## Culturally Based Audiological Services for Hearing Impaired Inuit in Northern Quebec

# Des services audiologiques basés sur la culture pour les déficients auditifs lnuit du nord du Québec

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### Abstract

The Project for Hearing Impaired Inuit of Northern Quebec (HIINQ) is an attempt to provide culturally based audiological services to the Inuit in northern Quebec who suffer from hearing loss that is primarily due to widespread chronic otitis media (COM). This article begins with a description of the medical, geographical, cultural, and linguistic context in which the HIINQ project came into being. Following that, the challenges that Inuit, medical professionals, and educators faced at the outset of the project are outlined. Next, the ongoing process of trying to create a culturally based approach to audiology is documented with specific examples taken from the project's past and present functioning as well as its future planning. Finally, the article concludes with a discussion of the training of native support personnel, autonomous native health care, and future research needs for the efficacious treatment of COM and hearing loss in the Inuit population of Arctic Quebec.

#### Résumé

Le projet pour enfants inuit avec problèmes auditifs (PEIPA) offre aux Inuit du nord du Québec des services audiologiques basés sur la culture. La principale cause d'atteinte auditive chez les Inuit est l'otite moyenne chronique. Cet article expose d'abord les contextes médicaux, géographiques, culturels et linguistiques qui entourent le PEIPA. Les défis auxquels faisaient face les Inuit, les professionnels médicaux et les enseignants avant la mise sur pied du projet sont ensuite présentés. Puis, le processus de création d'une approche audiologique basée sur la culture est exposé, accompagné d'exemples spécifiques concernant les modes de fonctionnement passé et actuel et la planification de l'avenir. En conclusion, l'article propose une discussion sur la formation du personnel de support autochtone, l'autonomie dans les soins de santé aux autochones et les besoins en recherche concernant le traitement efficace des otites moyennes chroniques et des troubles auditifs chez la population inuit du nord du Québec.

## Introduction

The Inuit population of Arctic Quebec suffers from an alarming rate of conductive hearing loss caused by chronic otitis media (COM) (Baxter, Julien, Tewfik, Ilecki, & Crago, 1986; Julien, Baxter, Crago, Ilecki, & Therien, 1987). Historically, access to appropriate audiological care has not been a reality for this population.

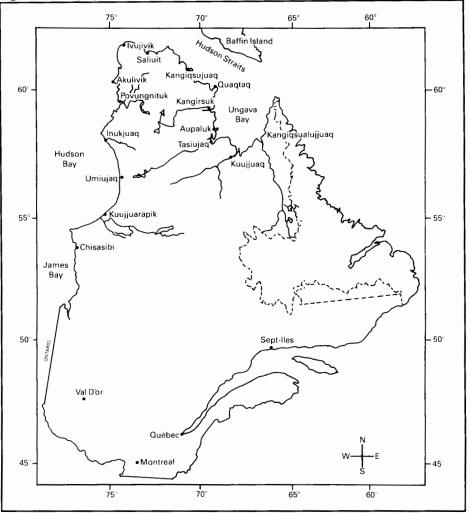
The Project for Hearing Impaired Inuit of Northern Quebec (HIINQ) was started in an attempt to address the challenges of delivering audiological services to a remotely located, culturally and linguistically distinctive population that has

#### Table 1. Guiding principles of the project for hearing impaired Inuit of arctic Quebec.

- 1. Trained Inuit personnel must be involved in all aspects of the service delivery.
- 2. The cooperation, advice, and participation of the Inuit must be sought.
- 3. Inuit language, culture, life-style, and attitudes must be considered in the project design.
- 4. The project should provide adequate counselling to the patients and their families at the time of treatment.
- 5. Follow-up and long-term contact is needed to insure the success of the program.
- 6. Services should be provided in the native language by a trained specialist rather than through the use of an interpreter.

#### Culturally Based Audiological Services





had limited involvement in its own health care. This project was the result of the joint efforts of Projet Nord, the community health program for Arctic Quebec, the northern hospitals of Ungava Bay and Hudson Bay, the Kativik School Board, and the School of Human Communication Disorders of McGill University. It was designed as a culturally based project to provide coordinated and cooperative service by the health and educational sectors of northern Quebec. Over time, it has been both southern, city-based and northern, village-based.

HIINQ has two fundamental aims. The first is to involve Inuit people in their own health care by training native personnel as specialists in hearing problems, hearing testing, and rehabilitation of hearing problems. The second is to provide audiological service delivery specifically adapted for the Inuit population. At the outset, HIINQ established a set of guiding principles (see Table 1) that were based on the UNICEF/WHO Committee on Health Policy's recommendations that there be increased community participation in health services with a focus on the need for respecting local cultural patterns and training local primary health care workers.

# The Context: Chronic Otitis Media and Northern Quebec

#### The Nature of the Disease

Chronic otitis media is a condition of the ear in which infection "persists beyond the period of time usually associated with acute otitis media either with or without the administration of antibiotics" (Scheidt & Kavanagh, 1986, p. xvi). COM, although often less painful than acute episodes of otitis media, is nevertheless often associated with chronic purulent drainage and persistent perforation of the tympanic membrane. Certain unresolved, serious cases seen in northern Quebec have been known to result in partial or complete erosion of the tympanoossicular chain.

COM has been documented to be a major health problem in many non-northern native populations, including Australian aborigines (Nienhuys, 1988; Sunderman & Dyer, 1984), native people of the Pacific Basin islands (Stewart, Annae, & Gipe, 1989), and native American Indians (Nelson & Berry, 1984; Stewart, 1986). The high incidence (nearly one-fourth of the school-aged population) and the specific nature of the disease in Canadian Inuit of the eastern Canadian Arctic have been described for two decades by Baxter and his colleagues (Baxter, 1981, 1982, 1983, 1984; Baxter, Katsarkas, Ling, & Carson, 1979; Baxter & Ling, 1972, 1974; Ling, Katsarkas, & Baxter, 1974; Ling, McCoy, & Levinson, 1969).

Research on the risk factors associated with COM has produced conflicting and controversial findings (Stewart, 1986; Todd, 1986). Despite this, certain risk factors such as bottle feeding, passive smoking, and upper respiratory infection are less controversial than others (Todd, 1986). Although race has been reported to be a risk factor for Native Americans, Aborigines, and Inuit (Todd, 1986), Baxter's (1983) work in the Canadian Arctic has shown that COM is a new disease in the Inuit population. He rarely found perforations in the eardrums of older Inuit. Baxter has suggested that COM is a contact disease that appeared in native populations after the arrival of Euro-Canadians and the ensuing changes in the Inuit way of life. Furthermore, the existence of COM in numerous native populations around the world in widely differing climatic conditions has meant that climate, by itself, is no longer accepted as a single risk factor for this disease (Stewart, 1986; Todd, 1986). Stewart (1986) described the multifactorial nature of risks associated with COM in native populations. Moreover, he ascribed part of its high incidence to the inappropriate or unavailable health care services for these populations.

COM is a disease that has a number of highly significant sequelae for children. Hearing loss is the most obvious complication. The hearing loss, in turn, leads to other important deficits. These include learning and behavioural problems (Ling, McCoy, & Levinson, 1969; Leviton & Bellinger, 1986; Silva, Kirkland, Simpson, Stewart, & Williams, 1982; Zinkus, 1986), language problems (Hasenstab, 1987; Menyuk, 1986; Teele, Klein, & Rosner, 1984; Wallace, Gravel, McCarton, & Reuben, 1988), and central auditory disorders (Eimas & Clarkson, 1986; Willeford & Burleigh, 1985). The impact of these complications for the Inuit population is particularly striking. With a quarter of the schoolchildren suffering from COM, the likelihood of language disorders in this population is high. Language disorders represent a particularly striking problem in a culture where there are critical demands on language learners. It is very important for Inuit that their children maintain their native language, Inuktitut. At the same time, Inuit children are required to become second language learners in order to survive in the school system and in most sectors of the cash economy. The impact of COM in Arctic Quebec, then, is especially pronounced because of the linguistic demands on this particular Inuit group.

#### **Geographical Location and Demography**

Approximately 6,000 Inuit in the arctic region of Quebec inhabit a land mass of 563,515 square kilometres (see Figure 1). One-half of the population is under the age of fifteen.

In the mid-1960s, Inuit from this area were moved into settlements to facilitate health care, schooling, and air transportation. During the last 20 years, these Inuit have undergone dramatic changes in lifestyle. They no longer live nomadically but inhabit modernized houses in settlements where schooling, new leisure-time activities, and different nutrition have been introduced into their way of life. The 14 settlements in northern Quebec are scattered along the coastal regions of the Hudson Bay, Diana Straits, and Ungava Bay. Commercial jet aircrafts require two hours to fly from the two most southern settlements to Montreal. Twin Otter airplanes fly to and from these two gate-way settlements along either coast on a regular, almost daily basis, weather permitting.

#### Language and Culture Differences

Inuit of northern Quebec speak Inuktitut on a routine, daily basis. Inuktitut has been described as one of the few languages of native North Americans with a possibility of longterm survival (Foster, 1982; Priest, 1985). Inuit in northern Quebec live by both cash and subsistence economies. Traditional hunting and gathering activities are still pursued by large portions of the population. Cultural values and childrearing practices differ markedly from the North American mainstream (Crago, 1988).

#### The Health Care and Audiological Service System

There are two hospitals in northern Quebec, the Hudson Bay Hospital in Povungnituk and the Ungava Bay Hospital in Kuujjuaq (see Figure 1). The 12 other settlements receive medical service through nursing stations. Emergency cases and patients requiring specialized care are flown out of the North to hospitals in Montreal. Nursing personnel, as well as the doctors in the hospitals, are typically non-Inuit southern Canadians who have a high attrition rate. The duration of the typical professional stay in the North averages eighteen months to two years. Medical professionals in the North and South have only minimal training in the nature of northern health

## Table 2. Audiological Service System for the HIINQ Project.

	Pre-Project Pre-1985	Phase 1 1985-87	Phase 2 1987-89
Screening	None	<ul> <li>In North</li> <li>By Inuit specialist supervised by audiologist</li> </ul>	<ul><li>In North</li><li>By Inuit specialist</li></ul>
Audiological Evaluation	<ul><li>In Montreal</li><li>Child alone</li></ul>	<ul><li>In Montreal (McGill)</li><li>Parent accompanies child</li></ul>	<ul> <li>In each settlement</li> <li>By the Inuit specialist supervised by the audiologist</li> </ul>
	<ul> <li>By audiologist with no special training in Inuit culture</li> <li>No Speech tests</li> <li>Use of interpreter</li> </ul>	<ul> <li>By the audiologist with the Inuit specialist</li> </ul>	Speech tests in Inuktitut
Hearing Aid Fitting	<ul> <li>In Montreal</li> <li>Aid sent after child returns to North</li> </ul>		<ul> <li>In each settlement</li> <li>By the hearing aid acoustician and the Inuit specialist</li> </ul>
Counselling	<ul> <li>None or minimal amount through</li> </ul>	<ul><li>In Montreal</li></ul>	In each settlement
	interpreter	<ul><li>By the Inuit specialist</li><li>In Inuktitut</li></ul>	<ul> <li>By the Inuit specialist minimally supervised by the audiologist</li> <li>In Inuktitut</li> </ul>
Follow-up	• None	<ul> <li>To the families</li> <li>To the school</li> <li>By phone from Montreal</li> <li>By the audiologist and aural rehabilitationist</li> </ul>	<ul> <li>To the families (in groups)</li> <li>To the school</li> <li>In each settlement and by phone</li> <li>By the Inuit specialist with and without consultation to audiologist</li> </ul>
Staff	<ul> <li>Hospital audiologists</li> </ul>	<ul><li>Audiologist (1.5 days/week)</li><li>Coordinator (2 hours/week)</li></ul>	<ul> <li>2-3 full-time Inuit specialist (Hudson)</li> <li>2 part-time Inuit specialists (Ungava)</li> <li>Full-time audiologist</li> <li>Part-full time secretary (2.5-5 days/week)</li> </ul>
Training	• None	<ul> <li>On the job</li> <li>Individual tutorial at McGill</li> <li>Course (3 days)</li> <li>Training course for Inuit and white teachers</li> </ul>	<ul> <li>On the job</li> <li>Northern workshops</li> <li>Training manual</li> <li>Training workshop for white teachers</li> </ul>
Finances	<ul> <li>Regular hospital budget</li> </ul>	<ul> <li>Pilot grant and regular hospital budget</li> </ul>	<ul> <li>Special budget from MSS \$300,000/year in perpetuity</li> </ul>

problems, the Inuit lifestyle, and the cultural tradition of the people that they serve. Before the HIINQ project, no training programs for Inuit health care workers existed. Inuit involvement in health care was limited to serving on the local health committee and working as interpreters, laundresses, janitors, drivers, and cooks in the hospitals and nursing stations.

Prior to 1985, audiological services for northern Quebec also were very limited. Ten children in northern Quebec had been diagnosed and treated for hearing loss. Two of them (aged two years old and four years old) had profound sensorineural losses due to meningitis, one had a moderately severe hearing loss due to congenital atresia of the external ear, the other seven had mild to moderate hearing losses resulting from chronic otitis media. None of these 10 children wore their hearing aids regularly.

The 10 children had been referred to Montreal for treatment (see Table 2). They were flown south, sometimes with no parent to accompany them. The procedure for evaluation and hearing aid fitting in Montreal was not coordinated in any specific fashion. Sequential referral and hospital waiting lists meant that several days sometimes elapsed between appointments, and the children had long stays in the South. Most of these children were sent home without their hearing aids, which followed some weeks later by mail. No batteries for hearing aids were available in the settlements. Counselling on the care and use of the aid was almost nonexistent, and whatever did take place was through the intermediation of an untrained Inuk interpreter. Follow-up services were very limited. No contact concerning the child's hearing loss was made with the school. The two children with profound losses had been recalled once to Montreal, six months after they received their aids. No remedial service was available. The boy who had congenital atresia was given an auditory trainer and headset when he was one year old. He never returned to Montreal for follow-up. The auditory trainer broke, and the child went unaided for the next five years. At age six, he had no spoken language. No instructions on what to do with a broken aid were given to children or their families. No insurance to cover replacement aids was made available.

## Summary: The Challenges

Thus, the situation surrounding COM and hearing impairment in northern Quebec presented many challenges (see Table 3) that needed to be addressed by the Inuit population as well as by the health care and educational systems. The development of a culturally based audiological service delivery system for northern Quebec meant formulating solutions to these existing challenges.

## Table 3. Challenges for audiological service delivery in northern Quebec (1984).

- Suspected, undocumented high incidence of chronic otitis media (COM)
- Extensive ear damage and subsequent hearing loss caused by COM
- Possible complications resulting from COM
- · The size of the Inuit territory
- · The distance from urban centres
- Language difference
- Cultural difference
- Disempowerment of Inuit in their own health care system
- Lack of hospital policy about native involvement in health care
- Limited financial resources for Inuit health care training and culturally based audiological services

## Solutions

## The Program for Combatting Hearing Disorders in the Inuit Population of Arctic Quebec

In February, 1984, a program was developed by a team coordinated by Projet Nord (the community health department of the Laval University Hospital) and funded by the Quebec Ministry of Social Affairs. The major aim of this program was to collect information on the natural course of chronic otitis media, its prevalence, and its consequences for Inuit in Arctic Quebec. The HIINQ project located at McGill University became a central part of this program.

## The HIINQ Project

The HIINQ project was designed to address the audiological and rehabilitative needs of the Inuit of northern Quebec. The southern project office is located at McGill University's School of Human Communication Disorders. The non-Inuit staff in this office have included an audiologist, an aural habilitationist, a secretary, and a part-time coordinator. Northern personnel work out of nursing stations and hospitals on Ungava Bay and Hudson Bay.

## Selection and Training of Inuit Specialists

Fundamental to the design of the HIINQ project was the training of Inuit from northern Quebec. The project began by training one Inuk hearing specialist, an Inuk teacher who was loaned from the Kativik School Board. This training was carried out at McGill University by two HIINQ staff members, the audiologist and the aural habilitationist. By 1987,

### Table 4. Audiological service schedule in Montreal.

Day 1	Explanation of schedule <sup>a</sup>
	Audiological assessment and hearing aid recommendations <sup>a</sup>
	Otological evaluation
Day 2	Hearing aid dispenser — earmold impressions
	Hearing aid counselling and loaner fitting <sup>a</sup>
Day 3/4/5	Other appointments, if needed, are scheduled during this time, e.g., assessments for speech/language and learning, other medical needs
Day 6	Hearing aid dispenser — fitting of hearing aids and earmolds
	Hearing aid evaluation <sup>a</sup>
	Hearing aid counselling <sup>a</sup>
Day 7	Departure
<sup>a</sup> Takes pl	ace at McGill University Clinic.

each of the two northern hospitals employed two hearing specialists trained at McGill. At that time, these Inuit hearing specialists divided their time equally between the North, where they did screenings, and Montreal, where they serviced children referred for hearing aids and where they received training.

The initial training of Inuit hearing specialists was by tutorials and on-the-job experience, and included a training course. Over a period of days, tutorials covered the following topics: basic anatomy and physiology of hearing, types and causes of hearing loss, interpretation of the audiogram, effects of hearing loss, basic information about maintenance, and trouble shooting of hearing aids. On-the-job training at the McGill University Audiological Clinic included: air and bone conduction testing, recognizing the need for masking, speech discrimination and speech reception testing, aided testing, taking case histories, and giving counselling relevant to hearing loss and hearing aid use. Medical staff provided training in otoscopic examinations on northern screening trips. In addition, a three-day training course was given in Inuktitut to six trainees. The instructor for this course was the first of the hearing specialists to have been trained. The trainees were two new hearing specialists, three Inuit teacher-counsellors, and one parent of a profoundly deaf child.

Selection of the hearing specialists was and still remains an important aspect of HIINQ. A detailed explanation of the duties, responsibilities, and travel commitments is important, as is consultation with respected members of the Inuit com-

#### Table 5. Audiological assessment.

- 1. Case history<sup>a</sup>
- 2. Otoscopy and pneumo-otoscopy<sup>a</sup>
- 3. Pure tone testing via air and bone conduction (masking performed by audiologist)<sup>a</sup>
- Speech reception threshold and speech discrimination using Inuktitut recorded materials<sup>a</sup>
- 5. Explanation of result to parent and child<sup>a</sup>
- 6. Hearing aid and earmold recommendations

munity. Most of the hearing specialists have worked previously either as teachers or as nursing station interpreters. Levels of formal education vary considerably and do not seem to be as important as the ability to accept responsibility, the desire to learn, and respected status in the Inuit community.

#### **Culturally Based Audiological Service Delivery**

The HIINQ project also was designed to provide culturally based audiological services. At the beginning of the project, the audiological services were divided between the North and Montreal (see Table 2). Selective hearing screenings took place in all northern communities once a year. They were carried out by one or two Inuit specialists, usually accompanied by a community health doctor. Screening procedures included otoscopy and case history review with the doctor, and audiometric air conduction testing by the Inuit specialists. Unmasked bone conduction thresholds were tested if a hearing loss was found. Following the screening, Inuit specialists counselled the parents of children with significant losses about their children's hearing and about the services that they would receive when referred to Montreal. Any children with hearing losses, regardless of the degree, were identified to the local school.

Children requiring further evaluation were flown to Montreal with their parents for a coordinated schedule of service as outlined in Table 4. The carefully worked-out schedule meant that all medical and audiological appointments, including the fitting of the hearing aids, were accomplished in one week's time. Audiological testing, hearing aid evaluations, and counselling sessions took place at McGill University's Audiology Clinic (see Tables 5 and 6) and were conducted in Inuktitut by the Inuit hearing specialists with the audiologist

<sup>&</sup>lt;sup>a</sup> Performed by Inuit hearing specialist, supervised by the audiologist and/or medical doctor.

## Table 6. Hearing aid evaluation.

- 1. Discussion with parent and child about success with the loaner aid<sup>a</sup>
- 2. Electro-acoustic evaluation of hearing aids
- Aided testing: thresholds to warble tones in sound field, speech reception threshold, speech discrimination at normal conversational level, tolerance to loud sounds<sup>a</sup>
- 4. Adjustments made to aid if necessary
- 5. Explanation of result to parent and child (depending on age)<sup>a</sup>
- <sup>a</sup> Performed by Inuit hearing specialist, supervised by the audiologist.

supervising when needed. In instances where the audiologist's services were required, the specialists served as informed translators. The Inuit hearing specialists also accompanied the patients to the otolaryngologists' appointments and to the hearing aid dispenser's office. This Montreal hearing aid dispenser provided rapid production of earmolds and a stock of necessary hearing aids. After being fitted, patients returned to McGill where hearing aid evaluations were performed. These evaluations included functional gain measurements and aided speech measures.

From 1985 to 1987, 111 children from northern Quebec were fitted with hearing aids in Montreal. Most children with COM were fitted with one or two post-auricular hearing aids coupled to vented or open earmolds. Constant earmold use was contra-indicated in the case of children whose ears were frequently discharging. Instead, these children were fitted with one post-auricular aid with two vented earmolds and one bone conduction hearing aid. Since bone conduction aids were not popular, they were recommended only if the children agreed that they would be willing to wear them. Counselling sessions concerning hearing aids were conducted by the Inuit specialists supervised by the aural habilitationist (see Table 7).

The importance of insuring the hearing aid was stressed with the parents. Insurance was a new concept to almost all Inuit parents and required careful explanation. Each family was given a battery tester, a stethoscope, hearing aid instructions in Inuktitut, a supply of batteries, cleaning equipment, and a list of telephone numbers at which HIINQ staff could be contacted.

## Table 7. Outline of counselling session.

- 1. Explanation of audiogram
- 2. Testing batteries
- 3. Handling the aid practice in putting in battery and learning about the controls
- 4. Practice putting on aid and adjusting control
- Discussion of volume when to adjust it (e.g., in noisy environment)
- 6. Demonstration of the problems of distance and noise
- 7. Demonstration of lip reading
- 8. Need to adjust to new sounds
- 9. Need for the family to speak in a normal voice
- How to check for faults using stethoscope; using 5-sound test
- 11. How to clean aid and ear molds
- 12. What to do when batteries or service is needed
- 13. The need to insure the hearing aid against loss or destruction

Note: All of above performed by Inuit hearing specialist, supervised by the aural habilitationist.

Follow-up during this phase of HIINQ was provided by telephone calls made to the Inuit families by the Inuit hearing specialists. Follow-up contact also was provided during the screening visits to each settlement. Finally, follow-up was provided in the schools by travelling Inuit teacher-counsellors who had received training through HIINQ. The audiologist and aural habilitationist also maintained ongoing contact with non-Inuit educational and medical personnel. Since 1986, annual workshops have been offered in French, Inuktitut, and English to all Inuit and non-Inuit teachers of northern Quebec. HIINQ secretarial staff in Montreal assisted in coordination of hearing aid repairs, earmold replacements, provision of batteries to village stores, and renewal of hearing aid insurance. Each settlement was provided with a supply of temporary listening tips to be used when earmolds were not functioning. Also, one extra hearing aid was given to each settlement which could be used as a loaner aid when a broken aid had to be sent to Montreal for repair.

Table 8. Problems re	eported in follow-	up of hearing aid use
(1989).		

1986	1989
Lost aid with no insurance for replacement	Lost aid with no insurance for replacement
No batteries	No batteries
Feels aid does not help	Feels aid does not help
Discharging ears	Discharging ears
Earmold fit is a problem	Shyness
Aid needs repair	Aids are noisy
Replacement part needed	

## **New Problems**

Although audiological services improved during this first phase of HIINO's functioning, there were problems experienced by the project.

## Life in the South

Inuit specialists lived for six weeks at a time in Montreal during the first years of the HIINQ project. This southern living was very difficult for most of them. HIINQ rented a furnished apartment near McGill University. This, however, provided little solace for people who were accustomed to living surrounded by family and friends in the alcohol-restricted communities of northern Quebec. All Inuit specialists found their time in Montreal difficult and in the worst situations, destructive.

## Travel Expenses

The expense of flying hearing impaired children and their parents to Montreal was very high. Only two patients per week could be seen at any one time. In addition, lodging for the patients had to be provided. This was another expense for the hospitals to absorb in their already constrained budgets. At the outset of the project, the Ungava Bay Hospital was financially unprepared for the large number of patients that the hearing screenings produced. For a period of almost six months, this hospital suspended services to hearing impaired patients.

## Hearing Aid Servicing

The majority of problems reported in follow-up contact concerned broken aids and poorly fitting earmolds (see Table 8).

Due to the distances involved in getting a hearing aid repaired, there was often a delay of several weeks before a hearing aid could be returned. Return visits to Montreal for new earmolds were not possible due to the expense and the growing waiting list of new patients that each screening visit produced.

## **Compiling Statistics**

Keeping track of audiograms and follow-up information and the systematic compilation of statistics were handled inadequately at the beginning of the project. It was difficult for both Inuit hearing specialists and southern professionals to keep track of the work that was going on in the North and in Montreal.

## Provision of Rehabilitation Services for Profoundly Hearing Impaired Children

Two children (aged two and four years old at the outset) from the community of Povungnituk were profoundly hearing impaired. HIINQ made several attempts to provide these two families with aural habilitation in Montreal. The children attended a summer day camp run by the Montreal Oral School for the Deaf. They also were followed every three months by the aural habilitationist at the McGill Project for Hearing Impaired Children. An Inuk teacher from the Povungnituk School accompanied the children and their parents to Montreal. She worked with the children and was a support for the families when they returned home. Despite these efforts, the children's very profound losses and the lack of constant rehabilitative services meant that the two children were not developing speech and language by the ages of four and six years.

## More Solutions

New solutions evolved and were created by the HIINQ project to address these ongoing problems.

## Informing the World and Expanding the Financing

When financial constraints threatened the HIINO project and caused the Ungava Bay Hospital to suspend services, the group course for trainees at McGill University was used as an occasion to inform the public of the extent of hearing impairment in northern Quebec. Coverage in the press, on television, and on radio helped inform the public about the project, its goals, and its methods. Three months later, Health Minister Claire Castonguay announced that the northern hospitals would be given an additional \$300,000 a year in perpetuity to service the hearing impaired Inuit under their jurisdiction.

## All Audiological Services Move North

Starting in February 1987, a new service delivery protocol was inaugurated with the help and guidance of the community health personnel in the Hudson Bay Hospital (see Table 6). All audiological services, including screenings, audiological evaluations, hearing aid fittings, and follow-up are now provided in each of the 14 settlements of northern Quebec. Each settlement is visited twice a year.

The first trip is a screening trip made by the Inuit hearing specialists. All kindergarten students are systematically screened. Any others may refer themselves or be referred by a teacher, nurse, doctor, or parent. Services have been expanded so that increased numbers of screenings take place with the elderly and preschool populations. Copies of audiograms from the screenings are sent to Montreal for review by the audiologist. Inuit requiring more complete evaluations are scheduled to be seen on the second yearly visit to each community.

The second visit to each settlement is made by an extended team. This team is composed of the two lnuit hearing specialists for that coast, a doctor, the project's audiologist, and a hearing aid dispenser. Most procedures are done by the Inuit hearing specialist under the supervision of the doctor, the audiologist, or the hearing aid dispenser. The team evaluates possible new hearing aid users, previously fitted hearing aid users, and any patients that have been difficult to test in the screenings. Otoscopy, audiological evaluations, electroacoustic evaluations, readjustments of the hearing aids, and impressions for earmolds are all part of the team's work.

Audiological evaluations are carried out in a quiet room in either the nursing station or the school. Audiological evaluation includes air and bone conduction testing, speech discrimination (using material recorded in Inuktitut), and discomfort level testing. Since most of the patients have bilateral perforations of the eardrums, impedance audiometry is not performed. Instead, tympano-ossicular function is evaluated using pneumo-otoscopy.

The hearing aid dispenser brings a supply of hearing aids with him on each extended team visit. Inuit requiring amplification can be fitted, therefore, with their hearing aids immediately, following their audiological evaluation. An instant mold is used in the fitting, and a silicone imprint is taken to Montreal and used to prepare a permanent mold. The permanent mold is then returned to the nursing station by post. The Inuk nursing station interpreter in each settlement is trained to make mold adjustments and troubleshoot for mold and hearing aid problems.

Most hearing aid users are fitted with moderate gain, wideband hearing aids with high and low tone controls, com-

### Table 9. Role of the Inuit specialist: Phase 2.

- 1. Cultural and linguistic advice
- 2. Screening for hearing losses in the North
- 3. Audiological testing
- 4. Counselling families
- 5. Follow-up (phone calls and visits to parents)
- 6. Follow-up with school teachers
- 7. Education of Inuit community through meetings and FM radio
- 8. Making hearing aid molds and repairing aids

pression, and maximum output adjustments. Aided testing in sound field is not possible due to equipment limitations. Tone controls are adjusted according to the shape of the hearing loss. Maximum output and compression levels are adjusted by measuring loudness tolerance to live voice. Following the hearing aid fittings, patients and parents receive counselling (see Table 7). New hearing aid users are seen a second time at the end of the team's stay in a community to check if any problems have been encountered with the aids.

Information on the consequences of hearing loss, care of hearing aids, and classroom management of hearing impaired students is provided to all the teachers (Inuit and non-Inuit) during the team's visit. In addition to this, each teacher of a hearing impaired student is seen separately in order to discuss specific students' needs and problems. Further follow-up with the teachers is done on the telephone by the Inuit hearing specialist using a questionnaire. When a child is not wearing his aids regularly, the decision may be made to keep the aids in school. A unilateral decision to keep all the hearing aids in schools has been avoided. HIINQ personnel felt that Inuit families must have the primary responsibility for the hearing aids. Therefore, it is only at the request or consent of a family that hearing aids are kept in school.

Recently, to increase parental involvement, a group discussion with all the parents of hearing aid users has been instituted at the time of each extended team visit. The discussion takes place in Inuktitut and is led by the Inuit hearing specialists. Discussions centre on parents' concerns about their children's hearing and hearing aids. The role of the Inuit hearing specialist has grown to include all the activities listed on Table 8.

## Northern Training and the Training Manual

Training of the Inuit specialists now takes place in the North. Training periods are scheduled for the mornings during ex-

	Population Screened (n = 1181)	Total Population (n = 3286)
Normal Hearing	494 (42%)	a
Hearing loss	687 (58%)	687 (21%)
Unilateral loss/ slight bilateral loss	502 (43%)	502 (15%)
Significant (mild-profoun bilateral loss	d) 185 (16%)	185 (6%)
Note: Degree of loss d 1K, 2K Hz).	etermined by b	etter ear PTA (.5,
Slight Mild Moderate Moderately severe Severe Profound <sup>a</sup> Unknown.	15-25 dB H1 26-40 dB H1 41-55 dB H1 71-90 dB H1 71-90 dB H1 > 90 dB H1	

Table 10. Screening results of Inuit in Hudson Bay communities of northern Quebec (1989).

tended team trips. During the afternoons, issues discussed in training are reviewed and demonstrated during actual practice. New topics covered have included masking, noise-induced hearing loss, hearing aid electroacoustic evaluation and fitting procedures, central auditory disorders, and pediatric testing. Previously covered material has been reviewed for the senior specialists in the context of teaching incoming specialists. In 1988, an evaluation of practical skills and theoretical knowledge was conducted so that each of the Inuit hearing specialists could receive feedback on his or her development and performance.

To provide the lnuit hearing specialists with appropriate resource material, a training manual was written. The training manual contains material covered during training sessions as well as the clerical procedures used on the project. Each nursing station has been given a shorter version of the training manual, which is updated after every visit to show the names of all the people screened, the audiological findings, and the recommended follow-up procedures. Table 11. Etiology of hearing loss for lnuit hearing aid users in northern Quebec.

Etiology	Degree of loss	Incidence
Chronic suppurative otitis media	Slight	63
outio modia	Mild	104
	Moderate	48
	Moderately severe	11
		Total: 226
Other causes:		
Meningitis	Moderate	5
	Profound	4
Presbyacusis	2 KHz worse than	35 dB 9
Noise induced	2 KHz worse than	35 dB 9
Various etiologies		27
		Total: 74
Note: Degree of loss d 1K, 2K Hz).	etermined by better e	ear PTA (.5,
Slight	15-25 dB H1	
Mild	26-40 dB H1	
Moderate	41-55 dB H1	
Moderately severe Severe	71-90 dB H1 71-90 dB H1	
Profound	> 90 dB H1	

## New Audiograms, Computerized Data Base, and the Facsimile Machine

New audiograms with multiple copies are now used in screening, fitting, and follow-up. These were designed in a multiple choice format so that all essential case history, otoscopic, audiometric, counselling, and follow-up information could be easily noted without having to be written up in detail by the lnuit hearing specialists.

Improvement in the compilation of statistics and data gathering has been made possible by the development of a computerized data base system. Questionnaire information and audiograms from the screening are sent to Montreal by facsimile machine, and the information on them entered into the computer. This has made incidence and follow-up information easier to collect and analyze. Incidence figures taken from the screenings appear in Table 10. The percentage of hearing loss is almost identical to the percentage reported earlier in this article from the Kuujjuaarapik pilot screening study. Information on normal hearing, however, is not available, since screenings do not involve the total population.

1	984	_	19	89	
(n	= 10)				ngava ≖ 122)
0	(0%)	98	(55%)	68	(56%)
0	(0%)	59	(33%)	34	(28%)
10(	100%)	21	(12%)	20	(16%)
10(	100%)	178	(100%)	122(	(100%)
	(n 0 0 10(	(n = 10) 0 (0%) 0 (0%) 10(100%)	(n = 10) 0 (0%) 98 0 (0%) 59 10(100%) 21	$\begin{array}{c} \textbf{(n = 10)} & \textbf{Hudson} \\ \textbf{(n = 178)} \\ 0 & (0\%) & 98 & (55\%) \\ 0 & (0\%) & 59 & (33\%) \\ 10 (100\%) & 21 & (12\%) \end{array}$	$\begin{array}{c} \hline Hudson & Ur \\ \hline Hudson & 0 \\ (n = 10) & (n = 178) & (n = 178) \\ 0 & (0\%) & 98 & (55\%) & 68 \\ 0 & (0\%) & 59 & (33\%) & 34 \\ \end{array}$

Table 1	13.	Regular	hearing	aid	use	according	to	degree of	
hearin	g lo	oss.							

		lson 178)		gava 122)
Slight	12/41	(29%)	14/40	(35%)
Mild	34/65	(52%)	28/44	(64%)
Moderate	32/47	(68%)	14/23	(60%)
Moderate-severe	16/17	(94%)	8/11	(73%)
Severe	4/5	(80%)	2/2	(100%)
Profound	0/3	(0%)	1/2	(50%)
Note: Degree of I 1K, 2K Hz).	oss dete	erminea b	y better e	ar PTA (.5,
1K, 2K Hz).		I5-25 dB I		ar PTA (.5,
0	1		H1	ar PTA (.5,
1 K, 2K Hz). Slight Mild Moderate	1 2 2	15-25 dB   26-40 dB   11-55 dB	H1 H1 H1	ar PTA (.5,
1 K, 2K Hz). Slight Mild Moderate Moderately severe	1 2 4 7	15-25 dB   26-40 dB   11-55 dB   71-90 dB	H1 H1 H1 H1	ar PTA (.5,
1 K, 2K Hz). Slight Mild Moderate	1 2 4 7	15-25 dB   26-40 dB   11-55 dB	- H1 H1 H1 H1 H1	ar PTA (.5,

Table 10 shows the etiology of hearing loss for Inuit hearing aid users in northern Quebec. The vast majority of hearing losses are a result of COM. Noise-induced losses and presbycusis are undoubtedly underrepresented in these data, since the total adult population has not been tested. Meningitis is the cause of four of the five profound hearing losses found in Inuit children of northern Quebec. The fifth is the result of a congenital syndrome.

Follow-up statistics for the two coasts of northern Quebec show that the majority of hearing aid users wear their aids regularly (see Table 12). This represents a dramatic improve-

Table	14.	Regular	hearing	aid	use	according	to age	for
Inuit o	n H	udson B	ay and U	nga	va Ba	ay.		

		ison 178)		java 122)
0-10	20/32	(62%)	8/13	(62%)
11-20	35/71	(49%)	38/68	(58%)
21-30	12/23	(52%)	6/10	(60%)
31-40	4/7	(57%)	4/7	(57%)
41-50	6/13	(67%)	2/4	(50%)
51-60	8/13	(62%)	3/6	(50%)
61-70	8/11	(73%)	2/5	(40%)
71	5/8	(63%)	5/9	(56%)

ment over the situation that existed in 1984 before the HIINO project. Regular hearing aid use varies with the degree of hearing loss (see Table 13). In general, the more severe the loss, the more likely the person is to use his hearing aid. The notable exceptions to this are the four children with profound hearing losses. In all of these cases, the children's ears discharge regularly as a result of COM. Nevertheless, the fact that severely hearing impaired children are not wearing their hearing aids is particularly serious because of its implications for their development of spoken language. Statistics also show that people of all ages now wear their hearing aids regularly (see Table 14). Problems prohibiting regular hearing aid use reported in 1989 show that hearing aid repairs and ill-fitting molds are no longer mentioned by Inuit as reasons for not wearing aids (see Table 8). This is presumably due to the provision of these services in the North.

## A Teacher of ASL in Povungnituk

In January, 1987, the Kativik School Board hired a person who could teach American Sign Language (ASL) to the two profoundly hearing impaired children in Povungnituk. She has given instruction in ASL to the children, their families, an Inuk teacher, and an Inuk school secretary. The Inuk teacher who originally worked with the children has continued to be a special resource person for them. The children are currently integrated in normal classes for half of their school day. The other half is spent in individual tutoring sessions. After 18 months, the two children have gained proficiency in ASL as have their classmates and families who eagerly communicate with them. At the present time, the Inuk school secretary is taking interpreter training courses in Ottawa so that she can serve as an auxiliary interpreter for the children.

## More Obstacles

As time has passed, the project has evolved. New obstacles have appeared, and some old ones have resurfaced.

## Turnover in Hospital Personnel and Reduction in Hospital Support

By 1989, all the doctors and hospital administrators who began the HIINQ project in 1985 were no longer working in the North. In the last year, hospitals have not provided a doctor for all extended team visits. This has meant that new Inuit hearing specialists have not been able to learn otoscopy and that many medical aspects of service delivery cannot be performed at the time of the auditory evaluation.

There also has been turnover in the audiological staff for the project. Even though based in Montreal, their work demands approximately 18 weeks of travel a year. This has made it difficult for women audiologists to continue working once they have started their families. Inuit hearing specialists also have left the project. Their average length of stay on the project is approximately two years. Most of the specialists found the continuous travel incompatible with family life or simply too tiring to do over a period of several years. Turnover in Inuit personnel has meant that training has been an ongoing process.

#### Lack of Batteries, Insurance, and Lost Molds

Old problems reappeared in the 1989 follow-up questionnaires (see Table 8). Batteries were no longer being stocked routinely by all the settlement stores. Initial improvements in this area had required constant follow-up on the part of the project secretary. When this was no longer done on a routine basis, the stores did not continue the initiative. Certain families have been reluctant to buy insurance, and the loss of uninsured aids continues to be a problem.

## Continued Inaccessibility of Rehabilitation for Preschool Profoundly Hearing Impaired Children

Rehabilitative care for preschool profoundly deaf children is still inaccessible. The responsibility for financing such rehabilitative care for preschool children is not clear. Three young babies have recently been diagnosed with severe to profound hearing losses, and none of them receive intervention on a regular basis. Inuit rehabilitation specialists, aside from the teacher in Povungnituk, have never been trained for aural rehabilitative work. Trips to Montreal are too expensive and disruptive for the families to make more than once every three months. Furthermore, the new profoundly deaf children do not live in the same community where the ASL teacher is located. In fact, two are on the other coast of northern Quebec.

## **Possible Future Solutions**

Problem solving continues to be a major part of the HIINQ project's functioning. Possible future solutions to some of today's problems are given below.

## **Personnel in Each Settlement**

A proposal will be made that junior level, settlement-based Inuit hearing personnel be hired by each settlement on a one-day-a-week basis. The role of these settlement hearing specialists would be to provide ongoing screening in their settlements. They also would be responsible for follow-up of hearing aid users and for providing the population with public health information on the causes and prevention of hearing loss. They would be supervised by regional, experienced senior Inuit hearing specialists, one working out of each hospital. Such a solution would mean that senior hearing specialists would need to travel only on extended team visits and that they would be able to obtain senior status commensurate with their experience.

### **New Training Possibilities**

The training manual is now being constructed with two levels of information on each topic so that it can be used in successive training sessions with different levels of Inuit specialists. In addition, senior, experienced specialists will be used increasingly as instructors during training sessions. This will allow training to take place in Inuktitut and will begin to ensure the continuity of the project within the Inuit community.

## **Discussion and Conclusions**

The development of culturally based service for special populations is not an easy task. There are very few models to follow and almost no literature or research to consult. There is no single way to develop these services that is appropriate to all places and all populations, and the obstacles and barriers are numerous (Harris, 1986). Solutions to problems do not stand for all time; they have to be constantly re-worked and developed anew. The HIINQ project is one example of an ongoing attempt to make audiological care accessible and meaningful for one of Canada's native populations.

The training and involvement of native people in the care of COM in their population recently has been proposed and put into effect in a number of countries (Harris, 1986; Nienhuys, 1988; Stewart, 1986; Stewart et al., 1989). The efficacy of the services provided by native workers has been documented in the Pacific Islands (Stewart, 1989). Additional efforts to show the effectiveness of native hearing specialists will provide health care administrators with incentives to institute similar programs. Furthermore, training programs for Inuit hearing specialists, such as the HIINQ project, can serve as a model for the training of native community health workers in general. Finally, efforts at training native supportive personnel need to be reported in the literature so that the strategies for organizing such programs do not remain elusive. The trials, tribulations, developments, and successes all need to be documented about for others to despair at, rejoice in, laugh with, and continue trying to implement.

The development of native support personnel needs to be closely scrutinized by the professional associations developing guidelines on the use of supportive personnel, both because of its merits and because of its possible shortcomings. The profession of audiology needs to recognize the essential and unique contribution that native people can make in their own health care as well as to question the nature and scope of professional practice in the context of community health. University programs need to consider their role in the training of both native people and the audiologists who will work with them. Community-based, certificate level training for native hearing specialists as well as course work for non-native audiology students on adapting service delivery models, understanding community health, and becoming acquainted with medical anthropology are possibilities for development within the curricula of training programs. In the final analysis, all service and training programs will have to decide how autonomous audiological health care by native people is to become and what the most effective way to achieve that degree of autonomy is.

Finally, there are a number of other needs that remain to be addressed. Culturally based services in the area of the speech and language deficits that are secondary to hearing loss resulting from COM need to be developed for Inuit populations. The central auditory consequences of COM in these populations need further study and management. Amplification possibilities need continued exploration. Finally, further research and development in the area of medical intervention and prevention of COM is essential in the efforts to control the disease. This Project for Hearing Impaired Inuit of Northern Quebec should be considered just a small beginning in the changing scope of audiological practice as it becomes adapted to the cultural dimensions of the populations it serves.

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