

# The Silent North: A Case Study on Deafness in a Dene Community

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*This article is based on a case study that explored one northern First Nation's response to deafness in the community. The study examines deafness from a cultural perspective rather than from a medical or pathological framework. Through the use of interviews and observations, participants critically reflected on their evolving perceptions of deafness and the supports and services necessary to create an accessible community. The study identifies that stronger culturally relevant linkages between northern communities and northern health professionals are needed in order to provide support and services that are responsive to the northern context.*

Ninety percent of deaf children are born to hearing parents who have had little or no exposure to deafness before the medical diagnosis (Magnuson, 2000; Lane, 1999; Poon, 1998). As with any event that forces people to cope with a series of atypical lifestyle challenges, having a deaf child requires tremendous learning for the immediate and extended family as well as the surrounding community. Families and communities experience a steep learning curve regarding the philosophical, psychological, and cultural issues, including challenges with communication, attitudes, acceptance, and understanding about deafness.

Families may receive an enormous amount of information immediately following medical diagnosis, which they then must digest in order to make informed, educated decisions fundamental to their deaf child's welfare. The key here is *may receive*. Because opposing philosophical views are held between the Deaf community<sup>1</sup> and the medical profession, families may receive inadequate or incomplete information. The information they do receive often depends on whom they turn to for "expert" advice. The consequences of delayed access to inadequate or incomplete educational materials about deafness are severe. Delays in deaf children's language, social, cultural, and cognitive development often result when initial diagnoses and subsequent access to resources are obstructed.

For parents of deaf children living in remote and northern communities, access to health care practitioners is often sporadic, and when it does occur it is usually a cross-cultural encounter. This study documents one northern<sup>2</sup> First Nation's situated response to having a deaf child in the community. The research also identifies gaps in the knowledge transfer on deafness between health care practitioners and communities, as well as gaps in availability and accessibility to this information.

## *Non-Indigenous Researchers in Indigenous Communities*

Non-Indigenous researchers have a perpetual history of intentionally or unintentionally exploiting Indigenous peoples in the name of research (O'Neil, Reading, Bartlett, Young, & Kaufert, 1999; Smith, 1999). Certainly the conduct of external

research in many Indigenous communities brings about negative feelings. "The word itself, 'research,' is probably one of the dirtiest words in the Indigenous world's vocabulary" (Smith, 1999, p. 1). Research is not a neutral, academic endeavor; it is the pursuit of knowledge that has something riding on it, and it takes place in a certain set of political and social circumstances. Therefore, it is important for both new and experienced researchers to grasp fully the many forms of injustice that have been committed against Indigenous peoples through science that include exploitation, misappropriation, and misinterpretation of knowledge so that such offences are not repeated. Further, researchers must consider the extent to which power relations may play a role in interactions with community members. The researcher-as-learner rather than the researcher-as-expert approach is one way to endeavor to strike a balance in the relationship between external researcher and community members.

As I am of Euro-Canadian descent, the research was a cross-cultural experience for both myself and the Indigenous community that participated. I was born in the Northwest Territories and have always had a strong desire to reestablish a connection to the north. My interest in conducting a study on deafness stems from several years of involvement in the Deaf community, first as an American Sign Language (ASL) interpreting student in Vancouver, followed by seven years of working for the Winnipeg Deaf community as an ASL interpreter, and then more recently as an instructor of ASL interpreters in Edmonton. I chose to investigate a First Nation's response to deafness after having pursued an undergraduate degree in cultural anthropology and Native studies.

In my academic studies I recognized similarities between the Deaf community's and the Indigenous population's experience of oppression<sup>3</sup> at the hand of dominant societies and began to identify a possible pattern of assimilation.<sup>4</sup> The hearing population has attempted to force the Deaf community to assimilate; the Euro-Canadian population has attempted to force Indigenous peoples to assimilate; so I also hypothesized that the Deaf community has followed a pattern of assimilation in that Deaf members shed their original identity. With this understanding in mind, I began to shape the study.

In addition to the formal academic requirements for approval to begin the work, it was necessary and culturally appropriate to seek permission to conduct the study from the community and to obtain a license for conducting research in the north. Because of the extremely poor historical reputation of the conduct of (ethical) research in the north, the territorial government has established a policy requiring researchers to obtain licensure before conducting any scientific (social or physical) research in their territory. A detailed application was made to the licensing organization for the Territory and to all community organizations that the research might affect. After contact with the Chief and Council of the community, the territorial Tribal Council, and the Territorial government, approval was granted and a license was issued. Without approval from these organizations this study would not and could not have taken place.

### *Significance and Framework of the Study*

Westerners, including many southern Canadians, have described the north as an inhospitable, vast wasteland unfit for human habitation. However, for a small but

steadfast Indigenous population, the north has not only provided the necessities of life, but also a backdrop for a culturally rich and diverse way of life. At the same time, the Indigenous population, which constitutes the majority of the northern population in Canada (Statistics Canada, 1996), endures a disproportionate burden of health problems (O'Neil et al., 1999). Included in this grim reality is the recognition that the incidence of hearing loss in the north is higher than in southern Canada (Bjerregaard & Young, 1998; Kramer & McCullough, 1998; Baxter, 1999).

Much has been written on the subject of Deaf identity (Lane, 1999). Lacking in the literature is discussion about the experience of hearing parents with deaf children living in remote or northern areas or the experience of Indigenous parents with deaf children. This study is significant in that it explores an Indigenous response to having a deaf child in the community. By sharing one family's journey into the labyrinth of issues about deafness, this case study is intended to initiate further research on the subject of deafness in the north.

The medical profession has historically situated deafness in a pathological<sup>5</sup> framework, and it continues to address deafness from this perspective. Where the Deaf community sees a language difference, the medical profession views deafness and hearing loss as medical problems that require rehabilitation (Frazier-Maiwald & Williams, 1999). Further, by describing a deaf child's difference using medical and biological terminology, often in ways that are intimidating to the hearing parents, the medical profession has pathologized deafness as a deviance (Lane, 1999). The labeling process has a profound initial effect on hearing parents and subsequently on the child throughout his or her lifespan. According to Gannon (1987),

deafness will be a prison as long as there are professionals, doctors, educators, counsellors, program administrators, who do not really understand deafness, but think they do and think they know what is best for us. They are often our worst handicap. (p. 5)

On the other hand, the Deaf community does not recognize a disability in their way of being (Lane, 1999). The Deaf community is as rich in heritage, folklore, norms, mores, and traditions as any of their hearing cultural counterparts (i.e., the Quebecois, the Cree, the Spanish, or the Chinese community). Most members of the Deaf community do not share their Deaf identity with their parents.<sup>6</sup> However, these deaf individuals also have an original linguistic and cultural identity that may be, for example, Quebecois, Cree, Spanish, or Chinese. Thus in the Canadian context, many deaf individuals have two or even three competing cultural identities.

Although qualitative studies are lacking in all areas of disability in the circumpolar north, and scant if not nonexistent with regard to deafness, quantitative studies on hearing loss are relatively abundant. Several studies have been conducted that draw similar conclusions: that in the circumpolar regions ear infections and hearing loss are common among children (DeCourtney, 1998; Jette, 1998; Kramer & McCullough, 1998). According to Martin and Macdonald (1998), "middle ear disease with related hearing loss continues as a significant burden for the children of the central Canadian Arctic" (p. 268). Although hearing loss is a considerable health problem among northerners, frequently cases remain un-

detected or untreated until school age. Health care practitioners are still being challenged to achieve satisfactory criteria for managing middle-ear disease.

At the same time, contemporary health services for northern residents have become increasingly available through advancements in transportation and medical technology. Most northern communities have nursing staff available around the clock. The larger northern urban centers (i.e., Yellowknife, Inuvik, Iqaluit, and Whitehorse) are equipped with a wide range of specialized medical services as more medical professionals take up transient or long-term residence either for higher salaries or a change in lifestyle. However, many services, resources, organizations, and materials are still not available to northern residents. For Deaf individuals and their families, access to professional services and support programs in the north continues to be severely limited. Despite various policies, the situation remains that some families with Deaf children have not benefited from them (Moore, 1990). Therefore, many families with deaf children in remote or rural areas relocate to urban southern centers in order to gain access to resources, services, and support networks.

#### *Getting at the Issue*

This particular research may be described as a descriptive, intrinsic case study. A number of methods were employed in the data collection including in-depth open-ended interviews, observation, formal and informal community meetings, and critical reflection. Opportunistic sampling, also known as continuous snowball sampling, was employed to identify interviewees (Garvin & Eyles, 2001; Babbie, 1992). The qualitative methods that I employed allowed me to follow the data as they emerged during the fieldwork, lending strength to a more comprehensive study (Patton, 1990). As a result, I obtained a number of perspectives.

Data were drawn from nine interviews based on the interviewee's relationship with the deaf youth, Arthur, who was the impetus for this study (see Table 1 and note #7). In addition to carrying out interviews, I engaged in numerous formal meetings and informal exchanges about the research. This included discussions with the Chief and with Council members.

#### *Ehchuse:<sup>7</sup> The Setting*

The community of Ehchuse is by conventional standards remote and isolated. Regular flights in and out of the community are available, although these are subject to weather conditions. Barge service is available once a year in the summer months. There is no road access. In addition, many residents rely on personal means of transport including motorboats and skidoos (snowmobiles) not only for travel between neighboring communities, but also for hunting, fishing, and trapping, the mainstay of the local economy. The community is located on a large lake—as is the case for many communities in the north—with a health center staffed around the clock. The closest northern urban center with a full-service hospital has a permanent population of approximately 17,000 people (there is a substantial transient population of 5,000). This center is located roughly 1,500 km north of the nearest metropolitan area with over 800,000 inhabitants. Ehchuse is home to approximately 300 residents. Aside from a small number of non-Indigenous people, residents are members of the Dene Nation; a Tribal Council



Table 1. Case Study Participants

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*Northern Voices*

Sandra	Mother of deaf child
Arthur	Deaf child
John	Father of deaf child
Carolyn	Paternal aunt
Margaret	Maternal aunt
Joe	Paternal step-grandfather and community Elder
Beth	Territorial Audiologist
Tarah	Community Health Representative
Barb	Community Social Worker
Jennifer	Community School Principal
George	Community Wellness Coordinator

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provides services; and the community is in a land-claim area. Both Chipewyan and English are used in the community and taught in school. A Chief and Council as well as an Elders' Committee govern the community.<sup>8</sup>

#### *Data Presentation*

They "over-institutionalized" him and they keep doing it to him even now! (Sandra, mother of deaf child participating in this study)

This research depended on the context of the particular community in which I gathered data. Those interviewed include both immediate and extended family members who are linked by family ties—but separated by interpersonal (communication), as well as physical distance that increased over time—and those with a professional relationship to the family (see Table 1 for a summary of those interviewed and their relationship or role in the family or community). I intended to do research that served the needs of the community where the study was situated. However, the stories that the participants told during the study were an indication that the research undertaken was significant not only to the community of Ehchuse, but to the wider northern population, the Deaf community, and professional health care workers and educators in terms of theory, policy, and practice.

After I had analyzed the data from the interviews and community meetings using open coding techniques, five themes emerged based on the various perspectives offered by the participants. The first theme addresses systemic racism embedded in the health system and how discrimination is carried out in the northern context. This theme also encompasses issues about cross-cultural awareness and sensitivity, as well as the degree of family and community involvement in decision-making processes. The second theme speaks to the critical need for early diagnosis and intervention, in addition to access to resources with respect to hearing loss and deafness, particularly given the high incidence of hearing problems in the north. The third theme concerns the notion of territory-wide health and social service policy for northern children with special needs. Policy without the means to implement it is doomed to fail. In regard to this theme, although local and territorial service provision was lacking at the time of the study, local solutions

were identified, but have yet to be operationalized. The fourth theme relates to the consequences of lost or overshadowed original Indigenous cultural and linguistic identity as a result of immersion in a Deaf and non-Indigenous environment. The fifth theme addresses the lack of support networks for families with deaf children throughout the north.

### *Racism*

Systemic racism embedded not only in our health care system, but also in all corners of our society may also explain differences in access to services (Canadian Council for Refugees, 1996). Racism is often unarticulated and unconscious in the minds of those who hold racist attitudes. These individuals often vigorously deny racism; however, racism continues to infect the lives of many Indigenous peoples. Reflection on systemic racism in the north is a necessary component to analyzing medical response to parents' concerns about children's health in the northern communities.

Historically, nurses who are born, raised, and educated in the south have staffed nursing stations across the north. This practice continues in Ehchuse with three-month rotations. A number of issues emerge from the practice. Twenty years ago when Arthur was born, only limited formal cross-cultural awareness or sensitivity training would have been provided in the nursing programs. Most if not all nurses going to northern communities for the first time undoubtedly experienced culture shock. Further, because most nurses were stationed in communities on a rotational basis, they were not in one community long enough to move beyond culture shock to cultural relativism and finally to cross-cultural understanding. Nor were they able to develop long-term relationships with the people. In addition, nurses were seen as authority figures in northern communities, which would have had a significant effect on relationships between patients and health care workers. Because of the high status accorded to nurses in the community, challenges to that authority would have been rare, a common phenomenon noted in the literature.

That the health care profession has historically gone unchallenged by the general public has further inflated discriminatory practices or *laissez faire* attitudes played out in the cross-cultural context. Several participants (both Indigenous and non-Indigenous) alluded to this conduct in several conversations throughout the data-collection process. In one case a non-Indigenous professional noted that despite parents' concerns about their child's potential hearing loss, the nursing professionals in the community frequently turned the parents away, simply citing a "nonthreatening" ear infection. Two years later, when the child was brought to the hospital, she was finally diagnosed with a severe hearing loss. This was also the situation with the participants in this case study. Sandra held that the community health professionals did not respond to her and John's (Arthur's father) concerns with the same degree of urgency that as parents they believed was needed when their son first became ill and on subsequent visits to the nursing station. Sandra and John instinctively recognized that there was something wrong with their son and believed that the medical intervention was not effective. They pressed the medical workers to try further intervention and initially questioned the methods, but the professional response was minimal and placating. In Arthur's case, a health

practitioner at a recent medical exam told Sandra that Arthur's deafness could have been prevented had the earlier practitioners done more thorough intervention. Another example is about access to services. According to the same non-Indigenous professional, past procedures for specialized testing, which required an airlift to southern Canada, were either not carried out or delayed as long as possible because of the expense.

Many professionals who are recruited from southern Canada find the northern experience extremely isolating. Although they may not use the term *culture shock* to describe their experience, they may indicate feelings of stress or exhaustion and have difficulty coping: typical symptoms of culture shock. These feelings are often manifested in ways that lash out against the local population. They frequently compare the current situation with their perception of what is "normal" from their own ethnocentric point of view. For example, in an interview with one non-Indigenous professional, she angrily voiced her frustration about the state of affairs, "the garbage they have to put up with in the community ... I mean every three to six months they've got new nurses up there." The audiologist, Beth, described the problems that she observed others experiencing. She noted that other professionals tended to have problems with "patients not showing up for their appointments or they'll go back six months later and nothing has been done and the recommendations haven't been followed through." She found this aspect of her job frustrating. The behaviors that Beth objected to may have had reasonable explanations from a cultural point of view. For example, the season might have compelled individuals to be out on the land harvesting, or the recommendations may not have been fully understood given the language and cultural differences. Beth in fact confirmed the latter instance, saying, "A lot of times they'll nod at you and you think they understand and then they go away and they don't have a clue ... and literacy is an issue."

Another problem Beth identified was that health practitioners were no longer compensated as they had been previously, so demand for qualified professionals has increased. As mentioned above, those who are in the north have an extraordinary workload, which can lead to employees being overburdened. In the past a major incentive for transitory southern professionals to go north was the lucrative remuneration packages available. Beth said,

For about a year we've been looking for someone, and they haven't been knocking down our door. But the money is not as good up here any more. My friends make the same down south as I am up here and think of the cost of living up here. It's not really worth it anymore.

Rather than having a constructive desire to work in a cross-cultural context, individuals were drawn to the region by the thought of realizing quick financial success and a rapid return to southern Canada.

In both large and small northern communities, non-Indigenous people have tended, and continue, to gravitate to other non-Indigenous people and do not interact with local community members except during business hours. This behavior insulates them from local people. By remaining in their own cultural network, these individuals do not move beyond culture shock to cultural relativism and cross-cultural understanding, nor do they develop strong, lasting relation-

ships with community members. The stress of being in an understaffed environment also has a significant impact on those external professionals who work in northern communities.

### *Diagnosis and Intervention*

The high incidence of otitis media among children in the circumpolar north is a documented reality. Left untreated, this can lead to hearing loss. Although this study focuses on only one case of a young person with a hearing loss in Ehchuse, it is clear that the community and the professional sector are concerned that other individuals with varying degrees of hearing loss may be present not only in the community, but across the territories and are as yet undiagnosed. From the perspective of both the health care professional and the educator interviewed in this study, the fact that no other individual in the community had been diagnosed was abnormal.

The medical and sociocultural literature consistently supports the need for early diagnosis and intervention with deafness and hearing loss in children. Despite this and regardless of geographical location, deaf infants are often not diagnosed for several months—for several reasons. First, parents are often initially unaware of hearing loss in their children, particularly if there is no history of deafness in the family (which is the situation in 90% of cases). Therefore, they do not immediately know what signs to watch for in identifying hearing loss. Second, as parents begin to suspect that there might be a problem with their child's hearing, they often experience a period of denial before seeking medical confirmation. Third, when parents do seek medical advice, there are frequently further delays in diagnosis for a variety of reasons including (particularly in the northern context) geographical distance from the necessary testing facilities; the child may have a current ear infection that impairs test results; sophisticated testing equipment may be limited in availability; and there may be medical uncertainty about test results. Fourth, after medical examination has confirmed a hearing loss or deafness, accessing support services for parents and their deaf children may be further delayed. In southern cities where the urban population has relatively direct access to medical services, attempts are made to keep these delays to a minimum. However, these delays increase exponentially when comparing the north with southern Canada. For example, at the time of this study there was only one audiologist for the entire territory.

When parents eventually do gain access to health care professionals for hearing loss and deafness, the breadth and depth of information they receive during the initial diagnosis phase varies. In addition, because parents are experiencing a significant event in their lives in terms of diagnosis, often they cannot assimilate the information they receive. The situation is further exacerbated when only limited and often inconsistent (transient) resource personnel are available to address the multitude of needs across the north. The audiologist interviewed in this case study confirmed this obstacle, describing it in her own words,

If you give them all the information at once, you know they're not going to remember it ... even if you give them a little bit of information about their child's hearing loss they don't hear what you say the first time ... I usually give them handouts ... but that's so overwhelming.

Although parents are flooded with information on deafness in a short period, extended families are not part of this process. In Arthur's case, the extended family did not have the opportunity to talk with health care professionals about deafness, how they could help, or how they might continue to play an active role in their relative's life. Consequently, they expressed frustration at the lack of information about deafness and were underutilized as resources in terms of supporting the family. Carolin, Arthur's paternal aunt, reflected on the need for information, indicating that it would have been extremely helpful in making her feel more confident in her interactions with her nephew.

In addition to the importance of early diagnosis and intervention with hearing loss and deafness among northern children, the high incidence of permanent ear damage resulting in hearing loss in mature adults and Elders in this community was raised on numerous occasions during my stay there. Ehchuse, through its own local observations, has identified this serious community physical and social health concern. The issue is probably of concern in many other communities across the north. Loss of hearing can have significant consequences in northern communities. Hunters with a hearing loss are at greater risk of occupational and environmental hazards while on the land, as they may not be able to hear other hunters or animals in their vicinity, or they may not hear ice cracking during winter trips. Hearing loss is a social concern as well, particularly in terms of multigenerational relationships. Elders and youth in the community have reduced communication as a result of late-onset hearing loss. The wellness director in the community made a point of articulating this concern and said, "The Elders are a source of information, traditional knowledge, and cultural knowledge ... we have to be able to listen to them." Elders are important links in maintaining culture and local knowledge through traditional oral history, as younger generations who were frequently removed from their families and communities to attend residential schools have been robbed of this tradition. Clearly this is one area that requires further investigation.

### *Implementing Policy*

It is critical for families to gain immediate access to information about their child's deafness, his or her needs, and their needs as parents. This is necessary for them to make informed, educated decisions about language use in the home and the type of school environment that will provide essential language education. The health care professionals I interviewed agreed that it was critical that decisions be made with parents with all the available information. As noted above, however, this has not always been the case across Canada. Families are often not aware of their rights to supports, services, and resources as laid out in provincial policies on health care. For example, in urban centers, gaining access to second opinions from other qualified medical personnel is not an problem. However, Sandra or John had no opportunity to seek a second opinion given their isolated geographic location. Further, the general public is often hesitant to challenge medical opinion or ill equipped to seek answers to questions they might have about diagnosis or treatment. In this case, the health care system failed to support Sandra and John fully concerning Arthur's health and his subsequent hearing loss.

The community as a whole expressed a sense of frustration and sadness because they were not able to provide the services that one of their community members needed. The family and the community had tried hard to bring qualified people to Ehchuse so that Arthur could remain at home. They needed more than sporadic service and support: they needed one-on-one service and support. The community health representative expressed what many of the local professionals were feeling,

There was nobody who could do anything—it was very sad ... we couldn't provide the service for him ... If a deaf person wants to move back here, there is no communication, no sign language, there's absolutely nothing for him, no services available and I am part of that professional team and I have absolutely nothing.

Despite the community's emotional involvement and the effort to realize these services, the family had to leave the community, and in essence relationships were severed. On reflection, many of the participants expressed remorse over the separation and eventual ending of this relationship, not just with the one community member because of his deafness, but with his entire immediate family.

Access to services, supports, and resources in the north is significantly limited compared with that available in southern Canada in terms of range and response rate. Limited services and delays in response are often due to geographical distance and the high cost of delivering these resources. However, they are also affected by a shortage of professionals willing to serve in a region that requires considerable travel in less than ideal conditions. The shortage of qualified health care professionals in the north is an ongoing problem. In this case, professional services and resources were delayed or absent in the prevention and treatment stages when Sandra and John were taking their son back and forth to the nursing station and to the hospital (outside the community), as well as in the subsequent intervention stage following Arthur's diagnosis. This may in part be attributable to transitory rotations and low retention rates of qualified personnel not only in the community, but also throughout the territories. As the audiologist testified,

In communities there are the nurses but they don't have a clue about [deafness] ... and another problem is turnover; every time you go to the nursing station there's a different nurse in there and you talk to them ... and then they're gone and you have to do it all over again.

The call from the northern health sector for universal screening of all infants cannot come soon enough. At the time data collection took place, universal screening of all infants born at the regional hospital had become policy. However, personnel at the audiology clinic still had not received training on the laboratory equipment. Although most expectant mothers are now evacuated to one of the larger urban centers for the birth of their children and will eventually have the benefit of early screening, many mothers still give birth in their home communities. Consequently, many children reach school age without having had hearing tests, so deaf and hard of hearing children will continue to fall through the cracks. Both the health care professional and the educator interviewed in this study expressed serious concern about the lack of universal screening at birth and at frequent intervals throughout the lifetime. They agreed that it was critical to have every child tested, especially in the north given the higher incidence of hearing loss there.



A territory-wide Special Needs Education Policy has been in place for close to two decades. This policy calls for service provision in communities in order to keep families together. However, when Arthur was a young child, the general professional recommendation was to send the deaf child to a residential school in southern Canada. This was because they could not provide the services necessary for him in Ehchuse or the regional metropolitan center. Even now, the audiologist reported, the services are still not in place, and she continues to recommend to parents that their best option is to send their deaf children south for health care and education. Policy without the means to implement it is meaningless.

### *Cultural and Linguistic Identity*

Before Arthur left the community to attend the School for the Deaf, the extended family including both the maternal and paternal grandparents entreated Sandra and John to keep their deaf son in the community, arguing adamantly that the residential school placement was too far away and that their grandson was too young. Despite the formidable influence of the extended family on Sandra and John, as first-time parents with no previous experience regarding deafness, they were swayed by professional medical opinion. By mutual agreement they decided to send Arthur at the age of 6 to a southern-based school for the Deaf approximately 1,500 kilometers from Ehchuse. Travel involved a one-hour flight by bush plane followed by an hour-and-a-half flight out of the north. The first year of separation proved difficult for the entire family, and at the end of that school year Sandra and John decided not to send Arthur back. However, a tragic accident on the land resulted in John's death, and Sandra was left as the sole caregiver for a deaf child and three younger hearing siblings. It was too much for her to manage on her own, and because of the lack of local or territorial resources she was forced to send Arthur back to the School for the Deaf.

The loss of traditional lifestyle, Dene culture and values, Chipewyan language, and interpersonal familial relationships were clearly observed and remarked on by participants during this study. Before Arthur took up permanent residence at the School for the Deaf, the family actively participated on the land, employing long-established Dene skills including hunting, fishing, and gathering. Sandra recalled how his grandparents used to sing to Arthur in Chipewyan when he was a baby. She and other members of her extended family grieved that he has not had opportunities to go back to his roots, to learn Chipewyan, to go out on the land, and to participate in cultural activities. These fundamental cultural and linguistic building blocks were not accessible from the time Arthur was sent to the School for the Deaf, and they continue to be beyond reach because of lack of support from the territorial Department of Health and Social Services. At the School for the Deaf Arthur was exposed to American Sign Language and the Deaf community and its culture, but received no exposure to his own cultural beliefs and practices or to Chipewyan, the first language of many community members including his only living grandparent. It was frustrating not only for him and his family, but for the entire community. One of the community members interviewed voiced the sentiment felt by many individuals who took part in this study on an informal basis, stating that she would like to see Arthur have the opportunity to learn his culture

and the Chipewyan language so that he would be able to speak at community meetings.

Members of the extended family noted the impact of Arthur's absence on the entire family. Carolin conveyed feelings of sadness that there had been and continues to be little or no contact with Arthur. She recognized the cultural need to keep the family together. Without his presence a gap is felt by the entire family. She felt deeply that he had been taken away from the family at too young an age and that it would have been healthier for him and the family had there been services available for him in the community. Joe, Arthur's grandfather, poignantly stated, "Before I die, I'd like to see my grandchild. The summer time—him coming here would be good. We could go for a picnic." Picnicking is an essential activity in this community. During my stay in Ehchuse I regularly went with people on picnics. Most residents were out every weekend on the land regardless of the weather engaged in hunting, fishing, gathering, drying meat, tanning hides, or picnicking.

From the community perspective, of great concern was the lack of opportunities for Arthur to interact with his peer group. Peer groups allow young people to be on an equal footing with others and to gain experience with interpersonal relationships. However, Arthur's peer group in the community did not share a common language with him, thus making it a challenge for any same-age interaction to occur at school or at play. Nevertheless, the community health representative furnished a logical solution to create a virtual network for deaf children and youth across the north in order to for them to remain in their home communities without experiencing isolation. In any event, she noted that if Arthur were to come back to the community now, he would be "totally lost, as he would have no communication with his peer group at all."

Arthur's parents sent him to a large urban center in the south to access resources, services, and support networks that were not available in the north. Then (and this is not uncommon among rural and remote families with deaf children), Sandra and her children relocated to the same city years later to be closer to him. The high costs of travel to and from the north restrict movement, and thus opportunities to return to the community have been severely hampered. However, moving south as an Indigenous deaf youth and entering a Deaf (primarily Euro-Canadian) environment did not necessarily mean inherent admission to his assimilated community. Based on communication with Sandra throughout the study, as well as personal observation of Arthur's current status, acceptance has been lacking, and he continues to face social and cultural barriers in the urban setting as well. Consequently, Arthur's original cultural and linguistic identity was and continues to be significantly affected.

### *Support Networks for Families with Deaf Children*

When a child with special needs such as deafness is introduced into a family, that family needs social support. After John died, Sandra found she did not have the support she needed from family and community members to cope with the death of her husband, a deaf son, and three younger hearing children. She acknowledged that Arthur's grandparents were sympathetic, but it was also a traumatic time for them with the loss of their son, and they did not know how to deal with Arthur's deafness. This lack of support is common as family members and friends often

experience turbulent emotions such as fear and apprehension during and after critical life events.

If support from the family is not provided or if the family breaks up for any reason, external support networks are critical. Social support and information provided by friends, relatives, and experts could have lessened the degree of Sandra's distress during this critical time. As it was, Sandra was left without external networks to turn to because she was living in a small, isolated, northern community that did not have access to professional support. However, although no external social support was available, Sandra has continued to fight for her child's rights and her own rights as a parent with a deaf son. She even went to the media in an effort to attract attention and garner support not just for herself, but also in an attempt to help other families in the north. Sandra is still struggling to obtain the necessary support that would allow her son to live an independent life in the north. Yet according to Sandra, "There is nothing [for deaf children or their families] in the [north]."

It is well established in the medical and sociological literature that families experience significant change when an infant with special needs such as deafness enters the family. Sandra and John, not unlike other new parents of deaf children, were required to learn an enormous amount not just about general parenting, but also about the extensive care and support their deaf child needed. At the same time, as noted in the literature, extended family members may experience turmoil, fear, and apprehension during the initial stage after diagnosis. This was clearly the case for the extended family members participating in this study. Although the extended family felt hesitant and unsure how they could be involved in Arthur's life, no professional support was offered to the extended family in terms of coping with a family member who was different. As a result, the extended family encountered an ever-widening gulf in their relationship with Arthur. Sandra recollected, "They just want to smother him with their love, but they didn't know how to deal with him." The extended family members who participated in this study all expressed regret at not having had the opportunity to learn sign language so that they could in turn learn about their deaf relative and understand his perspectives as a deaf individual.

On the whole, the general public lacks understanding about deafness. Deafness is often equated with mental disability or confused with other disabilities. I can recall countless times being asked if as an interpreter for the Deaf I could read Braille. I have been asked if Deaf people could drive, or if Deaf people could have children. Hearing people frequently make assumptions about the cognitive and physical abilities of the Deaf person based on ignorance. The general public in fact does not conceive of a Deaf cultural and linguistic identity. This perception emerged in the community of Ehchuse, and it was no different there than in the general population in terms of awareness about Deaf identity. They were similarly at a loss as to how to be involved. Sandra recalled that when Arthur was still in the community, a number of individuals used to refer to him as retarded. Clearly an informative cultural awareness program about deafness would be beneficial in the community and across the territories.

Finally, organized networks for parents of deaf children in the Territories are desperately needed. At the time of this study, no formal networks had been established to provide opportunities for parents to share their experiences with one another in order to equip themselves better for caring for a deaf child. Sandra made it clear from the beginning that she agreed to participate in this study based on her desire to help other parents in the territories gain a better understanding of her experience. During an interview she stated, "He may be the only one I know who is Deaf, but I am sure there are other parents who are going through what I am going through." Parents like Sandra who participate in studies such as this pave the way for parents with newly diagnosed deaf infants by sharing their experiences as hearing parents with obstacles and barriers as well as breakthroughs and accomplishments of and with their deaf children.

One finding of this study was a lack of correspondence with current literature in regard to the theory that parents with either family support or external support have a more positive relationship with their deaf child than those who lack either of these supports. According to the literature, receiving support as soon as possible after a child's diagnosis of deafness is critical, as such support has been shown to have a strong effect on the quality of parent-child relationships. In this particular case study, however, Sandra appears to have maintained a positive relationship with her deaf son despite the lack of resources. She continues to fight for her rights as a parent and for her son's right to access educational, social, and cultural support. Sandra clearly articulated her desire to keep her family together,

I want him to stay here where we live now ... I just want to be close to my family and nothing has happened yet. Arthur has waited so long ... I don't want him to wait any longer ... He wants to be here with his family.

### *Recommendations*

During formal and informal meetings and interviews with participants, the community revealed a desire to reestablish relationships, remove communication and cultural barriers, and create an accessible environment for all community members. All the participants, regardless of their professional or personal relationship with Arthur, were emphatic about the need for better resources, supports, and services in their community and across the territory. The family and the community also commented on the importance of conducting this study to serve the interests of other northern parents with deaf children in isolated communities. The need was clearly expressed for improved resources, services, and supports in their community and across the territory not only for deafness in children, but also hearing loss in young adults and Elders. Further, during the course of the study, several suggestions from the community were offered that would operationalize coverage of the gaps in service. These recommendations indicate that there are viable local solutions to local problems, and in this case the community has concrete ideas for creating culturally specific and relevant supports and resources for deafness (see Table 2).

### *Conclusions*

The message from this case study is clear. If the territorial government does not remedy its response to northern families with deaf members, it will continue to fail

*Table 2. Recommendations*

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1. Development of culturally relevant resources on deafness for both Indigenous and non-Indigenous people (e.g., produce a videotape on deafness from family, community, and professional perspectives for distribution in all northern communities).
  2. Provision of American Sign language (ASL) studies in communities across the territories for those interested in learning basic sign communication.
  3. Creation of partnerships between southern residential schools for the Deaf and northern local schools with deaf children (e.g., pen-pal programs, sharing resources, student exchanges).
  4. Provision of annual short-term ASL immersion training programs in northern cities staffed by Indigenous/Deaf instructors for families with deaf children across the north.
  5. Establishment of an electronic network to serve families of deaf children across the north.
  6. Creation of a position of Territorial Coordinator of the Deaf to implement above recommendations.
  7. Address disparities in legislation and development of new policies that meet the needs of the northern Deaf population.
  8. Implementation of universal screening for hearing loss and deafness at birth, early childhood, school-age, and periodically across the lifetime.
  9. Establishment of infrastructure to support and serve families and communities with deaf children and adults with hearing loss through additional government funding.
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in meeting their needs. All those involved in this study recognized that the supports, services, and resources were not there in the community if another family had a deaf child. The reality is that children in many northern communities with significant hearing losses have yet to be identified because of incomplete or inconsistent hearing tests, lack of qualified professional personnel, and other gaps in service.

A significant finding beyond the scope of this study was that greater awareness about the implications of hearing loss is needed in the north, especially in the aging population. Preventive care and systemic attempts to alter the factors causing hearing loss and deafness (e.g., improve housing conditions) are necessary. In this particular community, several adults and Elders had varying degrees of hearing loss, which has a major impact on the level of their involvement in community activities and events and the decision-making processes. Aboriginal communities are losing important contributors to their communities, as is the larger Canadian society, when Elders become disengaged from being active, contributing members of their communities due to their hearing loss.

Much has been written about chronic otitis media and hearing loss in the north from a medical perspective. However, little has been written about persons who experience deafness or hearing loss from a cultural perspective. Because the incidence in the north of both chronic otitis media and hearing loss in children continues to be a high, documenting this community's response to having a deaf child in the community, as well as additional studies in other communities, had the potential to serve northern families and communities who have called for improved services and support: calls that have fallen on deaf ears!

Notes

<sup>1</sup>The term *Deaf community* is used here in accordance with how the Deaf population interprets community as Lane (1999) describes:

membership in the Deaf community is not decided by diagnosis; in fact, it is not decided at all.... various culturally determined behaviors, and foremost among them language, reveal whether or not an individual belongs to a language minority or not. (p. 20)

In this article I capitalize *Deaf* when referring to the Deaf community. In all other cases I use *deaf* as I am not in a position to ascribe membership status.

<sup>2</sup>*Northern* and *north* in this particular study are defined as north of the 60th parallel in Canada.

<sup>3</sup>Kaiser (1990) states that

oppression is the "systematic mistreatment of one group of people by another group of people, in which there is an imbalance of institutionalized power." Systematic mistreatment refers to the methodical and widespread way in which psychological, physically violent, and verbal forms of abuse are directed at particular groups targeted for oppression. It often appears to happen to one person alone, but actually occurs on a societal and institutionalized level to all people belonging to that same targeted group.

An imbalance of institutional power is an essential part to this definition of oppression. *Oppression* in terms of Indigenous peoples refers to European attempts to "Christianize, civilize, colonize, and control" Indigenous peoples. The Deaf community has been oppressed by the dominant hearing majority in terms of denying the existence of a linguistic and cultural identity as well as political autonomy, limiting access to information, and eliminate deafness through the use of medical technology.

<sup>4</sup>In this case, assimilation means that both the hearing population and Euro-Canadians have tried to absorb and integrate the Deaf community and Indigenous peoples respectively into the dominant society, attempting to deny each group its own identity and distinct status.

Armitage (1995) summarizes the policy of Indigenous assimilation into Euro-Canadian society:

It is traced through five principal phases: a period of initial contact when the power relationships necessary to carry out the policy were established; a period in which the policy was passive and in which the aboriginal people were expected to die out or merge with the immigrant populations; a period of aggressive policy in which specific social policies were introduced to suppress aboriginal institutions; a period of integration in which it was thought that the policy could be achieved through disregarding the aboriginal existence; and the present period in which the policy is being reversed as aboriginal people re-establish control of their own social policy.

<sup>5</sup>The pathological framework, also known as the medical model, identifies deafness as a disability; in essence, "a broken part that needs to be fixed." Lane (1999) maintains that

The vocabulary and conceptual framework our society has customarily used with regard to deaf people, based as it is on infirmity, serves us and the members of the Deaf community less well than a vocabulary and framework of cultural relativity. (p. 19)

<sup>6</sup>For further reading on membership in the Deaf community see Castleden, 2002; Lane, 1999; Cohen, 1995; and Sacks, 1989.

<sup>7</sup>In order to protect the identity of both people and places, I use pseudonyms throughout. Ehchuse is the name used for the participating community in this study.

<sup>8</sup>I have only a superficial understanding of the process of local governance in this community and so do not attempt to elaborate further on this topic.

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#### References

- Armitage, A. (1995). *Comparing the policy of Aboriginal assimilation: Australia, Canada and New Zealand*. Vancouver: UBC Press.
- Babbie, E. (1992). *The practice of social research* (6th ed.). Belmont: Wadsworth.
- Baxter, J. (1999). Otitis media in Inuit children in the Eastern Canadian Arctic—An overview—1968 to date. *International Journal of Pediatric Otorhinolaryngology*, 49(1), 165-169.
- Bjerregaard, P., & Young, T. (1998). *The circumpolar Inuit: Health of a population in transition*. Copenhagen: Munksgaard, Special-Trykkeriet Viborg a-s.
- Canadian Council for Refugees. (1996) *Anti-racism policy*. Retrieved January 28, 2001 from <http://www.web.net/~ccr/arpolicy.htm>
- Castleden, H. (2002). *The silent north: A case study on deafness in a Dene community*. Unpublished master's thesis, University of Alberta.
- Cohen, L. (1995). *Train go sorry: Inside a deaf world*. New York: Vintage Books.
- DeCourtney, C. (1998). Alaska Native community assessment: Health care services, knowledge of health issues, and health education. *Circumpolar Health 96: Proceedings of the Tenth International Congress on Circumpolar Health* (pp. 656-661). Anchorage, AK: American Society for Circumpolar Health.
- Frazier-Maiwald, V., & Williams, L. (1999). *Keys to raising a deaf child*. Hauppauge, NY: Barron's Educational Series.
- Gannon, J. (1987). Deafness: A plate glass prison? *Canadian Journal of the Deaf*, 1(1), 5-12.
- Garvin, T., & Eyles, J. (2001). Public health responses for skin cancer prevention: The policy framing of sun safety in Australia, Canada and England. *Social Science and Medicine*, 3185, 1-15.
- Jette, M. (1998). A health profile of the Inuit of Nunavik: Report of the Santé Quebec Health Survey (1992). *Circumpolar Health 96: Proceedings of the Tenth International Congress on Circumpolar Health* (pp. 630-635). Anchorage, AK: American Society for Circumpolar Health.
- Kaiser, S. (1990) *Issues of culture and oppression in organizations*. Retrieved June 14, 2001 from <http://www.bizgrowth.com/culture.html> [2001, June 14].
- Kramer, A., & McCullough, D. (1998). The prevalence of otitis media with effusion among Inuit children. *Circumpolar Health 96: Proceedings of the Tenth International Congress on Circumpolar Health* (pp. 265-267). Anchorage, AK: American Society for Circumpolar Health.
- Lane, H. (1999). *The mask of benevolence: Disabling the deaf community* (2nd ed.). San Diego, CA: DawnSignPress.
- Moore, J. (1990). Delivery of audiologic service and prevalence of hearing loss in the western Canadian Arctic. *Circumpolar Health 90: Proceedings of the 8th International Congress on Circumpolar Health* (pp. 630-632). Winnipeg, MB: University of Manitoba Press for the Canadian Society for Circumpolar Health.
- O'Neil, J., Reading, J., Bartlett, J., Young, T., & Kaufert, J. (1999). *Integrating a focus on Aboriginal health research in the development of the Canadian institutes of health research: A concept paper*. Winnipeg, MB: Department of Community Health Sciences, University of Manitoba.
- Poon, B. (1999). *Parental reactions to deafness in children: A grounded theory investigation*. Unpublished doctoral dissertation, University of Alberta.
- Sacks, O. (1989). *Seeing voices: A journey into the world of the deaf*. New York: Harper Perennial.
- Smith, L.T. (1999). *Decolonizing methodologies: Research and Indigenous peoples*. London: Zed Books.