

THE BOUNDARIES OF INCLUSION FOR IÑUPIAT EXPERIENCING DISABILITY IN ALASKA

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ABSTRACT

For Alaska Natives experiencing disability and their families, encounters with “western” biomedical service-delivery bureaucracies represent a form of biopower that severely limits individual and community choice, reinforces normative alignments of difference and otherness, and hinders community inclusion for individuals labeled with a disability. This paper examines the dynamic interplay of power within disability service-delivery bureaucracy in Alaska by emphasizing agency as particular moments of constructive engagement with institutional constraint and introduces creative innovations in the planning process for people experiencing disability. To illustrate this, the experiences of an Iñupiat family in dealing with biomedical service-delivery institutions in Alaska and elsewhere in the United States are described. A fundamental question addressed is whether current service-delivery problems that exist in rural Alaska could be alleviated through cultural understanding regarding the appropriate care and treatment of community members.

KEYWORDS: disability, health service, Alaska Native, Iñupiat

BACKGROUND

Native Americans and Alaska Natives have the highest rate of disabilities of any ethnic group in the United States, at 21.9% (Bryan 1999; Marshall 2001). This compares with 20.0% for African Americans, 19.7% for Caucasians, 15.3% for Latinos, and 9.9% for Asian/Pacific Islanders (Bryan 1999; Houtenville 2005). The common definition of disability (used in the Americans with Disabilities Act of 1996) is “a person with a physical or mental impairment that substantially limits one or more major life activities such as walking, seeing, hearing, speaking, breathing, learning, working, or caring for one’s self” (Bryan 1999:5). However, definitions of disability are socioculturally generated and reflect biases concerning notions of health and normalcy. Few anthropological or other social-scientific

studies (Scheller 1995; Roberts et al. 2001; Wilcox et al. 2001) have examined the problems inherent in the cross-cultural delivery of services to developmentally disabled individuals among Alaska Native peoples. My MA thesis (Hedwig 2006) attempted to address this relative absence in the literature. Selectively condensing this work in the following text, I will examine precontact Iñupiat approaches to defining, classifying, and treating “disabled” community members and discuss how these cultural understandings were transformed through encounters with colonial medical institutions.

As a result of contact with non-Native groups, I argue that western biomedical modes of “managing” disability¹ were imposed upon Alaska Native communities through

1. Byron Good (1994) argues that it is necessary to (1) treat biomedicine as a cultural system with its own set of implicit value judgments and assumptions about the world and the human body that shape the experience of health, disease, illness, and healing; and (2) take seriously the medical practices of other cultures, not as part of a system of beliefs that is inherently flawed and in need of correction, but as sets of knowledge(s) that are continuously and selectively drawn upon in the context of everyday life.

sets of practices and techniques Michel Foucault referred to as biopower (Rabinow and Rose 2003). Foucault theorized biopower to be those practices of “legibility” (Scott 1998) by which governmental institutions extend control over and discipline the bodies made subject to its gaze of surveillance, often in subtle, covert ways (Foucault 1973). Power becomes productive, in the Foucauldian sense, when individuals interact with these institutions of the state through the experience of everyday life. For Alaska Natives experiencing disability and their families, encounters with “western” biomedical service-delivery bureaucracies represents a form of biopower which:

1. severely limits individual and community choice;
2. reinforces normative alignments of difference and otherness; and
3. hinders community inclusion for individuals labeled with a disability.

Modifying Foucault’s perspective and emphasizing agency as particular moments of constructive engagement with power, I will introduce creative innovations in the planning process for people experiencing disability. To illustrate this, I describe the experiences of an Iñupiaq family in dealing with biomedical service-delivery institutions in Alaska and elsewhere in the United States. A fundamental question addressed is whether current service-delivery problems that exist in rural Alaska could be alleviated through the use of cultural understanding regarding the appropriate care and treatment of community members.

Focusing on biopower runs the risk of denying agency to those individuals who interact with (i.e., subject themselves to) the institutional structures through which disability services are administered. It is for this reason that it is necessary to explicitly emphasize agency within the structures of constraint and practices of regulation and control imposed by the state. Overemphasizing these constraints at the expense of the strategic and calculated choices of individuals as they attempt to maneuver through such bureaucracies generates only partial understandings of the dynamic interplay between structural constraint and lived experience. Similarly, use of terms such as “western” and “biomedicine” run the risk of essentializing the diversity of forms and manifestations that exist within such theoretical constructs. In this regard, “biomedicine” as used here is not intended to imply a monolithic entity that destroys all ways of knowing in its path. Rather, it takes on new forms in diverse cultural contexts and may be understood and used in strategic ways by various indi-

viduals and groups. Thus, “encounters with biomedicine” need not always imply a one-sided power relationship with the “consumer” of services continuously being duped by biomedical authorities. As discussed below in the context of an Iñupiaq man experiencing disability and the encounters he and his family experienced in seeking out and obtaining services, these encounters represent possibilities for “changing the relations of surveillance” (O’Neil et al. 1998) and creating new forms of engagement with biomedical institutions.

RESEARCH METHODOLOGY

This paper uses information derived from experiences working with an Iñupiaq family and a local, nonprofit service agency where I conducted an internship sponsored by the University of Alaska Anchorage Department of Anthropology (spring semester 2003, extended through summer 2003) and was offered subsequent employment as a care coordinator (August 2004–July 2005) of services for this and other families. While an intern and employee of the agency, I learned about the current protocols and procedures for providing services to people who experience developmental disability through various federal, state, and local service-providing agencies and organizations.

The qualitative data presented here comes from field notes, observations, and interviews taken within the service-providing agency’s central headquarters in Anchorage, as well as their regional hub office on the North Slope. Some additional observations were made in an outlying North Slope village. Informal interviews were conducted with agency personnel as well as the family and individual receiving services. During my internship I learned about agency procedures and practices and engaged in internship tasks in two Iñupiaq communities. Approximately four weeks of my internship were based on the North Slope, returning to the Iñupiaq community in which intern data were gathered in February 2005 in order to facilitate the personal futures planning process (described below) for the individual and family who are the focus of this research. As an intern and employee with the nonprofit agency, I had access to strategic planning and financial documentation, as well as historical documentation, which I used to formulate an understanding of how decision-making has occurred in Alaska with regard to program development and implementation. Additional records were examined at public and university libraries

(including the Archives and Manuscripts Department at the Consortium Library, University of Alaska Anchorage) to contextualize my analysis.

ANTHROPOLOGICAL RESEARCH ON DISABILITY

Historically in the United States and Western Europe, people who experienced developmental disabilities (and their families) comprised a devalued class without much voice in what was done to and for them by more powerful groups within society (Ferguson et al. 1992). Medical professionals urged parents of children with developmental disabilities to place them in an institution, where, in many cases, horrific conditions prevailed. This approach is quite different in comparison to how various indigenous groups understood and responded to disability prior to the contact period.

One of the first anthropologists to study the social and cultural significance of disability was Ruth Benedict, who in 1934 studied the diverse ways in which epilepsy was treated in American Indian and Siberian cultures (Klotz 2003). Benedict noted that the trance-like states associated with epilepsy were valued and believed to be signs of spiritual authority and power. She contrasted this understanding with that of biomedicine, where the same condition is branded as “abnormal and reprehensible” and a diagnosis carries tremendous social consequences for some unfortunate individuals (Klotz 2003). This was an important contribution in terms of bringing scholarly attention to the ways in which disability is culturally constructed, but her analysis perhaps reifies the differences in cultural treatment of “disability” for “other” cultural groups.

Robert Edgerton’s (1993) *The Cloak of Competence: Stigma in the Lives of the Mentally Retarded* was the first ethnographic attempt to understand and analyze the experiences of people with disabilities from an emic perspective in the United States. His “passing and denial: the problem of seeming to be normal” identified the daily struggles that deinstitutionalized individuals with developmental disabilities face in a society that is not prepared for their inclusion. Passing and denial represented two distinct strategies used by people to negotiate disability in a world of nondisabled others. Edgerton’s work brought much-needed attention to the stigmatizing effects of being labeled “disabled” as well as the boundaries of inclusion and “normalcy” that prefigure relationships between disabled and nondisabled individuals.

Benedicte Ingstad and Susan Reynolds Whyte’s (1995) *Disability and Culture* was one of the first works to emphasize the importance of qualitative research methods in studying disability as a sociocultural construct. They note that the deprecating stigma associated with being labeled “mentally retarded” in certain “western” contexts is by no means universal and that definitions of and approaches to managing “disability” vary greatly across cultural contexts (Klotz 2003). The links between personhood, identity and disability are explored in various “local” contexts and presented as ethnographic case studies that together make a substantial contribution to anthropology and disability studies. A second volume entitled *Disability in Local and Global Worlds* was co-edited by Ingstad and Whyte in 2007. Among other things, this volume explores the changing contexts in which disability continues to be defined and lived in diverse cultural settings. It also examines the intersections of local, national, international, and transnational understandings of disability as embodied in various institutions such as the United Nations and the World Health Organization and lived by individuals, and the plurality of forms and appropriations of disability that emerge in various contexts. The formation of “association-al communities and collective identities around biomedical categories” (Ingstad and Whyte 2007:15), in this case disability, is referred to as biosociality. This is described by Ingstad and Whyte as a sense of belonging and relation (both to other people and the state) that is based in a biological condition, not as blind acceptance of biomedical hegemony, but frequently as a strategy of resistance and livelihood, where “disability” becomes a social, political, and economic bargaining tool.

Service delivery has benefited from scholarly research as well. Bryan’s (1999) *Multicultural Aspects of Disabilities* focuses on the problems inherent in service delivery cross-culturally and explains the historical and cultural significance of disparities between ethnic groups in terms of disability prevalence and local access to treatment services. Marshall’s (2001) *Rehabilitation and Native Americans with Disabilities* evaluates understandings of disability in American Indian and Alaska Native populations specifically and sheds light on barriers to successful service delivery that, she argues, are the result of indigenous cultural constructions of disability that differ from those of biomedical service-delivery institutions. Manson (2000) offers useful recommendations and directions for further research in program and policy development as well as general insight into the cultural problems associated with

service delivery to American Indians and Alaska Natives. Similarly, Browne and Fiske (2001) offer powerful firsthand testimonies of First Nations women's difficulties in dealing with Canadian health care institutions and highlight some of the fundamental obstacles in providing services that are responsive to local cultural understanding. While this literature review is necessarily selective and partial, it provides an overview of the intellectual genealogy of disability studies, anthropology, and health service delivery to Alaska Natives and highlights current research trends within this growing area of scholarly interest.

PRECONTACT IÑUPIAQ UNDERSTANDINGS OF "DISABILITY"

The degree of accommodation offered to individuals who required assistance for everyday life functions in traditional Iñupiaq cultures is a point of discrepancy in the literature. Dorothy Jean Ray (1975:244), for example, cites Dr. Edmonds (early 1890s), who noted that "the crippled and abnormally formed babies were quickly disposed of" and that infanticide was very common. Similarly, Robert Fortuine (1992:84) cites Captain Hooper (1881), who stated that the "northern Eskimos destroyed all deformed infants at birth," and he himself asserts that there seems to be little doubt that sometimes deformed or crippled individuals were allowed to die because of the greater needs of the community. While these examples would seem to support the infanticide "solution" to disability, they actually exist in stark opposition to traditional cultural values regarding treatment of fellow human beings. Early non-Native visitors to Alaska could not possibly have been exposed to the full range of scenarios and decision-making frameworks that families and communities considered to accommodate people with limiting conditions, and the literature appears to misrepresent traditional Iñupiaq treatment of such individuals in this regard.

There are numerous examples that support this hypothesis. Jolles (2002), for example, notes in her analysis of the Siberian Yupik community of Gambell that a mother who has a child with a condition that is perceived to cause and will result in death may take her own life in exchange for the life of the sick child. This concept is fundamentally different from the infanticide scenarios described in some of the literature. Rather than a burden to be eliminated, the affected child is believed to be healable, and in this example the life of the "incomplete" human child is valued over that of the parent. The cause of the affliction

is believed in many cases to be spirit possession or object intrusion, as opposed to genetic or biological causes that result in chronic, perhaps degenerative and untreatable conditions, and the mother's behavior is a sacrifice that is believed to be best for the survival of the child and ultimately the group. Infanticide was not considered to be an effective option in this example, and the mother's actions reflect her understandings of the cycling of life and death and the curability of her child's condition. These nuances would have been imperceptible to outside observers.

While Fortuine (1992) does cite numerous examples of what has subsequently been referred to as infanticide, he too points to the underlying value placed on caring for people, especially for the elderly and disadvantaged. He describes an account where Dr. Simpson in 1855 was impressed by the care that Barrow Eskimos provided to those who needed assistance and quoted Simpson as stating that clothing, food, and "every comfort they possess" was offered and these provisions could be relied upon (Fortuine 1992:84). An additional account by Beechey in 1831 noted that the oldest person in the vicinity of Cape Thompson was a "cripple," suggesting that there was community capacity for care and that individuals were cared for throughout the course of their lives (Fortuine 1992:84).

Providing for those who are in need and sharing what one has were important Iñupiaq values in precontact times and they continue to be today (Alaska Native Knowledge Network, www.ankn.uaf.edu). These values, passed on by elders to youth through careful teaching and rich oral traditions, constitute what it means to be Iñupiaq and are repeated in stories past and present. A relevant example comes from Robert Mayokok's (1960) *Eskimo Stories* where in his telling of "The Blind Man and the Polar Bear" lessons are revealed regarding fair treatment and care of those who are in need. In this story the socially and physically isolated blind orphan is living with his grandmother, who helps provide for his care. They are poor and live alone. The grandmother combed the beaches looking for dead seals and walrus and they preserved the meat to last them through winter. She also fished for tom cod and would travel to villages at times in search of meat and clothing. One evening a polar bear approached their shelter and tried to attack them. The grandmother ran and grabbed the blind boy's bow and arrow, and she directed him and helped him aim his shot. The bear was vitally wounded, but the grandmother told the boy he had missed so she could hoard the meat and keep it for herself. She continued to feed him scraps and she would eat at a

location away from the boy so he would not smell the fresh meat. As a result of the grandmother's selfish treatment towards the boy, a spirit in the form of a loon visited him and offered help. The boy crawled on the back of the loon and was taken on a ride diving down into the cold waters. When they surfaced, he could see again, and they repeated this several times until the boy's vision was fully restored. Upon returning to his home, the boy saw a polar bear hide hanging on the wall and he knew it was the polar bear that had attacked them. He did not say anything to his grandmother about what she had done, believing instead that it was best to "only return good for evil" (paraphrased from Mayokok 1960:18).

This story of the Blind Boy and the Polar Bear offers considerable insight into Iñupiaq notions of difference, the special spiritual attributes often associated with people who are different, and the values of sharing and taking care of and providing for others. Additional evidence concerning the inclusion of disabled individuals into traditional Alaska Native communities can be found in the exploration records of Captain James Cook and Lieutenant King (Ray 1975). Excerpts by both Cook and King describe a family consisting of a husband, wife, small child, blind elderly man (possibly a grandfather), and a "frightful cripple" that approached their ship in an *umiak*, asking for assistance in performing a healing act involving the blind elderly man (Ray 1975:42). Lieutenant King was directed to hold his breath and exhale on the elderly man's eyes and then spit on them. The "frightful cripple" was described by King as a young man who "had a disorder in his face which had already destroyed one eye, and the sides were much swelled, and one half of his mouth and nose in a sad condition...and his legs were so contracted that he was obliged to crawl about on his knees and hands" (Ray 1975:43).

There are several aspects of this exchange that warrant consideration. First, the "frightful cripple" was present as a member of that family, and the mother (who was there on behalf of the blind elder) was engaging him as well as her husband in the event and referring to him as a family member. Second, the "cripple's" presence suggests that this individual had access to a social support network and was not left behind. The question of why the family came to the white explorers in the first place for assistance is also interesting. Perhaps the reputation of explorers as men who had potentially useful items such as medicines factored in, or the diminishing status and effectiveness of the shamans (*afatkut*) in the face of disease and colonial

encroachment. It is also noteworthy that Cook and King were specifically instructed by the family to perform a procedure on the elderly man's eyes that was congruent with their Iñupiaq understanding of acceptable and appropriate treatment, despite their otherwise great eagerness to locate these men specifically and seek out their services.

Archaeological work in the vicinity of Point Barrow offers further evidence that care was provided to the disadvantaged, even in times of community hardship (Langdon 2002; Zimmerman et al. 2000). Autopsies of the "Frozen Family of Utqiagvik" revealed growth arrest lines due to periods of food scarcity as well as lung and bone conditions that would have had "disabling" consequences. This family provided care for each other even through periods of shortage, as evidenced by the presence of numerous growth arrest lines, suggesting that the difficult times were followed by periods of recovery. It is interesting to note that no family member was abandoned for their condition or limitation even during times of great strain on the community.

Similarly, Zimmerman et al. describe a frozen mummy of a five-to-eight-year-old girl with a chronic lung and liver condition that was dated to 800 years ago (nearly three centuries earlier than the frozen family). A number of growth arrest lines were present in this example as well, and her lower intestine was filled with gravel, sand, pebbles, and animal hair, suggesting that she was possibly chewing on hides during a period of great food shortage (Zimmerman et al. 2000). Zimmerman et al. suggest that the girl survived her disability because she had a family and a community to care for her. A toboggan made out of baleen, likely a transport device so that her family could assist her in getting around, was found buried alongside her (Zimmerman et al. 2000).

All of the above examples suggest that precontact Iñupiaq culture had an inherent capacity to provide care for those who would have required special assistance to meet the requirements of everyday life in harsh arctic environments. While some examples of infanticide have been noted in the historical record, it is my contention that this literature essentializes those practices that were witnessed (by outsiders) towards some people with observable differences and that the universality of such practice is unlikely. By observable, I am referring mostly to physical disabilities that would have been readily noticeable to outsiders. Developmental disabilities, mental illness, and other conditions more dependent on the culture-specific parameters that shape their experience and meaning

would have been very difficult if not impossible to identify. This is perhaps why early researchers had a tendency to correlate shamanic behavior with mental illness, or why John and Edith Kilbuck were inclined to declare an “insanity epidemic” in the Yup’ik village of Kwethluk in 1890 (Fienup-Riordan 1991). The fact that the earliest accounts of people with disabilities referred to physical conditions rather than developmental ones points to the problem of detectability in cross-cultural contexts and has led to a possible misrepresentation of Iñupiaq cultural tradition with regard to the care and treatment of community members.

From a cultural materialist perspective, infanticide serves the function of reducing strain on the group. When individuals cannot “earn their keep” in society, they are killed to alleviate the burden. This is an incorrect interpretation of the range of Iñupiaq decision-making strategies in my view, because it overlooks other possible options that were available to individuals with disabilities and assumes that the first reaction is always one of pure survival, with the child almost instinctively left to die. This is not to be taken as an argument that infanticide did not happen. There are examples of it happening, and during times of great strain, when the whole of the community was facing hardship, it may have been one of the only options. However, the above examples illustrate that it was likely a last resort only; that disabled individuals appear quite frequently in traditional stories as well as ethnographic and historic records; that developmental disability and mental illness would have been difficult to identify by outsiders; that disability was interpreted and managed in different ways by Iñupiaq people; and that traditional cultural values were and are strongly associated with sharing, respect, and taking care of one another, particularly the elderly and disadvantaged.

It is also possible that there were taboos attached to infanticide, that it was considered a potentially risky thing to do and that there were rules to be followed to ensure the spirit of the child was safe and protected. Simon Paneak of Anaktuvuk Pass tells an interesting story that may offer insight to a discussion of infanticide (Campbell 2004). He speaks of a mother who died shortly after the birth of her child and was hauled (along with her child) to a dry location outside the village and left there by villagers. It was winter, and a very cold scene is depicted, where it is presumed that the child too dies. The villagers do not hear an end to the crying, however, and the child comes to the village to try to “talk to the people who were trying to kill it” (Campbell 2004:13). The child was jumping around

incessantly until it turned into a “very bright fire and the people couldn’t see any child in it, except for the flying fire” (Campbell 2004:14). Paneak describes that only *afat-kut* (shamans) had the ability to get the child to stop jumping around, but he did not understand how it was done. It is difficult to ascertain the precise meaning of Paneak’s story, but it is significant that the spirit (presumably) of the abandoned child is seemingly disturbed as a result of the infanticide and that culturally specific steps needed to be taken by the shaman to appease it.

By incorporating this modified understanding of infanticide to disability and its treatment in precontact Iñupiaq cultures, the tenacious assumptions of biomedical categorization of disability become apparent and the interpretation of meaning difficult to speculate upon. Non-Native explorers, missionaries, traders, profiteers, military personnel, etc. observed a culture quite unlike their own, and their own behavior was often quite abnormal from the perspective of the Iñupiaq.

THE COLONIAL EXPERIENCE: HEALTH AND SOCIAL SERVICE DELIVERY FOR INDIGENOUS PEOPLES IN THE UNITED STATES AND ALASKA

Perhaps the best example of the distorted U.S. perception of the meaning of “helping Natives” with developmental disabilities comes from the contiguous United States with the passage of legislation in 1903 that created a separate facility for the treatment of Native populations in Canton, South Dakota, known as the Hiawatha Asylum for Insane Indians (Bhatara et al. 1999). The proponents of the asylum were concerned with alleviating suffering among Native Americans by providing better care than available in jails or hospitals. They argued that a separate institution for Native Americans was needed because they had unique mental health afflictions and would be better off living among members of their own “race” (Bhatara et al. 1999). Whether this was motivated by a sincere desire to help or a desire to control through removal and isolation is an important question to consider. Within three decades, however, the Hiawatha Asylum was shut down due to allegations of mistreatment. A 1933 investigation conducted by the Bureau of Indian Affairs determined that a “large number” of patients who had spent time at Hiawatha showed no sign of mental illness whatsoever (Bhatara et al. 1999).

This model of administering segregated care to indigenous peoples experiencing disability was replicated during the early years of U.S. “ownership” of the territory of Alaska. The first attempts to do so occurred at Sitka in 1867 (Fortuine 1992), the same year that the territory was purchased from Russia. Facilities consisted of the hospital already built by the Russians, but treatment was not offered to Native peoples initially. While some individual doctors offered their services freely, often at their own expense, with limited facilities, limited stocks of drugs, and few staff, most Native peoples were unable to receive care. In 1868, an incident involving a sick Tlingit woman who was moaning in pain in the streets of Sitka, noticed by an officer and subsequently given access to care, set a precedent in terms of government responsibility to provide care. A single room in the upstairs “wretched” portion of the hospital was set aside exclusively for the care of Native peoples (Fortuine 1992:142).

Due to U.S. Navy limitations in establishing regular medical infrastructure, health care for Alaska Natives was subsequently expanded and administered via the Revenue Cutter Service and the Marine Hospital Service (which later became the U.S. Coast Guard and Public Health Service respectively) (Fortuine 1992). During this time the need to provide a hospital for the exclusive care of Natives was increasingly recognized. There was also a growing awareness that the federal government would likely be forced to assume the burden of care, and “if it was the desire of the government to save the Native people from extinction,” a hospital was “absolutely indispensable” (Fortuine 1992:159). While such a hospital was not built for another decade (in Juneau), the concept that “as a nation” the U.S. owed it to the Natives to provide health care was beginning to gain momentum. In a study entitled “The Treatment of the Mentally Ill in Alaska, 1844–1912,” Thomas G. Smith stated:

From 1884 to 1900, the policy of the Federal government toward the mentally ill of Alaska was one of indifference and neglect. Although this neglect cannot be excused, it can be explained. First, the care of the mentally ill was traditionally a state and local responsibility. Second, the Gilded Age was a period of general federal neglect in territorial matters. Third, Congress considered other issues more important than the care of a few victims of insanity in Alaska. Finally, in a period of economic instability, the federal government wished to avoid the expense of caring for the insane of a remote and politically impotent terri-

tory. (Undated draft report, Albrecht Collection, Archives and Manuscripts, Box 20, University of Alaska Anchorage Consortium Library)

A common theme found throughout the historical analysis of outside medical intervention in Native communities is the belief that Native medical systems were ineffective and inadequate before European, Russian, and American arrival, and thus medical care for Natives was their responsibility, in order to “save them from extinction,” pull them out of savagery, and “fix” them culturally. Interestingly, the “tremendous need” for medical care for Natives was often only recognized through the inability of these groups, whether military personnel, teachers and missionaries, adventurers and traders, etc., to set up their own medical infrastructure. In other words, it was believed by American colonists that their own difficulties in setting up medical infrastructure meant that Alaska Natives must have an even greater need for this infrastructure. Because biomedical models of administering health care were difficult to implement in Alaska (due to lack of resources and personnel, rugged terrain, and lack of existing infrastructure), it was perhaps assumed that Native communities experienced particularly atrocious medical conditions that required intervention. This theme of assuming responsibility for the care of Alaska Natives was repeated throughout the contact period and used as justification for further colonial expansion and penetration.

When medical care did arrive for Native people in the Arctic, it was not offered to individuals who had previously consulted an *afatkuq*, because their practices were thought to be demonic (Blodgett 1979; Chance 1990; Fortuine 1992; Spencer 1959). Interestingly, the word for an *afatkuq*’s helping spirit (*tuunraq*) also came to be translated as “pretending to be a devil” (Fortescue et al. 1994). This linguistic correlation is likely the result of influence from the Presbyterian Church, and its presence is revealing about missionary attitudes towards shamanic practices generally, as well as the perception of threat to Presbyterian control associated with these practices. Not unlike that which occurred with the Hiawatha Asylum for Insane Indians (where many shamans were placed simply because they were shamans), shamans in Iñupiaq regions were often labeled as insane or as doing the work of the devil, partly because their work presented a challenge to the authority of the Presbyterian missionaries and the imposition of Christian values, but also because the behavior they were observing was taken out of context, and

the value, importance, and meaning (within an Inupiaq cultural framework) was lost. Shamans were framed as imposters, and the failure to cure newly introduced diseases, coupled with missionary propaganda and systematic downplay of the institution led to shamanism's decline (Blodgett 1979; Fortuine 1992; McLean 1997; Ray 1975; Spencer 1959).

The Congressional Act of June 6, 1900, gave authority to the governor of the Alaska Territory to make contracts "for the care and custody of the insane," and the Morningside Hospital in Portland, Oregon received the contract (contracts were granted to the lowest bidder) in 1904 and managed to hold on to it until 1962 (Foulks 1972). At Morningside, care was primarily custodial, conditions were unsanitary, and there were no educational or therapeutic programs or activities (Albrecht Collection, Archives and Manuscripts Department, Box 20, University of Alaska Anchorage Consortium Library). There was no differentiation between adults and children, and without separate rooms, the entire facility was filled with nothing but beds (no furniture), and staff, numbering so few, simply provided oversight and monitoring with little to no interaction with patients. For nearly two generations, individuals with disabilities and intensive medical needs were not regular members of communities, and community capacity for care was reduced, the result of the hegemonic thrust of American colonialist ideology, with biomedicine and its institutions simply one part of an overall process of cultural encompassment (Dufort 1992; Manson 2000; Marshall 2001).

In a report to the Department of the Interior in 1954, it was concluded by a committee established to research the problem that "the fundamental principle of contract care outside the territory was impractical," and it was recommended that a "modern mental hospital" of no less than 350 beds be established in Alaska (Albrecht Collection, Box 20; Fortuine 1992; Foulks 1972). A follow-up report by the U.S. Public Health Service in 1956 found that because of its distance from Alaska, vital contact with family and friends was lost to the "hospitalized Eskimo," which created "secondary psychiatric difficulties" (Foulks 1972). Also, it was found that many individuals ended up staying for much longer periods of time than necessary due to the high expense of transportation to and from Alaska. Considering the numbers of "crippled" individuals registered in Alaska at that time, and the many more Albrecht claimed were unregistered, it is clear that there was a tremendous lack of services available

for individuals experiencing disabilities under American policy and law at that time.

In 1962, the Alaska Psychiatric Institute (API) opened a 225-bed facility for the mentally ill in Anchorage, Alaska, and as more individuals who had been previously hospitalized at Morningside returned to Alaska, a second facility, the Harborview facility at Valdez, was built to accommodate the developmentally disabled and other individuals who did not suffer from psychiatric conditions but required long-term care (Albrecht Collection, Box 20; Foulks 1972).

DISABILITY SERVICE DELIVERY IN ALASKA SINCE THE 1970S

Several pieces of key legislation affecting individuals with disabilities and Alaska Natives emerged in the 1970s. Perhaps most significantly, the precedent-setting *Garrity v. Gallen* decision (in New Hampshire) mandated that all public mental institutions be shut down (Racino 1999). Other states (Alaska among them) had been following similar trends (often referred to as "normalization") since the early 1970s, but full deinstitutionalization did not occur for Alaska until the closing of the Harborview facility in Valdez in 1997 (City of Valdez 2005; Scheller 1995). For people with disabilities, Title V of the Rehabilitation Act (1973) and the Education for All Handicapped Children Act (1974) (later renamed the Individuals with Disabilities Education Act) were significant pieces of legislation (Scotch 2001; Wright and Wright 1999). Title V offered the first official form of legal protection from discrimination on the basis of disability, and the Individuals with Disabilities Education Act (IDEA) set forth "explicit requirements that all children with disabilities receive a free and appropriate public education and related services, regardless of the cost" (Scotch 2001:384).

Legislation pertaining directly to Alaska Natives includes the Indian Self Determination and Education Assistance Act of 1975. The two most significant congressional findings in relation to this act were:

1. This act was an attempt by the U.S. government to divert responsibility to provide health and other "service" programs back to Native peoples, using rhetoric such as, "prolonged Federal domination... has served to retard rather than enhance the progress of Indian people and their communities... and has denied the Indian people an effective voice in the planning and

implementation of programs...which are responsive to the true needs of Indian communities”; and

- Native peoples have the right to control their relationships “both among themselves and with non-Indian governments, organizations and persons” (Indian Self-Determination and Education Assistance Act 1975).

What this has translated into for disability service programs for Natives is that individual Native corporations, local governments, and tribal councils have an increased choice in terms of how to use federal and state funding and how to configure service-delivery infrastructure. For instance, in the North Slope Borough, services for people with disabilities are contracted out to nonprofit service-providing agencies, but funds are still channeled through the federal and state Medicaid Home and Community-based Waiver Program (HCBW)² (Ahmaogak 2003; anonymous communication 2003). In the Northwest Alaska Native Association (NANA) region, however, services are also funded through the Medicaid HCBW program but are delivered locally through the Maniilaq Association (anonymous communication 2003). This expression of regional autonomy and choice regarding services for people with disabilities is a relatively recent phenomenon, made possible in many ways by legislation passed in the 1970s. Many communities are learning (perhaps relearning) to provide care and opting to administer services and interface with federal and state funding agencies on their own, while others (including the North Slope Borough) are forging relationships with nonprofit agencies and developing new programs and capacities for care (anonymous communication 2003). While much work remains to be done, by promoting choice and creating new ways to allow for local control, new opportunities for the development of innovative programs designed to meet the specific needs of specific communities might be cultivated. Nevertheless, the bureaucratic maze through which services for people experiencing a developmental disability are currently negotiated is bewildering (Hedwig 2006:82–97), as seen in Figure 1.

One should try to imagine the impact on an Iñupiaq family when they encounter this process, and how the process becomes what Bourdieu (1990) refers to as a

“structuring structure”; that is, bureaucratic structures, principles and “dispositions” that shape the behavior and expectations of those who must interact with and conform to them. The underlying message of these structures is clear: families are not capable of supporting their developmentally disabled family members on their own and only by subjecting themselves to the clinical gaze and associated bureaucratic constraints can “appropriate” levels of support be obtained (Foucault 1973). However, despite these constraints, there remains potential for constructive engagement with power, both in the form of strategic manipulations of (and maneuverings within) such

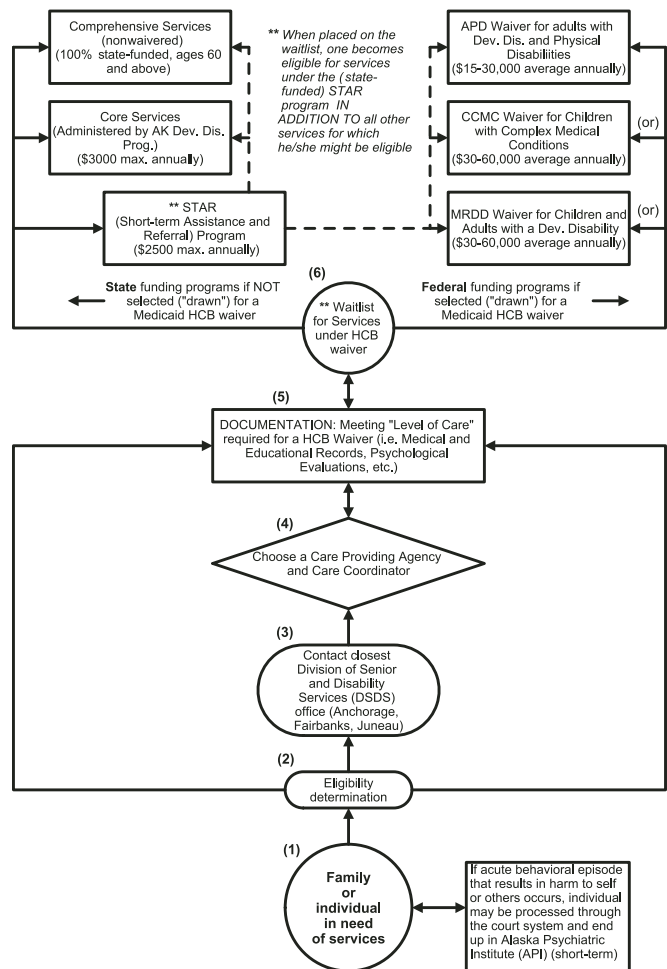


Figure 1. Developmental disability service delivery in Alaska and the Medicaid Home and Community-Based Waiver (HCBW) Program

2. A Home and Community-Based Waiver (HCBW) is a method of paying for services for a person who is deemed eligible. Under section 1915 (c) of the U.S. Social Security Act, individual states may request waivers of certain federal requirements to develop Medicaid-financed community-based treatment programs (Harrington et al. 2000; Kitchener et al. 2004). The Medicaid HCBW is the primary source of funding for individuals who experience a developmental disability in Alaska, and in 2001 the state spent \$82,023,871 towards the waiver program (Kitchener et al. 2004). There were 2,589 waiver recipients in Alaska in 2001, with an additional 1,002 on the waiting list for such services (Kitchener et al. 2004). Approximately 1,436 of all eligible participants (including the waiting list) were Alaska Native.

bureaucracies, and in the creation of new structures and practices of service delivery. The case study in the following section illustrates this.

AN IÑUPIAQ FAMILY EXPERIENCES DISABILITY

Jimmy (a pseudonym) experiences what biomedical practitioners have labeled a disability. According to his mother, when he was around fourteen or fifteen years of age, his family became concerned after observing him “staggering down the road” and behaving strangely. His performance in school greatly diminished and he reportedly failed the ninth and tenth grades, dropping out of high school altogether in tenth grade. Because the frequency of such incidents increased and Jimmy’s behavior was becoming increasingly uncharacteristic for him, he was sent to a treatment facility in Seattle for one month where little “progress” was reported (note the mode of sending the individual out of state for treatment) (researcher field notes, 2/11/2005; comprehensive psychosocial needs evaluation, 2/2005). Upon returning home, Jimmy was observed talking to himself frequently and laughing out loud at inappropriate times. His mother reports that he attempted suicide by taking pills, which precipitated a two-week stay at a hospital in Anchorage. Jimmy was subsequently placed in and out of various treatment facilities, including Charter North and API (the latter the result of refusal to take prescribed medications, which prompted a resurgence of aggressive behavior). It was only upon return home from his three-month stay at API that Jimmy’s mother recognized that he was abusing inhalants (i.e., “huffing”). This inhalant use is thought to be the cause of his current developmental disability. He was also reportedly using marijuana and drinking. Jimmy subsequently stayed upwards of six months at a school in Texas, and his mother reported that this turned out to be a horrifying experience for him.

In my experience working with Jimmy, his behaviors are understandable in light of his own internal struggles about his disability, personhood, Iñupiaq-ness, and sense of being in the world. When Jimmy looks at a cousin, sibling, or community member who he knows and sees them doing well, he experiences a real sense of grief and anxiety (researcher field notes 2/10/2005, 2/11/2005). He recalls what life was like before the instances of huffing and substance abuse left him “disabled.” This fills him with sadness, rage, jealousy, and anxiety. His mother reports that his behavior led to his being ostracized within the commu-

nity, and many of his friends and cousins have abandoned him. His younger brother is in a military unit outside of Alaska, and it makes Jimmy sad to think that (as the oldest child in the family) he has not been able to honor his family in the way his brother has. Due to his behaviors at home and in the community (including several run-ins with the law), a dwindling support network, and a general lack of support services to help Jimmy in his everyday life, he and his family decided it would be best for him to move to Anchorage, where it was believed a more extensive range of support could be obtained. Jimmy’s experience in an urban environment further complicates the ways in which he sees himself. How he negotiates this experience is evident in his continual requests to go home. Jimmy’s experience straddles two seemingly disparate worlds, and when he perceives his otherness with respect to either of them, he may position himself in opposition to this. For example, Jimmy may ask staff, “when can I go home,” but when he is reminded that his next trip home might not be for awhile, he may quickly follow up by asking, “when can we go to town.” His navigating the experience of disability operates in a similar manner.

Jimmy now engages in “passing and denial,” a struggle to appear to be normal in the eyes of his peers and community members (Edgerton 1993). This struggle is perhaps amplified by his personal reflections about his “disability” and competence, as well as his experience in an urban area. For example, he might talk about getting a nice car despite the fact that he does not have a driver’s license or a job, or fill out a job application that he knows requires a high school general equivalency diploma (GED), which he does not have. Jimmy appears to fiercely defend his personhood and normalcy by talking about things he perceives to be valued aspects of personhood but knows might be outside his reach. He shows this tendency towards his Iñupiaq cultural heritage as well. For example, he gets excited when talking about whaling, following leads in the ice, getting a job with the North Slope Borough, and raising a family in his hometown, etc., but his mother reports that she has heard him in his room crying at night and she believes that he gets depressed when thinking about his life and how he has not yet had an opportunity to go whaling and experience activities that others in his community have experienced.

While in community and social settings Jimmy strives to appear “normal” in the eyes of others, in clinical or medical settings he has learned to do the opposite and “play up” his disability when he knows it can be used

to his advantage (researcher field notes, 4/3/2003). This is what Ingstad and Whyte (2007) refer to as biosociality, where claims to personhood, social status, citizenship, and belonging are made with respect to a biological category, which becomes a basis for social bargaining and negotiation, or what Certeau (1984) referred to as spatial action within the practice of everyday life. During my research, before I even met Jimmy, I was given a standard briefing that included a stack of paperwork that was his case file to read. The file contained medical and clinical information, police records and histories of misbehavior, planning documents including the Plan of Care for the Medicaid HCBW, and various psychosocial evaluations. I felt overwhelmed myself by the paperwork on that first day and struggled to sift through it, imagining what Jimmy would be like when we met. I was advised to be cautious given his history of aggression but to get to know him at the same time. The paperwork itself became a substitute for actually spending quality time with Jimmy and getting to know him. I wondered why it was necessary agency protocol to read through all the negative aspects of his life; what was “wrong” with him medically, what he had been in trouble for in the past, what he has difficulty doing, etc. It seemed there was a person somewhere inside that paperwork that was not getting validated, whose voice was not heard. In an attempt to locate this person behind the paperwork, a new kind of planning process was developed in close collaboration with Jimmy, his family, and the care-providing agency. This process is outlined below.

PERSONAL FUTURES PLANNING

In contrast to the deficiency-based emphasis of service-delivery bureaucracy (which can be viewed as a technique of biopower), there are possibilities for constructively engaging the structuring structures that Bourdieu theorized. The personal futures planning process, initially developed by the agency in response to calls for “person-centered planning” by disability advocates and scholars but modified in the context of this research, is an example of this type of engagement (Callicott 2003). I had the opportunity to facilitate a personal futures planning session for Jimmy that involved his family, loved ones, and support staff. The objective was to help illustrate Jimmy’s personhood from his own perspective and provide a working “road map” of his goals and dreams (Figure 2). The process emphasizes the voice of the individual requesting services, which is frequently lost in stacks of medical and clinical documentation, and seeks to create a visual depiction of this voice in nonnarrative form. This depiction then becomes the cover sheet for a case file and the first document that medical, clinical, and agency staff would see. Jimmy’s personal futures plan, shown below, is an example of how the productive workings of biopower can be countered, rather than busily reinforced through the normal workings of service-delivery bureaucracy.

The narrative description of the plan (written by myself in close collaboration with Jimmy) is also included (see below), as both a descriptive compliment and a point of contrast to the visual depiction:

Jimmy is a strong, independent, capable, creative and family oriented full blooded Inupiaq, born and raised on the North Slope of Alaska, proud of his cultural heritage and upbringing, and diversified in his interests and pursuits. He values the relationships he has developed over the years, in his home village and elsewhere, particularly with his father, who helped teach Inupiaq cultural understandings and subsistence practices to him such as whaling and duck and caribou hunting. Jimmy is knowledgeable about the ice and its various forms, and knows how to “read” it in order to locate the bowhead whale, the most central subsistence pursuit within arctic coast Inupiaq cultural, economic and spiritual life. While Jimmy has not yet had the opportunity to work with a crew under the leadership of an umialik (whaling captain), this is a dream of his, and an important part of his understanding of personhood and identity as an Inupiaq male. His father has been a member of a whaling crew in



Figure 2. Artist's rendition of Jimmy's Futures Plan, 2006. (Completed by artist J. B. for Jimmy, May 2006.)

the past and Jimmy is extremely proud of this. He sees it as an important rite of passage towards manhood, leadership and independence, and would like to honor his father by having the opportunity to participate in the harvest, both as a whaler and community member.

While Jimmy has a deep respect for his Iñupiaq culture and would ultimately like to return to his home village to raise a family with the same values that his father taught him, he feels that he needs to “spread his wings” and be exposed to a more urban environment (like Anchorage or Fairbanks) so that he can enjoy a wider range of social and employment opportunities and receive training in construction and electrical engineering. He would ultimately like to give back to the community by working for the North Slope Borough, building houses and configuring electrical components. Jimmy has fond memories of helping his father complete their home and would like to continue honing his own construction skills so that he might one day serve his community and contribute to its character. He enjoys “cigar rides” with his father, as it provides an opportunity for male bonding, sharing of thoughts, feelings and experiences, and learning.

Jimmy comes from a loving and caring family, and the words “I love you” are exchanged frequently, especially between him and his mother. He is mathematically oriented, and is able to recite some formulas and has a general understanding of their potential applications. He also has a knack for poetry and abstract thinking. He has kept a journal of his various poetic creations, and expressed a desire to begin working on a new one, reflecting his paths in life and the ways in which he has grown and adapted to new situations. Jimmy would like to pursue a GED so that he can continue to refine his academic interests, as well as obtain a well-paying job (or an apprenticeship leading to a job) that might ultimately help him support a family. He plans on returning home after two to three years in Anchorage or Fairbanks with a “clean slate,” so that he can show his friends, parents, siblings and relatives (by example) that he is committed, has acquired useful skills, held a job and obtained the necessary training, education and treatment to be successful in his chosen path.

Jimmy is physically strong and active; he enjoys participating in sporting activities such as basketball, football and running. He is a great athlete, and can run considerable distances without tiring (although he admits that cigarette smoking has compromised this somewhat). He also enjoys

working out, and wants to own a bowflex exercise machine someday so that he can have a “bowflex body” that would be attractive to women. He is talented at drawing and loves music, including Black Sabbath and Metallica. On occasion, Jimmy will also listen to classical music, as it helps him to relax. Jimmy owns a guitar, and although he has never taken lessons, he likes strumming it and is musical with his phrasings. He has expressed a desire to take guitar lessons so that he can learn to play his favorite songs as well as write new ones.

Jimmy would like to live independently, find a woman with whom to settle down and start a family, and be a community leader and contributor. He has a lot of passion and energy, which offers virtually limitless potential and opportunity. Jimmy can be a loyal friend and is very loyal to his family. He values the importance of discovering his own manhood and personhood. He has taken some important steps in his life towards realizing his goals and dreams and will continue to do so with the support and dedication of family, friends and loved ones. (Personal Futures Planning Session, 2/10/05)

These documents could potentially help a staff or community member learn more about the experience of difference and exclusion than an entire case file. In my own experience working with Jimmy, had I been presented with his personal futures plan instead of the mass of deficiency-oriented paperwork that emphasized little more than his diagnosis and clinical history, I would have been better equipped to understand how he thinks and feels about himself in the world. I wondered why the agency personnel with whom he interacted had not prepared such a personalized plan for him earlier. This information would have been of far greater benefit to both Jimmy and his support team. It is also a way to counteract the dehumanizing and stigmatizing effects of engagement with biomedical modes of providing support for people with disabilities.

DISCUSSION

Contrary to much of the arctic literature, which essentializes particular observations of cultural practices towards “disabled” individuals in precontact Iñupiaq contexts (i.e., infanticide), this research emphasizes that the social parameters of difference and community inclusion are more fluid and socially situated than has been previously noted in Alaska. This is perhaps due to the fact that the non-Natives who generated these early writings were interpret-

ing their observations through their own cultural blinders and failing to recognize the subtle intricacies of Iñupiaq human organization and decision-making frameworks. Colonial medical administrators, missionaries, and education reformers used these same writings to justify “helping” or “saving” the Native peoples from the trappings of their own cultures, which were deemed inferior. Current biomedical service-delivery bureaucracies contain many of the same colonial assumptions about difference, personhood, normalcy, and community inclusion. However, there are perhaps more opportunities presently available for constructive engagement with these institutions to better meet the needs of people who experience a disability. The personal futures planning process described above represents one such opportunity. Other opportunities include the collaborative relationships being forged between tribal governments and service-delivery agencies and the exercise of agency at the local level in terms of how services are delivered (as seen in the differences between North Slope and Northwest Alaska administration of disability services).

As a result of innovations in the planning process, communication between Jimmy, his family, and the service-delivery agency greatly improved. Moreover, Jimmy has begun to take proactive steps towards the realization of his expressed desires by setting challenging yet attainable goals with his family and support team. At the planning meeting, Jimmy’s mother commented that “he was really shining,” as Jimmy spoke clearly and enthusiastically about his future. This event illustrates how the structuring structures of disability service delivery in Alaska, as a form of biopower, can be ruptured and potentially reconfigured to challenge rather than reinforce the structures of power, authority, and disciplinary control that shape the experience of disability. It also shows how individuals, families, and communities have a degree of maneuverability within these structures that allows for creative and strategic engagement. While these structures have certainly had a profound effect on traditional Iñupiaq cultural understandings of difference, belonging, and group membership, it is clear that current community-based disability service-delivery models in Alaska could benefit from deprivileging western biomedical understandings and focusing instead on honoring the expressed needs of Iñupiaq communities, families and individuals. The personal futures planning process is an important example of how care-providing agencies can learn to better listen to the communities they are in the busi-

ness of serving. It also provides a forum for families and supported individuals to voice their concerns and choose the service-delivery strategies most suitable for them. The extent to which traditional cultural understandings regarding care of individuals who experience a disability are accommodated should be entirely up to the community. If an individual or community decides to not receive agency support, that too should be honored.

RECOMMENDATIONS

In order to reduce the negative impact of depersonalized bureaucracies and “disabling” constructions of disability on Iñupiaq families who experience a developmental disability by way of a family member, I offer the following recommendations with respect to program and policy design and implementation:

The cultural background of service recipients must be considered as equal to the cultures of the service practitioners and providing agencies (Kagawa-Singer 1994). Policy cannot be developed in a vacuum and transplanted freely into any community. Rather, it must allow for and encourage dialogue and collaboration between Iñupiaq and other Alaska Native communities, care-providing agencies, and federal and state policy makers and purse-string holders and be sensitive to the “local” cultural, political, and economic nuances of the community in question.

Iñupiaq community and supported individual feedback must be continuously integrated by the agency into its service-delivery strategy. When working in an Iñupiaq or other Alaska Native community, the care-providing agency must work hard at establishing a visible and viable presence. Of paramount importance, the agency must be honest and understandable to the community regarding why they are there and what services they can (and cannot) offer. It is also important to communicate the structural, economic, and bureaucratic constraints that limit the possibilities for action.

The right to live in the community of the supported individual’s choice must be maintained and expanded. Also, service-providing agencies and communities alike must continue to work at the legislative level to advocate for the rights of individuals with disabilities to live in the communities of their choice by securing federal and state funds through the Medicaid HCBW program as well as other grants to allow for innovative and flexible program design.

Competitive agency salaries to encourage local administration of programs, and Native practitioner hire should be developed. The hiring and training of staff locally represents an ongoing challenge for any care-providing agency, especially those working in predominantly Native cultural regions of Alaska, where the number of potential employees varies considerably in response to seasonal subsistence activities, short-term employment opportunities, etc. (Hamilton and Seyfrit 1993). Allowing for these seasonal movements within flexible hiring protocols will encourage local hire without compromising other important community activities.

Flexibility in problem solving is needed by both the community and care-providing agency. Community-based care administered from the bottom up must play a central role in increasing access to services for individuals experiencing developmental disability in Alaska. In all instances, choice at the community level should be respected and honored.

Innovative and collaborative planning such as the personal futures process described above should become a regularly implemented planning tool for all individuals receiving support. This includes not only individuals supported in rural villages but also those living in large urban areas such as Anchorage, where over ninety different languages are represented (Feldman et al. 2005). Use of such planning methods can be a powerful de/restructuring apparatus in the face of bureaucratic constraint.

Ultimately, the commitment to work towards increasing opportunities and maximizing the quality of life for individuals experiencing disability must remain at the heart of any service-providing agency's organizational values. If the injustices of the past and present (towards both people with disabilities and Alaska Native communities generally) are to be responsibly addressed and eliminated, this goal must serve as the driving force behind all health service-delivery protocols and community engagements. It is my hope that what I have presented here will help create new dialogues about disability in Alaska, new directions for research, and new possibilities for transformation of existing service-delivery structures.

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