A report on the initial phase of the Health Canada and Indian and Northern Affairs Research Assessment of Medical Expenses and Service Provision to Children In-Care

PURPOSE

To provide direction to the departments of Indian and Northern Affairs (INAC) and Health Canada (HC) regarding the key research issues, the scope and cost of a thorough assessment of medical expenses and provision of services to children with special needs in the care of First Nations Child and Family Services (FNCFS). This assessment will help the departments with their respective authorities' renewal processes.

CONTEXTUAL ANALYSIS

Current situation

The INAC FNCFS program, established in 1991 under Cabinet authority, is one component of Social Policy and Programs which include a variety of social services that address individual and family well-being. The main objective of the program is to assist First Nations in providing access to culturally sensitive child and family services in their communities and to ensure that the varied social services provided to FN children and families on reserve are comparable to those available to other provincial residents in similar circumstances. Funded by INAC, designed, managed and controlled by First Nations the agencies receive their mandate and authority from provincial or territorial governments.

HC's Non-Insured Health Benefits (NIHB) program covers Indians registered under the Indian Act on and off reserve for specified benefits not covered under provincially or territorially insured health services. These benefits include dental, glasses, medical transportation, medical supplies and equipment, drugs and crisis intervention counseling. The NIHB program is guided by the principle of provider of "Last Resort".

For a variety of reasons which include differences in the policies and practices of provinces and territories regarding insured medical cost coverage of children in-care and NIHB's position that it will not offer benefits to First Nations children in the care of FNCFS, INAC has been funding medical costs for children in-care. This practice was identified as an anomalous business practice in 2002. Authority to extend this practice was sought and granted until March 2006. An extension to March 2007 is being sought pending resolution of the above mentioned jurisdictional issues.

Background regarding this issue

- 1979 Department of Health Act, Indian health Policy
- MOU between HC & INAC on Adult care states that NIHB are available from MSB to all status Indians and Inuit whether in institutions or at home
- MSB phases out medical foster home program for children with complex medical needs based on lack of authority to make such placements. A vacuum is created and FNCFS agencies have been expected to fill.
- 1989 Cabinet decision authorized the expansion of child and family services to First Nations people living on reserve.
- 1990 In an October 1990 Record of Cabinet Decision, clear references are found that DIAND's role is limited to funding social services on reserve.
- 1991 Directive 20-1 is issued. The Directive defines principles, program conditions and a formula for INAC funding of FNCFS.
- 1992 Memo from NIHB agreeing to pick up NIHB costs for Children in care on reserve in Manitoba. (January 22, 1992)
- 1996 Memo from INAC to HC confirming their understanding of a decision reached at a recent meeting that MSB will pick up NIHB costs for children in care of FNCFS agencies. (January 1996)
 - NIHB confirms that Payer of last resort policy is still in practice and that NIHB will not provide benefits to children in care. (November 1996)
- 1997 Cabinet approved renewed mandate of NIHB program based on 1979 Indian Health Policy.
- 2000 The Joint National Policy Review on First Nátions Child and Family Services was commissioned (McDonald & Ladd). This report led to a series of research reports to inform a new funding methodology for FNCFS. Phase 3 of this series was released in 2006.
- 2001 Joint paper commissioned by INAC & HC highlights the jurisdictional disputes between the two departments. The Keystone report was the deliverable. The issue of the responsibility for funding medical services for special needs children in the care of FNCFS was identified as an important issue needing resolution.
- 2005 Briefing note from INAC identifies the need to develop an MOU between HC and INAC for Children with Special Needs similar to the one reached in 1984 for Adult Care. (October 24, 2005)
- 2006 Meeting of HC, INAC & Treasury Board officials concerning INAC anomalies

Initiate research to assess scope of issue to lead to recommendations on improvements of service delivery model. (February 1, 2006)

METHODOLOGY

Documents reviewed

"A Review of Areas of Responsibility of Health Canada and Indian and Inuit Affairs for Health and Social Services to First Nations and Inuit Communities". (Summary) Keystone Consulting 2001

Audit Report of DIAND First Nations Child & Family Services Program. Pearmain Partners, March 2003

Bridging Econometries and First Nations Child and Family Services agency Funding: Phase One Report, "A Summary of Research Needed to Explore Three Funding Models for First Nations Child Welfare Agencies". First Nations Child and Family Caring Society Canada, December 2004

Briefing note to INAC Deputy Minister, March 15, 2002 on Keystone Consulting report.

Compliance Review of Mi'Kmaq Family and Children Services of Nova Scotia, 2004-05.

Departmental Audit and Evaluation Branch, Corporate Services, Department of Indian Affairs and Northern Development. November 1995.

Emerging Priorities for the Health of First Nations and Inuit Children and Youth. Madeleine Dion Stout and Gregory D. Kipling, September 30, 1999.

First Nation and Inuit Program Compendium, June 2001 Draft revisions to Non Insured Health Benefits (NIHB), February 2006

First Nations Child and Family Services, National Program Manual, Indian Northern Affairs Canada, May 2005

Joint Declaration of Support for Jordan's Principle to Resolving Jurisdictional Disputes Affecting Services to First Nations Children, FNCFS, 2006

The Joint National Policy Review on First Nations Child and Family Services (McDonald & Ladd, 2000).

WEN: DE Report, The Journey Continues. First Nations Child and Family Caring Society Canada, 2005Non-Insured Health Benefits & Health Canada's Payer of Last Resort Principle – Background Materials.

WEN:DE Report, We are coming to the light of day. First Nations Child and Family Caring Society Canada, 2005

Tools developed

Consultants developed a short statement of understanding of the issues and key questions to guide discussions with key informants. This was sent to them ahead of their interviews.

Meetings and contacts

March 23, 2005 Meeting with:

Kirstin Doull, Senior Policy Analyst, Program Policy and Planning Division Non-Insured Health Benefits Directorate First Nations and Inuit Health Branch Health Canada

Valerie Flynn, Senior Policy Advisor Program Policy & Planning Division Non-Insured Health Benefits Directorate First Nations and Inuit Health Branch Health Canada

Daryl Hargitt, Senior Policy Analyst Social Services and Justice Indian and Northern Affairs Canada

Telephone interviews

Betty Tower, A/Head Social Indian and Northern Affairs Programs Amherst, Nova Scotia

Mark Ziolkowski, Child Welfare Program Specialist Indian and Northern Affairs Social Development Regina, Saskatchewan

Irvin Smith, Negotiator/Policy Analyst Indian and Northern Affairs Policy Winnipeg, Manitoba

Given the sensitivities related to the release of the research reports pursuant to the *Joint National Policy Review of the FNCFS*, the consultants were advised by the contracting

departments to focus the interviews for this initial phase on the federal departments involved, INAC and HC. Provincial/territorial child welfare officials and FNCFS contacts were therefore not interviewed.

It was also decided, in a conference call with INAC and HC on March 2, that, given the time constraints for this project, a literature review would not be undertaken. The consultants did however ensure that the review of documents was sufficiently broad to solidly anchor the advice presented in this report.

OVERALL FINDINGS

Program profiles and authorities

Non-Insured Health Benefits (NIHB)

The Non-Insured Health Benefits (NIHB) Program provides a range of medically necessary goods and services, which supplement benefits provided through other private or provincial/territorial programs. Non-Insured Health Benefits include drugs, dental eare, vision care, medical supplies and medical equipment, short term mental health services and transportation to access medical services not available on reserve or in the community of residence. Health Canada's NIHB program is guided by the principle of provider of Last Resort (Directive 1.1).

The renewed mandate of the NIHB Program was approved by Cabinet in April 1997. The 1997 NIHB Mandate Statement describes and defines the nature of the Non-Insured Health Benefits Program (NIHB), built on the 1979 Indian Health Policy.

First Nations Child & Family Services (FNCFS)

First Nations Child & Family Services Program is one component of Social Policy & Programs, which include Adult Care, Children's Programs, Social Assistance, Family Violence Prevention and other social services that address individual and family well-being.

The main objective of the First Nations Child & Family Services (FNCFS) Program is to assist First Nations in providing access to culturally sensitive child and family services in their communities, and to ensure that the services provided to First Nations children and their families on-reserve are comparable to those available to other provincial residents in similar circumstances.

To this end, the program funds and promotes the development and expansion of child and family services agencies designed, managed and controlled by First Nations. Since child and family services is an area of provincial jurisdiction, these First Nation agencies receive their mandate and authorities from provincial or territorial governments and function in a manner consistent with existing provincial or territorial child and family services legislation. In areas where First Nations Child & Family Services agencies do

not exist, INAC funds service which is provided by provincial or territorial organizations or departments.

Several Cabinet and Treasury Board decisions since the 1960's have granted INAC approval and funding to enter into agreements with provinces, territories and First Nations organizations for the delivery of child welfare services for on-reserve First Nations children and their families. The authority is defined by Directive 20-1, Chapter 5.1.

Although contracting departments expressed a desire for the focus of this initial phase to be on the INAC Social Policy and Programs authority and on NII-IB, the next phase should also review the INAC Special Education Program. The program's authority could potentially be useful to consider when options are being developed.

Key issues and questions

The issues:

Several interrelated issues have been identified in this project:

1. <u>Jurisdictional disputes between HC and INAC</u>: FNCFS agencies across the country have pointed out the difficulties they face in getting reimbursed for exceptional costs related to the medical needs of children in care for many years.

The lack of clarity as to which department is responsible for non-insured health benefits and the resulting jurisdictional disputes were identified in the 2001 Keystone report. The authors point out what are still today the prevailing departmental positions:

HC, from a legal standpoint, is not obliged to pay these costs for on reserve First Nations children in the care of FNCFS. The agencies operate under provincial mandate and legislation and therefore are the responsibility of the host province/territory.

INAC non-insured health benefits are medical costs for which the department has no funding authority. The department's funding authority is limited to "social services" on reserves.

The Keystone report also mentions several challenges/issues that are still current; the confusion over definitions for health and social services; the burden for agencies and clients that need to apply to various regional offices for services; inconsistent eligibility criteria; excessive reporting requirements; lack of case work coordination which would reduce situations where children might be receiving similar services to deal with the same problem from different programs within the health and social services spectrum and finally, lack of an integrated

The soon

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approach to the development of policy frameworks for the clarification of roles and responsibilities.

In a July 2005 paper, "Extraordinary costs and Jurisdictional disputes", (WEN:DE Report, Were coming to the light of day, Chapter 6), Dr Gerald Cradock mentions that six of nine studied agencies reported jurisdictional disputes between the Health Canada and INAC over Non-Insured Health Benefits. He indicates that First Nations agencies find these disputes frustrating because "while they are not party to the dispute, they are responsible for the health and care of the children in question." Dr Cradock further suggests that the issue of jurisdictional disputes may be exacerbated by location in that agencies serving remote locations may be faced with larger demands for diagnostic and other medical costs with resulting large transportation costs. This researcher highlights the extraordinary costs born by FNCFS for children with complex medical, developmental and mental health needs and for medically fragile children and out-of-province institutional care and the inadequacy of current funding arrangements.

- 2. The diversity of practices across the country: The document review and key informant interviews confirmed the existence of a variety of practices vis à vis payment of medical costs for CIC. In most regions when the FNCFS agency has a child with special needs requiring non-insured benefits, the agency makes a first request to NIHB who, because of their policy regarding CIC, will refuse. The agency then forwards the request to INAC who usually pays. No written guidelines have been offered by officials interviewed to corroborate this practice. It appears also that at least in Alberta an arrangement has been made whereas NIHB will provide benefits to CIC. Again here the consultants were not given access to the agreement. Still, in his research paper, Dr Cradock refers to another situation whereas an agency has a clause in its contractual agreement with INAC that stipulates that INAC will pay anything with a medical component and will then sort it out with HC. Respondents also mentioned that it is quite possible that NIHB may be unintentionally paying for some CIC since there may be many cases where they are not made aware that the request is for a child in care of a FNCFS. NIHB application forms do not ask if the child requiring benefits is a CIC or is living with his natural family.
- 3. Jurisdictional disputes between FNCFS and the provincial/territorial governments: In the "Extraordinary Costs and Jurisdictional Dispute" paper, Dr Cradock mentions that only three of nine provinces are reporting disputes between agencies and the provincial governments. The disputes do not appear to be related to the provision of health services except in Manitoba where the respondent indicated that insured benefits are not available to First Nations CIC because the government deems that all on reserve people are the responsibility of the federal government.
- 4. The "human side" of the provision of services to special needs CIC: The impact of jurisdictional disputes on children with special needs in the care of FNCFS

agencies is not doubt "the" most important issue. The tragic story of Jordan, a young First Nations child who was born with complex medical needs and died at four years of age in hospital while governments feuded over medical supports that would have permitted him to return home, is a case in point. There are however other human aspects to the jurisdictional disputes over medical costs. For example, some families with extraordinary medical needs in Manitoba have had to move off-reserve in order to qualify for Provincial health benefits. Other families have had to relinquish guardianship of their children to the FNCFS agencies in order to access services and health benefits. There are also children's rights issues. The Convention on the Rights of the Child explicitly requires states to "strive to ensure that no child is deprived of his or her right of access to such health care services" (Article 14). There are also rights issues when First Nations on reserve children with special needs in care are denied access to medical services that are available to First Nations on reserve children living in their natural families.

5. The risk management dimension: Although we have not found a good analysis of those situations where the federal government has been found liable because of child fatalities or critical incidents relating to the failure to provide necessary medical services, we believe that they exist and that, unless solutions are found, they will continue to occur. The government is also at risk from being cited as in Breach of Article 14 of the Convention as mentioned above. In addition, the FNCFS audits of '94 and 2003 and the Joint Policy Review and follow up research studies all point out to a variety of reporting and funding inadequacies which no doubt are pertinent to the provision of services to children with special needs given the high proportion of children in care that are in that category.

The research questions:

Having articulated the key issues it is now possible to formulate the type of questions that phase 2 of this project would need to address. The questions relate mainly to clarifying the scope and complexity of the problem in order to permit the generation of well grounded solutions.

Purpose of the questions:

- 1. To clarify the arguments made in relation to the authority to fund health services to FN children in the care of FNCFS agencies.
- 2. To define the scope and nature of the financial liability for funding health services for FN children in the care of FNCFS agencies.
- 3. To develop a funding approvals protocol and service delivery model that clarifies the payer of services and which mitigates the likelihood of any delay in the child receiving necessary care.

Vis a vis children with special needs:

- How many FN children who have special needs requiring supplementary funding are in the care of FNCFS?
- What is the type and complexity of these needs i.e. medical, developmental, mental?
- Are these diagnosed or undiagnosed needs?
- What is the guardianship status of the children with special needs i.e. voluntary? Customary care? Kinship care? Court ordered? Temporary? Permanent?
- How many have been able to access NIHB? Where? What type of benefits?
- What type of information is kept about the children: case management records, case conferences, diagnostic assessment, reports, special needs plan of care?
- Are the delays in receiving approval for benefits either from INAC or HC recorded? Are the various steps taken to access benefits documented?

Vis à vis current practices in the country:

- What types of agreements related to the payment of medical costs for children in care exist in the country? How were they negotiated? Were they shared?
- Are they embedded in the FNCFS contracts with INAC? Have they been negotiated through tripartite discussions (agency, federal and provincial governments)? Through bipartite negotiations (agency/HC, agency/INAC)?
- What types of policies exist for payment of non insured health policies for First Nations children on reserve in the care of provincial child welfare authorities?
- How does the "payer of last resort" work in each agency?

Vis a vis costs incurred:

- What are NIHB costs related to children in care?
- What are INAC's costs related to the "medical" needs of children in care in its Social Policy and Programs Branch? Can similar costs be found in the Special Education program?
- What attempts have been made to break out non insured benefits from the overall maintenance line in agency budgets? What were they?
- Are there some new funding models being implemented somewhere to address extraordinary costs (understanding that recent research reports have proposed some funding options that are still being explored).

Vis a vis service definitions:

 What attempts have been made to clearly define the variety of non insured benefits that children with complex special needs must access and the roles and responsibilities of the various parties in addressing them? Where? Results?

Vis a vis risk management:

• Where has there been litigation related to the failure to provide medical services for children in care? Who was involved? What was the outcome?

Quality and availability of data

<u>Health Canada</u> (HC) in delivering the Non Insured Health Benefits (NIHB) program gathers a variety of data pertinent to services delivered and benefits paid in different categories. A list of the various categories of data collected is available in the Program Compendium.

While this data was not examined under the present exercise, discussions held with representatives of Health Canada has revealed that data specific to Children in Care would not be available directly from the data sources as such characteristic is not identified in the process of granting benefits.

It would appear that the only usable data could be through extrapolation, using global data for services to an age group and comparing to data regarding children in care. Again, caution would need to be exercised with such information as it would remain very subjective.

Indian and Northern Affairs Canada (INAC) collects program and financial data through its Social Development Program. Program statistics are available for each First Nation Child & Family Services (FNCFS) agency as well as other child welfare authorities providing services to status Indians and Inuit.

We have reviewed data provided for the fiscal year 2004-05 which outlined the number of children in care per category of services and related costs for each of the agencies. The data gives a good perspective of volume of children in care at two (2) specific points in the year in various categories of services but does not identify the actual volume of children served in year. Information regarding costs provides no insight into actual medical costs for these children as they would be included in the global maintenance related costs identified.

In our discussions with representatives of INAC in various regions, they further informed that Regional Offices do not collect additional data that could be specific to the issue of medical costs that FNCFS agencies would encounter.

We have also had an opportunity to examine a Compliance Review report completed for the year 2004-05 for one agency. That information was global but also delineated medical costs paid by that agency during the year. This would suggest that the agencies would have relevant information that could assist in scoping the practice of covering medical expenses by the FNCFS agencies. This was also confirmed by INAC regional representatives during our interviews.

PROPOSED PHASE 2 ASSESSMENT APPROACH AND METHODOLOGY

The following section outlines the key methodological steps for the second phase of the research assessment of medical expenses and service provision to children in the care of FNCFS. Fig 1 summarizes the methodological architecture.

Project Development of Development of process and TOR work plan oversight Key informant Site visits to Document interviews with sample of review Data P/T officials **FNCFS** Collection & Analysis Key Id of key Development of informant questionnaire informants Options interviews development Literature Synthesis review and Analysis Recommendations Final report

Fig.1. Architecture for the methodology

Project process/oversight:

Understanding that an Interdepartmental Working Group already exists and will be working on an INAC/HC MOU regarding special needs children, the consultants still believe that a Project Working Group (PWG) should be set up for the specific purpose of guiding this project which focuses on the issues related to the provision of medical non-insured benefits to children in care. The membership should include: FNIHB, INAC's Social Policy and Programs Branch, regional representation. The involvement of the FNCFS Caring Society on the federal PWG needs further discussion but is strongly advised.

Tasks:

Development of Terms of Reference for the PWG.

Development of a PWG workplan

Data collection:

Three main data collection activities are proposed: The review of key federal and provincial policy and program documents; site visits to a sample of FNCFS and key informant interviews with provincial/territorial child welfare officials. The skeletal architecture described below will need to be further developed by the consultants who will undertake phase 2.

Document review: This activity will permit the collation of all policy and
program reports/documents in HC, INAC and in provinces and territories related
to the provision of insured and non-insured health benefits to children. This
review is necessary given the acknowledged variations in the provision of these
services to FN in care. Information gathered will be used to guide the
development of lines of questioning for follow-up interviews with key informants.

Tasks: Identification and collation of documents
Review of documents
Synthesis and analysis

2. Site visits to a sample of FNCFS: This activity is crucial given the absence of information at the regional and national levels in INAC and in HC related to the issue under study. A representative sample must be selected to reflect the diversity of FNCFS: size, coverage, location (remoteness), maturity of the organization for example. The size of the sample and the involvement of the consultants in doing site visits will be conditional on time and cost constraints of the contracting departments.

Tasks: Definition of sample

Preparation of questionnaire

Pre-testing of questionnaire in selected sites by consultants

Training of site interviewers

Site visits
Synthesis and analysis

3. Key informant interviews with provincial/territorial child welfare officials: As already mentioned FNCFS function under provincial mandate and legislation, are funded by INAC and administered and delivered by FN agencies. This complex relationship is being brokered in a variety of ways across the country and different policies and practices have evolved. It is important to get a good understanding of these differing realities. The consultants believe that there are benefits to using existing tri-partite mechanisms for interviews with officials where they exist so that all parties involved have the opportunity to participate. Where they don't exist, consultants should try to "create" them for interview purposes.

Tasks: Identification of existing tripartite mechanisms
Development of a questionnaire
Interviews (in person or by phone conference)
Synthesis and analysis

Model/options development:

Having completed all data gathering and analysis, the formulation of options/models for the provision of medical services to special needs children in the care of FNCFS will be informed by two activities: key informants interviews and a literature review. It is anticipated that guidance will be required from persons knowledgeable in issues of disability, alternative funding models, information systems development and health service delivery to remote communities. The literature review will also explore these areas.

Tasks: Identification of key informants
Development of questionnaire
Key informant interviews
Literature review
Synthesis and analysis

{Note: Consultants understand that initial FPT discussions have taken place regarding current policies and practices in the area of Fetal Alcohol Syndrome Disorder (FASD) and that further meetings have been suggested. This forum could potentially be used to discuss issues and solicit perspectives regarding special needs children in the care of FNCFS.}

Report: overall analysis and recommendations

The research report will include a summary of findings, an analysis and recommendations for the resolution of jurisdictional disputes relating to service provision to FN special needs children in the care of FNCFS. Options guided by the key principle of the child's

best interest will be provided. They will propose funding protocols which will clarify what is paid for by whom and when.

PROPOSED TIMELINES AND COSTS FOR PHASE 2

Critical path: key milestones and number of days (see chart on next page)

The chart below is used for illustration purposes. The beginning timeline is conditional on Ministry approvals and direction. The consultants are proposing to do only the pretesting site visits, approximately 5, with the remaining visits, approximately 15 being done by trained regional staff. Both the number of sites sampled and the use of departmental staff are suggested as cost constraint measures and not as preferred practice. The total number of consulting days: approximately 55 at a per diem of \$800. plus travel related to site visits would then suggest a project budget of approximately \$44,000. plus travel. The final report could be delivered by the end of the first week in October assuming a beginning May 1st, 2006.

Critical path: Phase 2

Site visits of sample 20 agencies by regional staff weeks 1-3

CONCLUDING COMMENTS

This report was completed to provide advice to INAC and HC regarding the key research issues, scope and cost of a thorough assessment of medical expenses and provision of services to children with special needs in the care of FNCFS. The directions proposed in this phase 1 of this assessment project rest on information gathered from our readings and from discussions with key INAC and HC officials. The key findings can be summarized as follows:

- Jurisdictional disputes between HC and INAC regarding the funding of medical non insured benefits for children in the care of FNCFS are longstanding.
- 2. Generally, NIHB has maintained a firm stance that it will not assume responsibility for the payment of benefits for children in the care of ENCES.
- 3. Faced with the refusal of NIHB to assume those costs, INAC has been funding medical costs without the necessary authority to do so.
- 4. Policies and practices vary across the country in terms of how disputes are resolved.
- 5. Little documentation exists either at HQ or in regions in either department to assess the extent of the problem.
- 6. Provincial responsibility regarding insured medical services for children in the care of FNCFS is unclear in at least one jurisdiction.
- 7. Delays in the provision of needed services are penalizing children who already are at serious risk.
- 8. The federal government could face litigation regarding to this issue and the potential tragic impact on FN children in care.

As the partner departments embark on phase 2 of this project, it will be important to ensure continued strategic linkages with policy discussions occurring in other contexts pertinent to children with special needs in the care of FNCFS.

First, important research has been done and work will continue on the selection of either new or revised funding models for FNCFS. The issue of the reimbursement and tracking of medical costs for children with complex physical, developmental and mental health needs is an important dimension of any funding model.

Second, HC has already initiated discussions with P/T officials regarding continued joint work in the area of FASD. The P/T officials have been apprised of current policy work in FNIHB regarding children with special needs. It is anticipated that further F/P/T meetings will take place during which issues related to children in the care of the FNCFS could be raised.

Thirdly, both departments and Human Resources and Development Canada are continuing to look at the seamless provision of services to young children in First Nations and Inuit communities. When those discussions began in 2002, there was an

expression of interest to include FNCFS in the mix of services on reserve to be considered for greater coordination and potential integration in a "single window" type model. Issues related to the provision of medical services to children with special needs in the care of FNCFS must be considered in these discussions.

The current petition in support of "Jordan's Principle" highlights the dangers of unresolved jurisdictional disputes. HC and INAC are encouraged to proceed with Phase 2 of this project in a timely fashion. There are strong moral, administrative and fiscal reasons to do so.