult care programs, as well as present a serious dilemma for the Department. As matters currently stand, the Department could face the prospect of having to duplicate a costly network of Provincial health and welfare inspection, certification and monitoring of

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**Adult Care Program Review* (DRAFT discussion paper), DIAND, 1983, page 24.

> care standards for a relatively small and scattered population, unless the Provinces can be persuaded otherwise...*

But Province of Manitoba long-term care officials present a different view, reporting that they are prepared to be of assistance, with appropriate cost recovery, and that "no proposals have been received from the Federal Department in the eleven years that the long-term care program has operated."**

These questions concerning the Provincial role and the Federal/Provincial framework receive closer examination in Section 6 of this report.

2.7 Coordination Issues

The Adult Care Program is implemented by various levels of government and does not have one specific definition. Departmental division of service responsibilities remains unclear, despite The Memorandum of Agreement (1984) between INAC and MSB.

Lack of program definition and inconsistent coordination appear to have led to problems with program design, planning, and delivery.

2.8 Program Resources

2.8.1 Program Staffing

Staffing for this program poses an additional problem. The Federal (INAC) Adult Care Program has no professional or administrative personnel, and is generally run on a part-time basis by people who have other responsibilities.

2.8.2 Information Systems

Information available for program planning purposes (as of 1985) is poor. Figures are available regarding expenditures, and units of service for personal care homes, but not for other program activities. Overall it is difficult for managers to monitor program implementation or program impact.***

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*See: *Review Paper: Adult Care Program*, DIAND, June 1985, page 34.

**Personal communication from Ms. M. Redston, Long Term Care Program, Manitoba Health Services Commission, December 23, 1985.

****Adult Care Program Review Papers*, 1983 and 1985.

3. NEEDS OF ELDERLY INDIANS FOR INSTITUTIONAL AND HOME CARE

3.1 Background: Elderly Indians in Their Home Communities

Needs of elderly Indians for institutional and home care services are strongly affected by health conditions and other aspects of Indian communities, including housing, economic and sociological factors.

3.1.1 Health Conditions

Needs of elderly Indians for Adult Care are rooted in the typical human problems of aging and associated infirmity. These needs are amplified by the generally more severe health problems currently found in Canadian Indian communities.

The extent of health problems in Indian communities has been widely documented, in numerous studies.

Although cancer and heart disease are one-half* the National rate, diseases such as tuberculosis (which is nine times* higher among Indians), skin and ear infections, and nutritionally-based disorders are prevalent in Indian communities. Respiratory illness is the leading cause of hospitalization* and the third highest cause of death, after accidents and circulatory diseases. Death from violence and accidents are on the increase with an estimated 30-60% being associated with alcohol and drug abuse. One in five deaths are due to suicide. These factors combine to make the mortality rates nearly twice as high for Indians as for the rest of Canada.*

These health realities comprise an important part of the need for Adult Care in Indian communities. Because health needs and levels of infirmity of elderly Indians are high, needs for Adult Care services are expected to be greater than might be found in the generally healthier population of non-Indian old people in Canada.

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*Inuit/Indian Health Policy - Medical Services Branch, *Home Health Care* (DRAFT), January 1985, page 9.

3.1.2 Housing and Economic Conditions

High incidences of medical problems are significantly related to other conditions in Indian communities. Inadequate housing and poor nutrition are seen as major contributors to poor health. In his report regarding Indian and Inuit Health Consultation, Justice Thomas Berger observed:

> Indians are usually poor. Their homes are crowded, one-third, at least of their homes are unfit for human habitation. There is lack of clean water, and inadequate sewage and garbage disposal. The prevalence of respiratory illness among Indians is, of course, aggravated by the absence of central heating in a cold country...*

Poor diet, lack of proper accommodations, inadequate sewage treatment, low-income levels, lack of education, and reduced social recreational opportunities are all contributing factors to the higher rates of disease and mortality among Indians. All of these may impact on health care needs of elderly or disabled Indians.

The Adult Care Program identifies provision of adequate housing as a key foundation element in planning for effective home care for elderly Indians, but many elderly Indians lack adequate housing. Indeed, a recent National evaluation of INAC's housing program points out that three-quarters of Indian housing is inadequate, based on three criteria: (1) house condition; (2) crowding; and (3) access to basic amenities, i.e. water, toilet and bath or shower.** A number of this study's findings indicate that poor housing is a major factor which magnifies the problems of elderly Indians, and constitutes a central problem for the Adult Care Program. This issue is addressed further in Section 6.

3.1.3 Sociological and Community Factors

In addition to health and housing conditions, a number of social, community and other factors affect the needs of elderly Indians for Adult Care. Key sociological factors include the following:

- Increased Life Expectancy: The average life expectancy of Indian people has been rising in recent years.*** This increase in life expectancy results in increased need for appropriate services for elderly Indian persons.

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*Report of Advisory Commission on Indian and Inuit Health Consultation, 1985, Justice Thomas Berger - As taken from *Home Care Health Draft*, January 1985, page 9.

***Evaluation of the On-Reserve Housing Program (Summary Report)*, Indian and Northern Affairs Canada, June 27, 1985, page 6.

****Adult Care Program Review* (DRAFT), page 13.

Moreover, it is expected that by 1990 the numbers of aged Indian persons will increase significantly, similarly to the non-Indian population.*

- o Decline of the Extended Family: Traditionally, the extended family has played a very significant role in providing assistance to elderly Indians and to disabled family members in Indian communities.

  But the extended family no longer provides major support to persons in the larger non-Indian population. And the same is thought to be increasingly true in the Indian population, as larger numbers of Indians leave reserves for employment, education or other reasons. The implication -- that changing Indian families are less able to care for elderly family members in the traditional manner -- is supported by certain findings of this study.

  To the extent that this changing pattern of family relations represents a trend for the future, the need for community programs for elderly Indians can be expected to grow.

3.1.4 Program and Delivery System

To obtain Adult Care services to meet their needs, individual elderly Indians and their families must deal with a variety of programs and agencies. They find in many cases that needs which "ordinary" Canadians might have met with ease, simply cannot be satisfied.

For example, in Manitoba home care for the elderly and disabled is universal, with basic care provided at no cost to users, with the exception that the Provincial Home Care Program excludes Indians.** Assisted housing of high standards is readily available to seniors throughout Manitoba. An extensive network of personal care homes provides institutional care in every area of the Province. In general, the elderly in Manitoba have a full and wide choice of care options which include: staying in their own homes with assistance and support, obtaining adequate assisted (non-institutional) housing, or entering an institution close to home, when institutional care is required.

A very different situation exists for elderly Indians. Little standard housing for elderly Indians exists on Indian reserves. Most elderly Indians live in substandard housing lacking adequate heat and other basic services, and there is a lack of alternative housing models such as seniors apartments, group homes, etc. Only very limited home support services are available, with no access generally to services such as meals-on-wheels, adult day care, or respite care.

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*Andrew Siggner, Research Branch, Department of Indian Affairs and Northern Development, *An Overview of Demographic, Social and Economic Conditions Among Canada's Registered Indian Population*, September 10, 1979.

**See Section 2.6 and Section 6 for a discussion of the role of the Province.

3.1.5 Community Factors

To a great extent, problems with the delivery system reflect other aspects of community infrastructure. Program delivery is complicated by the very different situations of individual reserves in terms of resources (economic, administrative and social), related programs (such as housing), proximity to supportive resources (e.g. health facilities), and professional staff.

Particularly challenging problems in meeting Adult Care needs are experienced by remote reserves, and especially by very small reserves. Such small reserves lack the economic and professional resources to care effectively for their elderly and disabled members with ease. Many of their Adult Care problems are paralleled in other areas of service and social development, and in the design of rural human services generally; there are no simple remedies for the problems of these communities.

3.2 What Elderly Indians Say They Need

As part of the community survey, elderly Indians were asked what kind of help they needed. Specific questions dealt with four types of assistance available within the Adult Care framework: homemaker care, house repairs, home nursing care, and need for handicapped equipment. We also asked them more generally, as regards "other kinds of help" they needed to stay in their own homes.

3.2.1 Need for Basic Adult Care Services

Generally, a large proportion of elderly Indians indicated that they had need for these types of services, particularly: housing repairs; nursing service; and homemaker help, as is shown in Display 3.1 (next page).

DISPLAY 3.1
BASIC ADULT CARE SERVICES ELDERLY INDIANS SAY THEY NEED
(Estimated for a Population of 1,538 Elderly Indians On-Reserve,
Not In Personal Care Homes)

Type of Help Needed	Number of Elderly Indians Indicating That Help Was Needed	Percentage of All Elderly Indians On-Reserve, Not In Personal Care Homes
Housing		
Need help with work-repair on house or dwelling modification; basic facilities* in house; new home	1,197	77.8%
Homemaker Help		
Need homemaker help,** home support services generally	538	35.0%
Medical Services		
Need nursing care***	411	26.7%
Need handicapped equipment	427	27.8%

* Water, sewage, heat.
** Excludes elderly Indians already receiving homemaker services.
*** Excludes elderly Indians already receiving nurses' services.

3.2.2 Need for Other Services

These main areas of need discussed above, accounted for most statements of need or wants of elderly Indians, but substantial numbers also described need for other types of assistance, as is noted in Display 3.2 (next page).

3.2.3 Satisfaction with Services Among those Receiving Home Support Services

To assess satisfaction with home support services, we asked the elderly Indians surveyed whether the service they received was the "right kind" of help, or if they could have used more or different help. These questions were asked regarding homemakers' services and home nursing care.

DISPLAY 3.2
WHAT ELDERLY INDIANS SAY THEY NEED:
OTHER KINDS OF ASSISTANCE NEEDED

Type of Help Needed	Number of Elderly Indians Identifying Need	Percentage of All Elderly Indians On-Reserve, Not In Personal Care Homes
Need financial help	206	13.4%
Need more help generally	195	12.7%
Need help with getting water, wood	168	10.9%
Need not to be neglected	117	7.6%
Need better respect	92	6.0%
Need nursing home	80	5.2%
Need help with transportation	51	3.3%
Need help with yard/gardening	40	2.6%
Need checking to see if OK	32	2.1%
Other	52	3.4%

Generally, their responses pointed to additional needs: many indicated that they needed more homemakers' help or nursing help than they actually received. Over 70% of those receiving homemaker care reported they could use more help from the homemaker, but only 5% indicated that the help was the wrong kind of help -- generally, this type of help was regarded by elderly Indians as appropriate to their needs. Results for nursing care were similar, with 65% of those receiving nursing care indicating that they could use more help, but only 1.5% indicating that they received the wrong kind of help.

3.2.4 Why Elderly Indians Reported Not Getting Services

Elderly Indians reported a variety of reasons for not getting services they felt they needed. These were divided into several main types: no service available; financial reasons; don't know/elderly Indians lack information; and afraid or rejected.

DISPLAY 3.3
WHY ELDERLY INDIANS SAY THEY DID NOT GET HELP

Type of Reason Given	Number of Elderly Indians Reporting Reasons	Percentage of All Elderly Indians On-Reserve, Not In Personal Care Homes
Service/Help Not Available		
Didn't get help because not available	200	13.0%
Financial		
Didn't get help because support cut	180	11.7%
Didn't get help because no funding	143	9.3%
Didn't get help because don't qualify	69	4.5%
Didn't get help because unable to pay	23	1.5%
Elderly Indians Don't Know/Lack Information		
Don't know why I didn't get help	161	10.5%
Said I could have help but never got	137	8.9%
Never got answer when asked for help	122	7.9%
Afraid/Rejected		
Didn't get help because afraid to ask	143	9.3%
Didn't get help because Band doesn't care	29	1.9%

It is noted that because Band governments do not have the resources, the programs or the staff to provide effectively for their elderly members, elderly Indians and their families are often frustrated when requesting assistance. Survey results reveal that many elderly Indians do not understand why their needs are not being met or how Band programs operate.

3.2.5 Discussion

Overall, elderly Indians identified unmet needs for help in many areas, especially in the area of improved housing conditions and homemaker services. Substantial needs were also reported for nursing services, handicapped equipment, and additional help with wood and water.

As is shown in the sections to follow, a substantial portion of these needs are validated, not only by families of elderly Indians, but also by a Technical Health Needs Assessment provided by MSB nurses, Provincial Public Health nurses and Band nurses.

3.3 What Family and Others Say Elderly Indians Need

3.3.1 Assessments by Immediate Family

Our interviews with elderly Indians allowed for a short supplementary interview with family members when family was available at the time of the field research visits.

The purpose was to determine if there were important aspects of the elderly Indian's situation which our structured interview did not inform us about. Results of their comments were tabulated, and estimates (weighted to represent the population of elderly Indians) are presented in Display 3.4 (below).

DISPLAY 3.4
FAMILY MEMBERS' VIEWS ON NEEDS OF ELDERLY INDIANS
(Estimated for a Population of 1,538 Elderly Indians living on Manitoba Reserves, and Not In Personal Care Homes)

Type of Need	Number of Family Members	Percentage of All Elderly Indians On-Reserve, Not In Personal Care Homes
Need home support services	1,104	71.8%
Need help with work-repair on house	1,020	66.3
Need financial help	369	24.0
Need more help generally	304	19.8
Need help with adding basic facilities	209	13.6
Need homemaker help generally	200	13.0
Need checking to see if OK	171	11.1
Need help with transportation	134	8.7
Need a new home	89	5.8
Need handicapped equipment	65	4.2
Need help with getting water, wood	46	3.0
Need nursing home	26	1.7
Need help with medication/hospital	23	1.5
Need no help	498	32.4

3.3.2 General Assessment of Political Leaders, Health Professionals and Other Key Informants Re: Needs of Elderly Indians

Key informants identified a wide range of needs for Adult Care services, and appeared as a group to be somewhat split as to whether main needs were for institutional services, residential services, or home support services.

Analysis of surveys of key informants, and Adult Care needs identified in Band Profiles, revealed the following main needs:

- Need more or improved home support services generally (37 mentions);
- Need a personal care home (29 mentions);
- Need a residential facility (e.g. hostel, senior citizens' complex, etc.) (23 mentions); and
- Need a new personal care home (21 mentions, on reserves with existing personal care homes).*

Clearly, these assessments are not very different from the views of elderly Indians and their families, in placing considerable emphasis on home care as compared to institutional services. Elderly Indians and their families, in their comments, favour improvement of Adult Care services that would be provided to the elderly Indian *"at home"*, usually in the context of extended family and neighbouring networks.

Such a home-based program would be more supportive of the traditional role of elderly Indians in the community, as well as being more in keeping with contemporary concepts of effective care for the elderly.

As is shown below (in Sections 3.4 and 3.5), Technical Health Assessments of elderly Indians' health and needs for Adult Care services by MSB, Band, and Provincial Public Health nurses support a comprehensive home care program as the most effective main remedy for meeting needs of the elderly and the disabled.

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*See: *Appendix C: Problems with Adult Care and Remedies as Seen by Key Informants for Each Program Component,* for details.

3.4 Health Problems of Elderly Indians: A Validation of Needs

The realities of poor health discussed in Section 3.1 were strongly reflected in our own survey of nurses who provided data on major and minor health conditions of elderly Indians. Display 3.5 shows these data weighted to estimate incidence of health problems among the total population of elderly Indians living on Manitoba reserves. As can be seen in Display 3.5, a large percentage of older Indians have one or more major health problems (66% overall), with a very large percentage having such health conditions as high blood pressure, diabetes, arthritis and heart disease.

DISPLAY 3.5
ESTIMATES OF MAJOR HEALTH PROBLEMS AMONG
NON-INSTITUTIONALIZED MANITOBA ELDERLY INDIANS
(Estimated Population of 1,538 On-Reserve Elderly Indians,
Not In Personal Care Homes)

Health Problem	Number With Health Problem	Percentage of All Elderly Indians On-Reserve, Not In Personal Care Homes*
High Blood Pressure	393	25.6%
Diabetes	301	19.6
Arthritis	205	13.4
Heart Disease	195	12.7
Eye Disease	163	10.6
Lung Disease	163	10.6
Amputations	49	3.2
Alcoholism	48	3.1
Gout	48	3.1
Cerebral Vascular Accident/Stroke	44	2.9
Obesity	33	2.1
Cancer	31	2.0
Stomach Disease	30	2.0
Psychiatric/Nerve	28	1.8
Ear Disease	23	1.5
Congestive Heart Failure	20	1.3
Skin Diseases	19	1.2
Kidney Disease	13	.8
Hypothyroidism	11	.7
Fractures, Injuries	8	.5
Mentally Retarded	3	.2

* Not intended to add up to 100%.

DISPLAY 3.6
ESTIMATES OF MINOR HEALTH PROBLEMS AMONG
NON-INSTITUTIONALIZED MANITOBA ELDERLY INDIANS
(Estimated Population of 1,538 On-Reserve Elderly Indians,
Not In Personal Care Homes)

Health Problems	Number With Health Problem	Percentage of All Elderly Indians On-Reserve, Not In Personal Care Homes*
High Blood Pressure	144	9.4%
Diabetes	4	.2
Arthritis	139	9.1
Heart Disease	98	6.4
Eye Disease	236	15.4
Amputations	14	.9
Alcoholism	5	.3
Gout	11	.7
Cerebral Vascular Accident/Stroke	16	1.1
Stomach Disease	98	6.4
Psychiatric/Nerve	28	1.8
Ear Disease	112	7.3
Skin Problems	58	3.8
Kidney Disease	9	.6
Fractures, Injuries	16	1.0
Breathing Problems	27	1.7
Incontinence	9	.6
Haemoptysis	6	.4
Headaches	3	.2

* Not intended to add up to 100%.

Overall, nurses reported a high incidence of health problems among elderly Indians, a factor indicating high levels of need for Adult Care services.

3.5 A Technical Assessment of Elderly Indians' Needs for Adult Care Services

The points of view on Adult Care needs are diverse, and conditioned by very different concerns of the parties involved. Chiefs and other community leaders approach Adult Care issues with a wide range of social welfare and community welfare concerns. Elderly Indians and their families have their own concerns and anxieties which may not always lead to an objective or fully accurate answer about health or needs.

Such problems are common in surveys of the elderly, particularly where survey questions relate to the elderly person's fear of institutionalization.

This was found to be a major problem in this study, with many elderly Indians expressing fears (which we had to allay) that the interviewer had to do with "someone" wanting to "send them away" (to a personal care home).

Accordingly, it was decided to obtain a Technical Health Assessment of need for Adult Care health and social services, as a criterion against which current services (and wants of elderly Indians) could be more objectively evaluated.

3.5.1 Methodology of the Technical Health Assessment

Initial Data

To obtain a Technical Health Assessment, nurses providing nursing services to the elderly and disabled on the 13 study reserves were asked to provide a detailed health profile on each Indian person surveyed, including:

- o health problems;
- o need for nursing care and related assistance;
- o estimates of functional capacity (extent to which individuals are able to undertake activities of daily living without assistance);
- o assessment of the best type of care, if the individual needs assistance (i.e. is the best care situation for this person in a personal care home, a hostel, at home with support services, living on his/her own, etc.?); and
- o in the case of those deemed to need assistance: assessment of home-support type services (if any) that would be required, for those elderly or disabled Indians to stay at home in their own communities.

Nurses from Medical Services Branch of Health and Welfare completed most of these profiles, with additional profiles being completed by Provincial Public Health Nurses, and nurses from Band Nursing Services. In all, completed profiles were obtained for over 200 of the 250 elderly and disabled Indians surveyed.*

Nurses' Assessments

From nurses' estimates of the most appropriate type of care, and from the ratings on support service needs, a summary indicator of level of appropriate care was derived. This APPROPRIATE CARE indicator had three categories:

1. Needs care in a personal care home: this category was reserved only for those who nurses judged as being most appropriately placed in a personal care home (a portion of these persons were viewed however as being supportable in the community, as a second choice for care, with comprehensive home services).

2. Needs home care, based on need for one or more of three core home support program components: homemaker care; home nursing; and home improvements.

3. Needs no assistance or care (fully independent).

A variety of tests of the validity of this APPROPRIATE CARE indicator were undertaken, and suggested strongly that the nurses assessment was a valid and reliable view of health conditions and social requirements of elderly Indians (see Appendix B for reports on validity and reliability indicators).

*These Technical Health Assessments are combined in other analyses with comparable Technical Health Assessments for 130 elderly and disabled Indians already placed within both Indian-operated and non-Indian Manitoba personal care homes, so that the overall analysis is based approximately on 350 health profiles.

3.5.3 Summary Results of the Nurses Technical Health Assessment

The summary results of the Technical Health Assessment, weighted statistically to represent the overall population of elderly Indians residing on Manitoba Indian reserves, are in Display 3.7 (below).

Generally, nurses indicated that an estimated 116 elderly Indians *among those now living in the community*, required personal care home care. In contrast, a high level of need for home services was identified. Nurses reported that over 1,100 elderly Indians required home care services in order to maintain themselves in the community or in their own homes.* Overall, the results of the Technical Health Assessment pointed towards very extensive need for Adult Care services, particularly home support care.

DISPLAY 3.7
ESTIMATED DISTRIBUTION OF ELDERLY INDIAN
RESIDENTS OF MANITOBA INDIAN COMMUNITIES (BY AGE)
ACROSS 3 LEVELS OF NEED FOR ADULT CARE SERVICES*
(Estimated Population of 1,538 On-Reserve Elderly Indians
Not In Personal Care Homes)

Appropriate Level of Care (Nurses' Technical Health Assessment)	AGE 65-75		AGE 75+		TOTAL
	Number	Percentage	Number	Percentage	
Needs care in a personal care home	59	6.0%	57	10.4%	116
Needs home care (one or more key home support services)	693	70.3%	465	84.2%	1,158
No need for assistance or care (fully independent)	234	23.8%	30	5.4%	264
Total	986	100.0%	552	100.0%	1,538

*Shows the more elderly are more likely to require higher levels of care (e.g. 23.8% of those aged 65 to 75 are fully independent, compared to only 5.4% of those aged 75 or older). Statistics indicate that this relationship is statistically significant: x2 = 95.32956; p = .0000; Pearson's R = -.22; p = .0000; Gamma = -.53.

Our analysis in Section 3.5 below, will identify the extent to which these verifiable needs for home care are met (or not) by current programs. Section 3.7 will examine some more complicated aspects of need for institutional (personal care home) care.

*By themselves, or living with their extended family.

3.6 Comparing Home Care Needs to the Actual Level of Home Care Received by Elderly Indians Residing on Manitoba Indian Reserves

3.6.1 Informal Help from Friends and Family

To assess how well friends and family are able to assist elderly Indians, we examined the frequency with which elderly Indians received help with ordinary activities of daily living, from relatives, friends and neighbours. Results (Display 3.8 below) showed relatives to be the main source of help.

DISPLAY 3.8
LEVEL OF CARE FOR ELDERLY INDIANS LIVING IN THE COMMUNITY
BY SOURCES OF INFORMAL HELP RECEIVED FROM FAMILY,
FRIENDS AND NEIGHBOURS

	INFORMAL SOURCES OF HELP				
Appropriate Level of Care*	Relatives Helped	Friends Helped	Neigh-bours Helped	No One Helped	Total
Needs care in a personal care home	85 (73.2%)	28 (24.4%)	15 (13.4%)	22 (18.6%)	116**
Needs home care (one or more key home support services)	573 (49.5%)	37 (3.2%)	37 (3.2%)	584 (50.5%)	1,158**
No services needed (fully independent)	247 (93.7%)	0 (0%)	0 (0%)	17 (6.3%)	264**

*Nurses' Technical Health Assessment.
**Percentages of row total, row percentages, and column percentages do not necessarily add up to 100% because columns count several sources of help.

Overall, these results pointed towards a powerful impact of relatives and community in helping elderly Indians with ordinary activities of daily living. An analysis of the relationship of family help to needs of elderly Indians demonstrated clearly that family helps most when elderly Indians are more ill, lacking in functional capacity, etc. Yet the results also revealed a substantial number of elderly Indians who do not receive extensive help from families.

Several reasons appear to account for this absence of traditional support for some elderly Indians:

- o A larger proportion of elderly Indians do not have large families to support and care for them, due to the increasing mobility of many younger Indians (moving to find employment, attend school, etc.).

- o Many elderly Indians (singles and couples) live alone, away from children (12.1% are estimated to be living alone, with another 13.1% who are couples not living with children). Some 74.8% of elderly Indians are in the extended family living situation widely thought to be almost universal in Indian communities.

- o Certain of the care needs of elderly Indians are probably beyond skills and resources of families. In particular, needs for more medical-related attention probably cannot be fulfilled by families without training; need for housing improvements no doubt would strain the financial resources of most Indian families, who may have very low or modest incomes.

3.6.2 Formal Home Support Services Received by Elderly Indians

Allocation of Services

As can be seen in Displays 3.9 to 3.12 (next two pages), there is a strong correlation between need for a higher level of Appropriate Care, and provision of homemaker and nursing services. That is, as need becomes greater, elderly Indians are more likely to receive home help services.

For example, as can be seen in Display 3.9, there are no fully independent elderly Indians that received homemaker service, while 52% of those needing home support care received homemaker service, and 85% of those with the highest level of need (needs care in a personal care home) received homemaker service. Home nursing care in the home was similarly more likely to be allocated to those most in need. These indicate good program implementation at the delivery level, since it suggests that services are being directed to those most in need.

In contrast, housing repairs did not appear at all to be allocated to those with greater need for home care.

DISPLAY 3.9

APPROPRIATE LEVEL OF CARE FOR

ELDERLY INDIANS BY WHETHER RECEIVED HOMEMAKER/HOUSECLEANING HELP

(Appropriate Level of Care Determined by Nurses' Technical Health Assessment)

Appropriate Level of Care	RECEIVED HOMEMAKER HELP Number	Percentage	NO HOMEMAKER HELP Number	Percentage	TOTAL Number	Percentage
Needs care in a personal care home	99	85.3%	17	14.7%	116	7.6%
Needs home care (one or more key home support services)	610	52.7%	548	47.3%	1,158	75.3%
No need for assistance or care (fully independent)			264	100.0%	264	17.2%
Total Number	709	47.4%	829	52.6%	1,538	100.0%

* Statistics are: x2 = 266.5; P = .0000; Pearson's R = .41; p = .0000; Gamma = .91.

DISPLAY 3.10

APPROPRIATE LEVEL OF CARE FOR

ELDERLY INDIANS BY WHETHER RECEIVED NURSING CARE IN HOME

(Appropriate Level of Care Determined by Nurses' Technical Health Assessment)

Appropriate Level of Care	RECEIVED NURSING CARE Number	Percentage	DID NOT RECEIVE NURSE CARE Number	Percentage	TOTAL Number	Percentage
Needs care in a personal care home	93	80.4%	23	19.6%	116	7.6%
Needs home care (one or more key home support services)	310	26.8%	848	73.2%	1,158	75.3%
No need for assistance or care (fully independent)	48	18.2%	216	81.8%	264	17.2%
Totals	451	29.4%	1,087	70.6%	1,538	100.0%

* Statistics are: X2 = 138.7; P = .0000; Pearson's R = .24; p = .0000; Gamma = .58.

DISPLAY 3.11
APPROPRIATE LEVEL OF CARE FOR
ELDERLY INDIANS BY WHETHER RECEIVED HOME REPAIRS
(Appropriate Level of Care Determined by Nurses' Technical Health Assessment)

Appropriate Level of Care	RECEIVED REPAIRS Number	Percentage*	DID NOT RECEIVE HOUSE REPAIRS Number	Percentage	TOTAL Number	Percentage
Needs care in a personal care home	7	6.2%	109	93.8%	116	7.6%
Needs home care (one or more key home support services)	7	.6%	1,151	99.4%	1,158	75.3%
No need for assistance or care (fully independent)	47	17.9%	217	82.1%	264	17.2%
Totals	61	96.0%	1,477	4.0%	1,538	100.0%

* Statistics are: Chi-Square = 186.8; p = .0000; Pearson's R = .23; p = .0000; Gamma = .69.

3.6.3 Unmet Needs are Significant

More importantly, all three areas of home support care showed major gaps between specific needs as identified in nurses ratings, and actual home support received. Specifically:

- Over 1,100 elderly Indians were estimated to live in housing in need of basic repairs.
- Over 400 elderly Indians were estimated to be in need of homemaker services they were not receiving.
- Over 400 elderly Indians were estimated to be in need of nursing services they were not receiving.

Overall, there is a significant gap between needs and services provided. A summary view of this gap between appropriate level of care required and home support care services received, is suggested by Display 3.12 (next page). There it can be seen that an estimated 520 elderly Indians are estimated to be in need of care (484 requiring home support care and 36 requiring personal home care) receive no home support services whatsoever. **Over 40% of those in need of home support care received no home support care services.**

DISPLAY 3.12
APPROPRIATE LEVEL OF CARE BY NUMBER
OF HOME CARE SERVICES RECEIVED
(Appropriate Level of Care Determined by Nurses' Technical Health Assessment)
Table Shows Estimated Number of Elderly Indians, With Percentage in Brackets ( )

Appropriate Level of Care	No Home Care Services Received	One Home Care Service Received	Two Home Care Services Received	Three Home Care Services Received	Total
Needs care in a personal care home	36 (30.8%)	14 (12.5%)	66 (56.8%)		116 (7.6%)
Needs home care (one or more key home support services)	484 (41.8%)	539 (46.6%)	128 (11.1%)	7 (.6%)	1,158 (75.3%)
No services needed (fully independent)	212 (80.2%)	52 (19.8%)			264 (17.2%)
Totals	732 (47.5%)	605 (39.4%)	194 (12.6%)	7 (.4%)	1,538 (100.0%)

* Statistics are: X2 = 385.27; P = .0000; Pearson's R = -.36; p = .0000; Gamma = -.64.

3.6.4 Conclusion: Extensive and Critical Home Support Care Needs are not Provided for by the Current Adult Care Program

A substantial difference is evidenced between the theoretical goal of the Adult Care Program, of emphasizing home support care, and the actual program outcome -- which is a very partial and thinly spread program of home support.

This gap between goals and results is significant because:

- Important basic health needs are neglected and the potential of elderly Indians to contribute to their communities is undermined; and
- Failure to provide adequate home care creates artificial demand for institutional care.

The lack of home support care services for elderly and disabled Manitoba Indians is doubly striking because of the long established and universal home care program provided by the Province of Manitoba to all of its other elderly citizens. Principles of adequacy of care, cost-effectiveness and equal access to human services, all call for a change in this situation.

3.7 Comparing Needs to Institutional and Residential Care Received by Elderly Indians Residing on Manitoba Indian Reserves

3.7.1 Needs for Institutional/Residential Care

Our analysis of institutional care focused on personal care homes, because personal care homes account for nearly all institutional/residential care for elderly and disabled Indians in Manitoba.*

Method

Our analysis centred on a comparison of nurses' assessments of APPROPRIATE CARE, for elderly Indians in both Indian-operated and non-Indian operated personal care homes, and elderly Indians still living in the community.

The main objective of this analysis was to see if substantial numbers of elderly or disabled Indians would be found to need an appropriate level of care outside of what they were actually receiving. The analysis combined Technical Health Assessments for our community sample of approximately 200 elderly Indians with Technical Health Assessments completed for approximately 130 Indian residents of personal care homes.

General Result

Our analysis considered whether or not alternative "community" care might be possible for elderly Indians identified as best cared for in a personal care home.

The results (Display 3.13, next page) point out that substantial numbers of elderly Indians are receiving an inappropriate level of care:

1. An estimated 116 elderly Indians now living in their own communities were evaluated as needing personal care home care; and

2. Of some 97 elderly Indians in personal care homes in 1985, 22, or about 25% were evaluated by health professionals in personal care homes as not requiring institutional care, if appropriate housing and community care were available.

*As well, little data was available on the small numbers of hostels or other residential care available to on-reserve Indians in Manitoba, so that this type of care is not examined directly.

DISPLAY 3.13

APPROPRIATE LEVEL OF CARE FOR ELDERLY INDIANS ON-RESERVE, AND IN PERSONAL CARE HOMES

(Indicator of appropriate care based on nurses' technical health assessment)

Appropriate Level of Care	NOT IN PCH		IN PCH		TOTAL	
	Number	Percentage	Number	Percentage	Number	Percentage
Needs care in a personal care home	116	7.6%	75	77.3%	191	11.7%
Needs home care (one or more key home support services)	1,158	75.3%	22	22.7%	1,180	72.2%
No need for assistance or care (fully independent)	264	17.2%			264	16.1%

Statistics are: Pearson's R = -.32; p = .0000; GAMMA = -.70.

For these inappropriately institutionalized elderly Indians, a variety of reasons were offered for their residence in a personal care home, including: homelessness; family rejection; and abuse of the elderly person.

Personal care home nurses could readily identify alternative (less institutionalized) care that would be appropriate for this group, particularly return to care of family, or to more residential settings such as a group home or hostel.

The current Adult Care Program therefore is characterized by mis-institutionalization of elderly Indians, who could be cared for in less institutional settings or even merely through an effective home care program.

This mis-allocation of resources is undesirable in two main ways:

1. The type of care in question (in personal care homes) is very costly, and thus extremely cost-ineffective for persons who could be maintained in their own homes. Substantial numbers of dollars are expended which could be used to provide care to more elderly Indians, through a home care program.

2. Today, unnecessary institutionalization is not regarded as beneficial to wholistic concepts of health, and indeed, is highly contrary to Indian value systems.

Further, as we will note below, institutional care is seen as the least desirable care option by the vast majority of elderly Manitoba Indians.

Options for Elderly Indians Now in the Community

The above analysis suggested that more than 100 elderly Indians now living on Manitoba Indian reserves and not in personal care homes, ideally need personal care home level care.

Dealing with this need is challenging for several reasons:

1. These elderly Indians are estimated to be scattered over many reserves, while at most, only a few larger reserves would be able to support a personal care home.

2. These elderly Indians are generally opposed to going to a personal care home, as is illustrated below.

One answer may be to provide more residential care (hostels, group homes, seniors' units) under Adult Care, but the more direct remedy lies in the truly comprehensive home care program, need for which is suggested by the nurses' Technical Health Assessments.

Those health assessments indicated that most elderly Indians now in the community and requiring personal care home level of care could function in their own homes or with family if served by a comprehensive home care program. The need to move in this direction is emphasized by consideration of the views of the elderly Indians themselves.

3.7.2 Elderly Indians' View of the Choice Between Institutional and Home Care Tradeoff

Display 3.14 (next page) compares level of APPROPRIATE CARE as defined by nurses, to preferences of elderly Indians (three categories of possible care, personal care home, other residential care such as an apartment, or group home, and finally staying in the senior's own home).

DISPLAY 3.14
ELDERLY INDIANS' VIEW OF PREFERRED CARE
(Indicator of appropriate care based on nurses' technical health assessment)

Appropriate Level of Care	Prefer Personal Care Home	Prefer Hostel/ Group Home	Prefer To Stay At Home	Total
Needs personal care home	9 (7.8%)	13 (11.0%)	94 (81.0%)	116 (100%)
Needs home care (one or more key home support services)	131 (11.3%)	90 (7.7%)	937 (80.9%)	1,158 (100%)
No need for assistance or are fully independent	5 (1.9%)	5 (1.9%)	252 (96.2%)	264 (100%)
Totals	145 (9.4%)	108 (7.0%)	1,283 (83.4%)	1,538 (100%)

* Statistics are: Chi-Square = 123; p = .0000; Pearson's R = -.11; p = .0000; GAMMA = -.39.

Overall, these results illustrate dramatically, the preference of elderly Indians for care in their own homes over a personal care home or other residential care, and these preferences compared well to nurses' assessments.

Over 80% of seniors indicated a preference to stay in their own homes as their first choice for Adult Care services. This holds true even among the most infirm (those identified by health professionals as definitely or possibly needing personal care home care), suggesting strong resistance to institutionalization by elderly Indians.

Elderly Indians' resistance to institutionalization is an attitude which is shared by older persons in Canadian society generally -- but it is particularly significant here, since avoidance of institutionalization is more consistent with traditional Indian culture, and the values of smaller communities. This is especially a matter of concern where the personal care home or other institution is "off" the home reserve.

These attitudes represent a difficult challenge to those who would press for continued growth of Adult Care institutions by building additional personal care homes on reserves. Although such institutions may be regarded as powerful economic development tools (capital investment, job creation, training etc.), they promise a type of care which most elderly Indians do not need and do not want.

3.8 Conclusions on Needs of Elderly Indians for Institutional and Home Care Services

3.8.1 Need for Expanded Adult Care Service

The study results indicate a major need for expansion of service, if the Adult Care Program is to achieve its objectives. These needs lie especially in the areas of home-maker services and home help, but should include significant additional resources for housing repairs and upgrading, which are also major problems for health care of elderly Indians.

3.8.2 Towards a Comprehensive Home Care Program

As well, the above analysis points towards the need for a more comprehensive home care program consistent with the broad objectives of the program, and also the program concept underlying the 1984 INAC-MSB Memorandum of Agreement.

The full scope of such a home care program is suggested by nurses' assessments of a wide range of support services. Nurses were asked whether or not each service would be an important contribution to elderly Indians continuing to live at home. Their assessments (Display 3.15) stressed housing, transportation, help with wood and water, homemaker services and friendly visiting, as most important for the largest number of elderly Indians.

It is worth noting that such a comprehensive home care program would be broader in scope than the proposed Home Nursing-Medical Program (in Continuing Care Program) which MSB and INAC are reviewing.* It would include not only the current home support programs available from Bands (homemaker services etc.), but also a much expanded effort to assist with housing (most importantly), and assistance in other areas, such as transportation.

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*See: *Home Health Care*, Inuit/Indian Health Policy, Medical Services Branch, (DRAFT) IV, January 1985, for an excellent review of the health components of such a program.

DISPLAY 3.15
ESTIMATED NUMBERS OF MANITOBA ELDERLY INDIANS ASSESSED BY NURSES AS NEEDING VARIOUS HOME CARE SERVICES
(Estimated Population of 1,538 On-Reserve Elderly Indians Not in Personal Care Homes)

Home Care Service	Number of Elderly Indians Estimated to Need	Percentage of all Elderly Indians
Home repair help	1,062	77%
Transportation help	1,007	73
Homemaker services	885	64
Wood-water help	890	64
Friendly visits	871	63
Day care centre	615	44
Meals-on-wheels/cooking help	521	38
Nursing care	517	37
Special needs help	200	14
Special appliances	293	21
Other support	154	11

A program encompassing this full range of services will be more cost-effective, more satisfactory to elderly Indians, and suited to delivery in Indian communities of all sizes (unlike institutional programs which will only be feasible in larger communities).

As will be shown in Section 4, needs of the disabled provide further evidence in support of the above conclusions regarding need for a comprehensive home care program.

3.8.3 Institutional Care

Personal care homes certainly are required in the provision of a full continuum of care. The provision of this care on-reserve presents an important advance of the Adult Care Program in meeting needs of the elderly and disabled in a culturally appropriate manner, but these results suggest that future developments of personal care homes must be looked at closely, to assure that needs are met in a way that recognizes wants and preferences of elderly Indians.

4. NEEDS OF NON-ELDERLY DISABLED ADULTS FOR INSTITUTIONAL AND HOME CARE SERVICES

Needs of the disabled were examined in a format identical to that applied to elderly Indians. This analysis was somewhat less in-depth, because of the much smaller sample of disabled Indians surveyed (about 50 persons), and the resulting limitations in reliability of statistical estimates. Results, however, were decidedly similar to those found for elderly Indians.

4.1 What the Disabled Say They Need

Like elderly Indians, disabled persons surveyed were asked about four types of assistance available within the Adult Care framework: homemaker care, house repairs, home nursing care, and need for handicapped equipment. As was done with elderly Indians, we also asked them more generally about "other kinds of help" they needed to stay in their own homes. Overall, a large proportion of the disabled indicated that they had needs for these type of services, particularly housing repairs, nursing service and homemaker help.

DISPLAY 4.1
BASIC ADULT CARE SERVICES
DISABLED INDIANS SAID THEY NEEDED
(For an Estimated Population of 374 Disabled Persons)

Type of Help Indicated	Number	Percentage
Housing		
Need help with work-repair on house	301	80.6%
Homemaker Help		
Need homemaker help	223	59.6%
Medical Services		
Need nursing care	185	49.5%
Need handicapped equipment	96	25.8%

These three types of need accounted for most statements of need or wants of the disabled, but disabled persons also described need for assistance in a number of other areas: transportation (24%); financial assistance (22.3%); medication (13.7%); and education/work (6.5%).

4.2 A Technical Health Assessment of Disabled Persons' Needs for Adult Care Services

The summary results of the nurses' Technical Health Assessment, weighted to represent a general* estimate of the overall population of disabled individuals residing on Manitoba Indian reserves, are presented in Display 4.2 (below).

DISPLAY 4.2
ESTIMATED DISTRIBUTION OF DISABLED RESIDENTS* OF MANITOBA INDIAN COMMUNITIES ACROSS 3 LEVELS OF NEED FOR ADULT CARE SERVICE
(For an Estimated Population of 374 Persons, Appropriate Level of Care Determined by Nurses' Technical Health Assessment)

Appropriate Level of Care	Number	Percentage
Needs care in a personal care home	9	2.5%
Needs home care (one or more key home support services)	324	86.6%
No need for assistance or care (fully independent)	41	10.9%
Total	374	100.0%

* Note: based on a limited sample of about 50 persons.

Overall, the Technical Health Assessment suggested that disabled Indians have very extensive needs for Adult Care services, particularly home care. The numbers in need are small compared to overall need for elderly Indians, but demonstrate that even greater need for home care exists, for both populations taken together.

4.3 Comparing Needs to the Actual Home Support Received by Disabled Persons Residing on Manitoba Indian Reserves

4.3.1 Informal Help from Friends and Family

To assess how well friends and family are able to assist disabled persons, we examined the frequency with which disabled persons received help with ordinary activities of daily living* from relatives, friends and neighbours. Results (Display 4.3) showed relatives to be the main source of help.

DISPLAY 4.3
LEVEL OF CARE OF DISABLED (NON-ELDERLY) INDIANS LIVING IN THE COMMUNITY, BY SOURCES OF INFORMAL HELP RECEIVED FROM FAMILY, FRIENDS AND NEIGHBOURS
(Appropriate Level of Care Determined by Nurses' Technical Health Assessment)

	SOURCES OF HELP				
Appropriate Level of Care	Relatives Helped	Friends Helped	Neighbours Helped	No One Helped	Total*
Needs care in a personal care home	9 (100.0%)	-	-	-	9 (100.0%)
Needs home care	249 (76.9%)	26 (8.0%)	5 (2.0%)	49 (15.0%)	324 (100.0%)
No need for assistance or care (fully independent)	29 (70.7%)	-	-	-	41 (100.0%)

* Percentages of row total, row percentages, and column percentages do not necessarily add up to 100% because columns count several sources of help.

Overall, these results suggest that the disabled receive much more help from their families (and friends and neighbours), than was true for elderly Indians. We note that only 15% of our disabled sample with need for home support care received no informal help with activities of daily living, whereas half of the elderly Indians surveyed who were in need of home care received no informal help from any of the sources examined.

*See Section 3.6.

4.3.2 Formal Home Support Services Received by Disabled Persons

Displays 4.4 to 4.6 (below), show home support care services received by the disabled in the three areas examined (homemaker services, nursing services, and housing repair/ modifications).

DISPLAY 4.4
APPROPRIATE LEVEL OF CARE FOR DISABLED PERSONS BY WHETHER RECEIVED HOMEMAKER/HOUSECLEANING HELP
(Appropriate Level of Care Determined by Nurses' Technical Health Assessment)

Appropriate Level of Care	Received Homemaker Care	Did Not Receive Homemaker Care	Total
Needs care in a personal care home	9 (100.0%)	(0.0%)	9 (100.0%)
Needs home care (one or more key home support services)	137 (42.2%)	187 (57.7%)	324 (100.0%)
No need for assistance or care (fully independent)	(0.0%)	41 (100.0%)	41 (100.0%)
Total Number	146	228	374
Percentage (Row)	(39.0%)	(61.0%)	(100.0%)

* Statistics: X2 = 25.8; P = .0; Pearson's R = .27; p = .0; Gamma = 1.000.

DISPLAY 4.5
APPROPRIATE LEVEL OF CARE FOR DISABLED PERSONS BY WHETHER RECEIVED NURSING CARE IN HOME
(Appropriate Level of Care Determined by Nurses' Technical Health Assessment)

Appropriate Level of Care	Received Nurse Care	Did Not Receive Nurse Care	Total
Needs care in a personal care home	9 (100.0%)	0 (0.0%)	9 (100.0%)
Needs home care (one or more key home support services)	77 (23.7%)	247 (76.3%)	324 (100.0%)
No need for assistance or care (fully independent)	17 (41.5%)	24 (58.5%)	41 (100.0%)
Total Number	103	271	374
Percentage (Row)	(27.5%)	(72.5%)	(100.0%)

* Statistics are: X2 = 31.2; P = .0000; Pearson's R = .019; Gamma = .02.

DISPLAY 4.6
APPROPRIATE LEVEL OF CARE FOR DISABLED PERSONS
BY WHETHER RECEIVED HOME REPAIRS
(Appropriate Level of Care Determined by Nurses' Technical Health Assessment)

Appropriate Level of Care	Received Home Repairs	Did Not Receive Repairs	Total
Needs care in a personal care home	0 (0.0%)	9 (100.0%)	9 (100.0%)
Need for home care (one or more key home support services)	3 (1.0%)	321 (99.0%)	324 (100.0%)
No need for assistance or care (fully independent)	0 (0.0%)	41 (100.0%)	41 (100.0%)
Total Number	3	371	374
Percentage (Row)	(4.0%)	(96.0%)	(100.0%)

Conclusion: Unmet Needs are Significant. As with elderly Indians, all three areas showed major gaps between specific needs as identified in nurses' ratings, and actual home support received. Specifically:

- o over 200 disabled persons were estimated to live in housing in need of basic repairs (virtually none reported having received repairs in the past year);
- o over 130 disabled persons were estimated to be in need of homemaker services they were not receiving (distinct from over 100 other disabled persons receiving homemaker services); and
- o over 150 disabled persons were estimated to be in need of home nursing services they were not receiving (distinct from about 30 other disabled persons receiving home nursing services).

A summary view of this gap between appropriate level of care required and home support care services received, is suggested by Display 4.7 (next page). There it can be seen that an estimated 200 disabled persons requiring home support care according to the nurses' Technical Health Assessment (over 80% of those in need), received no home support services whatsoever.

DISPLAY 4.7
APPROPRIATE LEVEL OF CARE FOR DISABLED PERSONS BY
ACTUAL LEVEL OF HOME CARE SERVICES
(Appropriate Level of Care Determined by Nurses' Technical Health Assessment)

	HOME CARE SERVICES RECEIVED				
Appropriate Level of Care	None	One	Two	Three	Total
Needs care in a personal care home	9 (3.9%)	-	-	-	9 (2.5%)
Needs home care (one or more key home support services)	201 (83.2%)	91 (90.6%)	28 (100.0%)	3 (100.0%)	324 (86.6%)
No need for assistance or care (fully independent)	31 (12.9%)	9 (9.4%)	-	-	41 (10.9%)
Total Number	241	100	28	3	374
Percentage (Row)	(64.7%)	(26.9%)	(7.6)	(.9%)	(100.0%)

4.4 Comparing Needs to the Institutional and Residential Care Actually Received by Disabled Persons Residing on Manitoba Indian Reserves

4.4.1 Needs for Institutional/Residential Care

As with elderly Indians, our analysis of institutional care focused on personal care homes, because personal care homes account for nearly all institutional/residential care provided to elderly and disabled Indians in Manitoba.*

Method

Our analysis centred on a comparison of nurses' assessments of APPROPRIATE CARE, for disabled Indians in personal care homes, and those disabled still living in the community.

The main objective of this analysis was to see if substantial numbers of disabled Indians would be found to need an appropriate level of care outside of what they were actually receiving. The analysis combined technical health assessments for our community sample with technical health assessments completed for 24 disabled residents of personal care homes.

General Results

The results (Display 4.8, next page) suggest that a number of disabled Indian persons are receiving an inappropriate level of care:

1. An estimated 9 disabled persons living in their communities were evaluated as needing personal care home care; and

2. Of some 24 disabled persons in personal care homes in 1985, some 15, or about 3 in 5 were evaluated by health professionals as not requiring institutional care; rather these persons could be placed in the community if rehabilitation were provided and if adequate housing and home support services were provided.

*Because little data was available on the small numbers of hostels or other residential care available to on-reserve Indians in Manitoba, this type of care is not examined directly in this report.

DISPLAY 4.8
APPROPRIATE LEVEL OF CARE FOR DISABLED INDIAN PERSONS ON-RESERVE, AND IN PERSONAL CARE HOMES
(Appropriate Level of Care Determined by Nurses' Technical Health Assessment)

Appropriate Level of Care	Now in Community	Now in Personal Care Home	Total
Needs care in a personal care home	9 (2.6%)	9 (37.5%)	18
Need for home care (one or more key home support services)	324 (88.7%)	15 (62.5%)	339
No need for assistance or care (fully independent)	41 (8.7%)	-	41
Total Number Percentage (Row)	374 (93.9%)	24 (6.1%)	398

Unnecessarily Institutionalized Disabled Persons

As with elderly Indians, and perhaps to a greater extent, the Adult Care Program has resulted in inappropriate institutionalization of disabled persons. In a majority of cases, these individuals *could be cared for in less institutional settings or even merely through an effective home care program.*

4.4.2 Disabled Persons' View of the Institutional Home Care Tradeoff

The display on the next page compares appropriate level of care as defined by nurses, to the preferred care situations of the disabled themselves*.

*Three categories of possible care, personal care home, other residential care such as an apartment, or group home, and finally staying in the senior's own home.

DISPLAY 4.9

DISABLED INDIANS' VIEWS OF PREFERRED CARE
AS CONTRASTED WITH APPROPRIATE LEVEL OF CARE AS DETERMINED BY NURSES'
TECHNICAL HEALTH ASSESSMENT

Appropriate Level of Care	Personal Care Home	Hostel Group Home	At Home	Total
Need personal care home	-	-	9 (100.0%)	9 (100.0%)
Need home care (one or more key home support services)	5 (1.5%)	55 (17.0%)	264 (81.5%)	324 (100.0%)
No need for assistance or are fully independent	16 (39.0%)	-	25 (61.0%)	41 (100.0%)
Total Number	21	55	298	374
Percentage (Row)	(5.6%)	(14.7%)	(79.7%)	(100.0%)

Like elderly Indians, disabled Indian persons expressed a first preference to stay in their own homes, with home support. One difference from elderly Indians was that a higher percentage of the disabled indicated a preference for hostel or group home accommodation (14.6% of the disabled, as compared to 7.2% of elderly Indians). This may suggest an area for experimentation by Bands who would like to try out alternative housing forms.

4.5 Conclusion

4.5.1 Needs of the Disabled

Extensive needs of the disabled add to evidence that home care needs are not provided for by the current Manitoba Adult Care Program.

Noteworthy unmet needs for home support care were discovered in this analysis of the situation of disabled persons living on Manitoba Indian reserves. Specifically, study findings indicated:

- that 83% of disabled persons identified by nurses as needing care at home received no basic home support services (homemakers, nursing, home repairs); and
- that a majority of disabled persons in personal care homes were classified by personal care home staff as being more appropriately cared for in the community, with home support services.

It is difficult to examine these results and avoid the conclusion that the lack of a comprehensive home care program for Manitoba Indians has contributed to unwarranted institutionalization and cost-ineffective allocation of resources.

4.5.2 Needs of the Elderly and Disabled Combined are Significant

Together, some 685 elderly and disabled Indians were identified by nurses as needing home support care services but not receiving any of the three key home support care services we examined. Since this comprises about 45% of those in need, we may conclude that there was a deficit of at least 45% in home support care resources available in Manitoba in 1984-85 (the time period covered by the survey).

These findings add weight to the previously discussed needs of elderly Indians for home support care, and underline the urgency of certain program changes which are essential for Adult Care to achieve its objectives.

Issues of future direction and changes will be addressed in Section 6.

5. OTHER ANALYSES, FINDINGS AND ISSUES

5.1 Overall Assessments of the Adult Care Program by Key Informants

The Adult Care Program was assessed in an overall way, by asking key informants to evaluate the extent of problems in each of Adult Care's main program components. Nurses, CHR's, welfare staff, NNADAP staff, personal care home staff and community leaders (e.g. Chiefs or members of Band Council) constituted this group of key informants.

The results of their evaluation of key problems in the Adult Care Program are shown in Display 5.1. Overall, service components, and particularly lack of resources for these components, were identified by key informants as the most pressing problem. Among these program components, problems with lack of home care services or resources were most frequently identified as major problems.

DISPLAY 5.1
KEY INFORMANTS' EVALUATIONS OF PROBLEMS
BY PROGRAM COMPONENT OR AREA

% Reporting Major Problems	Program Component or Area
76.7%	Lack of Service Component Resources
56.5%	Home Support Component
50.6	Residential Care
50.0	Preventative Services
48.2	Institutional Care (including personal care homes)
71.8%	Planning for Adult Care
69.0%	Cultural Orientation
34.9%	Assessment and Referrals

* Combines responses of 66 key informant witnesses and 20 Band Profile reports, to provide data on 37 reserves.

It is interesting that in addition to key informants' great concerns with lack of service and lack of funding (see Appendix C), two far less tangible issues were also identified as important problem areas in Adult Care: planning for Adult Care (including the lack of staff and as some key informants put it "lack of a program", and cultural orientation of services. It is interesting as well, that the assessment process was evaluated as the least problematic aspect of the program (see Section 5.2, next page), since this area was identified in the evaluation assessment study as a problem area in Adult Care.

5.2 The Assessment Component of Adult Care

The assessment component of the program was identified as a particular concern by INAC at the start of the study. For example, the evaluation assessment study suggests that an unintended effect of the program may be that: "preventative and homemaker services are left to the Bands who are often not qualified to do proper assessments...."*

As well, a number of major concerns were raised about the assessment process in INAC's internal program reviews in 1983 and 1985 (draft reports):

> Most Band-level Adult Care Programs are deficient in care assessments, which is primarily a condition caused by the lack of necessary training in multi-disciplinary skills, and the lack of regional professional strength to provide assistance. This reduces the ability for effective case management and seriously limits the program's impact.**

> Homemaking is often seen by bands as little more than a "make-work" project intended to be "good works". Unless this deficiency can be remedied, misdirection of scarce resources and client abuse of service benefits will continue.***

Because of these serious concerns, a number of questions were asked about the assessment component in the survey of key informants (and in Band Profiles). As well, we considered certain objective data to assess this issue.

**An Evaluation Assessment of the Adult Care and Rehabilitation Services Program Component*, INAC, Evaluation Branch, October, 1982, page 15.

***Adult Care Program Review*, (draft), 1983, page 32.

****Adult Care Program Review*, (draft), 1985, page 52.

5.2.1 Reports and Views of Key Informants

The survey of key informants obtained a variety of information on assessments. First, the survey identified participants in the assessment process, and showed this assessment process to include a wide range of participants (centred around the CHR and nurse (see Display 5.2). As well, the evaluation examined the range of issues considered in assessments (Display 5.3) and found assessments to consider a range of appropriate concerns.

DISPLAY 5.2
REPORTS OF KEY INFORMANTS AS TO
WHO IS INVOLVED IN ASSESSMENTS

Types of Participants	Percentage
CHR's	87.9%
Nurses	77.3
Physician	72.7
Family and/or friends	72.7
Chief	56.1
Band welfare administrator	51.5
Social worker	48.5
NNADAP field worker	33.3
Other councillor(s)	33.3
Homemaker staff	27.3
Director, personal care home	25.8
Band Manager	13.6
Health educator	12.2
Health advisor from an Indian Organization	10.6
CHR advisor/coordinator	7.6
Environmental health officer	6.1

DISPLAY 5.3
REPORTS OF KEY INFORMANTS
AS TO WHAT IS CONSIDERED IN ASSESSMENTS

What is Considered in Assessments	Percentage
Individual's state of health	97.6%
Physical level of functioning	97.6
Physical environment	92.9
Mental level of functioning	90.5
Social level of functioning	88.1
Other Factors	14.3

Generally, the results showed little concern by key informants that the assessment process was inadeqate in any major way. Thus the point of view expressed in the INAC (draft) policy reviews was not supported by these key informants, most of whom were health professionals.

The main concern of health professionals and other key informants was that far too often, the appropriate treatment or disposition simply could not be undertaken because of lack of alternative care resources.

5.2.2 Some Objective Evidence Applied to Band Allocations of Services

To examine this issue more objectively, data presented in Section 3 were reconsidered, specifically for homemaker services (see Display 3.9, above). Comparison of need for home care (nurses' Technical Health Assessment) to actual receipt of homemaker services showed no instance of elderly Indians receiving homemaker care without need. As well, the correlations between nurses' Technical Health Assessment of need and actual receipt of homemaker services was quite high (Pearson's r= .41, GAMMA = .91), indicating that Band's allocation of services was very much in direct response to need.

No evidence was found, therefore, in the field surveys, to support the proposition that Band level assessments are deficient in a major way, or that any significant proportion of services are received by persons not in need.

The problems noted by INAC policy reviews may have occured in the past, or in other Provinces, but the weight of these survey results indicates clearly that assessments at the Band, or delivery end, are not a problem in Adult Care in Manitoba.

5.2.3 Implications for Training

These findings are not contradictory to the view that many Bands still need improved professional resources, as well as training in assessment and Adult Care generally.

Two factors probably account for good allocations by Bands in spite of need for training: (1) in many cases, the assessment function is strongly influenced by non-Band staff (especially MSB and Provincial nurses); and (2) in the current environment of insufficient resources to meet critical needs, allocation decisions are perhaps simpler: those with great needs are easy to identify, and once services have been allocated to these persons, resources are exhausted.

The implication for training and professional development is that implementation of an expanded Adult Care Program -- one that provides its target range of services, and one that meets needs effectively -- may surface significant need for training.

5.2.4 A Concluding Note on Assessments of Need for Care

The view provided above -- of assessments of need for care as an area of few problems -- was generally reinforced by personal care home survey results. Personal care homes reported some patients who did not need personal care home level of care* -- but they tended to be in the personal care home because of the lack of alternative care and services, not because of inadequate assessments.

5.3 The Personal Care Home Program Component

The evaluation objectives did not, per se, include examining the quality of institutional care provided under the program. Nor did the evaluation include any type of operational review.

Because institutional care, in general, fell within the evaluation's objectives, and because of concern with cultural appropriateness, a small survey was conducted of personal care homes serving elderly and disabled Manitoba Indians.

This survey included five Indian-operated, on-reserve homes, and six off-reserve homes with Indian patients. Only one of the Indian-operated homes was licensed by the Province, as compared to all of the non-Indian operated personal care homes.

5.3.1 Some Features of the On-Reserve Personal Care Homes

The survey pointed out some interesting (but not necessarily surprising) features of the Indian-operated personal care homes, as compared to the Provincially-licensed group. As compared to the non-Indian homes, our survey of personal care homes indicated that the Indian-operated homes were:

- more likely to provide Indian cultural programming for residents;
- more likely to express an interest in returning patients to the community;
- more likely to engage in more frequent case-conferencing;
- more likely to report lack of critical equipment;
- likely to report less frequent physician review of prescriptions;

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*See Sections 3.7.1 and 4.4.1, above.

- o less likely to have rehabilitation programs; and
- o less likely to have regular access to necessary specialists.

Thus the Indian-operated homes appear to provide care in a more community-oriented setting, but also to be more severely limited in resources and services.

This characteristic of strength in community linkages was examined more closely by testing the often repeated proposition that on-reserve personal care homes facilitate family linkages (i.e. that family will visit more if the elderly Indian is on-reserve, etc.).

5.3.2 Some Positive Impacts of On-Reserve Personal Care Homes

Reports on family visiting behavior were examined using data from the Patient Profile Survey, which were completed by personal care home staff. This was the same survey form used to generate the Technical Health Assessments reported earlier in Sections 3 and 4, (that form including a question asking staff to rate frequency of family visits for each patient).

Analysis of these data supported this key argument that families visit residents of on-reserve homes more often. Residents of on-reserve homes were reported to be twice as likely to receive frequent visits from family and friends, as shown in Display 5.4 (below).

DISPLAY 5.4
FREQUENCY OF VISITS BY FAMILY AND FRIENDS,
FOR ELDERLY AND DISABLED INDIANS IN
ON-RESERVE AND OFF-RESERVE PERSONAL CARE HOMES

	LOCATION OF PERSONAL CARE HOME	
	On-Reserve	Off-Reserve
Visited every day	11.6%	0.0%
Visited once a month or more	48.2%	36.4%
Visited less than once a month	40.2%	63.6%

Since one major shift in the past 5 years has been the more frequent placement of elderly and disabled Indians in on-reserve homes, it seems reasonable to conclude that cultural and community appropriateness have been improved by the increase in on-reserve personal care homes.

5.3.3 Licensing and Inspection

Licensing and inspection are major issues for the on-reserve personal care homes. Quality of care has not been identified in any way as a problem in Adult Care's institutional component, yet the general lack of a licensing or inspection mechanism is a serious concern.

The fact that there is no regulatory or quality assurance mechanism (outside of self-regulation) for four of the five homes means:

- that staff operating the four unlicensed homes are unsupported, and at risk in certain respects, as are Bands operating them; and
- that INAC has no method of assuring quality of care or well-being of residents.

Assuring such quality of care is a need that INAC has recognized, but temporized about for several years. To the evaluator's knowledge, no other government department in Canada operates personal care facilities without a system for assurance of quality. **Significant political and legal dangers exist in operating such a program without these protections, and accountability requires that this situation be remedied.**

The INAC position stated in its draft policy reviews over the past several years, is that the Province will not extend its inspection umbrella to cover on-reserve homes. But Provincial staff deny this, reporting that no proposals have ever come from INAC (see Section 2.6 of this report). The reality of these different perceptions is difficult to untangle, but points to the need for public airing of this important issue.

Regardless of the final resolution of this issue, some recommendations regarding inspection of personal care homes are offered in the concluding section of this report, as are recommendations for a more effective forum for discussion of possible Provincial roles in Adult Care.

5.3.4 Discussion

Personal care homes play a valuable role in providing one end of the full range of Adult Care alternatives. On-reserve personal care homes provide this option in a strong community context. In this respect, their role will be important, even in an Adult Care Program which increasingly emphasizes home care in the community. Accordingly, integration of personal care home programs with home care programs will be an issue of continuing concern.

5.4 Financial Needs Testing

5.4.1 Key Issues

The current program requires a financial needs or means test prior to receiving services. As the 1985 INAC (draft) Program Review states:

> The Adult Care Program policy, in keeping with the guidelines established under the Canada Assistance Plan, requires that some adult care services be subjected to an income test. The Adult Care Program, therefore, makes provision for user charges based on an individual's and family's ability to contribute to the cost of the assistance.*

Yet major problems occur at several levels, as the 1985 INAC (draft) Program Review notes:

> Many Band-level Adult Care Programs do not apply a needs test, and therefore provide assistance without reference to the recipients' ability or non-ability to pay for part or all of the cost of assistance. Furthermore, some regions are failing to insist on this requirement as a condition for band delivery of Adult Care assistance and services.**

The Review also notes two further difficulties:

> Some health care services that closely parallel Adult Care services are provided without income testing or user charges by MSB. These include such services as transportation for medical reasons, prescription drugs and eye glasses. For non-Indians, the cost of these items are met through Provincial income security or welfare programs. Since they are cost-sharing under the Canada Assistance Plan, they must be income tested. Medical Services Branch recognizes the problem but claims that they are unable to conduct income testing under their present health care policy.
>
> The universal provision of uninsured health services is supported by Indian people who believe in their inherent right to such services. Further, advocates of universal care based on need feel a financial test discourages adults from using in-home services, leading to deterioration of health status and increased institutionalization.***

**Adult Care Program Review*, (draft), 1985, page 53.

***Adult Care Program Review*, (draft), 1985, page 52-53.

****Adult Care Program Review*, (draft), 1985, page 53-54.

In fact, the application of a means or income test has been a matter of considerable controversy between INAC, and Bands, which have generally objected to the procedure.

5.4.2 Some Service and Cost-Effectiveness Considerations Which Argue For Removal of the Financial Needs Test

Four factors should be considered which, taken together, argue strongly against application of the financial needs or means test:

1. The means test for home care services such as homemakers does not parallel the Province of Manitoba policy for its home care program.* That program is offered universally without charges for basic services.

   Indians in Manitoba, in spite of their generally more disadvantaged economic position, must be means tested for a type of service which is available without charge to all other Manitoban adults with home care needs.

   Since one objective of INAC social service programs is equity with the non-Indian population, this constitutes a serious problem for Adult Care.

2. The application of the means test may prevent some elderly or disabled Indians from receiving home support care which they need, thus potentially contributing to their ultimate demand for institutional care.

   This impact would be contradictory to key goals of the Adult Care Program.

3. The interpretation of the Canada Assistance Plan requirement for individual means or needs testing is somewhat out-of-date. Federal-Provincial cost-sharing under CAP is now allowable for Provincial programs where the means test is replaced by a statistical proxy -- that is, where a statistical case can be made that the majority of the recipient population would be eligible if a needs test were applied.**

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*For a description of the Provincial Program, see "The Home Care Program in Manitoba", in *A Reader on Prevention and Social Policies*, Canadian Council on Social Development, and Social Planning Council of Winnipeg, Ottawa, 1982.

**Personal communication from Manitoba Region Health and Welfare, CAP Consultant, January 6, 1986.

This is the method by which Federal-Provincial cost-sharing supports the Manitoba Home Care Program, for Manitobans generally.

4. Finally, the means test itself consumes considerable Band staff time for administration, which is wasteful, since the vast majority of elderly and disabled Indians would qualify for assistance anyway.

   Provincial health experts* have indicated that one rationale for removing the means test is that the administration costs may be greater than the income regained, since most recipients are very low in income. This, is is suggested, is one reason for the universal program in Manitoba.

   It seems certain that the population of elderly and disabled Indians receiving home-support services would be much lower in income than the general population. It is therefore quite likely that the requirement in the Adult Care Program for the means test is highly cost-ineffective* on these grounds alone, not to mention its potential impact in increasing demand for costly institutional care.

These considerations raise serious concerns about the value of the means test in the Adult Care Program. The financial needs or means test seems to combine several unsatisfactory features: unequal treatment of Indian elderly and disabled as compared to other Manitobans, creation of obstacles to meeting needs of some elderly and disabled Indians, and probable cost-ineffectiveness.

This issue is also addressed further in conclusions and recommendations (Section 6).

*Ms. Betty Havens, Gerontologist for the Province of Manitoba, personal communication, December, 1985.

6. CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

The study points to a number of major conclusions about the Adult Care Program and its operation in Manitoba. These conclusions deal with needs, program impacts, imbalance in program components and some resulting cost-ineffectiveness, inadequate housing as an obstacle to effective program implementation, the personal care home component, alternative care models, need for clarification of program mandate, the role of the Province, and need for changes in the policy and program planning process.

A number of the conclusions relate to major problems in program design, and to significant differences in range and level of services provided to elderly and disabled Indians as compared to services provided to other Manitobans. (References to sections from which conclusions are drawn are provided in parentheses.)

6.1.1 Unmet Needs are Extensive

The study identified extensive needs for home support services. These needs were strongly evidenced in reports of elderly and disabled Indians we interviewed, and were also validated by Technical Health Assessments provided by MSB, Provincial and Band nurses. Most importantly, study results revealed:

- Need for **extension of home support services to a large proportion of elderly and disabled Indians in need of care.** Nurses' assessments indicated that some 40% of elderly Indians in need of home support received no home support services (Section 3.8.2), and that some 80% of disabled Indians in need of home support received no home support services (Section 4.3.2); and

- Need for **provision of a full range of home care services not now available to elderly and disabled Indians**, including home nursing care, meals-on-wheels, and respite care for families (Section 3.6.3).

The importance of these needs is underlined by changing patterns of family living that are likely to continue into the 1990's. Indian families are more dispersed and mobile than in the past, and are no longer always able to assume the care that the traditional extended family once provided for elderly Indians.

The **need for emphasis on home support as compared to institutional care was underlined strongly by elderly and disabled Indians surveyed in the study.** More than 80% of the elderly Indians surveyed and approximately 80% of the disabled surveyed indicated that their first preference was for care at home, rather than care in personal care homes or other institutions (Section 3.7.2).

6.1.2 Program Impacts are Appropriate but Imbalanced

Study results pointed towards important positive effects of existing services where these are provided:

- Most elderly and disabled Indians who received home support-type help reported that the help they received from Bands (mainly homemaker services) was the type of help they needed with everyday activities they could not do by themselves (Section 3.2.3).

- Available evidence seemed to support the view that on-reserve personal care homes provide more culturally appropriate care with better maintenance of family linkages than off-reserve institutions (Section 5.3.2).

Overall, however, the accomplishments of both of these program components were overshadowed by **unmet needs** (as noted above), and **imbalances in actual program outputs**, particularly:

- Lack of the continuum of services conceptualized for the program (Section 2.3) (the range of appropriate service outlined for example in the INAC-MSB Memorandum of Agreement, 1984); and

- Over-emphasis on institutional (personal care home) care as compared to home support care (Section 2.3.1).

6.1.3 Cost-Ineffectiveness Results from Program Imbalance

Because institutional care is more readily available, and home care unavailable relative to need, there is pressure to shift persons in need into **unnecessary institutional care.** Since institutional care is much more expensive, the result is cost-ineffective allocation of resources (Section 3.7.1 and Section 4.4.1).

6.1.4 Lack of Adequate Housing Provides a Major Obstacle to Effective Care

Nurses' reports indicated that more than 75% of elderly and disabled Indians reside in inadequate housing (Section 3.8.2). This factor is critically important to Adult Care, since **effective home care for the elderly and disabled cannot be obtained in poor, ill-heated housing.** This is recognized by the emerging Adult Care Program design, which identifies home repairs as an important component of effective Adult Care, but there is no evidence to date of resources being mobilized to deal with this problem.

This lack of adequate housing appears to be a major factor in the pressure by Bands for more personal care homes. It is also apparent that many elderly and disabled Indians are now receiving institutional care not because of personal disability, but simply because they have no other place to go. (Section 3.7.1 and Section 4.4.1.)

These effects of poor housing are, of course, contrary to basic objectives of the program, and reflect serious program design issues. As well, the contrast between the housing situation of elderly and disabled Indians and the range of housing alternatives available to non-Indian Manitobans is striking indeed*, and reflects the large gap between range and quality of services available to Manitoba Indians and those offered to other Manitobans. **Much of this problem could be remedied through adjustments in housing programs at the INAC (and Band) level to facilitate construction of senior citizens' housing units on reserves.**

6.1.5 Standards Are Needed for the On-Reserve Institutional Component (Mainly Personal Care Homes)

The Personal Care Home Component represents an important part of the continuum of Adult Care services, but standards are needed for Indian-operated personal care homes (Section 5.5.3). An operational review of the five on-reserve homes (or just the four unlicensed homes) should be initiated immediately in association with a steering committee formed by INAC in consultation with the Manitoba Indian Organizations, and the personal care homes themselves.

This review could be conducted with assistance by the Province (INAC would need to second or borrow Provincial staff), or by a private consultant or practitioner, or a committee of representatives from licensed nursing homes (preferably with experience with Indian patients). Considering the dangers of institutional health care (e.g. the recent epidemic in one Ontario nursing home), **this is a severe responsibility, in the absence of licensing, and one that should not be neglected any longer.**

There is also a need to review the hostel care provided on three reserves. This type of care is allowable under Adult Care, but is not currently funded under Adult Care in Manitoba Region. Since such care should be more economical than personal care home care, this warrants examination.

6.1.6 Alternative Care Models are Needed

There is a **need for new program models which provide for a more complete continuum of service** on reserves, including home nursing, more extensive homehelp and homemaker services, meals-on-wheels, and related services. (See Section 3.8.2 for related discussion.) Alternative care models also need to **integrate** this wider range of services, so that services are complementary.

New program initiatives in Manitoba may or may not include new personal care homes, but in communities where they do, care should be taken to assure that personal care homes provide support for an integrated Adult Care Program, and/or Adult Day Care. Similarly, home care

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*A wide range of housing options are available to elderly and disabled Manitobans. They have access to financially assisted, adequate housing, under programs sponsored by Canada Mortgage and Housing and the Province. Housing availability, especially for senior citizens, is high.

programs should be designed for delivery in conjunction with Adult Day Care programs, where these can be provided. As well, Adult Day Care programs could be coordinated with housing initiatives: where facilities suited for a Day Care program are to be constructed, these might ideally be co-located with senior citizen housing units.

6.1.7 Clarification of Program Mandate is Urgently Required

Overall, problems with Adult Care appear to stem from lack of a clear program mandate and lack of focused responsibility in a single Federal Department. A number of major administrative problems result: lack of program staff; problems in the program information system; and problems in program implementation (Sections 2.5, 2.7, 2,8). Resolution of these basic problems of mandate and responsibility would allow for more effective program planning.

The two Federal Departments have been unclear about responsibility for this program. To allow for effective program development, one Department, preferably the one with the technical expertise relevant to the program (HWC), should take the lead Federal role (Section 2.1.2).

6.1.8 Issues Regarding The Province of Manitoba

Problems in delivery of a comprehensive home care program are intensified by Manitoba's not being involved in Adult Care. This is a problem of particular note as regards the issue of standards and licensing of personal care homes, since the Province could efficiently assist INAC and Bands in this area (Section 2.6).

As well, some Bands might wish to access Provincial services, under Federal-Provincial cost-sharing agreements, as can be done in Ontario and Quebec.*

Lack of access to Provincial services is a major problem, since it restricts Bands' service provision options. Resolution of this problem would allow elderly and disabled Indians their due access (under appropriate Federal-Provincial cost-sharing) to the home care services which other Manitobans enjoy.

6.1.9 New Policy and Program Planning Mechanisms are Required

A number of problems in the Adult Care Program have gone unresolved over long time periods because of the lack of a central steering body. As well, effective treatment of program issues may have been hindered by the lack of a mechanism for Indian participation in this policy process. (Evaluator's conclusion, see Section 2.7, for discussion of INAC-MSB coordination.)

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* See: *Review Paper: Adult Care Program*, DIAND, (draft), June, 1985.

Accordingly, it appears that there is a **need for a new steering mechanism** for Adult Care, both Nationally and at the Regional level. A new steering body would have senior representation from major Indian Organizations, INAC and HWC, and would be designed for possible eventual inclusion of the Province. As a policy-making group, it would **introduce significant Indian input** to the Adult Care policy process.

Introducing a significant degree of Indian involvement in the policy and program development process is essential for three reasons:

1. A number of issues identified in this report call for urgent action (e.g. unmet needs, contradictory program impacts). Speedy and effective attention to these matters can only be achieved in a forum where all of the concerned parties can evaluate alternatives, and set future directions together;

2. Only Indians can ultimately design the program to reflect Indian concerns; and

3. A strong Indian role in a public setting will help to assure coordination between, and accountability of, the two Federal Departments*, and to clarify the appropriateness of Provincial involvements in Adult Care.

As well, a public forum for review of program issues will lead to better understanding of constraints faced by all parties.

6.1.10 National Implications

Study results reveal an Adult Care Program which lacks a clear National mandate and structure for implementation; leaves significant needs of the elderly and disabled unmet; and has a number of contradictory impacts including indirect encouragement of cost-ineffective institutional care.

The results, of course, apply most directly to Manitoba, since the study was done in Manitoba. But since a number of these problems stem from a confused mandate and administrative structure at the National level, it seems probable that they are manifest in varying degrees in other Regions as well. Accordingly, extension of some aspects of the type of research reported here, to other Regions, may be desired as follow-up to this report.

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* See Section 2.1.2 and Section 2.7 of this report.

6.2 Recommendations

Considerable change is essential in Adult Care services in Manitoba (and probably Nationally as well), if the important goals of the program -- to provide effective care for elderly and disabled Indians are to be achieved.

Ultimately, these changes should include increased resources for Adult Care, in recognition of the extensive unmet need evidenced by this study, and significant changes in program delivery mechanisms. These issues, and certain more specific concerns arising from the evaluation, are addressed in the following recommendations.

6.2.1 Need for Increased Home Support Resources to Extend the Range of Services

Recommendation 1: Additional resources should be provided to meet urgent needs of elderly and disabled Indians which are being met only in part, at this time, particularly in the area of home support services.

Rationale and Discussion: These needs are strongly evidenced in the Technical Health Needs Assessments completed for community residents by MSB and other nurses serving the 13 Bands studied.

Particular attention should be given to expansion of the Homemaker Program and related home help (e.g. help with wood and water) since these are easily expanded within existing Band structures and delivery capability.

Recommendation 2: The Home Nursing Program now under review by INAC and MSB (in relation to Continuing Care) should be approved and start-up begun as soon as possible.

Rationale and Discussion: Addition of home nursing services to the actual range of Adult Care services will greatly improve home support services to elderly and disabled Indians, and meet critical needs which cannot be dealt with in the absence of this program.

Overall, creation of a comprehensive home care program centred on these services will not only meet important human needs of elderly and disabled Indians, but also contribute to more efficient use of resources, by reducing demand for institutional care.

6.2.2 Immediate Housing Initiatives

Recommendation 3: A Task Force should be established between INAC, Canada Mortgage and Housing Corporation, and National Indian organizations to review the way in which housing programs currently serve elderly and disabled Indians. Its specific objectives would be:

(a) to identify obstacles to delivery of home repair services, senior citizens housing, and special purpose housing for the disabled.

(b) to identify interim funding for senior citizens' housing on Manitoba reserves, particularly for reserves which are now considering personal care homes;

(c) to assess need for housing for the Adult Care target group in other Regions.

Rationale and Discussion: Study findings point to inadequate housing as a core problem: (1) as a factor preventing effective treatment (e.g. it is difficult to treat an ill, elderly persons in a house which cannot be kept warm in the Winter); and (2) as a factor contributing to unnecessary and costly institutionalization.

6.2.3 Alternative Care Models and Relevant Professional Development Issues

Recommendation 4: A review and consultation process should be initiated, to identify ways in which additional Adult Care services could be added to the present range of services, within integrated program models. Specifically, this would include:

(a) identification of models for integrating personal care home facilities with home care services; models for integrated delivery of senior citizens' housing and adult day care; and models for integrated delivery of adult day care and personal care home care; and

(b) development of program design guidelines and training materials suitable for use by Band staff, to assist Band staff and Band Councils in evaluating alternative care models.

Rationale and Discussion: Individual Bands may vary considerably in specific types of needs and effective responses which will match local conditions and resources. Bands need these types of opportunities to explore or learn about new types of programs which have not generally been available on-reserve, such as adult day care, or meals-on-wheels.

6.2.4 Consolidating Gains in the Institutional Component (Mainly Personal Care Homes)

Recommendation 5: An operational review should be undertaken for the on-reserve personal care homes which are not now licensed.

Rationale and Discussion: Such a review is sorely needed as an interim step to provide personal care home staff and Bands with technical assistance and standards, and to identify any areas where changes may be desirable. Such a review would consider such issues as adequacy of buildings, and equipment, needs for staff training, etc., and would be a useful first step in reducing the legal dangers attendant to running such a program without licensing or standards.

This review should be conducted under supervision of the special purpose body described in Section 6.2.7, Recommendation 12, with full participation of Manitoba Indian Organizations.

Recommendation 6: A separate review should be conducted of hostels now operating in Manitoba on three reserves.

Rationale and Discussion: Hostel care is a component of Adult Care, according to the Memorandum of Agreement between INAC and MSB. Yet hostels are not funded in Manitoba under Adult Care. Since hostel care is expected to be more economical than that provided by personal care homes, this should be a concern in overall program development.

This review should be conducted under direction of the same group supervising the review of personal care homes.

6.2.5 Clarification of Program Mandate

Recommendation 7: A clear mandate for Adult Care should be obtained through a joint HWC-INAC submission to Cabinet, for authority and resources to fund and support a complete Adult Care Program.

Rationale and Discussion: Lack of "clear mandate" has been identified as a core problem for Adult Care, which contributes to a variety of specific problems due to lack of direction, lack of staff and related gaps.

Recommendation 8: Main Responsibility for the Adult Care Program should be placed with MSB of Health and Welfare.

Rationale and Discussion: This would include responsibility for Type I and Type II institutional care (personal care homes), which is now under INAC.

MSB has the appropriate technical skills to deal with the broad range of issues involved in this program, which INAC simply does not have. INAC's Adult Care responsibilities would then be mainly in the social services and housing areas.

This shift would result in more integrated service delivery as well as better response to local conditions, since the MSB (nursing) infrastructure extends onto most reserves.

Recommendation 9: A review should be undertaken to assure that the Adult Care Program information system (and standards) are in place and working, so that accurate program information (units of service and costs) are provided.

Rationale and Discussion: This information is essential for well planned and effective application of increased resources to Adult Care needs.

6.2.6 Clarification of Provincial Roles and Option to Use Provincial Services

Recommendation 10: Possible roles for the Province in Adult Care must be clarified, particularly to explore the feasibility of Manitoba Indian Bands accessing relevant social services, under cost-sharing agreements similar to those now in existence in Ontario and Quebec.

Rationale and Discussion: In many cases, especially for smaller Bands, it may be more economical for Bands to access existing services on a contractual basis, than to develop their own services. Bands should have this option.

Clarification of possible changes in Provincial role should be examined, initially in the new policy and program mechanisms proposed (Recommendations 11 and 12 below).

Recommendation 11: A National Review Committee should be appointed at the National level, with senior representatives of INAC, HWC and key Indian Organizations, to follow-up on recommendations of this study, particularly:

(a) to monitor clarification of program mandate and Departmental responsibilities;

(b) to establish program goals and priorities;

(c) to monitor achievement of program goals; and

(d) undertake a review of the financial needs or means test in Adult Care and the desirability/feasibility of eliminating it, either generally, or in Provinces where non-Indians are not required to complete a financial means test for similar services; and

(e) to consider the desirability of extending this type of research and other data gathering, to assess aspects of Adult Care in other Regions.

Recommendation 12: At the Regional (Manitoba) level, steps should be taken to shift responsibility for development of Adult Care policy and programs to a special purpose body comprised of INAC and MSB and Manitoba Indian Organizations (with majority Indian representation) solely concerned with Adult Care.

Rationale and Discussion: This body would operate in a public environment, representing all key parties, and eventually be supplied with staff sufficient to allow an effective role in program development.

Its immediate role would focus on: (1) formulating its own Terms of Reference; and (2) follow-up on the recommendations of this report, particularly the proposed operational reviews of on-reserve personal care homes and hostels.

Taken together, implementation of these recommended changes could significantly increase the ability of the Adult Care Program to effectively meet the serious unmet needs of elderly and disabled Indians.

APPENDIX A:
SAMPLING AND WEIGHTING OF SURVEY DATA

A.I Sampling

Because of limited study resources, and the initial "pilot" nature of the study, only a sample of reserve communities were included in the study. The wisdom of this approach is supported in part by sampling theory, which is discussed briefly below.

A.I(a) Sampling Theory

Sampling theory tells us that in most situations, a sufficiently large and scientifically selected sample of a population can provide estimates close in accuracy to estimates of a survey of the entire population at far less cost.

Indeed, contrary to the "common sense" expectation, a high quality survey of a representative random sample will usually produce estimates that are more reliable than a lower quality survey of the entire population. As well, only a careful and "random" sampling can assure selection with known probabilities, and thus confidence that estimates are reliable (within limits allowed by size of samples) and objective. It is important therefore that sampling be conducted in a planful and scientific manner.

Sampling for this study was done in two stages: (1) reserve communities were selected; and (2) respondents were selected for inclusion in surveys within each community.

A.I(b) Selection of the Communities for Study

Manitoba reserve communities differ greatly in key characteristics such as availability of personal care homes and other facilities, community resources, isolation and other factors which can affect both the need for and the delivery of a program such as Adult Care. Therefore, it was important that communities representative of each major type be included in the study.

Key variables considered for sample selection included: (1) presence of an on-reserve nursing home; presence of other health facilities and services (such as nursing stations, health centres, hospitals, etc.); (2) location of reserve (i.e. non-remote/remote);* and (3) size of reserve (i.e. total population and number of elderly residents).** Reserves within MKO, FNC and BIN were grouped into six strata as noted in Display A.1 (next page), based on the nursing home and health facilities variable, and remoteness.

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*For this study, we have defined types of reserves in the following manner. A remote reserve is accessible only by water, air, or cannot be accessed by an all-weather road. Non-remote reserves can be accessed by an all-weather road (although some of these may usually be accessed by air).

**We have classified reserve size in the following manner: a small reserve has a population of less than 500; a medium reserve has a population between 500 and 1,000; and a large reserve has a population of more than 1,000.

DISPLAY A.1
DISTRIBUTION OF ALL FNC/MKO/BIN RESERVE
COMMUNITIES IN 6 STRATA

	Non-Remote	Remote	Total
Has personal care home	5	0	5
Has other health facility	24	11	35
Has no health facility	16	4	20
Totals	45	15	60

In relation to the distribution of number of reserves by strata: four of the five reserves with personal care homes were included in the sample for the community surveys; three reserves were selected from each of the other non-remote strata, with selection based on PPS;* two were selected from the remote, has health facilities strata (selection based on PPS); and one selected from the remote, no health facilities strata (selection based on PPS). This distribution is as shown below in Display A.2.

DISPLAY A.2
DISTRIBUTION OF SAMPLE

	Non-Remote	Remote	Total
Has personal care home	4	0	4
Has other health facility	4	2	6
Has no health facility	3	1	4
Totals	11	2	14

*PPS indicates "probability proportionate to size", where larger reserves have (because of their larger population), a higher likelihood of being selected.

Of the 14 reserves selected, all but 1 agreed to participate in the study. The final sample studied included the following 13 reserves:

Reserves with on-reserve nursing homes:

- The Pas (north, not remote);
- Fort Alexander (south, not remote);
- Norway House (north, not remote); and
- Peguis (Interlake, not remote).

Reserves without nursing homes:

- Oxford House (north, remote);
- Split Lake (north, not remote);
- Sandy Bay (south, not remote);
- Lake St. Martin (south, not remote);
- Waywayseecappo (south, not remote);
- Shamattawa (north, remote);
- Brokenhead (south, not remote);
- Moose Lake (north, not remote); and
- Fairford (Interlake, not remote).

These represented a wide range of reserve types, with six reserves from Northern Manitoba, two from the Interlake area, five from Southern Manitoba; eleven "non-remote" and two "remote"; and (roughly proportionate to the distribution of population) seven large reserves, four medium and two small reserves.

A.I(c) Selection of Respondents

On eleven of the thirteen reserves, those to be sampled were chosen in the following manner:

1. A list was obtained from Band officials, indicating elderly and non-elderly persons estimated by social services and health staff as:
   - not having need for Adult Care services; and
   - having need for Adult Care services (this was broken down into four needs sub-groupings).
2. From each sub-group, a random sample was selected for the actual interviews.

On the remaining two reserves, lists indicating level of need could not be obtained in advance, so community residents were selected at random from a list of the elderly and disabled. Actual selection within each group was random, with a higher proportion of those in the high needs group being selected. (In the analysis, this higher probability of selection was offset by a sampling weight (see below)).

A.II Weighting of the Survey Data

A.II(a) Sampling Weights

Within each age group and disability group, sampling weights were computed to offset the initial variations in probability of selection, for each disability group. The sampling weights (SWTS) were computed as:

$$SWTS = \frac{\text{Band NPopulation, for each Band for each needs/age group}}{\text{Band NSurveyed}}$$

where

Band NPopulation = number of elderly Indians in the population for each needs group for that specific reserve; and

Band NSurveyed = number of elderly Indians surveyed within each needs group for that reserve

A.II(b) Population Weights

Throughout the report, statistical survey data have been further **weighted** to represent the Manitoba population of elderly Indians living on reserves and not in personal care homes. This was done in computer runs using the "weight" function of the Statistical Package for the Social Sciences, appropriate weights being projected for a population of 1,538 Manitoba elderly Indians living on reserves and not in institutions.

To weight the data to represent that population, we first had to estimate the population of on-reserve elderly Indians not living in personal care homes. This was done using published INAC statistics.* The number of elderly Indians in on-reserve personal care homes was subtracted from the on-reserve totals.

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*Data taken from: *Population Projections of Registered Indians, 1982 to 1996*, Indian and Northern Affairs Canada, 1985; and from: *Social Development Program: On-Reserve Services to the Elderly and Handicapped*, Social Development, Indian and Northern Affairs Canada, Winnipeg, January, 1985.

Next, we estimated the breakdown for the two main age groups considered (ages 65 to 75, and 75+), and for the various survey strata population.

Population weights (PWTS) for each case were then computed as:

$$PWTS = SWTS \times \frac{NPOPULATION, \text{ for each sample cell}}{NSURVEYED, \text{ for each sample cell}}$$

where

NPOPULATION = estimated number of elderly Indians in each cell; and
NSURVEYED = number of elderly Indians surveyed.

The average weight applied was 7.7, to present all estimates in terms of the Provincial population of elderly Indians on-reserves, but not in personal care homes. A similar procedure was followed for the disabled, the assumption being that the incidence of disability would be similar for Manitoba reserves not included in the study. Accordingly, an average weight of 6.4 was estimated for the disabled Indian adults surveyed.

As a result, tables represent study estimates *of actual numbers of elderly Indians in any given category* (these estimates being reliable to within plus or minus approximately 5%, 19 times out of 20).* Weighted estimates are also provided for the disabled Indian population, but these must be regarded as more illustrative, because of the small sample size of disabled persons included in our survey.

*This range depends upon the sub-group considered, and also the assumptions used in estimating confidence intervals. If the computation is based on the assumption that the screening survey (by Band staff) provides, in effect, an initial screening of the entire population of elderly persons, then the confidence interval is about ±3%, 95 times in 100. If the estimate is based on the assumption that the sample of @ 200 is a random sample simply of the population of elderly persons on the 13 sampled reserves (about 680 residents), then the confidence interval for percentage estimates is computed as accurate within ±6%, 95 times in 100.

APPENDIX B:
ASSESSING RELIABILITY OF DATA

B.I Reliability of Data: Basic Concepts

A key question for the evaluation team (and for users of the evaluation) was: to what extent might the survey data be regarded as reliable and valid?

Reliability of Indicators and Survey Data

Reliability is a key concern in studies in the human sciences. This concern in measurement theory derives from the supposition, derived from scientific method in the physical sciences, that observed occurrences will (if real change does not occur) repeat themselves systematically if the phenomenon observed is stable, and if the measurement device itself is reliable. Thus, for example, a ruler is a reliable measure, because it usually gives us the same answer when we measure the same object.

Similarly, in the human sciences, and particularly in survey research, the researcher becomes more confident in the measures obtained in a study, if he finds that repeated measurement provides similar answers. So for example, a respondent in a survey might be asked one day -- "how old are you?" or "how satisfied are you with the job you have?" and asked the same question again the next day. The researcher becomes more confident in his data, if the answers are highly correlated from one day to the next. (Some data from interviews are, of course expected to be more reliable than others: e.g. age data will as a rule, be more reliable than will job satisfaction data.)

Consistency as an Indicator of Reliability

One key test of validity/reliability involves the examination of survey responses to assess the extent to which *internal consistency* indicates reliability and validity. Internal consistency, like test-retest reliabilities, indicates coherence (and thus theoretical or construct validity), and is a primary method of assessing reliability/validity of data in the human sciences.

In the context of this study, aspects of internal consistency of prime importance are those which are sensible or predictable from our theoretical understanding of aging. Two approaches to consistency were considered to appraise the study data. Firstly, *within individual surveys*, survey responses were tested for consistency, to assess the extent to which responses made sense, or followed a meaningful pattern.

Here we examined the extent to which survey indicators were inter-correlated in a fashion predictable from hypotheses about health, aging and human needs. Primary reliance for this assessment is placed on factor analysis technique. The second approach to consistency is to examine *consistency between surveys*, that is, to examine the extent to which different survey groups (e.g. elderly Indians, family members, nurses) provide similar results.

B.II Statistical Methods/Criteria

Magnitude of Correlations Expected in Reliable Measures

In the assessment of reliability and validity, a key question will be **what size correlation is indicative of reliability or validity?**

This question is often difficult, because few cases are encountered where survey research measures of important phenomena result in reliabilities (correlations) which are extremely low (say in the .0 to .2 range), and since even extremely good measures may not achieve very high reliabilities (say over .9). Therefore, in most cases when we pose the question "Is this data good enough?", our answer will be a matter of judgement.

As well, the question as to whether data is "good enough" depends to a great extent on how the data will be used, particularly: (1) whether individual survey questions will be analyzed or whether individual items will be combined into multi-item indicators; and (2) whether quantitative estimates are to be derived from the data, or merely trend data.

The reliability of responses to individual questions will usually be much less than the reliability of multi-item indicators combining the same items. This is because repeated measurement, through a greater number of interrelated questions, tends to greatly reduce measurement error.

As a rule, we would argue that indicators to be used for policy inferences should have reliabilities (for example, the ALPHA indicator) in the .7 to 1.0 range. Recognizing that multi-item indicators can achieve this level of reliability if individual item reliabilities and intercorrelation are in the range of .3 or higher, our analysis has applied this standard to the data examined to test reliability.

Internal Consistency as Evidenced by Factor Analysis

Factor analysis is an analytic technique used extensively in the human sciences, to identify the dimensional regularities of a complex field of data. It relies on multi-variate analysis to identify one or more underlying factors which explain a large number of variables.

For example, in a study of organizational functioning, dozens of measures might be taken of various aspects of employee satisfaction, inter-departmental communications, vertical communication, perceptions of objectives, perception of senior staff's ability, and so on. Through factor analysis, a few key factors or sets of variables might be identified to summarize organizational features, such as organizational cohesion, leadership, division of labour. With a more simplified assessment of key "factors" affecting operations, more reliable indicators can be created (multi-variable indicators are gerally more reliable in quantitative analyses), and policy inferences drawn with greater precision. In this study, factor analysis is focused on indicators of disability.

B.III Results

B.III(a) Internal Consistency

Two main indicators were examined for internal consistency, using factor analysis. These were difficulties with activities of daily living (ADL), as estimated from survey responses for elderly Indians, and ADL as determined from nurses' assessments. As well, a formal indicator of reliabilities (ALPHA) was estimated.

These were factor analyzed, and a single factor extracted for each. Results are shown below in Display B.1. These results show good factorial structure, the ADL items forming a single factor for both survey groups.

DISPLAY B.1
FACTORS UNDERLYING ELDERLY INDIANS' AND NURSES'
REPORTS OF ACTIVITIES OF DAILY LIVING

Activities of Daily Living Items	Main Factor Loadings* for Elderly Indians	Main Factor Loadings* for Nurses
Going out of doors in poor weather	.75	.88
Getting in and out of bed without help	.81	.80
Personal care things like washing, bathing, and dressing	.83	.88
Doing heavy work (like cleaning floors, windows, cutting firewood or carrying water, etc.)	.58	.79
Going places, like church or the store, or going to see friends or relatives	.78	.87

*The factor loading is the correlation of the individual question item with the underlying factor or dimension.

Estimates of reliability using the ALPHA statistic were ALPHA = .90 for nurses' estimate of ADL, and ALPHA = .81 for elderly Indians' reports in ADL. These are strong indications of reliability. As well, correlations between key variables pointed to overall validity in the data examined. Nurses' assessments of ADL were correlated with their rating of major health problems (r = .29); and need for homecare (r = .16). Elderly Indians' assessments of ADL were also correlated with age (.11) and perceived health problems (.45).

B.III(b) Between Group Consistency

Several tests were run to determine if views of Adult Care needs, particularly need of individual elderly Indians, were reliable and consistent between key survey groups. These tests included comparing family perceptions to nurses' reports, and also comparing nurses' perceptions and assessments to those of elderly Indians and family members.

This test was limited for family perceptions, since only open-ended questions were asked to provide the family perception side of this comparison. (These were coded into "needs" categories to allow statistical correlation with responses of elderly Indians and nurses.) Nonetheless, correlations between family members' reports and nurses' assessments were very high on two variables examined (r = .56 and .82), as is shown below in Display B.2:

DISPLAY B.2
CORRELATIONS BETWEEN FAMILY REPORTS OF NEEDS OF ELDERLY INDIANS, AND NURSE'S TECHNICAL ASSESSMENTS

r*	Items
.56	Indicates need for home repairs
.82	Indicates need for home support services

* Pearson's r.

Significant correlations were also found between Band assessments of need, nurses' assessments of ADL, and self-assessments of ADL by elderly Indians, as is seen in Display B.3.

DISPLAY B.3
SELECTED CORRELATIONS BETWEEN BAND ASSESSMENTS OF NEED, NURSES' ASSESSMENTS OF NEED, AND SELF-ASSESSMENTS, BY ELDERLY INDIANS

VARIABLE PAIRS	r
Band assessments with ADL* responses of elderly Indians	.47
Band assessment with nurses' assessment of ADL*	.56
Nurses' assessments of ADL* with ADL* responses of elderly Indians	.46

* Activities of Daily Living, see B.III(a).

B.III(c) Conclusion

Overall, these results seem to point to a high degree of reliability and validity for the survey data base used in this evaluation.

APPENDIX C:
PROBLEMS AND REMEDIES AS SEEN BY KEY INFORMANTS, FOR EACH PROGRAM COMPONENT

DISPLAY C.1
PROBLEMS AND REMEDIES: INSTITUTIONAL COMPONENT
(Numbers in brackets represent number of times
each item was mentioned by respondents)

PROBLEM	REMEDY
Lack of facility (29)	More funding (13) Open centre on-reserve (18)
Present facility inadequate (21)	Build addition/improve facility (13) More funding (3)
Disabled/disturbed needs (5)	Open centre on-reserve (5)
Special facilities/equipment needed (4)	Get funding (4)
Special services/trained personnel (4)	Get funding (4) Provide training (1)
Cultural/religious problems (2)	More Native/staff services (2)
Lack of transportation (1)	Should be provided (1)
Husband/wife separated in nursing home (1)	New senior/nursing home (1)
Band not concerned (1)	Educate Band members (1)

DISPLAY C.2
MAJOR PROBLEMS AND REMEDIES: RESIDENTIAL COMPONENT
(e.g. group homes, foster care homes, etc.)
(Numbers in brackets represent number of times
each item was mentioned by respondents)

PROBLEM	REMEDY
Need residential facility (24)	Get funding (6) Open centre on-reserve (15) Family should be responsible (2)
Inadequate facility (8)	Open centre on-reserve (2) Get funding (1) Expand/improve present facility (5)
Lack of Indian input (1)	Native education (1)

DISPLAY C.3

MAJOR PROBLEMS AND REMEDIES: NEEDS ASSESSMENT COMPONENT

(Numbers in brackets represent number of times each item was mentioned by respondents)

PROBLEM	REMEDY
Lack of proper program to fulfill assessment (waiting period etc.) (13)	Get funding (1) Build facility on-reserve (6) Do report recommendations (1) INAC should provide (2)
Lack of communication/co-operation (3)	More band input (1) Get funding (1) Program of residential housing for winter only (1)
No cultural awareness (2)	Train more staff/Native staff (1)
Lack of professional involvement (2)	More visits by doctors/nurses (1) Train more staff/Native staff (1)
Lack of services/equipment (1)	Do report recommendations (1)
Improper assessments (1)	Involve registered nurse (1)
Cultural difference (1)	Adjustment to new environment (1)

DISPLAY C.4

MAJOR PROBLEMS AND REMEDIES: HOME-SUPPORT SERVICES COMPONENT

(Numbers in brackets represent number of times each item was mentioned by respondents)

PROBLEM	REMEDY
Lack of services/specialists (37)	Get funding (25) More staff/specialists (6) Staff program (7)
Untrained staff (7)	Provide training (4) Get funding (3)
Poor housing (4)	Repair and fix (4)
Lack of co-ordination (3)	Co-ordinate way needs are met (3)
Incomplete medical assessments (3)	More staff/specialists (1) Complete assessments (1) Build facilities on-reserve (1)
Transportation (1)	Get funding (1)
Inadequate medication (1)	Counselling (1)
Counselling need (1)	Should provide (1)
Unawareness of program (1)	Educate/make aware (1)
Family not responsible (1)	Make aware of responsibilities (1)
Lack of manpower (1)	Better salaries (1)

DISPLAY C.5

MAJOR PROBLEMS AND REMEDIES: PREVENTATIVE SERVICES COMPONENT

(Numbers in brackets represent number of times each item was mentioned by respondents)

PROBLEM	REMEDY
Lack of services/staff (17)	Provide services (6) Provide training (5) Involve community (1) Band should speak up (2) Set up program (2)
Untrained workers (10)	Provide training (9) Band should speak up (1)
Provide transportation (2)	Get funding (2)
Co-ordinate personnel (1)	Co-ordinate under 1 program (1)
Problem of cultural appropriate-ness (1)	Co-ordinate under 1 program (1)
Lack of communication (1)	Information workshops (1)
Lack of activity (1)	Provide classes (1)
Apathy (1)	Don't know (1)

DISPLAY C.6
MAJOR PROBLEMS AND REMEDIES: PLANNING COMPONENT
(Numbers in brackets represent number of times each item was mentioned by respondents)

PROBLEM	REMEDY
Lack of planning (10)	Provide training (1) Form a committee (2) More community involvement (4) Awareness of need (2)
Lack of staff (4)	Get funding (4)
Lack of training (3)	Provide training (2) Get funding (1)
Committee inadequate (3)	Provide training (1) Form committee (2)
Lack of transportation (2)	Provide transportation (1) Get funding (1)
Lack of senior government program (1)	Get MSB and INAC to decide (1) Develop program (1)
Lack of community participation (1)	Provide transportation (1)
Irregular information workshops (1)	Make regular workshops (1)
Lost interest, despair	No remedy
Need for "units" (1)	Build "units" (1)
Lack of community involvement (1)	Get community involved (1)
Child care workers drunk (1)	More planning (1)
Lack of special services (1)	Build ramps (1)
Care home low priority to Band (1)	Inform proper authorities (1)

GLOSSARY

Adult Day Care:* This is a program usually provided for the elderly through a centre providing a range of services on a daily basis. The elderly persons come to the centre. The centre emphasizes the maintenance and enhancement of social, emotional and spiritual well-being of the individual by providing a variety of social, recreational, nursing and nutritional programs while the person continues to live in his/her own home. It acts as a liaison between isolated home life and the activities of the community.

Correlation: A measure of statistical association between two numeric variables, or indicators which can be assigned numeric values. Usually correlations range from "-1." (indicating perfect negative correlation, to "0.", indicating no relationship, to "+1.0", indicating a perfect positive relationship).

Counselling:* Counselling is provided to or arranged for Indian adults who require but lack family support in the effective use and mobilization of personal, financial and community resources. The provision for personal assessment of care needs and referral to appropriate health and social service agencies as described above is a function of this activity.

Factor Analysis: A statistical technique used to identify the underlying "dimensions" which statistically explain a larger number of variables. For example, in this study, a factor analysis of difficulties that elderly Indians reported in doing a number of things like "going out of doors", "getting in and out of bed without help", "doing heavy cleaning", found that most variation in these things could be explained by a single dimension which in literature on aging is often referred to as: functional capacity, or difficulties in activities of daily living.

Foster Care:* Here, the adult takes up residence in a family which provides the care as though it were the person's actual family. The foster care services are for adults who require care and supervision in the activities of daily living and receive such care by staying with the foster family. Recruitment and selection focuses on Indian families so as to preserve a familiar home milieu and continuity of life style. Despite its obvious potential for maintaining individuals in a family-like setting in their own community, the use of foster care of incapacitated adults is very limited.

Group Home:* Group homes accommodate individuals who have fair functioning abilities but require more supervision than is feasible in a foster home. Group home care is more commonly utilized for mentally retarded individuals with a limited ability to function in the community. Group home care for adults have not been extensively utilized for Indian people. The advantage of this setting is the provision of direction and support while allowing considerable individual freedom in a peer interaction and support framework. This approach allows flexibility and reduced cost while supporting social development.

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*Adapted from: *Adult Care Policy Review*, 1985.

Home (Support) Care: is care provided in the home to elderly and disabled individuals, and encompasses the somewhat narrower component "in-home care" as defined by INAC. In-home care is generally regarded as limited to homemaker and home help service. In contrast, the broader concept of home support or home care would also include home nursing, and a wide range of home support services, including adult day care, respite care, meals-on-wheels, and related services.

Homemaker Services: Includes light housekeeping, shopping, and meal preparation, etc.

Hostel(s) Facilities (as defined by Manitoba Health Services Commission): For persons requiring organization of their daily routines and supervision and/or guidance. There may be minimal need for direct intervention in physical care. Individuals may need administration of their medications on a regular basis and may require mechanical aides for ambulation. The medical component to their care will usually be of a preventive/supportive nature.

In-Home Care:* In-home care is delivered to adults in their own homes with the purpose of enabling them to maintain or regain adequate functioning levels and, at the same time, remain within familiar surroundings. In-home care supported by INAC is generally limited to non-nursing services in the home of the eligible client and may include homemaker services, (not including medical care or personal services) counselling and referral, meals-on-wheels, help with drawing water, hauling wood and other related services. These services which are currently used extensively in most regions are generally provided by Band members and paid from appropriate social development funds only when the family is unable to provide care.

Institutional Care:* Five types of care are approved by the Federal/Provincial Advisory Committee on Health Insurance in November, 1973, and now used by National Health and Welfare for purposes of planning, development, administration and research, may be summarized as follows: Type I - Residential, ambulant or limited personal care; Type II - Intensive personal care with nursing supervision or nursing home care; Type III - Extended care in a chronic care unit or hospital; Type IV - Special care for a stable disability in a rehabilitation centre or hospital; Type V - Acute care of seriously or critically ill in a hospital.

Meals-on-Wheels: Provision of supplementary nutritional meals delivered to the persons's own home.

Personal Care Home(s) Facilities (as defined by Manitoba Health Services Commission): For persons requiring long-term supervision and assistance with activities of daily living, basic nursing care under the supervision of a registered nurse and usually with a medical component to their care; and/or for persons requiring continual supportive and/or restorative care under medical direction and professional nursing supervision, with professional nursing staff required to perform direct, skilled nursing care.

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*Adapted from: **Adult Care Policy Review, 1985.**

Random Sampling: Sampling for surveys or other purposes, where every case has a chance of selection which is similar to every like case. Such cases are usually selected using a table of computer-generated random numbers. In many cases, a systematic sample (where every 10th or 5th or 2nd case is selected from a list of the population) is regarded as approximately a random samle. In this case, respondents were chosen using a table of random numbers from Band lists.

Rehabilitation Services:* Rehabilitation services are a part of a broad spectrum of services under health, social and other auspices to meet the needs of adults who have physical, mental and social disorders and who have potential for improved functioning. It may also include members of their respective families and other significant persons. Components include: (1) Casework and Counselling, including individual and family assessments; the mobilization and constructive use of relevant services; and referral with or without responsibility for case integration, coordination and accountability; (2) Residential Care and Treatment: Halfway Houses; Community Residences; Maternity Homes; Transition Homes; (3) In-Home Care; and (4) Advice and Training.

Reliability: The extent to which a measure is repeatable -- gives the same results every time. For example, a reliable measure of need for home care would usually indicate that an elderly person needed home care, regardless of who administered the measure, and it would give the same result one day as the day before. Survey indicators do not usually exceed 70% to 90% reliability.

Respite Care: A temporary alternative arrangement is made to provide relief for the spouse or other person who normally provides assistance or care. May be provided in a nursing home but not necessarily. The arrangement may be provided in the person's own home.

Senior's Housing Units: Subsidized independent housing arrangements specially designed for elderly persons. Separate cooking facilities are provided, but communal (or common) eating arrangements are also available. A supervised environment is sometimes provided outside the resident's own unit, but residents are regarded as "at home" in their own units.

Validity: The extent to which a measure measures what it is supposed to measure, and not something else: in this study, the correlation of views of family, elderly Indians, and nurses, on needs, suggests that measures of need are valid in a way that at least in part, spans personal and professional points of view.

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*Adapted from: *Adult Care Policy Review*, 1985.