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## THE CULTURAL POLITICS OF FETAL ALCOHOL SPECTRUM DISORDERS AND THE DIAGNOSIS OF DIFFERENCE

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THE CULTURAL POLITICS OF FETAL ALCOHOL SPECTRUM  
DISORDERS AND THE DIAGNOSIS OF DIFFERENCE

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DISSERTATION

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A dissertation submitted in partial fulfillment of the  
requirements for the degree of Doctor of Philosophy in the  
College of Arts and Sciences at the University of Kentucky

By

Travis H. Hedwig

Lexington, Kentucky

Director: Dr. Mary K. Anglin, Associate Professor of Anthropology

Lexington, Kentucky

2013

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## ABSTRACT OF DISSERTATION

### THE CULTURAL POLITICS OF FETAL ALCOHOL SPECTRUM DISORDERS AND THE DIAGNOSIS OF DIFFERENCE

This dissertation is based on an ethnographic study of Fetal Alcohol Spectrum Disorders (FASD) and the racial, cultural and political considerations that shape the meaning of diagnosis for Alaska Native individuals and families in Anchorage, Alaska. During the period from August 6, 2010 to through August 5, 2011, I worked with foster families and extended natural families living with and supporting individuals diagnosed with FASD. Documenting the experiences of families in their interactions with clinical, state, tribal and non-profit institutions, I sought to understand how a diagnosis of FASD structures opportunities, outcomes and everyday life experiences across several critical life domains, including health, education, employment, kinship and identity. Family narratives and experiences are highlighted to illustrate the ways in which difference is reproduced in everyday public understanding and clinical practice.

**KEYWORDS:** Medical Anthropology, Disability, Health Inequality, Fetal Alcohol Spectrum Disorders, Alaska

Travis Hines Hedwig  
Student's Signature

6/24/2013  
Date

THE CULTURAL POLITICS OF FETAL ALCOHOL SPECTRUM DISORDERS AND  
THE DIAGNOSIS OF DIFFERENCE

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This research greatly benefited from conversations with community, tribal and organizational leaders both in Anchorage and elsewhere in Alaska. Specifically, I would like to thank the FASD Family Support Center at Stone Soup Group, the Grandfamilies Support Network at Volunteers of America and Hope Community Resources for providing opportunities to meet and learn from families. These interactions were critical

in formulating my research questions and understanding the consequences of diagnosis for individuals, families and communities in Alaska.

Lastly, I would like to thank the National Science Foundation, Arctic Social Sciences program, for providing funding for this research (federal award ID number 1025899).

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# The Cultural Politics of Fetal Alcohol Spectrum Disorders and the Diagnosis of Difference

## Chapter One: Introduction

This dissertation is based on an ethnographic study of Fetal Alcohol Spectrum Disorders (FASD) and the racial, cultural and political considerations that shape the meaning of diagnosis for Alaska Native individuals and families in Anchorage, Alaska. The term FASD is a medical diagnosis that refers to a range of physical and cognitive (including learning and behavioral) symptoms of prenatal exposure to alcohol during pregnancy (Jones and Streissguth 2010; Johnson et al. 2010; Malbin 2002). First recognized as a medical diagnosis in 1973, FASD has received increased attention as the leading identifiable cause of preventable cognitive impairment in the United States and Western Europe (Sokol et al. 2003; Stratton et al. 1996). Preventable in this sense refers to the avoidance of alcohol as the only known strategy to eliminate risk of FASD.

Alaska has the highest rate of FASD in the United States, with an estimated 14.4 out of 1000 live births described as being affected by maternal alcohol consumption during pregnancy (Centers for Disease Control and Prevention 2012; Schoellhorn and Podvin 2002; Schoellhorn et al. 2008). This compares to an estimated rate of 9.1 out of 1000 live births for the U.S. population generally (Amendah et al. 2010; Burd et al. 2010; Ryan and Ferguson 2006; May et al. 2009). Rates for Alaska Native populations are reported to be significantly higher than other racial/ethnic groups in Alaska, with an estimated 48 out of 1000 live births described as “at risk” for FASD (compared to 12.6

out of 1000 described as “at risk” for all ethnic groups combined) (Burd and Moffatt 1994; Johnson et al. 2010; Schoellhorn and Podvin 2002; Schoellhorn et al. 2008).

Establishing population-based prevalence rates across states has proven challenging, and estimates vary widely (Burd et al. 2010; Jones and Streissguth 2010; May et al. 2009; Sokol et al. 2008; Spohr et al. 2007). Although key diagnostic features are generally well-established, including central nervous system impairment, growth deficiency and dysmorphic facial features (Egeland et al. 1998; Malbin 2002; Sokol et al. 2008), specific assessment techniques, surveillance practices and statistical measurements used to make a definitive diagnosis are still debated today (Astley and Clarren 2000; Drabble et al. 2011; May et al. 2009; Stratton et al. 1996). Differences in state expenditures on FASD, which include funding for diagnostic services, surveillance and data collection, and prevention efforts, further complicate the establishment of nationwide prevalence data (Amendah et al. 2010; May et al. 2009). While variations in reported estimates persist, what is not debated within these studies is the fact that impairments associated with FASD are life-long and involve considerable personal and societal costs (Amendah et al. 2010; Johnson et al. 2010). Annual expenditures associated with FASD in the United States are currently estimated to be over four billion dollars, with the lifetime cost for one individual estimated to be approximately two million dollars (Centers for Disease Control and Prevention 2012).

### **Description of the Research**

The purpose of this study is to examine the social and cultural assumptions that shape knowledge about FASD as well as the consequences of diagnosis for individuals

and families in Alaska. During the period from August 6, 2010 through August 5, 2011, I worked with foster families and extended natural families living with and supporting individuals diagnosed with FASD. Documenting the experiences of families in their interactions with clinical, state, tribal and non-profit institutions, I sought to understand how a diagnosis of FASD structures opportunities, outcomes and everyday life experiences across several critical life domains, including health, education, employment, kinship and identity. I interviewed 43 people, including 18 foster/adoptive parents, 10 extended natural family (i.e. grandparents, aunts/uncles), 10 direct service professionals, including program administrators and parent support professionals in state, tribal and non-profit organizations, and five adults over the age of 18 who have a diagnosis of FASD.

The specific questions that guided my dissertation research include:

1. Under what circumstances do individuals receive a diagnosis of FASD? Who is involved in identifying individuals suspected of having FASD and referring them on to a diagnostic team? At what point does adoption out of nuclear families and relocation into adoptive or foster families in Anchorage occur?
2. How does a diagnosis of FASD influence patterns and relations of family, kinship and indigenous identity for Alaska Natives? How does adoption into particular family forms (i.e. natural grandparents or non-Native adoptive parents) structure access to and utilization of health, educational and disability resources?

3. What strategies do adults diagnosed with FASD and their families utilize to manage both the stigma of disability and the everyday life challenges of impairment?

These general questions were used to develop three separate interview guides, one for parents, one for professionals and one for individuals with a diagnosis of FASD. Due to the family focus of the organizations I was working with, particularly Volunteers of America, Stone Soup Group and Hope Community Resources, many of the relationships I formed with families extended beyond the interview setting. For example, Volunteers of America, which houses the Grandfamilies Support Network, consists of grandparents raising individuals with disabilities, many of whom are diagnosed with FASD. The support network proved to be an invaluable resource for meeting families and understanding the role of extended kin in parenting individuals with disabilities. Similarly, Stone Soup Group, which houses the statewide FASD Family Support Network, was a critical source of information and networking with families. Hope Community Resources, a non-profit community organization and largest service delivery provider in Alaska provided the opportunity to speak with care coordinators and disseminate the consent form explaining my research within their agency. Several of the families I worked with through these organizations became critical springboards for the information I was finding, and led to further interviews with other families, both natural and adoptive. In addition to monthly support group meetings, I met and interacted with many families throughout the course of research at FASD-related community functions, including the Fascinating Families Camp hosted by Volunteers of America, Family

Stories sessions hosted by Stone Soup Group, family picnics, conferences and other public presentations. In addition, I met families in their homes, attended several Individualized Education Plan (IEP) meetings at schools and observed planning meetings where families worked with agencies to determine eligibility for services and navigate service delivery. These interactions provided context to situate the everyday stories and experiences collected during research. Without the support and consent of these families, this study and the personal stories and narratives contained in it would have been impossible to conduct.

### **Notes on Methodology**

While I have been interested in the anthropology of impairment/disability in Alaska for over 10 years, my first experience with FASD as an example of health inequality occurred in the context of pre-dissertation research. I entered the bureaucratic maze of program administration and service delivery with the intention of learning about what critical issues are most pertinent in relation to disability in Alaska. I met with program administrators and parent support staff in several community-based organizations in Anchorage, including Stone Soup Group, Southcentral Foundation, Volunteers of America, and Hope Community Resources.

As a statewide parent support hub offering training, information and referral services and support groups for individuals and families experiencing disability, Stone Soup Group was my first point of contact. Stone Soup Group is a grassroots organization that was founded in 1992 by mothers raising children with special needs that were concerned about meeting the health care needs of their children. One of the most

important services Stone Soup Group provides is a free service known as parent navigation. Their primary role involves connecting families with resources and services and guiding them through the complexities of disability service eligibility, access and delivery. I met with one parent navigator who is also an adoptive parent of an individual with FASD and organizer of the statewide FASD family support network (which is also housed at Stone Soup Group). It was in this context that I first learned about FASD and the disparities in reported rates for Alaska, particularly Alaska Natives.

Interested in learning more, I contacted the research director at Southcentral Foundation by phone and met with the administrator and parent navigator staff at the diagnostic clinic to follow up on this initial conversation. Southcentral Foundation is an Alaska Native owned and operated, non-profit health service organization. During this meeting I learned that Southcentral Foundation was the only diagnostic team in Anchorage at the time and that there was a need to expand FASD diagnostic capability in Anchorage. However, the clinic is funded (though self-administered) by the Indian Health Service and primarily serves American Indian/Alaska Native patients. When I asked why there were no other diagnostic clinics in Anchorage, it was explained to me by program staff that there is limited funding to set up additional clinics, that previous attempts to do so had failed, and that there was a real need in both Anchorage and elsewhere in the state to expand services and diagnostic capability. The waiting list to be seen by the clinic at Southcentral Foundation was at this time upwards of 6 months or longer, and due to limitations in resources and staffing, there was very little follow up for families post-diagnosis.



I was struck by these initial encounters and questioned what the implications of diagnostic access might be with regards to establishing reliable prevalence rates, especially within non-Native populations, where access to the same channels for services were not available. As I continued to meet with professionals in the field (in state, tribal, and non-profit settings) as well as with individuals and families living with FASD, I began to see the social implications and assumptions that drive current thinking about FASD in Alaska. Specifically, I began to see the disparities surrounding diagnostic access as a visible expression of inequality and decided to focus my dissertation research on the social meanings and consequences of diagnosis.

### **Research Activities**

The major research activities of this project included three sets of interviews—one for foster, adoptive and extended natural parents (i.e. grandparents), one for professionals in state, tribal and non-profit organizations, and one for interviews with adults who have a diagnosis of FASD (see appendix A). Eighteen of these interviews were conducted with foster and/or adoptive parents living in Anchorage. Interviews took place either in research participants' homes or in community settings of their choice (i.e. coffee shop, library, community center, etc.) and focused on issues related to living with and supporting a person experiencing FASD. Topics of discussion included the circumstances leading to fostering/adoption, subsequent changes in family forms and patterns of residence, and experiences with diagnosis. In addition, access to and interactions with services and support systems in the areas of education, health care, employment and other critical life domains as relayed by research participants were

discussed. On several occasions, I was invited to observe Individualized Education Plan (IEP) meetings held in the schools where individuals with FASD (whose parents I had interviewed) were receiving Special Education services and reporting difficulty in obtaining needed educational accommodations. These meetings became critical windows to observe both the challenges families faced and the strategies they utilized to meet the everyday care needs of their children.

In addition to interviews with foster/adoptive parents, ten interviews were conducted with extended natural family members of people with a diagnosis of FASD living in Anchorage. Several of these families relocated with the hope of receiving better services, or in response to challenging situations in home communities, including custody disputes, domestic violence or abuse, and Office of Children's Services (OCS) interventions that require separation from natural parents. As the narratives contained in this research will illustrate, tenuous relationships between families and the systems of care set up to assist them are common. Problems at the family and community level, including depression, sexual and domestic violence and substance abuse have prompted wide-scale state, tribal and non-profit intervention efforts. Such programs and initiatives have been successful in raising public awareness of FASD and providing a variety of forms of assistance to families. However, from the perspective of families, the presence of such entities are often seen as remnants of a long history of outsiders making decisions on behalf of their families and communities. While significant gains have been made towards improving cultural sensitivity with respect to how programs are administered and delivered, much work still needs to be done. OCS emphasis on family reunification, for example, illustrates the increasingly recognized value of family and community at the

state level, yet is still perceived as culturally insensitive and ethnocentric by research participants. In many cases, for example, grandparents take on a parenting role and utilize a variety of strategies to avoid uptake into the OCS/foster care system.

Natural grandparents and other extended family member care givers were recruited primarily through networks and related contacts established through interactions with the Grandfamilies Support Network housed at Volunteers of America. Many of the initial contacts made through this network became some of my most important sources of information. Stories and experiences conveyed by members of this network proved to be critical in understanding how a diagnosis of FASD can influence family forms and reconfigure patterns of kinship and residence.

In addition to parents, I also interviewed five adults with a diagnosis of FASD in Anchorage. Due to ethical considerations involving interviewing children who experience a disability, only adults were targeted for participation. Interviews were conducted either in research participants' homes or in community settings of their choice. Finding participants in this category proved challenging due to several factors. First, adults are less likely to be diagnosed due to limited diagnostic services in previous decades and difficulty documenting and confirming fetal exposure to alcohol. In addition, current diagnostic teams in Anchorage focus primarily (although not exclusively) on children under the age of 18. Finally, overall readiness to discuss personal medical histories may be limited due to current involvement in the diagnostic process or interactions with behavioral health and criminal justice systems. I made an explicit choice not to impose additional stress or burden on individuals and their families in such situations and this greatly limited the sample of available participants. Due to the

sensitivity of the information collected from these five interviews as well as the relative lack of adults with a diagnosis that expressed a willingness to interview, I have avoided drawing upon their stories in this dissertation. Future work could benefit from targeting these voices more explicitly so that individuals who experience the everyday realities of FASD most closely can create new spaces to safely narrate and share their own lives on their own terms.

An additional limitation of this study includes the lack of voice given to natural birth mothers. This was not an intentional omission but rather the result of difficulty locating natural mothers. There are a variety of reasons for this. For example, in instances where grandparents were raising individuals with FASD, natural birth mothers were often involved in criminal justice or rehabilitation programs, or were restricted from seeing their children due to ongoing or pending custody disputes. In at least three cases, the natural mother was deceased. The exclusion of the voices of birth mothers runs the risk of furthering stereotypes of dysfunctional motherhood by their very absence. Without a space to speak against such stereotypes, a critical perspective on community, parenting and family continuity is missing. Future research would benefit from targeted inclusion of mothers' voices as well as the voices of adults with FASD. This would allow for a more nuanced understanding of the circumstances and everyday constraints that may influence individual and family choices. It would also provide insight into the potential reasons that some women may have consumed alcohol during pregnancy, such as intimate partner violence, depression and other mental health concerns, lack of social and community supports and a variety of other possible factors.

To provide context and background with regards to current policy issues related to FASD in Alaska, I also interviewed 10 professionals at a variety of levels, including the State of Alaska Office of Children's Services, Division of Senior and Disability Services, Governor's Council on Disabilities and Special Education, Alaska Mental Health Trust Authority, tribal entities including Southcentral Foundation, Alaska Native Medical Center and Cook Inlet Tribal Council, and a variety of non-profit organizations whose work directly involves people and families who experience FASD. While several staff at the diagnostic clinic were interviewed, research participants were ultimately not recruited from this site because the families typically seen involve very young children just getting a diagnosis and research was primarily focused on the disability/family histories of adults with FASD and their foster/adoptive and/or extended natural families. Interviews were conducted either at respective places of work or in community settings of the participants' choice.

During the process of interviewing, I also recorded disability and family histories of all 28 parents. These narratives were autobiographical in nature, focusing on experiences of parents raising individuals with FASD. Issues related to health and disability, family, re/location, employment and other life circumstances were relayed by participants and used to conceptualize current life events within the broader life experiences of each interviewee. These conversations provided critical background for the interviews and proved to be invaluable sources of information that helped me situate interactions with clinical institutions historically and from an intergenerational perspective.

In addition to the above-mentioned research activities, participant observation was conducted throughout the entire study period. Specific settings examined included homes of research participants (in instances where interviews were conducted in the home), meetings of community agencies, including both parent support groups, trainings (including the state-sponsored FASD 101 and 201) and in some cases staff meetings, and state and tribal offices where interviews with professionals were held. I attended monthly meetings of the Anchorage FASD council, parent support groups at Stone Soup Group and Volunteers of America, family camps and foster family picnics as well as a variety of trainings, conferences and public presentations offered by agencies involved in information and referral as well as direct care services for individuals experiencing FASD and their families. During these activities, I was able to meet and observe families interacting with one another, sharing stories and experiences and learning from one another. While in these settings, I took detailed observational notes that helped situate data collected during the interview process. In addition, the Arctic FASD Regional Training Center housed at the University of Alaska Anchorage offered information and trainings, conferences, guest lectures and a variety of other opportunities to network with both families and professionals. They also provided an opportunity to disseminate information about the research (i.e. consent form) on their listserv. These community collaborations were critical sources of information throughout the study period.

### **Ethnographic Context: Anchorage, Alaska**

According to 2010 U.S. census data, Anchorage is the largest city in Alaska, with a population of 291,826 (Demographic Profile for Anchorage Municipality,

<http://live.laborstats.alaska.gov/cen/dp.cfm>). Approximately 40% of Alaska's total population of 731,449 resides in Anchorage. The ethnic composition of the Anchorage area is approximately 66% Euro-American, 8% American Indian/Alaska Native, 8% Asian, 5.6% African American, 2% Native Hawaiians and Other Pacific Islanders, 7.6% Hispanic or Latino, 8.1% identifying with 2 or more ethnic groups, and 2.3% identifying with "other" ethnic groups (Feldman 2009; Feldman et al. 2005; U.S. Census Bureau, <http://www.factfinder.census.gov>). Kerry Feldman (2009) notes that if Alaska Natives who also identify with another ethnic group are included, the number of American Indians/Alaska Natives in Anchorage is 28,839 individuals, or 10.3% of the total population of Anchorage.

The increasing ethnic complexity of Anchorage has been the subject of recent anthropological study (Feldman 2009; Fienup-Riordan et al. 2000; Fogel-Chance 1993; Goldsmith and Frazier 2001; Kurtz 2006; Lee 2002, 2003). One readily identifiable expression of this diversity is that fact that over 90 languages are currently spoken in the Anchorage School District (Feldman 2009; Feldman et al. 2005). This increasing ethnic complexity requires close examination with respect to cultural change and continuity. Alaska ranks number 1 in the nation for the percent of its population comprised of indigenous people (Feldman 2009). However, cultural identity among Alaska Natives is still intimately linked to subsistence and other cultural activities in rural areas, despite the fact that approximately half of this population resides in Anchorage. As such, Anchorage can be viewed anthropologically as a highly fluid site, with mobility and migration to and from rural villages a common part of everyday life (Hamilton and Seyfrit 1994; Lee 2002).

While few ethnographies of Anchorage exist, increased attention to “indigenous Alaska Native cosmopolitanism” (Feldman 2009:13) as well as the hybridity of Alaska Native cultures generally represent an important turn for anthropology in indigenous North America (Biolsi 2005; de la Cadena and Starn 2007; Dole 2012; Fienup-Riordan 2000; Kishigami 2006; Lobo 2003; Sissons 2005; Strong 2005). Since Anchorage is the central headquarters for the Alaska Native tribal health system, travel to Anchorage from all parts of the state for the purposes of healthcare is commonplace. The Alaska Native Medical Center campus, which includes Southcentral Foundation, is a central meeting place for many Alaska Natives traveling to Anchorage. In addition to offering health care services, there are lodging accommodations (i.e. Quyana House) as well as a number of cafés and other meeting places where people can connect with family and friends from all over the state. These kinds of spaces offer support and community for urban and rural Alaska Natives alike. Similarly, the support groups that I attended during research (at both the Grandfamilies support network at Volunteers of America and the Family Support Network at Stone Soup Group) were opportunities for people to meet up, share stories and experiences and build urban community.

With at least half of all American Indians and Alaska Natives living in or near a major city (Johnson 2007), situating research in Anchorage offers an opportunity to examine urban life as an active site and unique form of community making. Since health and health care frequently become the context and reason for movement both to and within Anchorage, understanding how family forms are adapted in response to everyday life challenges and circumstances in this urban setting is critical. Urban migration and fluidity in this sense shapes and constrains the experience of health, identity, family,



community and belonging in important ways and offers unique possibilities for anthropological investigation (Feldman 2009; Hamilton and Seyfrit 1994; Lawrence 2004; Sejersen et al. 2008). Narratives collected from individuals with FASD and their foster and/or extended natural families in Anchorage illustrate urban life as a site through which indigenous identity is articulated and affirmed rather than denied or erased (Fogel-Chance 1993; Lee 2003; Lobo 2003). In the context of my research, urban residence and location, coupled with the experience of impairment/disability, challenges traditional notions of indigenous identity, inclusion and belonging and offers a lens for rethinking anthropological approaches to kinship and community. Furthermore, since Anchorage offers the most extensive diagnostic and direct care service infrastructure in the state, Alaskans experiencing disability interact with and travel through this space extensively in managing their health care needs. Documenting these movements in the context of individuals and families experiencing FASD thus offers an opportunity to understand the strategies families utilize in negotiating the constraints of everyday life and meeting the care needs of their loved ones.

### **What is FAS/D? History and Expansion of a Diagnosis**

The emergence of FASD as a medical diagnosis must be situated in both social and historical context. While not formally recognized until 1973, the link between alcohol consumption and possible birth defects has long been documented (Armstrong 2003; Armstrong and Abel 2000; Conrad and Schneider 1980; Golden 2005; Jones et al. 1973; Jones and Smith 1973; Jones and Streissguth 2010; Streissguth et al. 1985; Ulleland 1972). Several scholars have traced the historical roots of alcohol as a social

problem (Armstrong 2003; Golden 2005; Jones and Streissguth 2010) that was deemed to be a threat to societal order and control. The “gin epidemic” which began in England in 1720 with economic subsidies to the distilling industry, for example, led to a rise in alcohol consumption among the poor and working classes and fueled public perception of uncontrolled alcohol consumption as a form of social deviance (Armstrong 2003; Golden 2005). Public perceptions of chronic inebriation as an intergenerational problem of “alcoholic degeneration” (Golden 1995) affecting urban poor and working classes led to concerns over public order, health and safety. Offspring of alcoholic mothers were believed to have a “starved, shriveled, and imperfect look” (Jones and Streissguth 2010:374), and public fears of social disorder and dependence led to efforts to control alcohol sale and consumption.

At one end of the policy debate was the issue of controlling alcohol itself, with prohibition in the United States being perhaps the most visible example of this. On the other was the issue of controlling what was perceived to be a social sickness or deviance (Armstrong and Abel 2000; Conrad and Schneider 1980; Prussing 2011). As Janet Golden notes, “by 1941 thirty states permitted compulsory sterilization and more than 38,000 individuals had been deemed unfit to breed and subject to surgery” (2005:29-30). The notion of unfit, deviant alcoholics who suffered from an intergenerational “disease” (i.e. alcoholism) that required treatment, intervention or even punishment provided the political and social context out of which FAS/D emerged as a formal medical diagnosis.

Medical diagnoses reflect the social meanings and beliefs assigned to them at any given time or place. The linking of alcohol use with social deviance fuelled public perceptions regarding the need to intervene on behalf of the unborn child and regulate the

bodies and pregnancies of women. In other words, regulating women's bodies became a strategy for managing risk to society and protecting future generations of citizens (Armstrong 2003; Beck 1992; Browner 1999; Browner and Press 1996; Heriot 1996). As an increasingly medicalized event, pregnancy embodies multiple sets of overlapping concerns with regards to the relationship between mother and unborn child and the role of the state in regulating or managing behaviors deemed to be potentially harmful to the unborn baby. In this sense, the "discovery" of FASD as a medical "disorder", "reflects not only a recognition of the pattern of growth retardation, neurological dysfunction, and craniofacial abnormalities that is the core of the diagnosis...but also a need to impose order on a disorderly society" (Armstrong 2003:21). Once established as medical knowledge, the issue of managing risk shifts from the consumption of alcohol per se to the greater moral question of what kind of mother would subject her child to such suffering and what could be done to manage such "deviant" motherhood in the future. This kind of focus diverts attention away from underlying historical and structural conditions that shape risk factors and constrain everyday life choices, including access to social supports, prenatal and behavioral health care and safe and clean living and working accommodations (Armstrong and Abel 2000; Golden 2005; Mullings and Wali 2000; Rockhill 2011; Tait 2003). Furthermore, it reinforces the perception that FASD is a problem of poor, minoritized women, single mothers, and families on welfare, despite universal constructions of risk and the continued public health message that FASD "threatens all pregnancies" (Armstrong 2003; Armstrong and Abel 2000; Golden 2005; Tait 2001, 2003, 2008).

This perception exists in stark contrast to research findings showing that drinking during pregnancy is more common among women of middle and upper classes (Armstrong and Abel 2000; Centers for Disease Control 2012; Floyd et al. 1999). A recent study conducted by the Centers for Disease Control and Prevention, for example, found that among pregnant women, “the highest prevalence of reported alcohol use were among those who were aged 35-44 years (14%), white (8.3%), college graduates (10%), or employed (9.6%)” (2012:1). Drinking, in this case, was defined as having at least one alcoholic beverage in the last thirty days, while “binge drinking” was defined as having 4 or more drinks in one sitting within the last thirty days (Centers for Disease Control and Prevention 2012). By this definition, the numbers presented in the study are strikingly at odds with FASD prevalence rates, which show disproportionately high rates of FASD among minority groups. Similarly, Floyd et al. (1999:1) used survey data collected by the National Center for Health Statistics and found that “being unmarried, being a smoker, being white non-Hispanic, being 25 years of age or older, or being college educated” were the most common risk factors for “frequent drinking” (as defined above). Given these data, why then are FASD rates concentrated on minority groups (Tait 2003, 2008; Woods et al. 2011)? If drinking during pregnancy is more common among white, non-Hispanic women, why don’t actual FASD rates reflect this?

While FASD is considered to be an "equal opportunity affliction", in that drinking during pregnancy can cause birth defects in some cases, it is not an equal opportunity diagnosis (Armstrong 2003; Golden 2006; Hunting and Browne 2012; Salmon 2011). Currently in Anchorage, Alaska Natives have far greater access to surveillance and diagnostic services, as the primary diagnostic team is housed at a tribally owned and

operated clinic and primarily serves Indian Health Service members. As a result, disparities in FASD rates may be attributable in part to inequities in diagnostic access, which fuel perceptions of FASD as a “Native problem”, despite massive efforts on behalf of Alaska Area Indian Health Service programs to address the issue. While some efforts to expand diagnostic access to non-Natives by creating additional clinics have occurred, this work has only just begun, and relatively few diagnoses have been made to date. Of all diagnosed cases of FASD in Alaska, approximately 85% are Alaska Native, and of these 85%, approximately 80% are raised in Anchorage by non-Native foster parents (personal communication, CS-002-002). Such high rates of foster parenting indicate that a diagnosis of FASD contributes to significant rupture and reconfiguration of family, community, kinship and social location (Hunting and Browne 2012; Rockhill 2010; Tait 2003).

FASD refers to a continuum of physical and cognitive impairments that includes FAS on the severe end of the continuum and a variety of less severe combinations of physical and cognitive impairment on the other. To receive a diagnosis of “full blown” FAS, 4 conditions must be present; (1) A “characteristic” set of craniofacial deformities, including flattened upper lip, philtrum and midface, (2) Evidence of growth retardation, including low birth weight, decelerating weight over time not due to malnutrition and disproportionately low weight for height, (3) Central nervous system abnormalities, including decreased cranial size at birth, structural brain abnormalities, neurological impairment (including poor hand-eye coordination, seizure disorders, etc.), impaired fine motor skills, poor tandem gait, hearing loss or cognitive impairment, (4) Documented

incidence of “excessive” drinking during pregnancy (Armstrong 2003; Golden 2005; Stratton et al. 1996).

Due to the fact that all 4 of these conditions are only present approximately 5% of the time, the diagnosis has been expanded and is now more generally referred to as FASD (Kleinfeld and Wescott 1993; 20009; Malbin 2002). This expansion has been described as a process of both medicalization and demedicalization (Armstrong and Abel 2000; Armstrong 2003; Golden 2005; Salmon 2007; Tait 2003). It refers to the construction of biomedical legitimacy as a diagnosis alongside growing public/moral concern and increasingly non-medical involvement (i.e. school teachers, parents, etc.) in the generation and dissemination of knowledge about risk, prevention and appropriate intervention. This has led to an array of confusing public health messages ranging from “not a single drop” to the recent finding that “low to moderate” drinking during pregnancy poses no risk of fetal harm (Centers for Disease Control and Prevention 2012; Eriksen et al. 2012). Such contradictory messages reflect a significant degree of biomedical uncertainty with regards to the etiology of FASD (Lock and Nguyen 2010) but perhaps more importantly, they highlight the broader cultural politics that shape and inform understandings about FASD. Definitions of risk, as well as the relative degree to which the issue of drinking during pregnancy has been minimized or amplified vary widely, both within the United States and internationally (Drabble et el. 2011). This is due largely to differing social and cultural attitudes regarding not only drinking during pregnancy and the imprecision with which a diagnosis is made but also differing perceptions regarding the role of the state in controlling and regulating women’s bodies, pregnancies and ultimately babies.

In the United States, expansion of the diagnosis into FASD has also led to a so-called expansion in expertise, whereby “physicians and researchers in a wide variety of subspecialties heralded with entrepreneurial zeal (the) new opportunities for research” that expansion of the diagnosis offered (Armstrong and Abel 2000:278). It provided a means of gaining medical legitimacy while at the same time influencing public perceptions of “good” (or conversely, bad or “unfit”) motherhood (Armstrong 2003; Golden 1999; 2005; Rockhill 2011; Tait 2003). In this regard, sociocultural norms help facilitate the creation of a new diagnosis, and the solidification and expansion of that diagnosis can in turn shape sociocultural norms and expectations for behavior, including notions of “appropriate” or “unfit” motherhood and the circumstances “requiring” state intervention.

The implications of diagnosis have stigmatizing consequences for families and communities due to suspicions related to maternal alcohol consumption during pregnancy and its possible role in contributing to the presence of impairments. Diagnosis of FASD is not clear-cut. Rather, it encompasses a broad range of physical, cognitive and behavioral impairments in various combinations and degrees of severity and varies tremendously in its expression case by case. With the so-called classic craniofacial features only present 5% of the time, FASD is quite difficult to “see” medically (Armstrong 2003; Burd et al. 2010; Golden 2005; Rosenberg 2002; Vedder 2005). Furthermore, documented evidence of maternal alcohol consumption during pregnancy is not always required under the current, 4-digit diagnostic coding system, which was developed at the University of Washington School of Public Health and Community Medicine in 1997 (Astley 2004). Prior to this time, there were no standardized diagnostic

instruments and this raises critical questions as to how potential cases were located and what other factors influence who gets diagnosed with FASD.

In Alaska, as well as the other states in the National FAS Surveillance Network (including Arizona, Colorado, New York and Wisconsin), the 4-digit diagnostic system is used to diagnose individuals with FASD. In total, there are 256 possible diagnostic codes, which are grouped into 22 general diagnostic categories, ranging from FAS to “sentinel physical findings” (no alcohol exposure) (Astley 2004). The 4-digit diagnostic system was the first attempt at developing a standardized diagnostic instrument that could be used nationally to compare FASD prevalence rates. Prior to its development and adoption, a diagnosis was much more difficult to make, as diagnostic criteria varied widely. The surveillance network lists being an American Indian/Alaska Native woman as a risk factor unto itself for having a child with FASD (Burd and Moffatt 1994; Schoellhorn and Podvin 2002), reflecting the subtle ways in which gender, class and ethnicity shape perceptions of risk and blame and naturalize inequality in both public perception and clinical practice.

Since the Indian Health Service led many of the first efforts at surveillance in Alaska, prevalence rates were not surprisingly quite biased, as data were only collected for Alaska Natives. This in turn contributed to a public perception of FASD as a “Native problem” despite diligent efforts on behalf of tribal health organizations to better understand and monitor what was becoming a growing public health concern. Diagnoses tend to be clustered around and amplified across several locations of difference simultaneously, including race/ethnicity (Salmon 2007; Schulz and Mullings 2006; Tait 2003) and class/socioeconomic status (Armstrong and Abel 2000; Golden 2005).



Construction of knowledge about FASD is fueled in part by public perceptions and assumptions regarding family, culture, kinship and “proper” motherhood. These perceptions, in turn, shape clinical knowledge and practice with respect to how FASD is located and acted upon in the form of clinical and state intervention. As such, diagnosis is just as much a moral judgment as it is a medical determination and one's social location figures centrally in how clinical and state interactions, as well as post-diagnostic outcomes and experiences, unfold. The over-representation of American Indian/Alaska Natives with FASD in the child welfare system (Tait 2003; Woods et al. 2011), criminal justice system (Burd et al. 2010; Jeffery 2011) and foster care system (Long and Curry 1998; Kirmayer et al. 2000; Tait 2003) are all powerful examples of the broader structures of inequality that shape disparities in health outcomes. As the family stories and narratives described in the chapters below speak to, they influence the everyday lives of people in profound ways and provide a powerful example of how even the most well-intentioned program, policy or public health effort can serve to further entrench structures of inequality and reinforce disparities in health access and outcomes.

### **FASD in Alaska: Who's Doing the Counting, Who's Getting Counted?**

In Alaska, the first (and at the time, the only) attempts at identifying potential cases occurred in the 1980's through the Alaska Area Native Health Service, which is the Alaska administrative branch of the federal Indian Health Service (Schoellhorn and Podvin 2002; Alaska Area Indian Health Service 2012; Alaska Fetal Alcohol Syndrome (FAS) Surveillance Project 2012). This was the first major attempt to monitor FASD in Alaska and create a mechanism of surveillance. However, Alaska Natives were the only

group under surveillance at this time, and programs were still entirely administered by the federal government. Such one-sided attention to American Indian/Alaska Native populations played a key role in shaping and reifying perceptions of FASD as a “Native problem”. Indeed, no other ethnic group was even being counted at this time in Alaska’s history. In addition, because the diagnosis was only just beginning to be more widely accepted within the medical community and there were as yet no standardized diagnostic tools or surveillance data to monitor incidence and prevalence rates within and between states, it was difficult if not impossible to get accurate nationwide estimates of FASD rates.

Several pieces of federal legislation made it increasingly possible for tribal organizations to assume control and administrative responsibility for education, health and social service programs. Title V of the Indian Self Determination and Education Assistance Act of 1975 (Case 1984), for example, paved the way legally for tribal organizations to enter into contractual relationships with the Indian Health Services to administer programs and services. In this regard, the history of FASD in Alaska closely parallels the history and expansion of tribal health governance (Kickbusch 2005), as the earliest efforts to track and monitor rates, increase diagnostic services and create public health initiatives were led by tribal health organizations.

The shift to tribal health governance continued throughout the 1980’s with a series of congressional public laws. Specifically, public law 93-638 gave tribal health organizations control over dentistry, optometry, community health, injury control and, by 1987, substance abuse treatment services (Indian Health Service, Office of Tribal Self-Governance 2012; Southcentral Foundation History 2012). There were several important

implications of this shift to increased tribal health governance. On one hand, tribal organizations, in an effort to respond to growing awareness of the dangers associated with consuming alcohol during pregnancy, may have inadvertently reinforced reported disparities in FASD. This is because no other organization in Alaska was collecting such detailed information in their clinics and as a result non-Native women were not being looked at with the same scrutiny in clinical settings. Several professionals I interviewed explained how tribal organizations have far more thorough screening and documentation procedures that are not always part of clinical practice outside tribal health settings. This information is helpful in terms of making an accurate diagnosis and setting up an accommodating and supportive environment for an individual with FASD, but since it has not been historically collected for people seen outside of tribal health clinics, it may have had the unintended consequence of reinforcing public and professional perceptions of who is at risk and where the focus of intervention should ultimately be.

On the other hand, increased tribal governance of health programs led to an increased collaboration with several other entities, including the State of Alaska and a variety of health and social service non-profit entities. Tribal organizations like Southcentral Foundation have been leaders in these collaborations and have led to several important developments with regards to improving surveillance and diagnostic services statewide and expanding resources for services and supports for individuals and families living with FASD. They also helped raise public awareness about the potential risks and long-term consequences associated with fetal exposure to alcohol.

In 1990, the Alaska Area Native Health Services collaborated with the Alaska Department of Health and Social Services and the Centers for Disease Control and

Prevention to create the Alaska FAS Prevention Project (Schoellhorn and Podvin 2002). This was the first attempt at developing standardized methods of case identification in Alaska and it generated the first published prevalence data for the state. By 1994, nearly half of all Alaska Area Native Health Services programs were under tribal administration, and by 1997 all programs became fully owned and operated by tribal organizations, the result of congressional passing of Public Law 105-83 (Roderick 2008; Southcentral Foundation History 2012). This coincides with the opening of the Alaska Native Medical Center, which is now co-managed by Southcentral Foundation, an Alaska Native-owned, non-profit health care organization, and the Alaska Native Tribal Health Consortium (Southcentral Foundation History 2012). Southcentral Foundation, which can diagnose Alaska Natives within the ages of 3-18, was the only diagnostic center in Anchorage until late 2010, when a second diagnostic team was established at a non-profit service delivery agency known as Assets. The diagnostic team at Assets will see anyone within the ages of 3-22 but has only diagnosed a few people to date.

The State of Alaska Office of Fetal Alcohol Syndrome (Department of Health and Social Services) was established in 1998 as part of a targeted effort to increase surveillance and prevention efforts and coordinate statewide efforts and initiatives. In the same year, the Center for Disease Control (CDC) created the 5-state National FAS Surveillance Network, which included Alaska. Funding from this network was utilized to launch the Alaska Fetal Alcohol Syndrome (FAS) Surveillance Project. Now funded through the Office of Fetal Alcohol Syndrome (but housed in the Department of Public Health, Women's Children's and Family Health, Maternal and Child Epidemiology), the surveillance project continues to monitor the prevalence of FASD in Alaska over time.

However, data is aggregated into just two categories, “Native” and “non-Native”, which may obscure results and serve to further racialize the diagnosis.

The ethnographic data presented in this dissertation offer a glimpse into the lives of individuals and families who, due to their unique interactions with state institutions, social and health service delivery agencies and tribal health facilities, have had their lives changed in profound ways. Utilizing the stories and experiences related to me by families, I will explore how a diagnosis of FASD is made, and how racial, gendered and cultural perceptions of risk, blame and suspicion of fetal alcohol exposure trigger particular sets of clinical interactions that disproportionately affect Alaska Native families and communities and shape the experience and meaning of impairment/disability in critical ways. My analysis reveals that disparities in FASD rates among Alaska Natives reflect broader inequities in diagnostic access as well as cultural and historical perceptions of difference that work to pathologize indigenous peoples and cultures and create conditions whereby Alaska Natives are more likely to be diagnosed. These perceptions of difference and risk radiate into and inform professional attitudes and create institutional constraints that lead to significant rupture and reconfiguration of family, community and indigenous identity.

My research examines the ways in which FASD diagnosis has been racialized through a dynamic interplay of public perception, professional knowledge and clinical practice and looks at the consequences of these framings on families and communities in Alaska. I focus my analysis on families to illustrate the ways in which diagnosis can lead to significant reshaping of kinship forms, patterns of residence, and sense of identity and belonging. As the stories collected during research reveal, widespread family dislocation

for individuals with FASD (even suspected FASD in some cases) is common. For some families, custody arrangements with extended kin become important strategies of resistance to state modes of intervention and serve as critical links to indigenous identity and family back home. In other instances, involvement and participation in activist networks or support groups become opportunities for the creation of new forms and relations of kinship and identity. Nevertheless, structural inequalities in both diagnostic access and mainstream representations of risk and blame can be read as powerful examples of how deeper historical inequalities persist in subtle ways in clinical practice and everyday life in the present. The stories and everyday life experiences of individuals and families highlight the ways in which knowledge about FASD is socially and historically constituted (Prussing 2011) and expressed through the bodies of individuals and families as a result of interactions with clinical and diagnostic institutions. They also speak to the ways in which historical misunderstandings and stereotypical representations continue to inform both public and lay understandings of FASD. However, these representations are both contested and appropriated at various times by individuals and families as strategies to manage the stigmatizing consequences of diagnosis.

As the family stories and experiences described below illustrate, my analysis focuses on social and cultural meanings surrounding FASD. I examine differences in family outcomes on the basis of social location and discuss current “best practices” with respect to FASD diagnosis and document everyday life experiences of individuals and families in their interactions with state, tribal and non-profit institutions. As several scholars have pointed out, considerable uncertainty pervades our understanding of the relationship between alcohol and reproductive outcome (Armstrong and Abel 2000;

Armstrong 2003:6; Drabble et al. 2011; Eriksen et al. 2012; Golden 2005). Both epidemiological and etiological understandings rely on the assumption that alcohol is the only teratogen at work and the diagnosis is increasingly presented as a medical certainty. However, there are many other potential factors that may contribute to the presence of birth defects, including living and working environment, smoking, malnutrition, high parity (i.e. the number of previous births), advanced maternal age, etc. How this uncertainty is packaged as medical fact in everyday clinical practice and grafted onto Alaska Native bodies is thus an important consideration anthropologically, as the consequences of diagnosis are far-reaching and unequally distributed.

In Alaska, this is particularly troublesome given the high levels of Alaska Native uptake into foster families and disproportionately high involvement with the criminal justice system, which threatens to dramatically alter the composition of families in villages throughout Alaska. As such, Anchorage has become a major hub for the movement and relocation of Alaska Natives “moved by the state” as well as an important site of new community and kinship building.

### **Ethical Considerations, Researcher Positionality and Readiness to Participate**

Talking with individuals and families about their experiences with FASD is a sensitive topic. Historical representations of indigenous peoples and communities, both in anthropological and other scholarly accounts as well as mainstream media sources, reinforce ethnocentric and racist assumptions of Euroamerican cultural superiority and normativity and influence negative perceptions of American Indian/Alaska Native peoples to this day (to be discussed in detail in chapter 2). In the case of FASD and the

racial and gendered assumptions associated with maternal alcohol consumption during pregnancy and the risk of fetal harm, such perceptions and “stereotyping logics” work to pathologize and confine Nativeness to a biological risk factor, where simply being an Alaska Native woman comes to be viewed as a risk for having a child with FASD. Several clinicians I spoke with described how they thought Alaska Native women were looked at with additional scrutiny for FASD in comparison to other ethnic groups, creating the conditions whereby it is more likely to for an Alaska Native child to be diagnosed with FASD. Discourses about FASD in both public and professional settings are laden with assumptions and cultural meanings that make it difficult to even discuss the topic, for fear of stigma and moral judgment. As a researcher, this made it difficult to meet families, as my initial presence in many cases was met with skepticism.

I was an outsider, a non-Native studying at a University outside of Alaska. This peculiar positionality prefigured many of the first meetings I had with families. For example, one natural grandparent I met early on in my study at a support group meeting at a church in Anchorage (sponsored by Volunteers of America) commented to me in response to a question about perceptions of FASD and the ways in which Native communities are being affected, “You westerners always want to know why. Native people have been labeled their whole lives. I don’t know why, but the stigma just seems to have stuck with Native communities” (personal communication 2010). These comments were my first glimpse into the world of morally charged racial discourses about FASD, risk and state intervention. I replied that how people think about FASD was one of things I wanted to learn about through my research and that I was interested in her experiences raising her grandson. This exchange was a critical point of entry into the



community of grandparents and other extended kin involved in raising individuals with FASD. It served as an anchor for me, a reminder of what was at stake and the importance of her story.

At the meeting, I was given an opportunity by the organizer of the support group to discuss my research goals and explain that I was interested in learning from people in the group about their experiences with FASD and how it has influenced their everyday lives. I had an opportunity to meet approximately 12 family contacts at that first meeting and all but one led to an interview as well as additional contacts. Once families understood the questions I was asking and broader interest in the cultural politics of FASD they seemed much more willing to share their stories. I was genuinely interested in listening to their experiences from their own perspective and several families approached me saying they were glad someone was even asking. Repeated visits to meetings and support groups along with explanation and open discussion of what I was looking at and why family stories were so critical to understanding this problem from a cultural perspective helped further the trust and relationship building that occurred as a result of these first research experiences.

The encounters I had with families and professionals were critical in formulating and refining my research questions. I began to see the diversity of family experiences and responses as a critical link between the social perceptions and constructions of FASD and the clinical and state practices and interventions that shape and constrain the lives of individuals and families. Many of the people I interviewed expressed a willingness to meet throughout the research process and offered opportunities to check in at various points and reflect on what I was learning. Without any promise of direct benefit or

improvement in life circumstances, people shared their lives with me and answered difficult and sensitive questions. Their courage, openness and willingness to share sensitive details about their lives made this research possible.

At the same time, honoring their stories and voices poses an ethnographic challenge. Focusing on the ways in which Alaska Native families and communities are uniquely affected by FASD diagnosis and the broader social and structural inequalities embodied in clinical practice runs the risk of inadvertently reproducing the very phenomenon (linking indigenous experience with biomedical pathology) that this research contests. Instead, I emphasize the diversity, plurality and multivocality of the lives and stories collected during research. While there are broad patterns that shape the experience and meaning of FASD in different ways based on social location, including the pattern of kinship and family residence and whether or not an individual resides in a foster, adoptive or extended natural family, each individual and family I worked with had a unique story to tell. Their experiences shed light on the multiple, overlapping and oftentimes competing racial, cultural and political meanings surrounding FASD and highlight the tenuous relationships between public attitudes and perceptions, knowledge production and the experience and practice of everyday life for individuals and families labeled with a disability.

Due to the sensitive nature of this research, only individuals and families that expressed overall readiness to meet and discuss their experiences were included in this study. Since diagnosis of FASD can be a traumatic, stressful and highly disruptive event for families, I avoided recruitment of participants who have just begun their (lifelong) journeys managing both the social stigma and everyday life impairments associated with

FASD. Rather, families more seasoned in their journeys were specifically recruited so that potentially stressful situations could be minimized and interviewees could speak with a certain degree of distance, comfort and readiness about their experiences. For example, as described to me by one research participant,

“I share my story because I am ready to share. My story is common, but I am in a unique position to share. I know I’m not alone. There are 3 generations of women at this table. We have lost a lot of kids to the system. We need to do this for our kids and grandkids. It is up to us to be whole again. These are not just Native issues, you know. These are issues that affect Native communities, but also all communities.” (TA-001-017).

By specifically seeking out individuals who were willing and ready to share their experiences, the discussion and recollection of painful memories, while still difficult, was mitigated. Nevertheless, the stories people shared with me are passionate, emotional and thought provoking. They speak to the social and cultural construction of human difference at such profound levels and offer possibilities for thinking about health inequalities in a new light. As stated by a research participant at the end of an interview, “It’s not easy to get up and really talk about this stuff, but more people need to hear our family stories” (SC-001-004).

### **Theoretical Overview**

This research draws upon medical anthropology, disability studies, reproductive health studies and indigenous studies for its primary theoretical foundation. FASD is an important subject of examination for both medical anthropology and disability studies for

several reasons. Because of its broad range of physical, cognitive and behavioral presentations, FASD offers a unique lens to articulate and build upon impairment-disability theory (Ablon 1988; Ingstad and Whyte 2007; Kohrman 2005; Shuttleworth and Kasnitz 2004; Snyder and Mitchell 2006). Impairment-disability theory argues for the necessity of analytically separating and distinguishing impairment, defined as a “negatively construed, cultural perception of a bodily, cognitive, or behavioral anomaly” in terms of function or some other culturally needed competency, and disability, defined as a “negative cultural response to a perceived impairment” (Shuttleworth and Kasnitz 2004:141). By this definition “disability” becomes a social process of othering, based on a perception of incompetence (i.e. impairment). FASD by definition requires theorizing impairment-disability as multi-layered and multi-faceted, involving multiple sets of differences that shape the lives of people with disabilities in different ways. Since FASD encompasses such a broad range of impairments and experiences under the umbrella of one named disability, it provides a unique opportunity to examine the disabling processes that shape and constrain the everyday lives of individuals and families.

In terms of the ways in which impairments coalesce into named disability through diagnosis, studying the experiences of Alaska Natives with FASD will build upon the scholarship of several medical anthropologists who study disability as a critical location of human difference (Ablon 1988; Dossa 2005; Ingstad and Whyte 2007; Kohrman 2005; Rapp and Ginsburg 2001). These scholars have examined disability as a social location of otherness that is transcribed onto individuals through diagnosis and managed through various practices and techniques of government. However, through their ethnography they are able to articulate both the structures that constrain life choices for people

experiencing disability, as well as the strategies and practices of agency people use to negotiate their everyday life experiences with disability. It is within these spaces, where the interplay of structure and agency plays out in everyday life, that the impairment-disability relationship is best examined. Choices and strategies of everyday life that families employ to manage the disabling and stigmatizing effects of FASD are structured by family and kinship forms and illustrate broader structural constraints that limit available options to families. I attempt to present in this research a theoretically grounded, descriptive ethnographic approach that connects the lived experiences of research participants to broader discussions of power, structure, agency and the construction of human difference.

A substantial body of current medical anthropological literature draws upon intersectionality theory to examine health inequalities along a number of lines of difference (Collins 2000; Krieger 1999; Mullings and Wali 2001; Schulz and Mullings 2006). Scholars of intersectionality are concerned with the ways in which health and health disparities are structured and shaped by one's social location, which includes the mutually constitutive, simultaneous influences of race/ethnicity, gender, socioeconomic status, citizenship and impairment-disability. Rather than isolated, discrete categories used to neatly "explain away" health inequalities, these variables are treated as complex sets of social relations that intertwine to produce inequitable health outcomes. Social location shapes and constrains health choices and outcomes in critical ways and provides opportunities for reconfiguring the boundaries and borders of family, community, identity, citizenship and belonging. Expanded kinship networks and new circles of social and political supports associated with relocation to an urban area, for example, offer new

sites of activism and modes of citizenship and political engagement that offer opportunities for negotiating meaning and building community (Dossa 2005; Rapp and Ginsburg 2001; Salmon 2007). In this context, collected family narratives can be read as “unnatural histories, visions of lives lived against the grain of normalcy” (Rapp and Ginsburg 2001:552). These theoretical perspectives are critical considerations in light of structural inequalities related to FASD diagnostic access and the gendered, raced and classed assumptions that shape both public and professional perceptions of risk, blame and appropriate intervention.

Anthropologists studying reproductive health have called attention to the racial and gendered politics of accusations about fetal exposure to alcohol (Armstrong 2003; Browner 2000; Browner and Press 1996; Golden 2005; Inhorn et al. 2009; Kaufert and O’Neil 1993; Tait 2001) and their role in justifying and reinforcing structural and historical violence and paternalism towards women (Anglin 1998, 2006; Dudgeon and Inhorn 2003; Hunt 2013; Jacobs and Gill 2002; Lawrence 2000; Smith 2005; Weaver 2009). For these scholars, the production and representation of FASD can be read as an example of neocolonial oppression and hegemony, a critical part of an ongoing colonial legacy whereby the bodies of Alaska Native women are subject to a variety of state controls and interventions. Assumptions and judgments about “proper” ways of living and “appropriate” ways of childrearing become pretexts for intervention upon women’s bodies and reproductive health experiences. In Alaska, diagnosis of FASD can trigger sets of clinical and state interactions that lead to profound disruptions of family, kinship and community and highlights a critical context to examine how the racial, gendered and ethnocentric cultural assumptions that informed colonialist attitudes towards indigenous

peoples in the United States and Alaska persist in more subtle forms to this day. For many of the individuals and families I interviewed, such forms and structures of violence are actively contested in the context of everyday life. Their stories can be read as critical moments of agency, survival and transformation amidst several overlapping structures of constraint.

Recent scholarship within the fields of anthropology and indigenous studies further informs this research. Urban migration and residence, as an expression of indigeneity intimately connected to colonial and postcolonial processes and practices, has received much needed scholarly attention (Lawrence 2004; Lobo 2003; Sissons 2005). A social location that is becoming increasingly common for American Indians and Alaska Natives, life in an urban area shapes and constrains the experience of health in important ways. Several anthropologists working on health inequalities in indigenous communities have argued that a nuanced ethnographic approach integrating critical scholarship with engaged work involving communities in the research process enables research participants to take on a central role in the telling of their own stories and experiences with health, impairment-disability and well being (Adelson 2000). It is also an effective way to “change the relations of surveillance” and construct an “alternative discourse that challenges the legitimacy of the dominant epidemiological discourse and contributes to the production of knowledge about Aboriginal communities that is liberating rather than repressive” (O’Neil et al. 1998:230), thereby leading to increased health governance (Kickbusch 2005) and overall improvement in health and impairment-disability outcomes (Adelson 2000; O’Neil 1989; Stern and Stevenson 2006).

In the following chapters, I will situate the problem of FASD more broadly, and present the stories and experiences of individuals and families collected during research within the theoretical and conceptual framework outlined above. Chapter 2 explores historical representations of indigenous communities in North America generally and Alaska specifically. Family narratives of relocation and reconfiguration are positioned as a contemporary analog to the history of forced relocations of indigenous peoples through boarding schools, Indian Health Service and forced sterilizations, and other attempts at state control of indigenous bodies through the regulation of women's reproductive health and birth outcomes. Chapter 3 offers a critical perspective on how biomedical knowledge creation about FASD, coupled with the inequitable diagnostic landscape in Anchorage, can be read as a powerful example of inequality that serves to justify and naturalize a variety of clinical and state interventions. FASD is situated as a relatively recent diagnosis with inherent problems and a considerable amount of biomedical uncertainty in terms of diagnostic approaches and instruments of surveillance. Issues of tribal health governance will also be examined with respect to several key pieces of legislation, including the Indian Child Welfare Act (ICWA). The role and importance of ICWA as well as how it shapes attitudes and perceptions of "ideal" family outcomes and raises fundamental sovereignty issues pertaining to who has jurisdiction over family court matters involving tribal members will set the context for the family narratives to be presented in chapter 4. The racial, gendered and cultural politics of accusations about fetal exposure to alcohol will be traced through the narratives and everyday life experiences of research participants in chapter 4. How different family forms shape experiences of migration and relocation, kinship and indigenous identity and constrain



options for individuals and families will also be explored. Chapter 5 draws upon data collected through interviews with professionals in a variety of state, tribal and non-profit settings. The tenuous history and expansion of FASD diagnostic clinics in Alaska is explored and current program and policy initiatives (along with their potential consequences) are discussed. This information will be used to highlight critical service delivery gaps and illustrate the stakes of diagnosis. Chapter 6 presents the everyday life experiences of individuals and families as they navigate the bureaucratic mazes of service delivery and seek to manage both the stigmatizing consequences of disability and the challenges of impairment in the contexts of health, education, vocation, family, kinship and identity. Chapter 7 situates FASD in Alaska as a critical bridge linking anthropologies of impairment/disability with broader conversations occurring in medical anthropology and indigenous studies dealing with health inequalities, the state and issues of structural violence and social justice.

# The Cultural Politics of Fetal Alcohol Spectrum Disorders and the Diagnosis of Difference

## **Chapter Two: History and Representations of Indigenous North American Communities**

### **Colonizing Frameworks**

Anthropological representations of indigenous communities in Alaska and North America have a long history that is intimately linked to colonial expansion and oppression. The criticism of anthropology as the “handmaiden of colonialism” (Asad 1973) notwithstanding, anthropological accounts have long suffered from deep ethnocentric bias rooted in assumptions of racial and moral superiority, and the inevitability of the “demise” of Native cultures. Part of a specific mode of “salvage ethnography” (Baker 1998) whereby indigenous “others” and their cultural life ways were probed, documented, essentialized and romanticized under the assumption that they would soon be absorbed into newly introduced Euro-American settler-societies, anthropologists since Franz Boas have contributed to images and representations of the indigenous peoples of North America. Much of this work has depicted (and in many cases continues to depict) indigenous communities as static, bound in place and time, and confined to remote, hidden landscapes. Such representations mask the diversity, fluidity and movement of indigenous identities and ideas, both past and present, and serve to reinforce an othering language that denies or erases indigeneity to those living in urban communities.

Indigenous peoples around the globe vary significantly in both their historical experiences and relationships to colonial governments and in present day conditions and circumstances. In North America, anthropology has had a peculiar relationship with respect to indigenous peoples (Deloria 2003). As anthropologist Talal Asad argues (1973:17),

“Anthropology is rooted in an unequal power encounter between the West and Third World which goes back to the emergence of bourgeois Europe, an encounter in which colonialism is merely one historical moment. It is this encounter that gives the West access to cultural and historical information about the societies it has progressively dominated, and thus not only generates a certain kind of universal understanding, but also reinforces the inequalities in capacity between the European and non-European worlds (and derivatively, between the Europeanized elites and the ‘traditional’ masses in the Third World)”.

Asad argues that even well intentioned anthropologists sometimes inadvertently reinforce and work to maintain the structures of power represented by the colonial system. Research was historically dependent upon colonial authorities for permission and funding and was often justified in imperialist terms. Early government programs and policies were designed to assert control and forcibly alter indigenous cultural lifeways. The Dawes Act (also known as the General Allotment Act) of 1887, for example, fundamentally changed indigenous notions of land use, as it imposed a system of individual property rights to Native peoples (Case 1984; Chance 1990; Jaimes 1992). This legislation ran counter to indigenous concepts of collective rights and obligations regarding use of land and led to the sale of trust lands and subsequent disenfranchisement

of Native peoples. Of the Dawes Act, president Theodore Roosevelt stated, “the General Allotment Act is a mighty pulverizing engine to break up the tribal mass” (Getches 1996:1584). The “Indian problem”, from the perspective of the paternalistic colonialist state, could only be dealt with through cultural isolation and ultimately integration.

The federal government's educational policies included boarding schools as mechanisms of assimilation and resulted in massive upheavals in Native family structures (Getches 1996; Fournier and Crey 1997; LaDuke 1999; Lawrence 2004; Shanley 1997; Tait 2003). The federal Indian boarding school movement had the explicit objective of assimilating Native peoples into mainstream, white Euroamerican society (Lawrence 2000; Napoleon 1996; Tait 2003; Smith 2005). Removal of Native children by way of government-run institutions of education, health and criminal justice, were powerful mechanisms of assimilation, regulation and social control that led to profound disruptions and reconfigurations of family, community and culture. One of the central goals of governmental assimilation policies was to eliminate contact with kin and tradition, specifically parent-child and elder-youth contact (Napoleon 1996; Smith 2005; Tait 2003), and to imbue Native peoples with “American” cultural values. Traditional education systems, which relied on close and frequent contact with elders and extended kin and emphasized values of humility, respect, sharing, care for elders and cooperation, were undermined and students were forbidden from speaking their indigenous languages. Residential schools fused the underlying goals of both the state (assimilation) and the church (Christianization), to transform traditional family and leadership roles of women and instead prepare female students to become “good” wives within patriarchal nuclear households headed by men (Brown and Fiske 2001; Tait 2003).

Similarly, moved by the devastating effects of infectious diseases, the Bureau of Indian Affairs (BIA) launched major health initiatives that laid the groundwork for the present-day Indian Health Service (Case 1984; Roderick 2008). Initially administered by the U.S. Department of War, BIA programs were transferred to the Department of the Interior in 1849 (Lawrence 2000). The BIA began contracting health and sanitation related concerns to the Public Health Service (PHS) in 1928, and by 1955 total responsibility for Indian Health Service programs was transferred to the Public Health Service. The PHS, which was a division of the Department of Health, Education, and Welfare (HEW), formed the Division of Indian Health, which was renamed the Indian Health Service in 1958 (Chance 1990; Lawrence 2000:401; Fortuine 1992). While these institutional expansions were framed as positive steps towards better health (i.e. sanitation improvements, vaccination campaigns, etc.), they also imbued particular sets of American cultural values and shaped health outcomes in critical, often negative ways.

Among the most powerful examples of how social injustices and structural violence were masked under the guise of improving the health and life conditions of Native peoples occurred in the area of family and reproductive health. “Stratified reproduction” is defined as the “hierarchical organization of reproductive health, fecundity, birth experiences, and child rearing that supports and rewards the maternity of some women, while despising or outlawing the mother-work of others” (Rapp 2001:469). The concept of stratified reproduction is quite useful in examining the ways in which social location embodies powerful processes of othering that define the parameters of a normative, health reproductive experience through the maintenance of an abnormal, pathologized other. Family planning and reproductive health services were first offered

under IHS authority in 1965 and the primary scope of intervention involved providing different methods of birth control, including birth control pills, intrauterine devices, spermicidal jellies and creams and, most disturbingly, sterilizations (Lawrence 2000:402). The goal of these programs was to fundamentally change family compositions by reducing what was deemed by government administrators to be an excessively high birth rate. In fact, according to the 1970 census, the average American Indian woman bore 3.79 children (all tribes combined), compared to an average of 1.30 children in 1980 (Lawrence 2000:403). Additional studies suggest that between the years 1970-1976, as many as 25% of Native women between the ages of 15-44 were sterilized without their consent (Lawrence 2000:410; National Library of Medicine 2012). The perspective of medical personnel and program administrators within such colonial frameworks was that by limiting the number of children women could have, the financial burden on federal and state welfare programs would be lessened (Kluchin 2009).

These practices are problematic in light of their direct linkages to racist eugenic policies specifically designed to regulate and control the bodies of indigenous women. Involuntary sterilization continues to be justified under a variety of circumstances to this day (Brady 2001; Pfeiffer 1994). Colonial policies and practices mask deeply embodied structures of inequality that deprive women of fundamental health and human rights (Hernandez-Avila 2005; Prussing 2011; Rosenberg 2002; Smith 2005). They also demonstrate how reproductive health encounters, profoundly shaped by social location, embody western cultural values and serve as a critical vehicle of assimilation and culture change. Aside from being powerful examples of how institutionalized structural inequality can create and perpetuate health disparities, colonial medical practices

illustrate the “violent and often virulent racist attitudes and behaviors” directed against Native American women by state sponsored biomedical institutions (Jaimes and Halsey 1992:326-327).

### **Regulating “Nativeness” through Oppressive Authenticity**

Native peoples of North America are uniquely required to prove their heritage through the submission of a biological sample. Anthropologists refer to the linking of indigenous identity with biology (or pathology) as a form of “oppressive authenticity” (Sissons 2005) that “encases Native peoples in hard-edged frames that (often) don’t make sense to them” (Fast 2008:1). Under this externally imposed practice of defining Nativeness, identity is “measured” and managed politically with respect to the amount of “Native blood” one has or doesn’t have. In Alaska, to qualify for tribal enrollment individuals must have what is referred to as a Certificate of Degree of Indian or Alaska Native Blood (CDIB) (Bureau of Indian Affairs 2013; Fast 2008; Schmidt 2011). This demand and expectation of indigenous purity and authenticity, “requires that the distinctions between ‘native’ and ‘settler’ be continuously reproduced, although always in new guises” (Sissons 2005:39). The consequences of this imposition of biological or oppressive authenticity on Native peoples is that it acts as a mechanism of exclusion when imported and appropriated by tribal organizations as a way of defining and regulating group membership (Sturm 2002). This linking of biological authenticity with cultural authenticity can become divisive within a politics of identity. It relies on stereotypical and romanticized images of “idealized simplicity and ecological belonging” (Sissons 2005:39) associated with “characteristically Native” rural village life. These

“authentic” representations are articulated in opposition to what are positioned as inauthentic or impure others, including Native peoples of mixed descent or those living in urban areas. However, these essentialized depictions ignore the colonial legacies from which they came. For example, Bonita Lawrence argues that urban Native peoples,

“Represent the other half of a history of colonization, the children and grandchildren of people removed, dispersed, and continuously bled off from Native communities as a result of ongoing colonization policies—residential schooling, termination and relocation, the theft of Native children into the child welfare system, and a century of removing Indian status from Native women and their descendents. For urban mixed-bloods and tribal people to meet, from different current locations but with an acknowledgement of historic connections and to find ways of working together across current differences, could represent another stage of rebuilding the shattered hoops of different nations, a powerful process of decolonization” (2004:14).

“Traditional” cultural values continue to play an important role in shaping the perceptual orientations of many contemporary indigenous North Americans, in both rural and urban contexts alike. However, rather than static, fixed cultural laws that require strict adherence by its members, these values serve as important orienting principles and ways of living and being that speak to the ways in which history, culture and collective memory continue to be lived in the present. While new cultural locations of Nativeness have emerged, as evidenced by a broad array of new art forms and mediums and expressions of indigenous identity, they are no longer confined to the hidden landscapes of the north. Rather, they include life in urban areas in Alaska and beyond, draw upon



shared understandings and experiences with other indigenous peoples in Alaska and the circumpolar north more broadly, and provide meaning and continuity in an ever-changing world.

The recirculation of historical accounts shape contemporary identity politics (Adelson 2000; Searles 2006). Challenging monolithic conceptions of culture that both researchers and Native peoples use to advance claims of authenticity, Searles argues that the whole concept of culture must be rethought to account for “highly mobile persons, highly flexible capital, highly porous boundaries, and highly politicized debates about ethnicity and cultural diversity” (2006:10). Struggles for autonomy are often deliberately grounded in cultural and historical particularisms and notions of “real” Natives are constructed and positioned with respect to proximity of some idea of “traditional”. This can be attributed to historical misrepresentations of “other” cultures, as well as contemporary indigenous expressions and strategic self-essentializations (Spivak 1995) used as creative strategies in exercising legal claims to sovereignty and governance. Such articulations, however, have the potential to marginalize and alienate those who live in urban areas, have parents of mixed ethnic heritage, or receive schooling and employment outside of “home” communities (Searles 2006:99). A prime example of this is the distinction often made between more traditional peoples living subsistence lifestyles in rural areas and “city Natives” living in urban centers such as Anchorage.

In articulating the structural plurality and diversity of experience characterized by modernity, Michel-Rolph Trouillot argues that “modern historicity hinges upon both a fundamental rupture between past, present, and future—as distinct temporal planes—and relinking along a singular line that allows for continuity” (2003:44) and shared

experience. This relinking involves the articulation of an imagined past and a retelling of history that appropriates common themes and creates a shared sense of being and belonging. Such articulations transcend the individual self and are linked to “larger strategies of cultural assertion and resistance in a dynamic balancing of power between the State, the disenfranchised group, and the individual” (Adelson 2000:9). Notions of “real” or “traditional” are connected to these imagined pasts in important ways. They are mobilized in the present both as a political identity and a form of engagement with the structures of everyday life.

The complex linkages between “traditional” cultural icons and the “institutionalization of tradition”, whereby “traditional” Native cultures become commodified objects to be bought and sold in tourist markets, are also critical considerations within a politics of identity (Fast 2008; Wachowich 2006:121). This linkage has become an important livelihood strategy for some Native peoples who, in order “to ensure their economic survival in the contemporary arctic environment, must incorporate into their established harvesting activities what might variously be understood as a hunt for tradition or a hunt for identity” (Wachowich 2006:122). Such commodification offers contemporary Native peoples new opportunities to earn income that, in turn, can be used to purchase the supplies necessary to make trips out on the land to hunt, fish and camp in “traditional” ways. However, this is also an essentialized view that assumes the importance or even necessity of participation in subsistence activities or rural lifestyles as the only ways to be Native. Once again these depictions rely on essentialized (often self-essentialized) representations of Nativeness that shape and constrain opportunities for urban community, identity and meaning making in important

ways. Urban areas, by definition, are sites where meanings of indigeneity are actively constructed and contested. While the performance of essentialized identities have become important and sometimes profitable ways to build cultural capital, these performances often hold little meaning for urban indigenous peoples as they go about their experiences of everyday life in an urban area (Fast 2008). By re-centering the discussion of indigenous identity onto the multivocality of everyday life as experienced by people of a diversity of social locations, common notions of “Indianness created by the colonizer” (Lawrence 2004:18) are destabilized and relations of power, authority are reconfigured.

### **Contemporary Locations of Indigeneity**

The various constructions and articulations of the term indigenous make it a notoriously problematic topic of investigation (Sissons 2005; Stern and Stevenson 2006; Strong 2005). A remnant of the colonial encounter, the term indigenous “has come to underscore a group’s persistent vulnerability, after decolonization has transferred power to the dominant group in the territory concerned” (Dean and Levi 2003:5; Tuhiwai Smith 1999). Often used as a synonym for categories such as Native, the term indigenous implies a fixed, uniformly experienced social location that obscures the diverse ways in which people live their everyday lives. An identity with political, economic and cultural dimensions, the multiplicity of contexts in which indigeneity is deployed make it impossible to apply a universal definition. However, indigeneity also implies a social location of shared colonial experience with respect to historical injustices, including usurping of Native lands, waters and resources rights and the role of the state in defining

and regulating who gets to be included as indigenous for the purposes of compensation and claims settlements (de la Cadena and Starn 2007; Jorgenson 1990; Martinez-Novo 2006). Such politics of state regulation represent important areas of research as they serve as divisive spaces of exclusion that can have profound consequences on future generations (Fast 2008; Lawrence 2004; Sissons 2005).

Challenges to such categories have become important catalysts for the creation of new spaces of indigenous solidarity, belonging, resistance and transformation (Napolean 1996). In this regard, indigenous identity “provides an idiom of social belonging for a wide range of peoples whose histories, habitats and life ways distinguish them from dominant national populations” (Dean and Levi 2003:8; Sissons 2005). As modes of political practice, indigenities are used to assert or deny autonomy, structure access to resources, construct national and transnational communities and create pockets of resistance and solidarity between groups (Brown 2003). These alliances have become important political strategies for indigenous peoples worldwide in their engagement with and resistance to various state and non-state entities.

The experience of living in an urban area, as a contemporary expression of indigeneity, is inextricably linked to colonial and post-colonial processes of urbanization (Lawrence 2004; Lobo 2003; Sissons 2005). It is a social location that stretches the physical, social, political and economic boundaries of indigenous identity. Strategies for navigating the complexities of life for indigenous peoples in urban areas include the creative mobilization of indigenous identities as a social, political and economic bargaining tool and the construction of urban-based social networks, alliances and layers of belonging as new articulations of indigeneity. As increasing numbers of Alaska

Native peoples migrate to urban areas (Hamilton and Seyfrit 1993; 1994), understanding the experience of urbanity has perhaps never been more important. How negotiations of indigeneity play out in the context of everyday life in urban areas speaks to the role of movement of bodies, ideas and notions of belonging as well as the role of the state in structuring everyday life circumstances and interactions.

While various scholars have studied the experiences of Inuit urbanity (Kishigami 2006, in Montreal, Canada; Fogel-Chance 1993 and Lee 2002 & 2003, in Anchorage, Alaska; Thuesen 2006, in Nuuk, Greenland and Copenhagen, Denmark), these studies have not explored how coerced relocation challenges and offers possibilities for reconfiguring “traditional” constructions of family, kinship, community and identity. While tribal organizations are becoming increasingly important in shaping collective social and political identities, they also play a critical role in recirculating stereotypical representation of Native peoples and reinforcing the boundaries of inclusion, exclusion and authenticity imposed by colonialist regimes. While rural articulations of Native identity continue to be intimately related to “traditional” subsistence lifestyles and the specific challenges and opportunities of village life, urban social locations are frequently excluded from or undermined within such articulations.

Understanding and documenting the experience of life in an urban area can help destabilize stereotypical representations of indigenous peoples and highlight the diversity of everyday life circumstances contemporary indigenous peoples face. It is too often assumed that indigeneity is an essentially rural condition, or that cities, “magically strip indigenous peoples of their cultural distinctiveness in order that they might join the working masses or the ranks of the unemployed” (Sissons 2005:61-63). Conversely, in

emphasizing the cultural creativity of urban indigenities, this does not imply that those living in rural areas are locked in timeless tradition or any less “contemporary” than their urban counterparts. This tension appears to be part of the colonial strategy, however, as an effective means by which “others” become subjugated globally is through the denial of the means (i.e. a public) to develop a critical political consciousness and practice resistance as a form of solidarity and an affirmation of shared experience and group membership (hooks 2001). Oppressive authenticities, whether imposed by colonial regimes or reinforced through the politics of identity, serve as an obstacle towards the creation of shared, collective identities and can reinforce arbitrary notions of difference and exclusion.

Indigenous identities are not bounded cultural entities separate from the rest of the countries in which they are situated, but rather a social location that is constantly in dialogue with itself, and therefore, like all cultures, in constant transformation (Brown 2003; Sissons 2005). As an articulation of Native solidarity and autonomy in the face of political, economic and cultural threats from external groups, the formation of collective identities serves as a form of resistance and an active (often contested) negotiation of what it means to be indigenous. Internal conflicts brought about by the conjunction of forces representing industrial, corporate, profit-making interests on the one hand with those who resist such structures in favor of more “traditional” forms of organization on the other represent a challenge to group cohesiveness. Due to substantially increased cash flow into Native communities, newly affluent people and communities face a problem of maintaining cultural boundaries and affiliations under conditions that promote increased dependence on externally produced goods and services.

Urban life is a form of spatial reimagination that stretches “traditional” kinship forms and highlights the ways in which new social relationships are produced and reproduced through friendship, the formation of and participation in new forms of community and the shared experience of renegotiating social and cultural meanings in an urban area (Kishigami 2006:215). In other words, urban indigenous social locations expand and reconfigure social, cultural, political, and economic structures and interactions, thereby creating new possibilities for the articulation of indigenous identities. This may create new opportunities for organization and political mobilization in some contexts, but it may also create new conflicts and struggles over meaning, belonging and group membership. It also raises critical questions regarding the regulation of indigenous identities through the recirculation of oppressive authenticities. Linda Tuhiwai Smith warns against such framings and argues that,

“For the indigenous world, western conceptions of space, of arrangements and display, of the relationship between people and the landscape, of culture as an object of study, have meant that not only has the indigenous world been represented in particular ways back to the west, but the indigenous worldview, the land and the people, have been radically transformed in the spatial image of the west. In other words, indigenous space has been colonized” (1999:51).

Her “decolonizing methodologies” involve shifting the relations of power and surveillance and participating in collaborative engagements with “western” structures and institutions such that indigenous sovereignty within spaces that have historically denied indigenous voices can be rearticulated and affirmed.

A powerful example of how urban life creates new challenges and opportunities for rethinking indigeneity is provided by Nancy Fogel-Chance, who explores the ways in which “living in both worlds” for North Slope Iñupiaq women in Anchorage, Alaska influences their experience and strategic decision-making (1993). She found that women actively negotiate urban space within a dynamic and interactive field that both contests and reinterprets what it means to be traditional (1993:98). Despite pressure to conform to Euroamerican conventions upon moving to Anchorage, women contested these roles and asserted their own sense of traditional beliefs about mothering, households and sharing (1993:97). Fogel-Chance’s work raises questions as to whether urban life creates a context for the erasure of Nativeness or becomes the context of its affirmation (1993:94).

Molly Lee offers another useful example of the tensions and contested meanings surrounding Nativeness in her work on the linkages between women vendors, market art and political activism in Anchorage, Alaska (2003). She explores the creative strategies employed by urban Native women who sell their “traditional” crafts in Anchorage markets. Alaska Native arts communities represent an important political, economic and social networking tool for urban Native peoples, as well as a creative and strategic deployment of indigenous identity (Lee 2003:587). However, Alaska Native art markets tend to “fossilize indigenous creativity into an imagined precolonial Native art look” and the “open-ended negotiations between artists, their communities and among themselves is still under construction” (Fast 2008:4). Having access to creative community spaces facilitates the expression and articulation a more fluid sense of self, identity and indigeneity. In this way, the urban setting becomes an opportunity for meaning making that simultaneously reinforces and contests “traditional” understandings of what it means



to be indigenous. It also offers the opportunity for creative “alternative economic strategies” (Pickering 2000) that offer a buffer against uncertain job markets and other risks associated with urban life. Creative strategies such as microenterprising, participation in art, music, theater, subsistence activities and rural-urban commodity exchanges have become essential aspects of urban indigenous livelihoods.

While it is clear that urban life represents a transformed and transformative social, political and economic field of interaction, articulations of identity within these spaces may conflict with more traditional, strategically essentialized identities mobilized by people living in villages in rural areas or by various political organizations. While access to “traditional” indigenous identities, whether through the consumption of subsistence foods, display of traditional clothing, appropriation of traditional cultural values regarding parenting and motherhood (as discussed by Fogel-Chance), harvesting of materials such as whale baleen, ivory and sea lion whiskers for “native crafts”, or the maintenance of ties to home, the unique challenges associated with life in urban areas require unique solutions and mobilizations of identity that may differ from those in rural areas. While not the stereotypical, “noble savage” image of indigenous peoples living “authentic” subsistence hunting and gathering lifestyles in harsh, arid, icy landscapes, urban indigeneity represents a creative expression of identity that challenges stereotypical representations of Nativeness and forces a rethinking of the ways in which multiple identities and social locations overlap to create new possibilities of belonging and group membership.

## **Discursive Associations of Alcohol and Native North American Communities**

Historical representations of alcohol and indigenous North American communities are powerful examples of how homogenous, totalizing depictions of indigenous experience written largely by outsiders can become normalized and accepted as part of a broader, hegemonic justification for cultural intervention. Such depictions mask the diversity of experiences individuals, families and communities face and serve to further entrench and circulate the idea that “being Native” is a cultural (in some cases even biological) risk factor for alcohol abuse and by extension, FASD. Cultural difference is essentialized and perceptions of risk and blame become racialized and gendered across an already inequitable diagnostic landscape.

While this ethnocentric association of Native communities and drinking is a popular trope in North American scholarship (Prussing 2011:10), the further association of FASD as a “Native” disease or pathology is more recent and problematic. In his best-selling and controversial work, *The Broken Cord* (1989), Michael Dorris situated Fetal Alcohol Syndrome (before the umbrella term FASD was coined) as a product of colonialism and the ongoing legacies of social inequality that specifically and disproportionately affect American Indian/Alaska Native communities. Drawing upon his experiences raising the Lakota boy he adopted, Dorris in many ways recirculates and extends many of the racial and gendered assumptions inherent in popular stereotypes of Native peoples and alcohol. For example, his rendering of colonial history as a monolithic force imposed upon a static, monolithic Native North American culture masks the diversity of experiences individuals, families and communities faced across a tremendously diverse social, cultural, political, economic and geographical landscape.

As a result, rather than focusing on the multivocality of everyday life experiences and the ways in which colonial narratives are contested and meaning negotiated by active agents, Dorris's work, by the very nature of its ongoing popularity, is both dated and yet current. It has the continuing effect of homogenizing the experience of indigenous north America. Stereotypes of Native women in particular echo and reinforce colonial narratives of conquest, assimilation, forced relocation and social inequality and further entrench the overarching meta-narrative of manifest destiny, complete with its hegemonic imperative of intervention. While his work contributed greatly to raising public awareness about FAS, in his search for answers about his son he perhaps unwittingly reinforces those stereotypes that he seeks to expose, sometimes making extreme claims in the process. For example, in a frustrated attempt to locate a source or cause of his son's impairments, Dorris suggests:

“The truth of the matter was that alcohol threatened the million and a half contemporary Indian people as virulently as, 500 years ago, a plethora of Old World diseases had decimated Western Hemisphere populations, eliminating by infection, in some cases, nineteen out of twenty people in a given community within a brief period of time” (1989: 87).

Dorris's analogy denies the agency and diversity of Native experiences in naming alcohol itself the “infectious” agent and effectively pathologizes the entire population in a totalizing narrative whereby being Native becomes synonymous with risk, dysfunction and historical trauma. It also becomes a pretext for assigning blame and justifying intervention. Despite his efforts and intentions, Dorris's work, now decades old, reinforces two major tropes in colonial accounts that have endured through the present.

First is the idea that contemporary Native North American communities are a homogenous group experiencing some form of collective historical trauma and that alcohol use and FASD is an intergenerational social and moral “disease” entrenched within a “culture of poverty”.

The second, extending out of and reinforcing the first, is the notion that Native peoples are genetically or biologically predisposed to alcohol use and FASD risk. This linking of social perception with presumed biological reality can distort medical understandings and constitutes a form of “bioethnic conscription” of American Indian/Alaska Native ethnicity (Montoya 2007). Bioethnic conscription refers to a process whereby biological “facts” are racialized through social constructions and perceptions of difference. It is a “representational slippage” or blending of social constructions of racial/ethnic difference and biological fact that serves to pathologize ethnicity and shape how difference is seen medically. The ways in which racialized discourses become entrenched within biomedical institutions and ways of knowing is of critical importance. Diagnosis embodies deep cultural meanings and assumptions that shape health outcomes in powerful ways. This kind of “race-based medicine” (Briggs 2005:270) operates to create and control the production, circulation and reception of discourses and knowledges about health, disease and healing. In this manner, the process of medicalization can be read simultaneously as a process of racialization. This is particularly relevant to a discussion of FASD and the ways in which Nativeness comes to be implicated as a risk factor within biomedical understandings and framings.

The power and authority of dominant groups is naturalized and legitimized through the biomedical encounter, and this has a profound affect on the health outcomes

of subjugated groups. The “spheres of communicability” (Briggs 2005:271) associated with colonial medicine are some of the most overtly powerful and epidemics and other public health scares can serve the interests of colonial expansion by providing a space for extending control and further asserting the epistemological dominance of more powerful groups. Health inequalities become normalized within these contexts and attention is drawn away from the global patterns of health and political economy that structure inequalities and onto the ways in which the “losers” in health disparities become “incarcerated in culture” and blamed for their afflictions (Briggs 2005:277). Structures of hierarchy, power and privilege are reinforced through everyday clinical encounters via the language of biomedicine. This language has its roots in the highly racialized discourses of colonialism, and can be seen operating in clinical settings to this day, particularly with respect to FASD and discourses about risk, blame and state intervention.

Despite anthropology’s relationship to colonial governments and its role in facilitating colonial expansion and naturalizing social inequalities, through critical, reflexive self-examination there is an opportunity to destabilize and transcend colonial power relationships and question ethnocentric, taken for granted assumptions. This requires a sensitivity to the ways in which our own perceptions shape how we see and construct “others”. When confronted and challenged, the deep-rooted historical inequalities that have characterized colonial and post-colonial relationships between indigenous nations and the federal government can help provide the context for new forms of resistance and alliance. It can also facilitate the development of a “critical intersectional analysis (that) can provide a framework for analyzing the health effects of racial/ethnic, gendered and class-based inequalities in the United States and help provide

a theoretical foundation for claiming (equity in) health as a human right” (Schulz and Mullings 2006:15). By reconfiguring the structures and relations of power, privilege and authority and disrupting oppressive regimes through critical analysis, the negative effects of health inequalities can potentially be eliminated.

# The Cultural Politics of Fetal Alcohol Spectrum Disorders and the Diagnosis of Difference

## Chapter Three: Constructing FASD, Reproducing Inequalities

### Enduring Colonial Legacies

The previous chapter examined how biomedical institutions as active agents in the expansion of disciplinary capabilities of colonial governments served to naturalize the authority of white Euroamerican paternalism and undermine indigenous values, families, communities and sovereignty. Many elements of this colonial core of biomedicine still operate today, albeit in more subtle ways, making the historical continuities between old and new forms of biopower (Foucault 1973) a necessary consideration in thinking about FASD and its expansion and racialization in Alaska. In this chapter, I will consider how biomedical knowledge creation about FASD, coupled with the expansion of diagnosis across an inequitable medical landscape in Anchorage, can be read as an example of neocolonial hegemony that reinforces racial stereotyping logics and serves to justify and naturalize a variety of state interventions and impositions into Alaska Native lives, families and communities.

Focusing on discourses, grammars, and concepts “to show how an older language of racism lends its weight to the power of contemporary discursive practice” helps to critically understand how mainstream Euroamerican normative alignments become encased in new forms of governmentality (Kurtz 2006:604). The clinic is a powerful thread of continuity between old and new hegemonic discourses and examining the specific contexts in which racial discourses are mobilized is of critical importance to

understanding how health inequalities are perpetuated. Part of the anthropological project involves revisiting history and exploring the ways in which particular renderings of history locate and reify difference and actively construct “others”. Through critical re-readings of history, the processes, practices and techniques of governments used to manage “others” can be better understood. In Alaska, colonial biomedical regimes were and continue to be powerful mechanisms of social control. The clinic, as a site through which the exercise of colonial power, authority and control occurs, becomes a powerful “sphere of communicability”, a “radiant environment” where Euroamerican beliefs, values and assumed cultural dominance were imposed upon Alaska Natives (Butler and Parr 1999:16; Briggs 2005). As an apparatus of the state, biomedical institutions were important modes of colonial penetration, serving to delegitimize traditional medical understandings and seize control over the health and health outcomes of Alaska Natives. Under the hegemony of western biomedicine, with its implicit set of values, judgments and cultural attitudes (Good 1994), significant disparities in health and health care access emerged that continue to disproportionately affect Alaska Natives in both rural and urban contexts.

### **FASD as Health Inequality**

In Alaska, FASD is an illustrative example of how historical structures of inequality and violence are mobilized in the present to bioethnically conscribe FASD onto Native peoples and, by extension, communities. Differential focus on populations predetermined to be at risk has led to a variety of confusing and conflicting public health messages (Drabble et al. 2011; Johnson et al. 2010) and state interventions that rely on



unstable, socially buttressed biomedical assumptions. Public perceptions of risk, fueled by recirculated colonialist stereotyping logics, reinforce the idea that the state must intervene into the lives of “morally degenerate or medically diseased” (Prussing 2011:9) Alaska Native communities. Mobilization of culture of poverty discourses are used to construct a logic of intervention under the guise that “unfit” mothers, from unfit families and communities, are incapable of providing care for their own children and hence must be “helped” by the state. Such stereotyping logics pervade both public and clinical perceptions of FASD and influence the lives of Alaska Native communities in profound ways. They reinforce colonial narratives of manifest destiny by “positioning Native peoples at the moral margins of the social order in the United States” (Prussing 2011:11) and are more likely to accompany health behaviors that tend to provoke intense moral response, such as alcohol and drug use.

Recent work in public health and behavioral science focuses on “social determinants” of health and disease in an effort to explain why, in reductive terms, health disparities exist for certain populations (Castor et al. 2006; Ritmanova and Gustafson 2012; van Ryn and Fu 2003). Focusing on such variables as socioeconomic status, infant mortality and alcohol and drug consumption, these studies reinforce raced, classed and gendered assumptions about risk and create a sphere of communicability that naturalizes the existence of health disparities through everyday clinical practice. While health disparities are identified as a “major problem to be addressed”, the only solutions offered are to increase funding for better research and surveillance systems (Castor et al. 2006:1484). With no consideration of the structural inequalities that underlie health disparities or the ways in which race, gender, class, identity, and citizenship intersect to

create diverse health experiences, socioeconomic status becomes a relatively meaningless catchall causal mechanism used to explain away disparities. The “solutions” to health “problems” within this framework are thus seen to exist only within the context of the system that created them. Such a perspective extends the hegemonic authority of biomedical discourse and serves to perpetuate, rather than to eliminate, health disparities.

Another common discourse that circulates in clinical contexts situates health inequalities and their alleviation within the unhealthy behaviors and lifestyle choices of people or populations in need of correction and incorporates a “save oneself” strategy of intervention (Dressler et al. 2005:234). This “individualistic fallacy”, which assumes that the causes of health inequalities lie in individual “risk factors” such as behavior, lifestyle, culture and/or genes, insists on clearly delineated and pre-figured “clinical targets” and relies on cultural assumptions to reinforce its truth claims and tailor interventions. This leads to “victim-blaming” patterns that place the problem of health inequalities within individuals or communities deemed “at risk”, thereby deflecting questions away from the structural and social factors that underlie the existence of health disparities. The narrow focus of individualized, depoliticized medicine overlooks the structural constraints that limit the ability of “unhealthy others”, incarcerated by culture, to make healthy choices.

It is important to begin discussing and problematizing standard public health and epidemiological definitions of health and inequality. As researchers, however well intentioned, we cannot allow unquestioned assumptions and essentializing discourses to pass unchecked into everyday understanding and practice. Rather, we must carefully and critically make an analytical distinction “between social relations, where the violence of inequality is most often expressed in ritualized form, leaving visible traces on the body,

and those where the violence of inequality is transcribed onto the body as biological difference and expressed as ‘risk’ to be managed through techniques of government” (Nguyen and Peschard 2003:448). By situating our understanding of health disparities within a historically grounded framework that examines inequality as an embodied form of structural violence and documents the experiences of health, illness and suffering ethnographically, anthropologists can articulate the linkages between policy, practice and everyday life and contribute to the elimination of health inequalities.

### **Biomedical Uncertainty and the Racialization of FASD**

The formalization of FASD as a medical diagnosis and construction of knowledge about risk was produced by and through preexisting and mutually constitutive processes of racialization and medicalization (Briggs 2005; Reitmanova and Gustafson 2012). Dressed within a language of universality and biomedical certainty, popular discourses often depict it as a “disease of others” (Reitmanova and Gustafson 2012:912). Images of dysfunctional, unfit motherhood are grafted onto gendered, raced and classed others and codified through diagnosis. Biomedicine thus “speaks beyond its explicit reductionist reference through the implicit ways it teaches us to interpret ourselves, our world, and the relationships between humans, nature, self and society...Although biomedicine both constitutes and is constituted by society, this interdependency is nevertheless denied by biomedical theory and ideology which claim neutrality and universality” (Gordon 1988:19). It is precisely this claim of neutrality that serves to further entrench and “pathologize” Native risk in the context of FASD in Alaska.

According to Michel Foucault, the “fundamental act of medical knowledge is the drawing up of a map: a symptom is situated within a disease, a disease in a specific *ensemble*, and this *ensemble* in a general plan of the pathological world” (1973:29, italics in original). These maps both structure and codify the spaces that people live in and walk through in the context of everyday life. In the case of FASD in Alaska, racial and cultural differences are codified in everyday clinical language and practice. Despite such high levels of biomedical uncertainty regarding etiology and causality, discourses of risk surrounding drinking during pregnancy (and Native drinking in particular) continue to exaggerate the linkages between the consumption of alcohol during pregnancy and alcohol-related birth defects.

This “knowledge” becomes demedicalized in its transformation and social recirculation in popular cultural imaginings and subsequently translated into public policy by way of increased regulation, surveillance and loss of control of pregnancy. Examples of this include the mandatory printing of warning labels on alcoholic beverages explicitly linking drinking during pregnancy to the risk of alcohol-related birth defects (the United States is the only country in the “developed” world to do so), public health campaigns such as “Not a Single Drop” (a program utilized by Southcentral Foundation), and the construction of drinking during pregnancy as a moral issue (or disorder) requiring a variety of state controls and interventions.

The transformation of an uncertain biomedical diagnosis into a demedicalized “moral panic” requiring public awareness and intervention is especially problematic (and dangerous) in relation to indigenous North American communities. The disproportionate levels of risk reported for Alaska Native women do not take into account the gendered,

raced and class-based assumptions that reinforce “stereotypes about the universality and severity of ‘Indian drinking’” (Prussing 2011:10) and pre-figure Native women and children as “at risk”. High levels of state involvement in intervention, including removal of children from families and relocation to Anchorage as a result of allegations or assumptions of maternal alcohol consumption (Rockhill 2010; Tait 2001) reflect broader social and structural inequalities. This results in the perpetuation of a hegemonic narrative that “accommodates moral ambivalence about Euroamerican colonization while ultimately justifying it” (Prussing 2011:10).

“Moral panic” surrounding FASD was facilitated by strategic manipulations of what exactly constitutes “risk” biomedically (Armstrong 2003; Armstrong and Abel 2000). By lowering the level of alcohol consumption that is considered “dangerous” to have during pregnancy, greater numbers of “victims” are created, thereby fueling the moral panic and justifying the need for state intervention (Armstrong 1998, 2003). Such discourses intentionally disassociate factors such as race, class, gender and citizenship in order to make universalist claims about risk. Insisting that FASD “crosses all lines” serves to mask the ways in which one’s social location (and not how much or how often they drink per se) defines their level of “risk”. Such considerations are generally missing from biomedical and epidemiological reports showing disproportionate rates of FASD prevalence in Native communities.

Data for Alaska, for example, shows a wide range of prevalence rates across studies, but consistently shows vastly higher rates of incidence among Alaska Natives in comparison to other racial/ethnic groups (Burd and Moffatt 1994; Egeland et al. 1998; O’Leary 2004; Quintero 2001). However, these studies fail to mention the broader

inequities in diagnostic access or the social and cultural attitudes that inform both public and professional perspectives on FASD. The raced, classed and gendered assumptions that shape “expert” knowledge about FASD are hidden and attention is effectively diverted away from inequalities in diagnostic practice. In this regard, FASD serves as a powerful example of the dangerous relationships between the authority of biomedical knowledge, the reproduction of social discourses about risk, and the everyday lives of Alaska Native women, children, families and communities.

Pregnancy and women’s reproductive health is a critical site of racialization. Biomedical knowledge and technology has fundamentally transformed the relationship between mother and unborn child, with profound consequences for women’s health and access to care (Boling 1995; Ginsburg and Rapp 1995; Hartmann 1999; Heriot 1996; Ladd-Taylor and Umansky 1998; Michaels and Morgan 1999). Literally “seeing” the pregnant woman and the unborn child as two distinct individuals rather than one, the relationship between the two becomes problematic. Increasingly, the act of illuminating the fetus serves to erase the mother, and controlling reproductive health outcomes takes precedence over the health and human rights of women. Increasingly seen as “potting soil” and managed by a “gestational gestapo” that controls the lives and freedoms of women in the name of fetal protectionism (Ladd-Taylor and Umansky 1998), the racial, gendered and class-based accusations surrounding perceptions of maternal alcohol consumption during pregnancy problematize the moral politics of risk and blame even further. How reproduction becomes managed and assisted through biomedical and state intervention and naturalized (or pathologized) through public acceptance (or outcry) has thus become an important research direction for anthropologists interested in

understanding how cultural meanings pertaining to health, illness, normalcy and risk are constructed, contested and inscribed onto bodies of otherness. It also offers a space to examine the implications of the medicalization and racialization of reproduction on the lives and reproductive health experiences of Alaska Native women, children, families and communities as well as the various ways in which these technologies are contested, strategically utilized or avoided, and rendered meaningful by people who encounter them.

Tensions between patients and professionals are often reflected in competing dialogues about medical risk and decision-making with regard to appropriate care and treatment. For example, Patricia Kaufert and John O'Neil examine the extension of medical control over childbirth among Inuit women in Northwest Territories and argue that medicalization has contributed to reproductive health disparities, particularly for women living in rural areas. Tracing the history of colonial medicine in the north, they discuss the role of nursing stations in delegitimizing traditional practices of childbirth, and uncover the ways in which Inuit women were forced to give birth in far away hospitals removed from their family and loved ones. This was due to perceptions of biomedical authority and superiority, whereby it was assumed that western biomedical clinics would unquestionably be better places to have children. Loss of control over reproductive health was the result. The state naturalized these circumstances through its race-based data and surveillance practices (Briggs 2005) which, in turn, were used to justify additional intervention and extend further control over the reproductive health and lives of Native women and communities (Fournier and Crey 1997; Kaufert and O'Neil 1990; Salmon 2011; Smith 2005; Tait 2001; 2003).

## **Tribal Sovereignty, Health Governance and the Indian Child Welfare Act (ICWA)**

As mentioned in chapter 1, the history and expansion of FASD in Alaska closely correlates to the colonial history and expansion of biomedicine, and, in more recent decades, the return of control of Indian Health Service administration to (some) tribal organizations. After several decades of indigenous activism and increased calls to decolonize health services provided under federal IHS administration, some Native communities in the United States have successfully established local control over a variety of health services (Prussing 2011:19; Tuhiwai Smith 1999). This was partly due to increased recognition of historical atrocities committed under its auspices (as discussed in the previous chapter), but also at least partly motivated by economics, as limited funding and staffing posed logistical and administrative challenges. Alaska is relatively unique in that all IHS programs are currently tribally administered. This was made possible by several important pieces of legislation, some of which are unique to Alaska.

For Alaska Natives, the discovery of oil in Prudhoe Bay in 1968 and subsequent passage of the Alaska Native Claims Settlement Act (ANCSA) in 1971 represented the most profound legislative imposition into their lives. Under the act, 44 million acres of land and nearly 1 billion dollars were offered by the U.S. government as compensation for the extinguishment of all other Alaska Native land claims, which totaled 330 million acres, and the ceding of surface rights to the land for the purposes of oil and natural gas exploration/development (Case 1984; Chance 1990; Jorgensen 1990). Additionally, ANCSA created thirteen regional, for-profit corporations (12 in-state and 1 for non-resident Alaska Natives) and over 200 village-level corporations for the purpose of



management of “corporate assets” such as land, natural resources, and socio-economic capital.

In relation to health and human services, ANCSA made no comprehensive provisions, but it required federal responsiveness to the “real economic and social needs of Natives” and sought to maximize participation in the decision-making processes that affect their lives (Case 1984). On some levels, participation in the bureaucracies of outsiders and the very existence of “corporate” tribal entities could be construed as an example of neocolonial hegemony. Power shifts from that of the panoptic, disciplinary workings of power to that of governmentalities from afar, which rely increasingly on the self-disciplining practices of subjects (Legg 2007). However, within these spaces of engagement, the potential for new spatial practices (de Certeau 1984) and relations of power and surveillance are possible. This latter view offers an interesting point of entry into questions of health governance and how the experience of disability for Alaska Natives is shaped in these contexts.

Another critical piece of legislation pertaining directly to tribal health governance in Alaska 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

2) 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, [edworkforce.house.gov/publications](http://edworkforce.house.gov/publications)).

What this has translated into for health and social service programs for Alaska Natives is that individual Native corporations, local governments and tribal councils have an increased amount of choice in terms of how to utilize federal and state funding and how to develop service delivery infrastructure to best meet community needs as defined by the community.

The next major piece of legislation that specifically addressed issues of health governance was the Indian Health Care Improvement Act of 1976, which was made permanent in 2010 (Heisler and Walke 2010). This act is considered to be the cornerstone legal authority for the provision of health care to American Indians and Alaska Natives. The statute establishes numerous funding programs “to further the goal of recruitment and retention of medical practitioners to service tribes and urban Indian organization, as well as to provide funding for training so that individuals may qualify to enter into accredited programs in various health care fields, as well as funds for scholarships so that individuals (not necessarily Indians) may obtain accreditation and thus provide services to tribes or urban Indian organizations” (National Indian Health Board 2010). This was significant in Alaska, both in terms of the transition to tribally administered health care as well as the establishment of various programs that have assisted in training Alaska Native practitioners in a wide variety of fields, including nursing, midwifery, dentistry, mental health and general practice. These programs have

been instrumental in providing training for younger generations of Alaskans, many of whom then find jobs in their home communities or in urban areas such as Anchorage.

Within a health governance framework, perhaps the most significant piece of legislation (and the one that has most affected the lives of Alaska Native women, children, families and communities) is the Indian Child Welfare Act (ICWA) of 1978 (Case 1984). The intention of ICWA was “to ensure that Indian and Alaska Native children were not removed from the communities and cultures in which they were born” (Wan 2004). However, in practice, this has been difficult to uphold, as the imposed ideas and procedures of ICWA “do not comport with the underlying principles of the cultures they were intended to protect” (Wan 2004:44). In addition, there has been inadequate support for the development of viable tribal courts to hear cases involving Alaska Native children.

ICWA “implicitly recognizes that tribal jurisdiction is not a delegation of federal or state jurisdiction to tribes, but rather is a *return of jurisdiction* that has been abrogated by statute or otherwise” (Wan 2004:46). This recognition is a critical acknowledgement of past injustices committed under federal assimilationist policies that removed Alaska Native children from families. However, it is written within a language based solely on American value systems and it requires exerting jurisdiction effectively (i.e. knowing how to utilize the system), which is often quite difficult for families. Even finding access to a tribal court can be difficult (as described in chapter 6). In addition, the congressional findings with respect to ICWA reinforce earlier attitudes of federal “stewardship” over Indian matters. For example, ICWA states that (1) “through this and other Constitutional authority, Congress has plenary power over Indian affairs” (2) that it “has assumed the

responsibility for the protection and preservation of Indian tribes and their resources”; (3) “that there is no resource that is more vital to the continued existence and integrity of Indian tribes than their children and that the United States has a direct interest, as trustee, in protecting Indian children who are members of or are eligible for membership in an Indian tribe”; (4) “that an alarmingly high percentage of Indian families are broken up by the removal, often unwarranted, of their children from them by non-tribal public and private agencies and that an alarmingly high percentage of such children are placed in non-Indian foster and adoptive homes and institutions; and (5) that the States, exercising their recognized jurisdiction over Indian child custody proceedings through administrative and judicial bodies, have often failed to recognize the essential tribal relations of Indian people and the cultural and social standards prevailing in Indian communities and families” (United States Code Title 25, Indian Child Welfare 2012).

This language is revealing in several ways. First, while it recognizes and places strong emphasis on tribal sovereignty over matters involving Indian children, it does so within an overarching, hegemonic framework that ultimately reinforces federal and state jurisdiction. In this sense, the right of Indians to self-government has always been vulnerable to abrogation by Congress (Getches 1996). Second, it acknowledges both the “alarmingly high” rates of removal of Indian children from families (and resulting family and community disruption) and the “alarmingly high” rates of foster parenting and adoption into non-Native families. Despite strong trends towards health governance, including efforts to decolonize health services through increased indigenous control over how programs are managed and administered, variations in historical experience as well

as differences in local and regional economic resources present challenges in implementation (Prussing 2011; Tuhiwai Smith 1999).

While Alaska has proven to be a leader in developing health governance models, health and social service delivery in rural areas poses ongoing challenges, including high cost of care, infrastructure development, training and retaining personnel as well as geographical challenges such as weather, terrain and lack of road access. Furthermore, cultural perceptions, enduring colonial legacies and “entrenched non-Native ambivalence about Native cultural survival in the United States have helped to continually reproduce health inequalities over the course of five centuries, often through haphazard and underfunded health services” (Prussing 2011:19). In this context, tribal efforts to address FASD within Alaska Native communities can be read as a powerful example of how health inequalities can be reproduced by expanding diagnostic capacities for predetermined social locations. In addition, lack of attention to FASD across all ethnic groups serves to reinforce the perception that FASD is a problem that uniquely affects Native communities. This kind of bias is highly visible within the State of Alaska’s current surveillance system, which lumps surveillance data into “Native” and “non-Native” categories only.

While the federal government has a long standing position of honoring tribal sovereignty (at least on paper), the last several decades have seen indications of a gradual slipping away of its commitment to honor tribal self-government. Relationships between State Office of Children’s Services and tribal organizations, for example, are often strained by historical perceptions each has of the other. ICWA continues to shape and reinforce these perspectives in many ways to this day. For example, the history of “theft”

of Indian children into State custody is well documented and serves as a thread of connectivity that informs present day experiences for many families (to be discussed in more detail in chapter 6). Under these circumstances, the authority to decide what the “best interests” of a child are is of central importance. There are often assumptions made about Native culture and/or rural life that lead to misjudgments about parental and community capacity to provide care that can shape the context and outcomes of child placements. These institutional encounters can disrupt family forms and reconfigure patterns and relations of family, kinship and indigenous identity.

### **What Can Anthropology Contribute to Current Understandings of FASD?**

The knowledge production process with respect to FASD can be confronted by calling attention to the ways in which structural inequalities contribute to the creation of manifold layers of difference and social injustice that become replicated in everyday clinical settings (Schulz and Mullings 2006:15). Working towards more collaborative, participatory research approaches that “privilege and support the voices, insights and actions of multiply subordinated groups” is offered as an alternative to conventional scientific research paradigms (Weber 2006:44). Under these conditions, research and more specifically ethnography, becomes an active dialogue whereby the relations of authority are transformed and the “researched” take on a central role in articulating how health inequalities shape and constrain the experience of everyday life. Examining how difference is reinforced across multiple socially constructed categories of otherness offers a unique vantage point from which to work towards a more equitable and inclusive society where health inequalities do not exist (Morgen 2006:406; Weber 2006:48).

Anthropologists are particularly well positioned to deepen our understanding of the ways in which FASD is shaped by broader historical and structural inequalities. By integrating a critical, historical analysis that questions the biomedical assumptions, categories and causal mechanisms that are frequently used to “explain away” (and inadvertently reinforce) health inequalities, we can begin to deconstruct and decolonize our approaches and thus eliminate disparities in health outcomes. Working alongside professionals from a variety of disciplines, anthropological perspectives can be used to help develop a more nuanced understanding of how and why disparities in health outcomes persist. By critically questioning our own ethnocentric assumptions and understanding how they shape the construction of knowledge about FASD and inform both social perceptions and beliefs about appropriate intervention, these kinds of collaborations are becoming increasingly imperative as the structural conditions of inequality deepen and worsen (or become more effectively hidden), and the gap between healthy and “unhealthy others” widens.

In Alaska, understanding the ways in which the racial and cultural politics of FASD have played out over the last several decades can help to correct past social injustices and build more responsive, inclusive and collaborative modes of engagement with tribal, state, federal and non-profit organizations and the people they serve. A reading of current legal and jurisdictional issues surrounding removal of children from families and placement into non-Native foster care shows the ways in which gendered, raced and class-based cultural assumptions regarding possible maternal alcohol consumption during pregnancy shape and inform state agency interventions.

Critical theoretical insights can be incorporated into existing biomedical structures and legal institutions, thereby “changing the relations of surveillance” (O’Neil et al. 1998) and building more collaborative health care relationships and jurisdictional arrangements (Adelson 2000). Researchers from a wide variety of disciplines have been complicit in allowing for the continued marginalization of and paternalism towards indigenous peoples. This, in turn, has reinforced public stereotypes and perceptions of risk and blame. As researchers we need to be more aware of the potentially harmful consequences of research and seek out ways to build strategic research partnerships. Shifting the relations of surveillance, in this context, is a matter of enabling the “subjects of investigation (to) produce (their own) disciplinary narratives” (O’Neil et al. 1998:230). Such a shift necessarily involves loosening the biomedical “power over” the production of knowledge and authority and creating alternative discourses that challenge the legitimacy of dominant epidemiological and legal understandings.

In the next chapter, I turn to the stories, narratives and experiences of individuals and families in order to illustrate how the above-mentioned inequalities shape experiences of everyday life. For Alaska Native families and communities, the stakes are high, as diagnosis, even suspicion of diagnosis, can set in motion particular types of clinical and institutional interactions that are not present to the same degree across ethnic groups. Profound family and community disruption, including removal and relocation of children, are often the result. The specific stories and family narratives that were shared with me speak to both the importance of addressing health inequalities at the structural level as well as the necessity of improving programs, policies and service delivery



practices for all families who face the everyday challenges associated with living with and supporting a family member experiencing impairment/disability.

## The Cultural Politics of Fetal Alcohol Spectrum Disorders and the Diagnosis of Difference

### **Chapter Four: “So, the First Thing, Without Even Talking it Over, They Took the Baby”: Narratives of Family, Community and Cultural Dis/continuity**

Structural inequalities in FASD diagnostic capacity and program implementation disproportionately affect Alaska Native families and communities and reinforce perceptions of risk, blame and appropriate intervention. In this context, Anchorage is an ideal location to examine how the experience of impairment/disability proceeds as a result of diagnosis. High rates of state involvement frequently and disproportionately result in removal of Alaska Native individuals from home families and communities. Many of these interactions involve relocation to Anchorage, where community, identity and kinship are reconfigured in profound ways. Sometimes relocations can be temporary, pending court hearings or parental compliance issues, while other times they can be permanent placements (often solidified through adoption). For example, of the 28 families interviewed during research, 18 involved placements in non-Native foster or adoptive family settings, while 10 involved placements with extended natural family members, such as grandparents, aunts or uncles. In extreme cases, interactions can involve relocation to an out of state Residential Psychiatric Treatment Center (RPTC) or involvement with the criminal justice system. Stories provided by families illustrate the ways in which these interactions constrain everyday life experiences in a number of ways and require creative strategies for families to stay together and mobilize the supports needed to manage the impairment/disability of their children.

## **Deviance, Compliance and the Racial and Cultural Politics of Risk and Blame**

Living under the umbrella of state surveillance or suspicion with respect to FASD can trigger sets of interactions and impositions that affect Alaska Native families in particular ways. Ethnocentric cultural assumptions regarding Alaska Native communities (particularly in rural areas) often pre-figure these interactions and relationships. For example, as described by a tribal leader I interviewed,

“I think there is a lot of misdiagnosis. In a lot of the villages, a lot of the children from the villages, and I know this for a fact, they have issues at home, so how have the western doctors and teachers and clinicians been dealing with them in Bethel and I am sure in other locations throughout the state, like Barrow, Kotzebue, Nome, where they’re coming from villages where assumptions are being made and they don’t even know the families? And the doctors, many of them are interns that make a diagnosis like that without even really having the training or the background” (LA-001-009).

Fully aware of the implications of diagnosis and the ways in which even suspicions related to maternal alcohol consumption during pregnancy can affect families and communities in profound ways, this individual further explained,

“It’s kind of like a diagnosis for two. If they give out a diagnosis of FASD to a child, that implicates the mother as well. One family that I know of, they were really insistent that their child had ADHD or something like that because he was having trouble at school and he was misbehaving. I was probing a little bit about the history and they just didn’t want to go there, you know. And I understand.

And the thing is, I think a lot of families are doing that whether they are Native or not because of the stigma around it. Because if you talk to me and I said, no, I don't drink, yet I may have a child who is having some challenges. But then you go and talk to someone else in the community and she says, oh yeah, she drinks every weekend. You are going to hear people say nasty things about each other. You can't rely on just that one source. You have to go back and ask a variety of people, and that's not what's happening. You are getting the input of one person in the community like a schoolteacher or a school psychologist that isn't even from here" (LA-001-009).

These comments are revealing in a variety of ways. They speak to both public perceptions about stigma, risk and blame as well as an awareness of the ascribed social difference embodied in diagnosis. In this manner, diagnosis is clearly understood to have social, political and family consequences. Furthermore, the general sense of distrust when referring to "outside" teachers and clinicians as not understanding the families and communities they are working in speaks to the underlying racial and cultural politics that shape the context of diagnosis and intervention.

### **Moved by the State**

Diagnosis of FASD (in some cases, even the suspicion of diagnosis) has a profound influence on patterns of residence/location, family/kinship forms and disability outcomes. As described in the following examples, it sets in motion particular sets of state practices, discourses and institutional relationships that vary tremendously based on

race/ethnicity, cultural identity, socioeconomic status and other dimensions of difference that, taken together, constitute social location. Such encounters reveal the ways in which everyday life constraints for families become part of a broader hegemonic and neocolonial narrative of Native cultural degradation, which is then used as justification for state intervention. Several people I spoke with described family disruption and relocation as prominent themes in their everyday experience. However, the manner in which individuals and families became “on the radar” (Ryan and Ferguson 2006) of state surveillance and intervention was often the result of cultural misunderstanding based on pre-clinical assumptions, accusations or suspicions. For example, in describing her experiences in obtaining custody of her grandchildren following years of custody disputes, foster care placements and interactions with state institutions such as the Office of Children’s Services (OCS), a natural grandparent I spoke with explained:

“Until I came back up here to Anchorage, my son’s kids were in OCS custody. He was having problems (with his job and family life) and I tried to step in and help. I turned around and they said, that was the first thing that came out of OCS’s mouth, ‘well, she is considered an unfit mother’” (SL-001-006).

This grandparent describes how, despite her best efforts to comply with OCS directives, caseworkers were highly skeptical of her ability to raise a child, even suggesting dislocation from family and community and relocation to Anchorage as the best remedy for her situation. They were having difficulty making rent, her son was having respiratory problems that required hospitalization and ultimately surgery, and from her perspective, professional caseworkers were using her challenging life

circumstances as evidence of her inability to raise a child, which caused her great emotional hardship. She explains further:

“My caseworker back home said to me, ‘the only way you’re going to keep these kids is to move out of town’. So, as soon as I got the kids back I moved and then we came up here (to Anchorage). It was the only way we could keep them. It was really hard when we first came here. I didn’t have hardly any money at all. I did the best job I could to find a suitable place for us. I have five grandchildren down there. But, you see, I came up here because my son needed me and he needed that help. The place we were staying in was twice as small as what we were in down south (in Juneau), the carpets were moldy and it was just unbelievable the way OCS was treating us” (SL-001-006).

The experiences of this grandparent reflect the ways in which historical and structural inequalities can bleed into contemporary practice and serve to discipline the movement of bodies across time and space. The everyday life constraints of both her and her son became a pretext for a whole series of associations ranging from uncleanliness to poverty to suspicions of alcohol and drug use. Her story speaks to the ways in which locations of impairment/disability, community and cultural identity shape clinical perceptions of difference. Discourses of risk, blame and moral authority to intervene in the lives of Alaska Native families and children are constructed in a variety of strategic, often competing ways by the foster, adoptive and extended natural families I interviewed. Differences in how these narratives are constructed thus represent critical windows for

anthropological analysis. As another extended natural family member (grandmother) explained,

“There was a home visiting nurse from the hospital here. And she was, uh, how would you say, she thought of herself as a social worker and she didn’t have the training. And she just dabbled too much into our lives and she didn’t like the way we lived, you know, not at all. I had been cutting up some caribou and the house maybe wasn’t as clean as I would have liked. She thought we were too dirty and she kept harping on it, saying this or that was unsanitary, that I needed to be careful of germs while cleaning the meat, everything. And at the time I think I was between jobs. I was having to deal with her because my daughter was pregnant and she’s got a brand new baby and I was helping her but having some difficulties in getting a new job, and we had money problems. We just had problems galore, you know? She didn’t seem to care about that at all” (HJ-001-007).

Her undermining of the authority and knowledge of the caseworker provided an opportunity for her to explain and situate the challenges she was experiencing in everyday life. They also provided an opportunity for her to assert her motherhood and articulate the great lengths she was prepared to go in order to keep her family together. Her daughter, adopted from a family within her tribe, struggles with mental health problems such as depression and experiences learning disabilities. She was involved in an abusive relationship with a man who was hitting her and she became pregnant. She struggled with depression throughout her pregnancy and had been receiving behavioral

health services. Following the birth of her son, she experienced severe post partum depression, which prompted a home visiting nurse from the hospital to do a home visit. They were struggling to pay rent and keep up with household responsibilities, and based in this initial interaction the home visiting nurse reported the family to the Office of Children's Services (OCS). The woman's mother, appalled by the treatment they had received, explained,

“I think I was too much embroiled in this terrible situation of this house being so dirty and my daughter was just incapacitated by her depression and I was getting depressed and neither of us were working and just totally out of it with a brand new baby, just the whole works. So, the first thing, without even talking it over, they took the baby. We went down to a meeting that we were required to attend and they said, and besides not only that, I had a broken arm at this time too and I couldn't drive or do anything so my brother drove me down and I had the baby and they said, 'we are taking the baby right now'. Just like that. The nurse had the baby in her arms, she was, you know, just holding him. She said later on to me that she almost cried and that she was so shocked that they, just like that. Just like that, no talking, no nothing. They didn't do anything to try to relieve the situation or give us a chance to keep the baby. It all started because they had this rule that if a patient, a mother, had learning disabilities or any type of emotional/mental health issues that a nurse has to do a home visit” (HJ-001-007).

This initial interaction set in motion a long and emotionally taxing set of events that led to the child being placed in foster care and a long and difficult battle with the state



over custody. Her struggle raised several fundamental issues of sovereignty and authority to decide what is in the “best interests” of an Alaska Native child. As further explained,

“I was doing everything I possibly could to get the baby back. They already had me in the system because I adopted my daughter and so I have dealt with them (OCS) before. And they said, ‘unless you have a family member who can take the baby we are going to put him in a foster home right now’. And I was so shocked, I didn’t know what to do. I’m not from here. My family is not from here. I came here to try to help my daughter and her baby and this was what was happening to us. So anyway, that started a really rough road. They tried to get him adopted into another family and OCS and the nurse all agreed that he was happier over there, but he wasn’t. He was terrified. He used to cry after us when we visited him. He would crawl after us as fast as he could and cry. He would scream. It was a really bad situation. And OCS didn’t like me because I was too forward. I was too outspoken. I went to all the meetings my daughter had with them. It was just really, really bad and it went on and on and on. And they were going to cut off parental rights. You know, we were just not fit to be parents for this baby that wanted nothing more than to be with his family” (HJ-001-007).

This narrative speaks to several important issues, including the assumptions made based on cultural perceptions of difference that severely constrained this grandmother’s options and limited her ability to obtain custody of her grandson. While her daughter continues to have mental health challenges, she now lives in an assisted living facility

and the grandmother, after a long series of bureaucratic hurdles, was finally able to bring the baby back home. However, as she explained,

“They gave me back the baby and so my daughter came over to see him. She was living in an assisted living home at this time. We had a meeting scheduled at my house and so the caseworker could see and when she came over that’s when they said nope. Taking the baby right this moment, this is totally against the rules. She is not supposed to have any contact whatsoever with the baby. I said, ‘well nobody told me’. If I had known that she wasn’t supposed to be there I wouldn’t have let her and not only that, I wouldn’t have announced it publicly and told on myself. And they didn’t care. They didn’t listen to a word I said” (HJ-001-007).

Failure to comply with a requirement she was unaware of, this grandmother lost custody of her grandson yet again. OCS was now seeking a permanent placement for the child and her “deviance”, coupled with a perception of cultural difference and otherness that assumed her lack of parental capability and fitness, was used as justification for removal. Frustrated with the lack of response she was getting in trying to retain legal assistance to complete a formal adoption process so that her grandchild could stay living under her care, she further described,

“Nobody was helping, nobody wanted to get involved. Nobody in the world would help. I called legal services. They wouldn’t help. I eventually refinanced this condo and hired a lawyer to get the case moved out of the state and into the tribe. It cost me twenty five thousand dollars, but we got the case moved out of the state and into the tribe. It took a little over a year. We’re still waiting for the

adoption to become official. As soon as we transferred it, the tribe said I could have him back because, what's wrong with me? There's nothing wrong with me" (HJ-001-007).

This narrative speaks to the great lengths this natural grandparent was willing to go in order to retain custody of her grandson. It also demonstrates her knowledge and experience navigating a complex social, political and legal landscape. Additionally, the fact that she needed to leverage twenty five thousand dollars in legal fees to pursue the case and had those resources available raises critical questions about those who may not have access to such resources. As discussed earlier, only those who demonstrated an overall willingness and readiness to participate in this research were interviewed. It is easy to see how someone in the midst of learning how to interact with and utilize available resources would be overwhelmed by these institutional interactions, perhaps to the point of avoidance altogether. The grandparents I spoke with all would likely have had their family members placed in foster care or permanent adoptive placements if not for their diligence, knowledge and desire to have their family remain with them. As described by another grandmother,

“You know, the whole reason why I do this is because it makes a difference whether a child goes with a non-Native foster family or can stay and in some way stay connected and rooted in culture and family” (CM 001-013).

While this comment echoed that of many other grandparents in its commitment to family and community preservation and re/unification, it stood out to me as an important

way of addressing this problem—extend natural and community level supports and build more inclusive and accommodating communities by hearing peoples’ stories and learning from their experiences. In addition, we can develop a heightened sense of awareness of the ways in which structural inequalities persist and are reinforced by cultural constructions and perceptions of difference. These constructions are recirculated in everyday diagnostic and clinical practice and inform program and policy implementation in ways that perpetuate rather than alleviate health inequalities with respect to FASD.

### **Sovereignty, Health Governance and Indian Child Welfare**

The apparent and understandable distrust many natural families feel with regards to state channels for resolving legal custody disputes is reinforced in a number of ways. For example, one natural grandparent, in describing her struggles in finding and transferring a custody case to tribal court, described a tumultuous legal battle over jurisdiction that lasted over a year. As she explained,

“They fought the transfer. The state wrote this terrible thing about the village, about how terrible they were, how biased they are. It was really, really bad. They just tore into the Natives in that thing. So the judge and the lawyer responded and said, ‘the issue here is that this is an Indian Child Welfare Act (ICWA) case and it should be decided by tribal court, by the tribe. And that’s the whole issue and the issue is not at this point who gets the child or what happens, but the issue is jurisdiction” (HJ-001-007).

While the grandmother was ultimately granted custody of her grandson, she had to mobilize all available resources to her and leverage whatever options were available to regain custody. Her willingness to refinance her condo, comply with OCS directives at every step of the way and sacrifice all she had speaks to both her perseverance as well as her creativity in engaging a variety of channels and locating the appropriate resources to resolve her grievances. In addition, the legal and jurisdictional issues this family experienced highlight the broader racial and cultural politics that shape family outcomes as well as the broader institutional inequalities that reinforce perceptions of difference through a variety of state, tribal and clinical practices. These differences can be seen in the highly essentialized discourses research participants would draw upon to inform their experience as well as the language used within the institutions themselves. For example, while the family described how distrust characterized their perceptions of state caseworkers and outsiders in general, the state also had its perceptions of difference and misunderstandings that affected family outcomes in profound ways. Within tribal court settings, it was further explained,

“The state viewed the tribal court as biased. They were acting like, ‘oh, here comes another ICWA case’. They don’t even know the court. That the court is just going to do what I want and can tell the court what to do and what to say just because it is a Native child. It doesn’t work like that. They have their ethics too and they have their procedures to follow, but anybody who knew this case first hand knew that I was the best person to get the child because out of all the people in his whole life, I was the one that was there from the beginning. I was there at

his birth. I was the first one to see when he got cleaned up. I was there and I have been with him all his life” (HJ-001-007).

My research reveals that the experiences of this family as they were related to me are not uncommon. As an outsider, I was continuously impressed by peoples’ strength and willingness to share their stories with me. Perhaps it was partially due to my status as an outsider that people felt more comfortable in sharing their stories and experiences with me. More importantly, it seemed as if simply having someone to listen to was important for families. At one point during the interview, I reiterated to one grandmother that I was willing to sit and listen as long as she was willing to share. I told her that I was learning a lot from just listening and that I thought her story was an important one that others could learn from. At that point she quite candidly asked me, “How many Natives have you interviewed”? I replied that I was trying to talk to as many people as possible and her response was,

“You won’t find many of us, because children like my grandson almost always end up in foster care, and most foster care situations, even most adoptive situations are non-Natives. And that was the whole reason why I got into this in the first place. I said, look what’s happening, you know? These kids are getting separated from their culture and their families and communities. Their own culture. I mean it’s just so totally different. I wanted him to be involved in our tribe and our traditions. That just doesn’t happen enough” (HJ-001-007).

These sentiments were reiterated by another tribal leader who, in discussing the importance of keeping children in their home communities and learning new ways of accommodating individuals who experience impairment/disability, stated,

“One of the most important things that needs to happen is to keep children in their home communities. Instead of saying, let’s let someone else take care of them because they don’t understand what is going on in the child’s mind or in his body or his emotions, we need to train our family and community members to know how to deal with that child. If we don’t know how to raise our children with disabilities, how can we successfully raise them and put them out in society, and be a part of society and contribute? And it is frustrating for the kids too, you know. Sitting in school, struggling in reading and math, and the kid is wondering, ‘how come I am not getting it and everyone else is getting it’? And even the stimulation over the lights or not having a quiet place to sit down and take a rest” (LA-001-009).

These comments illustrate an awareness of the need to keep families and communities together through increased access to tribal courts as well as the need for increased knowledge, education and training to improve community capacity for care. This was reiterated by another natural grandparent, who discussed the importance of expanding access to tribal courts and improving relations with state courts. As she describes,

“I would like to see Alaska Native villages and corporations strengthen their court system and legal system. When I tried through my original village where I was

born, they don't even have a court because I no longer reside there and they would have to hire a lawyer to draw up all kinds of papers to incorporate the whole thing to make it fall under ICWA, because they would have to get a lawyer (funded) under ICWA so they would have money to pay the ICWA workers and so on and so on. This is a really big issue. Not everyone has access to a tribal court depending on where you are in the state and what tribe you are affiliated with and where you live. Since I live in Anchorage, they tried to say that I didn't fall under any tribe. We tried and tried and were finally able to get it transferred to a tribal court but it took a long time and they made me check with just about every other tribal court in the state before they accepted me. Each one had to send a letter saying that they wouldn't take me because I'm not a resident. They had to do this for their records because they were taking somebody who is not from their tribe and thank goodness for them. This is what I had to go through just to have the case even heard in tribal court" (BM-001-015).

Sovereignty and the issue of jurisdiction was a central theme that emerged in collected interviews. For Alaska Native families, the stakes are high, as interactions with state entities, which are at least partially shaped by the racial, cultural and gendered politics of accusations of maternal alcohol consumption during pregnancy, can contribute to high levels of family and community disruption as well as a negotiation and reconfiguration of family, kinship and indigenous identity. For many of the extended natural families I interviewed, relationships and interactions with state, non-profit and other outside entities were characterized by high levels of tension and distrust.



How the best interests of a child are defined in a court of law and enforced through a variety of practices is thus largely a cultural consideration (Blackstock et al. 2004; Wan 2004; Tait 2003). Frequently, assumptions were made about Native culture, particularly in rural areas, that are used to justify and naturalize intervention. These interactions, in turn, reinforce essentialized (oftentimes racist) discourses of risk and blame and serve to alienate Alaska Native families from the very institutions that were set up to provide assistance. As a result, it becomes difficult to develop meaningful dialogue around the issue of “best interest”, as ethnocentric cultural assumptions and misunderstandings continue to characterize the relationship between Alaska Native communities and outside institutions. This also has a polarizing effect on how discourses surrounding FASD are constructed and operationalized in everyday life. For example, for many of the Alaska Native extended families I worked with, interactions with the state could lead to, in extreme cases, removal of a child from the home family and community. This was often described as “theft” of children (i.e. “the state stole my child”), and the highly emotional accounts of families losing loved ones or perhaps relocating themselves to be closer to their family members speak to this.

Conversely, within non-Native foster or adoptive families, cultural assumptions regarding Alaska Native families and communities fueled perceptions that Alaska Native women were more likely to be “unfit” mothers incapable of keeping their children, even when their family history was unknown. While distrust tended to characterize the perceptions extended natural families have of “outside” intervention, households in which foster parents were raising a child with FASD frequently recirculated popular stereotypes about “Native drinking” and perceptions of risk. For example, as one non-

Native adoptive parent who explained the history of how she came to adopt her children described:

“Her mother couldn’t or didn’t want to take care of them. She was dropped off at the shelter with a suitcase. The mother of these girls is a homeless person on the streets here in Anchorage. She is an alcoholic and undoubtedly has a lot of mental illness. I don’t know her well. They camp around the woods, eat at Bean’s and live at Brother Francis when it’s cold. Unfortunately, this is pretty common in Anchorage and I’m just glad the state is doing something to protect these children” (WJ-001-002).

This narrative is revealing in a number of ways. First, it contains elements of popular (mis)representations of contemporary indigenous life, including social dysfunction, mental illness, alcoholism and homelessness. This is elaborated through the imagery of camping in the woods adjacent to the major urban center, the “degraded Indian”, lost in an unfamiliar urban landscape hanging on to the last vestiges of the wild, remote, hidden landscapes from which they came. This kind of “stereotyping logic” (Prussing 2011:9) distorts the diversity of indigenous experience and reinforces essentialist claims about the “inevitability of ‘Indian drinking’” (Prussing 2011:20), as well as its causes and appropriate “solutions”. In addition, this narrative speaks to the trope of protectionism, whereby the state must protect children (in this case through removal) from their own families, communities and cultures.

Such essentialized discourses were uncovered at various points throughout the research process. In this regard, it was almost as if one’s social location influenced the construction of both “the problem” and its appropriate solutions. This was also apparent

in the professional settings examined where assumptions about the presence (or absence) of FASD were often made before an individual had even seen a diagnostic team (to be explored in more detail in chapter 5). While these general patterns of response are revealing and important in a number of ways, it is critical to point out the diversity of responses and lived experiences collected during research. No two experiences are alike and while there were many similarities shared across the interviews conducted, there were also important exceptions. For example, as one foster parent described,

“Sometimes you have no idea what these children have gone through. The state (OCS) intake goes to these houses, investigative workers. They find out or hear in some way that there’s an issue, and they really don’t know what that child or family is all about. What they’ve gone through, how they act, behave, what their lives are all about. What their history is. And they see them for less than twenty-four hours and they bounce them from place to place. These foster parents get these children and, well, here you go” (PM-001-011).

This foster parent’s comments reflect an awareness of the systemic level problems and inequalities that contribute to uptake into state foster care systems. While stereotypical, essentialized discourses of risk and blame are mobilized in a variety of different ways, they also appear to be actively negotiated and contested. As explained by another foster parent,

“I think there are a lot of misconceptions out there (towards Native communities). Not everybody thinks the same or lives the same or acts the same. Even within families, sometimes parents don’t even agree about how best to raise the children.

You have to be understanding, and open to people's behaviors. You don't have to accept them all, they are not all acceptable, but you do have to be open and understanding that not everybody is going to be just like you and not everybody was raised just like you. Some of these things are really engrained though, you know? I mean, I remember my mother used to tell me that if a Native woman has even one drink of alcohol, she is an alcoholic. How crazy is that? My family consumes alcohol at get-togethers. How is that any different?" (WJ-001-002)?

These comments reflect sensitivity to the ways in which racial and cultural misunderstandings circulate in ordinary, everyday language and discourse and become reified through clinical and institutional practice. They also illustrate that while there are common misperceptions among people of differing social locations, people actively challenge and contest these representations through critical dialogue with other families, community members and a variety of state, tribal and non-profit entities. For example, as one natural grandparent and tribal leader explained,

"There needs to be a lot of educating of both families and communities, as well as with people over at the state and OCS and all these places. There is a lot of back and forth. A lot of accusations on both sides of the fence. And I think that is one of the biggest issues with OCS/tribal court. They aren't working together. Both are supposedly working for the child. What's best for the child, and they also need to be looking at what's best for the family and community. It's all one piece. It can't be separated out like that. And that's not what's happening. It is always about what is best for the individual child. And it's, you know, the person

who's writing the paper, who's signing the forms saying, 'this is what's going to happen to the child'. They are not looking at the whole picture. They labeled the mother. They have already decided what her future is like. And it needs to be a family systems program where we are involving everybody" (LA-001-009).

These comments similarly reflect an awareness of the ways in which polarizing discourses of risk and blame are reinforced in some contexts yet contested in others. Her call for a more open and collaborative dialogue about how we think about and construct "best interests" culturally suggest a recognition of the need to address inequality at a systems level and broaden the conversation to include community members from a variety of sectors, including those who may not be directly involved in the lives of people with FASD and their families. As was further explained,

"We need to educate, you know, the whole family. We need to educate the villages, the communities because there's that stigma of, you know, she's an alcoholic, she got her kids taken away again. So what can we do to help her succeed? What can we do to help the family and community succeed? Instead of shunning her or labeling her, we can say, you know, let's help you. And the kids too, you know, 'oh this is just an FASD Kid, let's send him to Anchorage'. We need to look at how this is affecting our communities too" (LA-001-009).

Listening to the perspectives of community leaders as well as family members who live with and have experienced the consequences of cultural misunderstandings and stereotyping logics most closely is a critical step towards understanding how difference is

constructed at multiple levels and how it constrains everyday life possibilities for families and communities. It also offers an opportunity to construct a more nuanced dialogue that captures the diversity and plurality of everyday life experiences across communities in Alaska and beyond.

### **Experiences with Diagnosis**

A common theme among the foster, adoptive and extended natural families I interviewed was the difficulties they encountered in learning about the impairments of those they live with and support. As one adoptive parent explained:

“It was recorded that mom was drinking and the child was having major behavioral issues. She was two years old. What do you expect from a two year old? And I had two kids of my own in the house and we brought them home. We picked them up from day care and the emergency placement dropped them off and we met them there to introduce ourselves and she left. When they got out, we took them home that day and that was it. And they came with a garbage bag full of stuff. And we didn't know what to expect. She was very quiet. A beautiful little girl. We were just so excited. Then it started where she was afraid to go into the bathroom. Afraid to have a bath. And she wasn't potty trained at that time. She wouldn't go to bed. She would stay up and wanted to lie down in the bedroom. It got to the point where we'd just let her fall asleep, wherever she was and then put her to bed. Little things like that you have to go through. You don't know what you're getting. She's two years old and you've never met this child. You didn't raise her. You don't know what to expect. She'd get up in the middle of the night and find her way to

the kitchen and make food. As time progressed, she would sneak around the house. You know, at two years old! What do you expect? You're sleeping. You think everything is normal but it's not" (PM-001-011).

This narrative illustrates the uncertainty and subsequent challenges in accommodating the impairment/disabilities of a newly placed child. For this foster parent, not knowing exactly what was going on with the child, including the history, made it difficult to respond as a parent. As she further explained,

"The behaviors were a concern for us. As a foster parent, you never quite know what's going on. You find out they've been in several foster placements and none of them have worked. What do you do? How do you help that child? In some cases, they've been in placement as long as they've been alive, but everyone says they were fine or the foster family is fine or the adoptive family was fine and then you find out it wasn't all that good of a placement. It wasn't all fine. You almost ask yourself, 'can I keep them'? There was a lot of change. She has been moved around a lot. We were in the middle of a move ourselves and she changed schools. She lost it. She didn't understand the move, the change, the house. She was totally lost" (PM-001-011).

Another parent, both foster and adoptive, echoed these feelings of uncertainty and frustration in trying to learn how to communicate and interact with educational and service delivery systems. He suggested that FASD is unique in comparison to other

impairment/disabilities due to the wide variety of presentations that fall under “the spectrum” as well as its relative invisibility. As he described,

“It’s like, we know he’s experiencing some challenges. He’s struggling at school. He’s not connecting with others. He’s not following instructions. If you know a kid is coming to school in a wheelchair, you don’t wait for him to fall before you build a ramp, just like you don’t ask an amputee to hold a cup for you. Why aren’t you taking it? My expectation is that everybody has two arms. They can go for it. I think that’s it. You know we’re too tired as human beings to do it. We’ve been trying. We’ve been working at it. What you need, what you really need, is an environment around that kid, you talk about like a cognitive wheelchair but it’s more than that. It’s a cognitive ramp. It’s a cognitive house” (OT-001-005).

Another adoptive parent of two girls with FASD described the differences in their experiences. One came to her with a diagnosis and the other, while strongly suspected, did not. As she describes,

“One of my daughters came with a diagnosis. The other has never been diagnosed but she is beginning to realize that in all probability this is what is going on with her. It was a night and day difference. It was almost like we knew what we were getting into with one but not the other. Well kind of. She was diagnosed early in school and that was during a time when they were doing this big thrust of finding kids who have FASD. At the very least, this helped us focus our efforts with the school and helped us develop strategies to work with



her. This was also true for my other daughter, but we just didn't have that certainty. We didn't know, even though as time went on, more and more we started becoming more aware that this may be going on. I think she struggled more because of this" (WJ-001-002).

Experiences with diagnosis and subsequent attempts at working with educational, health and social service entities, institutions and bureaucracies vary considerably from one family to the next. Some of the specific strategies that families and communities are utilizing to advocate for their children and community members are the subject of chapter 6. In the next chapter, professional framings of FASD and its appropriate solutions and interventions will be examined, including current policies and initiatives that are affecting individuals diagnosed with FASD and their families in critical ways.

# The Cultural Politics of Fetal Alcohol Spectrum Disorders and the Diagnosis of Difference

## Chapter Five: “Must be an FASD Kid”: Framing FASD and its Solutions

### Disabling Worlds

Living with and supporting a person with FASD can be challenging, stressful and, at times, overwhelming for families. Few community based resources, services and supports are available through state, tribal and local community organizations for individuals who experience FASD, due in part to its newness as a diagnosable biomedical condition. There are difficulties inherent in neatly fitting the range of impairments associated with FASD into one, catchall diagnosis. Many of the impairments associated with FASD (such as learning and mild cognitive impairments) are not easily noticeable and express themselves in a variety of ways from case to case. As a result, many individuals have difficulty obtaining the specific, individualized supports they need in the areas of education, daily living skills (including personal safety), social/community inclusion and employment.

Policies and practices with respect to FASD in Alaska have undergone substantial changes over the course of the last few decades. This tenuous history has been marked by expansion in diagnostic access as well as expansion of surveillance techniques to monitor the epidemiology of FASD over time. As discussed earlier, many of these early efforts were characterized by inequalities in public perception, diagnostic access and focus of prevention/intervention. While many improvements have been made at the systems level, many of these inequalities persist to this day. Of particular concern,

however, are the ways in which these inequalities permeate into professional and other “expert” settings. These settings are powerful vehicles for the reproduction of health inequalities and must be examined critically to avoid the unchecked, hegemonic perpetuation of authority and misunderstanding.

### **The Problem of Locating FASD**

As described in chapter 3, this history of FASD in Alaska is only a few decades old. The earliest diagnostic work was targeted exclusively towards Alaska Natives and drew upon federal Indian Health service funds. This was prior to the health governance movements, which facilitated the transfer of administrative responsibility for administering tribal health programs to tribal organizations. Unlike more concretely definable impairment/disabilities, FASD can be difficult to “see” biomedically. The so-called “classic” craniofacial features are only present in approximately 5% of total cases on the spectrum, making diagnosis relatively difficult to make. Prior to the institution of the 4-digit diagnostic system in Alaska in the late 1990s, there were no statewide coordinated efforts with regards to FASD. This began to change with the establishment of the state’s Fetal Alcohol Syndrome Surveillance Project in 1998. Early seed money from federal and state funding sources provided the resources for the earliest diagnostic clinics modeled after the 4-digit diagnostic system. This work was further developed under a five year, twenty nine million dollar prevention, education and intervention earmark provided by the late Senator Ted Stevens (OT-001-005). Several diagnostic teams were developed, including the one at Southcentral Foundation (which serves primarily Alaska Natives), and another at Providence Medical Center in Anchorage that

only lasted a few years and was never fully established, and several in Kodiak, Dillingham, Barrow, Fairbanks, Nome, Kotzebue, Kenai and Ketchikan (BD-001-001).

Currently there are two diagnostic teams in Anchorage, one at Southcentral foundation and the other recently established at a service-providing agency known as Assets. There are additional clinics in Bethel, Fairbanks, Juneau, Kenai, Mat-Su and Sitka. The clinics in Anchorage (predominantly at Southcentral Foundation, as the clinic at Assets is still relatively new) diagnose more individuals than any other clinic in the state. Furthermore, because of its location as a major transportation and service hub for the state, Anchorage is a central site to investigate the various cultural locations of FASD.

Individuals suspected of having FASD get “on the radar” primarily through referrals. According to a professional I interviewed, approximately 45% of referrals come through OCS (formerly the Division of Youth and Family Services) referrals, another 40% from physicians and pediatrics clinics and the rest through word of mouth, foster family networks, etc. (HA-002-004). As another professional described,

“In terms of the process, we would get a referral from, say, a pediatrician. Their case manager would work with the initial family, gathering some initial records and then refer to us. Our parent navigator, the only way we could keep a parent navigator was basically to hire, we didn’t allow volunteers. Our agency policy didn’t allow us to do that. We hired them as essentially an administrative person to do medical records and some coordination. So the parent navigator, after some initial contact through referrals, we really turned it over to the parent navigators to work into the system. And by work into the system I mean, what can you expect out of this process? Or what kinds of surprises might come up just in the process

of doing a diagnosis? I mean, the diagnostic process is a pretty lengthy process and at that time the way that our program was set up, we were treating it as if it was going to be essentially a one stop shopping kind of thing. There was no guarantee we were going to get the kiddo or the family back in, so we wanted to make sure as long as we had them engaged in this process we were going to do a full tune up” (BM-002-001).

This narrative is revealing in several ways. It illustrates how “doing the diagnosis” was seen to be a priority in this clinical context. Since the clinic at the time was serving primarily Alaska Natives, many of whom required travel to Anchorage to see the diagnostic team, the theme was to “push the diagnosis” under the assumption that they may not be able to get the family to return to the clinic for a second visit. It was also a mechanism to assure reimbursement for the time and professional expertise. In this regard diagnosis provided a billable product. This idea can be traced through the following narrative:

“And so it was, we had physicians and speech and physical therapists and the psychologist. We really didn’t skimp on things at all. So we got full neuro-psych batteries on kids. We did a speech and language work up on kids and a physical therapy work-up on kids. We did measurements and the physical stuff that go along with the diagnostic system, but generally because they were referred from the pediatricians coming through the clinic we were able to get that evaluation and current medical records. So between all the evaluations and write-ups and expertise, I mean it could range anywhere from 50-70 hours or personnel time or

more. More really when you factor in all the write up time and team meetings and all that stuff. It was quite a considerable amount of time” (BM-002-001).

What strikes me the most about this passage is the fact that, during the time period being described, the only people being subjected to this kind of biomedical probing and scrutiny were Alaska Natives. It is as if the clinical goal was to confirm the already predetermined presence of FASD. As one professional further elaborated,

“The family would show up at 8:30 in the morning and from 8:30-noon the kid would be working with some of the providers and getting a speech and language evaluation. While that was going on, the parent, caregiver, foster parent and/or social worker would be with the physician and the parent navigator to gather information while the kids weren’t there. So the parent navigator would be there as support to the family person, but then also interpreting the medical stuff during the evaluation component and then as we wrapped up and sorted out diagnosis and recommendations and provided feedback, they would also be there to slow things down, catch things, make sure that people were understanding, the families were understanding. They took a pretty active role” (BM-002-001).

Once this exhausting, day-long process is completed, it can take additional time for each team member to compile their individual report, at which time they are assembled as part of a final evaluation, which includes recommendations post diagnosis. At this time, the team is generally assembled once again, if possible. This is often quite

difficult for families that have flown into Anchorage to see the team, as they are unlikely to fly everyone back for a follow up meeting. As was further explained,

“We generally invite the family back for a follow up a month to six weeks after the clinic. For awhile we tried to do some kind of follow up, if only a phone call, at three months down the road to check in and see how things are going, but we generally had difficulty maintaining long term contact with families. We would ask what the experience was like for the family and offer recommendations, which sometimes included getting the results to schools so they could set up an Individualized Education Plan (IEP). We helped them try to figure out the next steps. Who to contact. And if they were hard pressed, then our parent navigator would help. One thing we know in Alaska is that providers turn over pretty quickly, anywhere from a year to 2 years depending where you are. So now there was a document that documented this whole process and provided the information, recommendations, and medical charts needed to provide continuity across family and care settings” (BM-002-001).

When asked whether historical inequalities and stereotypes about “Native drinking” persisted in clinical settings in the present, the same professional acknowledged,

“I think the stereotype is there. When you look at the data, I definitely think that’s out there that this is a Native issue, but you also have to look at the fact that the data that’s going into many of these systems is being identified and has been identified for as long as data has been collected in Alaska, in Native health care

systems. So if you are looking at who is contributing more information into the data that's being mined, it's just that. A really good example is that when I was in the diagnostic clinic and a large number of the kids that we saw were born into our system through the Native Medical Center so we had access to them. There were some that were actually born out of the system through Providence and when we would get records (from the now defunct Providence clinic) there was never any documentation about prenatal alcohol exposure. You know, in all the prenatal care it's like it was never documented, so it doesn't exist. So of course there is a skew. A lot of the data have been pulled from the tribal system or the Indian Health care system since the 1970s and alcohol has been an identified issue that they've wanted to address and so within their systems of care they ask about alcohol and they are doing prenatal screenings. So that's one of those disparities, one of those double-edged swords. The data are pulled from that more heavily than the non-Native system. In the systems that are in place, are non-Native families being asked about it or not" (BM-002-001)?

Several of the professionals I interviewed echoed these sentiments. It appears that many of the structural and historical inequalities that created an epidemiological "problem" of FASD for Natives in the first place are continuously reproduced in the present. The issue of surveillance and data collection is a powerful example of how it is possible to locate a problem at the site where one happens to be looking. Furthermore, the racial and cultural politics that shape everyday understandings of FASD in both public and professional settings serve to mask these deeper structural inequalities and



further entrench ethnocentric assumptions and misunderstandings about Alaska Native peoples, cultures and communities.

### **Removal as Political Economic Practice**

In extreme cases, without needed supports, many adult individuals with FASD end up in prison or have been sent to Residential Psychiatric Treatment Centers (RPTC). All the professionals interviewed discussed the extremely high prevalence rate of FASD within Alaska's prison population. In addition, due to the lack of in-state facilities (Alaska is fully de-institutionalized), 400-500 children have been transferred to RPTC's out-of-state through the behavioral health system (Bring the Kids Home 2010), reflecting profound dislocation and proclivity towards exclusion and removal. It is estimated that as many as half or more of these individuals either have or are suspected of having FASD (CS-002-002). These statistics highlight the need for increased federal and state programming for community-based services as well as the need for more providers to reduce costs associated with out of state and/or prison placements.

As one Alaska Native tribal leader, caseworker and grandparent described:

“There is a big problem of community awareness. The community doesn't understand how to deal with people with FASD. They don't understand the disability. Families will spend 12 years working with schools to come up with things that work. Lots of trial and error. But the fact is, once they age out of the school system, there is not much for them. They become homeless or end up in jail or in institutions. I've seen one of the boys here and he was from the village and he had FASD. So I'm talking to him for awhile and I said, 'What are you

doing’? He says, ‘Oh, I’m trying to find work’. And I said, ‘Is anyone helping you’? ‘No, I am trying to do it by myself’, he says. And I said, ‘That is a really good idea but there are a lot of people here to help you’. I told him he needed to learn to ask for help, that it’s OK to ask for help. You see, these are the people that are falling through the cracks in the system. I say ask for help. I tell my children and my grandchildren if you don’t understand something in school, and you’re not doing well, there are people there for you to ask and if you’re still not getting the help you need then you go somewhere else and ask. That’s not the end of it. There is always another way. People in the village think because we don’t have as much resources as the big city that we don’t know what to do. They don’t have the resources but it’s also a matter of not knowing who to call. What help is available to me? They don’t know who to speak to and they don’t know what questions to ask. They may not even know the history of their child, grandchildren, their niece or nephew or whoever it is that has FASD. They don’t know what to do and so it just becomes, I don’t know, it becomes kind of invisible. And these are the kids that end up in the criminal justice system or in out-of-state institutions” (LA-001-009).

These comments speak to the heart of the problem of sending children out-of-state for care. It is as if FASD is viewed as a burden to be cast away. Even current prevention efforts, including the “not a single drop” campaign, largely ignore the thousands of children with FASD right now who are over represented in prisons and out of state RPTCs. While these efforts are important for raising awareness of FASD in a broader

community sense, it overlooks the need to improve existing systems and infrastructure so that we can build more inclusive communities and encourage the creation of accommodating environments in peoples' home communities of choice.

Long-term health and well being was an almost universal concern for the families I worked with. Frustrated with the lack of available community support options for his son, one parent commented,

“As sad as it seems, I often wonder if my son will end up in prison. In some ways, he might do really well there because it's such a controlled environment. They are told when to wake up and when to go to sleep. They are fed. But it's expensive if you think about it in those terms. Not only is it costing these kids their lives, they are around bad people and they don't really deserve it. But the justice system will take them in. It's one of the only places that will take them in. And a lot of them end up there. Just talk to the probation officers” (OT-001-005).

The same parent, in describing his son's challenges and interactions dealing with the behavioral health and criminal justice systems, highlights the problem of out of state placements from a number of perspectives. As he explained,

“All the places he went to. I spoke with everyone. Nobody knew anything. No one had been in-serviced in FASD. Nobody knew what to do. He was getting pretty outrageous. So they recommended we send him to an RPTC. It was the Provo Canyon School in Utah. He's seen a string of psychologists. Been in an out of just about every place you can think of, and their solution? Send him out of state. Well, we've been involved with these people forever, so we listened. My

son went down there and they were taking \$11,000 a month, \$132,000 a year to treat him, so I go down there. Part of the deal was that they send a parent down every ninety days to check in and see how things are going. I canvassed them. None of them had any training in FASD. And we are paying them \$11,000 in Medicaid money for medical treatment. And my son wasn't the only one down there. You know the whole 'Bring the Kids Home'? There was a big FASD faction down there. Huge. He got sent to another one, they were happy to see him go. He never even made it to level 1" (OT-001-005).

The trope of removal is a common thread in the history of dealing with Alaska's most vulnerable populations. Despite extremely high costs and a poor track record of success, sending children out of state for care continues to occur. The Bring the Kids Home initiative is critical in this regard. However, the lack of community capacity for care, particularly within the realm of behavioral health, remains. Without the capacity to provide services in peoples' home communities leads to a vicious cycle of interaction with corrections systems that, in extreme cases, leads to incarceration. Expanding current service delivery infrastructure is thus of critical importance to provide lifelong supports for individuals, families and communities as well as avoid federal and state expenditures on out of state residential care. To help articulate the gaps and limitations in existing infrastructure and how they affect the lives of individuals with FASD and their families, the next section will examine whether or not and how a diagnosis is helpful for families in meeting the educational and support needs of their family members.

## **“Dancing With the Devil”**

FASD diagnosis, as described above, can be a double-edged sword. Individuals encountered during research reported that diagnosis does not necessarily help in terms of getting needed services and supports. In fact, it may hinder efforts to reunify families and serve as a further marker of difference for both the person diagnosed and his or her natural family. FASD is essentially a diagnosis for two, mother and child, so having the label can have profound consequences on family preservation and reunification efforts. However, families who “had a diagnosis to work with” also found that understanding the nature of the impairment(s) and learning about possible accommodations to support everyday life activities was helpful. One research participant referred to this dynamic as “dancing with the devil.” She knew she was subjecting her family and son to additional scrutiny by diagnostic teams, state agencies and service delivery organizations, but she did so in order to learn more about her son. Like many families, due to limited resources for FASD, she was required to pursue disability services under a different diagnosis and, due to the severity of her son’s impairments, succeeded in doing so. However, her case was an exception in that most individuals with FASD are relatively high functioning and do not qualify for services under typical funding streams for disability.

Another foster parent, in discussing the value of diagnosis explained,

“It’s not helpful at all. It’s pretty much just a stepping-stone to find someone to help me deal with it. And that’s only if you know where and how to look. OK, now that my child has FASD and it’s written, now help me to help her lead a normal life. Or as normal as she can. It did give me an idea of where to leave

her, where to guide her so she can have a life. Otherwise, what's she got? She's got a label and can't do anything for the rest of her life" (TA-001-017).

Several other parents shared similar experiences of frustration and ambivalence about diagnosis. One parent in particular, exhausted by the process of working with the school system explained,

"After we got the diagnosis (for our son), we tried to work together. I was hopeful that the diagnosis would help focus the energy of his (IEP) team, but there is nothing to be done, even now, because the teachers don't know" (OT-001-005).

This parent expressed frustration with the ways that the school tested and reported requirements. The clinical language he found himself immersed in made it difficult to truly learn about his son. As he explained,

"That word, triggers. Behaviorism is so engrained in our corrective psychology. That is what teachers use. That's what psychologists use. That's what special education uses. That stimulus-reponse. They want to know the triggers so they can correct them. Well, nothing is triggering it. He is just in a state of high arousal. A lot of stuff will set him off. It's not a cause and effect thing at all, and cause and effect doesn't work. You teach him something one day, it's not there the next" (OT-001-005).

The frustrations families feel are heightened during times of transition. When moving from place to place, family to family, and school to school, it is difficult to build a supportive environment to provide continuity of support across all areas of life functioning. This is especially true in educational environments, where getting to know teachers, students, support staff and other patients becomes critical. Despite the challenges families oftentimes report in securing adequate educational supports for their children, school remains a critical context for the teaching and learning of life skills that will follow that child for life. It is also a legally mandated set of supports, in large part due to legislation such as the Individuals with Disabilities Education Act (IDEA), which requires states to provide educational supports through high school age (ET-003-004).

Another parent I interviewed articulated this frustration repeatedly. However, he also realized that his son's school was one of the only resources available to him and his family at the time. As he describes,

“We had some real screamo parent-teacher conferences. My son only qualifies for IDEA since the reauthorization in 1997. And in that reauthorization there was one exception, I think it's the tenth one, it was 'other health impaired', which was added to include things like attention-deficit hyper activity disorder. And since all these kids apparently have it, that's your in. Once you have that, supposedly you can then have an Individualized Education Plan (IEP). But the Anchorage School District uses these menus. The kids will do this or that for 80% of the time with whatever percent accuracy. They will do this. They will do that. You know it's not an individual. And they are not willing to give up. For example, when I went to my daughter's last IEP meeting, they asked, 'what's the

exception'? I said, 'It's FASD'. Well, it wasn't on the drop down menu, so they wouldn't put it in. They wouldn't let me write it in. And you're going to call that an Individualized Education Plan" (OT-001-005).

The language of distrust and overall frustration reflects the difficulty of developing "one size fits all" solutions for FASD. The spectrum covers an extremely wide range of impairments and what works for one student may not work for another. Several of the parents I worked with reported frustration over working with educators and support staff and teaching about their child's impairment/disability. Many reported trying over and over to help explain what challenges their children faced and what may or may not be working at home. One parent reported how the school seemed to be "trying things over and over and expecting a different result", even though things clearly weren't working. He further articulated,

"You know, it's their job to help these kids out. They would have had to really individualize, and they would have had to use different tests. They have these tests, IQ tests. My son scored 119, so there's nothing wrong with him. That's a good score, you know. Spatial orientation is 97, executive function is 30. You know, that averages out. But the thing is, IDEA says the test has to be appropriate for the disability that you are testing. That's right in the law. So if you test a kid for capacity to hear, you give them a hearing test. Yeah right. The test they use for IQ, it doesn't test them in-site. It doesn't test them in a crowded classroom. They are getting tested one-on-one in a quiet room with a teacher who is giving them one-on-one attention. That will skew your test" (OT-001-005).



Parents and families reported similar kinds of frustrations almost across the board. This tension between pushing the diagnostic category and advocating for individualized educational and other supports on the one hand and avoiding “rubber stamp” solutions on the other, proved to be difficult terrain for families to navigate. Part of this was a factor of educators not fully understanding the concerns of families as they described difficulties transitioning from school to home environments, to different schools, or the frustrations of their children who were struggling to accomplish certain tasks. For example, as one foster parent explains,

“I remember when my son finished his last day of kindergarten. I went to pick him up and he looked at me and smiled, ‘Oh good. That’s over’. And I was like, ‘you still have 12 more years of this’. He cried. He knew it. He cried. I felt like a failure. You can’t imagine how that feels. You get angry because of the lack of understanding everywhere. It felt like nobody wanted to deal with him because they would have to do something, or, do something different. They would have to really individualize, you know” (CM-001-013).

One grandparent and tribal leader clearly articulated how we need to change our perspective and look at accommodation more broadly. As she explained,

“Once we can develop a broader understanding of what’s going on and educate more people in our communities, they are going to look at that child and think and act and respond differently. They will be there for that person and hold him by

the hand for as long as he needs us and help him succeed. Not just, ‘He’s done. He’s graduated, he’s done’” (LA-001-009).

This notion of “aging out of the (education) system” was repeated by several parents. The school system is viewed as one of the only available support structures but once they graduate (or “age out”), there are limited options for families. Without continuity in supports across all areas of life functioning through the education years and beyond, individuals with FASD and their families struggle to find opportunities for meaningful inclusion, belonging and group membership. As explained by another parent,

“In the eyes of society, when my son turned 18, he got cured. He got cured a week or so before his birthday I guess. According to the state, a person who is 18 has reached the age of majority even though he’s maybe 13 in some ways. So, he lived with us for a year and didn’t do anything. We finally told him, ‘Hey, you know, you can’t do this’. He attempted suicide. Went to town (Anchorage), was in the psych unit at Providence. We know the psychiatrist there. He said, ‘Well, what are we going to do’? I said, ‘Well, here is what you need to do. You need to get him in a social setting. You need to provide continuity in medical care through this transition. He needs to have social care. He needs to have pharmaceutical care. He needs to have job training’. And they’re like, ‘We don’t do that for anybody’. So that’s what you do. That’s what’s needed and is not being done” (OT-001-005).

Transitions into adulthood represent some of the biggest challenges families face. Given the existing gaps in service delivery infrastructure, how are individuals and families managing everyday life challenges? How do differences in family forms structure opportunities and outcomes for families? These questions are beginning to be addressed through a variety new programs, policies and initiatives designed to strengthen community capacity for care and expand access to services and supports for individuals with FASD and their families in their home communities of choice.

### **New Programs and Initiatives**

Some new sources of funding have emerged specific to FASD, in particular, the State of Alaska's Modeling, Mentoring and Monitoring (or "3M") pilot project (RPTC/FASD Waiver Project 2011). This funding source is part of the state's Medicaid Home and Community Based Waiver program. The waiver, while limited in availability, provides funding for community-based services for a person who meets "level of care" requirements and is deemed eligible. This is a much needed source of funding, particularly in light of the Bring the Kids Home initiative, as kids who return to their home communities under this program (and their families and communities) will require extensive supports upon their return. However, while some improvements are being made, there is still a long way to go. As one professional described,

"There have been several issues (with the 3M project). The age limit was too high. The initial criteria were set too stringent and too restrictive. It wasn't fluid enough to respond to the range of presentations we see with FASD. It is a great model, great planning, but there was this planners vs. implementers vs. people in

Medicaid kind of things going on. Each one had a different responsibility and each one doesn't understand each other's work and each one didn't understand the realities of it. So they set up this really great program and some needed services and basically people could get paid to do things that hadn't really been possible before. But they couldn't find organizations that were willing to be providers. You'd think, 'They should be jumping all over this', and what the organizers of the 3M project didn't realize is that for an agency to jump in it's not as simple as that. There is a big learning curve going on around this right now" (BM-002-001).

With increasing awareness at the policy level coupled with initiatives to improve diagnostic services and community capacities to provide supports, the rights of individuals with FASD and their families to live and work in their communities of choice is being maintained and expanded and the continuity and power of colonial and post-colonial discourses dismantled. Coordinating efforts across critical life domains and building more inclusive communities also involves working closely with the justice system to educate law enforcement personnel and expand access to mental health courts. Recent legislation allowing FASD to be considered as a mitigating factor in sentencing is critical in this regard (Alaska FASD Partnership 2012; Burd et al. 2011; Thiel et al. 2011). These kinds of initiatives and efforts towards systems integration are important directions for Alaska and elsewhere. As a research participant explained,

“Corrections and juvenile justice need to be able to talk to behavioral health who need to be able to talk to the schools who need to be able to talk to parents. I

think the urgency or the need for that is highlighted even more so when working with the FASD population. Something really needs to be done to help individuals and families manage difficult transitions, from simple ones like graduating from middle school to high school, to managing a return home from a RPTC. There are real barriers for transition aged youth. They are becoming, legally they're an adult so at 18 they are legally an adult, yet they are really kind of still living in and out of the system and so they haven't, they aren't ready, and if they don't have a good transition plan or supports into adulthood, that's where lots of challenges happen. We all have a part to play in this" (SC-001-004).

Improving and expanding community level awareness also includes working to change cultural perceptions of risk and blame. In the next section, I examine how cultural misunderstandings of FASD continue to influence everyday clinical encounters and shape impairment disability outcomes for families.

### **Pathologizing Nativeness**

Within the professional and community contexts studied, collected discourses about FASD frequently position, even pathologize Nativeness as a risk factor to be avoided (or checked in the context of diagnosis/suspicion of diagnosis). For example, several professionals interviewed corroborated that a child (and that child's natural family) is generally looked at with additional scrutiny if Alaska Native. Additionally, several professionals referenced a phrase used in clinical contexts, "What part of town are you from"? As described above, this was seen as an indicator of diagnosis, with

characteristically “Native” parts of town being associated with relatively higher rates of FASD. In one instance, a professional case manager, in response to learning the neighborhood where a recently referred family resided responded, “Must be an FASD kid”. This type of non-clinical, non-medical diagnosis-at-a-glance was not uncommon within the professional contexts examined during research. In contrast, a person living in a more affluent part of town such as the hillside was thought to have Autism. These kinds of knee jerk professional reactions reflect the racial, gendered and class-based assumptions that inform perceptions about FASD. For example, as described by a professional interviewed during research,

“I’ve worked with families and seen families that are in and around the community and it’s like, this is not Autism. There hasn’t been a lot written about the possible overlap of Autism spectrum and FASD but there are some similarities and it is possible that there may be some misdiagnosis (of Autism) going on. There’s also a subpopulation in some of the Autism literature that shows there is microcephaly and those individuals tend to have some challenges that are maybe a little more within the range of prenatal alcohol exposure” (BM-002-001).

The potential overlap between FASD and Autism Spectrum Disorders could have profound consequences on the ways in which discourses of risk and blame surrounding FASD are constructed. The fact that professionals in the settings I examined have seen this linkage in everyday clinical settings speaks to the ways in which cultural misunderstandings may become grafted into clinical thought and practice. Another

professional I spoke with, in discussing the same issue, stated, “one of the things we know is, when you look, you find” (SC-002-003).

Normalization of a disabling language that referred to adults with FASD, like many other disabilities, as “kids”, became part of everyday clinical practice. It prefigured clinical relationships and shaped long-term disability outcomes in important ways. Similarly, foster/adoptive parents were generally more critical of rural or “village life” and associated it with general safety concerns for children, including FASD risk, whereas extended natural families tended to contest this by focusing on family connections and the need for tribal sovereignty over custody related issues. The phrase, “Must be an FASD kid” indicated a particular kind of framing loaded with negative (often racist) assumptions and perceptions of both the impairment/disability associated with FASD, as well as contemporary indigenous life, particularly in rural areas. In many clinical settings, FASD became a point of entry into a broader “culture of poverty” discourse that assigned blame for the “affliction” of an “FASD Kid” on the “unfit” Native mother from assumed unfit family and community. This then became part of a justification for why an individual may be having behavioral or emotional difficulties (“Oh he’s an FASD kid”) as well as justification for why that child may be “better off” in a foster or adoptive family setting in Anchorage. In this context, a diagnosis of FASD (even suspicion of diagnosis) is imbued with negative stereotypes that pathologize Nativeness and prefigure the clinical encounter in ways. The expansion of the diagnostic category from Fetal Alcohol Syndrome (FAS) to Fetal Alcohol Spectrum Disorders (FASD) has profound implications when viewed in this light.

Ultimately, building a more equal and equitable diagnostic and developing community-based support systems for all Alaskan families requires a coordinated effort that must necessarily involve new ways of engaging community members. This is not a problem or an issue for only certain kinds of “others” whose lives are lived largely in the margins of mainstream society. Rather, how we build and develop community is of central importance for all people, not just those who experience impairment/disability and their families. As one adoptive parent and community leader explained,

“I think the most critical need is to have a knowledgeable workforce and be able to provide coordinated, competent care. More importantly, we need to build more knowledgeable communities and teach about accommodation. People are getting care, but I don’t know that it’s the most optimal care. So I think there’s really a need for an integrated system that includes society itself” (SC-001-004).

While the data presented above illustrate the diversity of challenges and everyday life constraints that individuals with FASD and their families face, in the next chapter I turn to the specific practices and strategies that families utilize to advocate for their family members and develop long term impairment/disability supports.



## **Chapter Six: Strategies of Family, Kinship and Community**

### **Everyday Life Challenges**

Strategies families utilize in managing both the stigma of disability and the challenges of impairment are also shaped by social location. This includes whether or not and how to utilize services, the role and extent of state vs. tribal legal channels to resolve custody disputes (as described in chapter 4), and overall attitudes and perceptions regarding the role of extended kin in supporting individuals with FASD. For example, Alaska Native households in which members of the extended natural family were raising a child with FASD generally reported distrust towards state and non-profit service delivery agencies and difficulties navigating service delivery systems. In several instances, families chose to avoid interactions with these institutions altogether.

While relationships between families and service delivery institutions were oftentimes constrained by misperceptions each had of the other, families managed to interact with these institutions in creative ways to meet everyday life needs. Such strategies ranged from learning how to navigate complex service delivery systems to forming new social networks to share stories and experiences and offer support and advice to other families. For example, one parent, in describing what she considered to be her role as advocate for her child explained,

“As a foster parent or advocate, you really have to fight. Nobody else knows these kids like you do. They have them on paper, but you have them in reality.

And they don't understand it all the time, but I think foster parents need a lot more say. I mean, there are some good foster parents and there are some bad foster parents. Some of them aren't in it for the right reasons. You've got to pick the right fights. And I've got a big mouth! And I will fight for the right reasons. I have fought some battles over the years but I have nothing against the people who have to follow the rules and regs. When they have to say and do what they have to do. You know, I understand a lot of it, but I don't like it" (PM-001-011).

Families respond to everyday life challenges and stressful circumstances in a variety of ways. When faced with the everyday stigma of impairment/disability, it is difficult to find the strength and resources to "fight" the broader, social, community and institutional battles while still remaining focused to advocacy and everyday support for family and loved ones. Oftentimes structural and environmental factors, such as living and working conditions, make it difficult to take the time and energy to stay engaged in advocacy and community organizing. While families actively resist the structural constraints (which are exacerbated by institutionalized race, gender and class discrimination) on their lives and developed creative strategies of resilience to cope with these stressors, these strategies themselves became additional sources of stress and strain (Mullings and Wali 2001). For example, as one grandparent describes,

"Right now, we are just trying to get everyone situated. We have had major problems with this apartment and I can't afford to move. The landlord just doesn't seem to care about this property. Getting him to do anything is like pulling teeth. But right now, my biggest problem is getting all these kids to

school and making sure they are clean, making sure this house is clean. Making sure they have all their shots, don't miss their medical appointments, all these kinds of things. It's a lot of work" (SL-001-006).

Part of the everyday life challenges associated with managing the stigma of FASD include equipping people with FASD and their families with tools to help connect with other families and develop a safety net of support. One parent, discouraged by how her daughter was getting treated by her peers and then getting upset at herself as a result, explained,

"One of the things I think about all the time is how to let her know that she is loved. That she is valued. That everything is ok. That it's not her fault. How do you help someone come to peace with it, especially once they come to realize what caused it? I don't even think she discusses it with some of the friends she has met though a support group she attends. It's like, there is such a stigma with that, she doesn't want anything to do with it. I have tried to talk to her about it many times. I think it is important for her. She carries a lot of guilt and shame, you know. And I try to tell her she doesn't have to. That we are trying to find ways to help her" (WJ-001-002).

Social stigma surrounding FASD not only affects the individual diagnosed, but the whole family as well. Parents deployed a variety of strategies to manage stigma, both for themselves and their children. As one parent describes,

“It is really hard for me when I talk to people about my son and his issues. It is hard for me to say he is FASD because I am afraid that people are automatically going to look at me differently. So I usually lie and say he is Autistic because I don’t want to be, I don’t want to be automatically looked down upon, you know? And I don’t want people looking down upon my son. Maybe I am wrong for that. Some people I tell he is FASD and other people I can kind of feel how they’re going to react. Like I can tell what kind of person they are and so it depends on who it is whether I tell them FASD or autistic” (OA-001-014).

Another parent, when faced with the same situation out in the community or in clinical or professional settings, utilizes a different strategy:

“Yeah. Sometimes people look at you like you were drinking or something and they may even treat you differently or look at you with a disgusted look or something. I guess you kind of get used to that. I just laugh at that stuff nowadays. People just don’t get it and it’s sad. You learn to roll with it” (WJ-001-002).

This quote illustrates the powerful role that public perception can play in shaping attitudes towards FASD. The “disgusted looks” this respondent reported seeing were based on cultural assumptions and a lack of understanding of this particular family’s experience. Persistence and perseverance were commonly reported strategies that parents described as being critical in their management of both the everyday life impairments associated with FASD and the stigma of disability. One parent, describing her

difficulties in getting needed services and supports for her son through his early school years describes,

“Getting my son into the early intervention preschool program was one of the best things that ever happened to him. I remember it took awhile to get the ball rolling with that but we just kept bugging the right people I guess and they let him in, mostly because of his behavioral issues. This ended up being a good thing I guess, because it helped him get an early diagnosis of developmental delays, which also helped him become eligible for other things. He has a diagnosis of FASD too, but I don’t think we would have gotten very far with that diagnosis. So in a strange way, we are lucky I guess” (OA-001-014).

Not all families have this same experience however. One parent, for example, described a situation of “butting heads” in his interactions with state and non-profit institutions. As he explained,

“You know what? Even if you’re screaming at the top of your lungs and going to school board meetings and you have a diagnosis by Sterling Clarren himself, the school board would say, ‘We don’t recognize it. We don’t know’. I’d say ‘You know about my kid. I don’t care about the rest of these guys. You know about my kid. So make a program for him’. And they’re like, ‘Well, uh, uh, um’. It’s an Individual Education Plan. These guys need individual life plans and that’s what I’m constantly fighting for” (OT-001-005).

The experiences families have in securing and providing supports for their children are frequent sources of frustration and disappointment. Interacting with state and non-profit institutions can be enormous sources of stress. How families manage these stresses can have significant consequences on their ability to effectively advocate for their children. In the next section, I examine strategies of organization and community making that families utilize as a way of sharing stories and experiences, learning from one another and finding comfort and inspiration in each other's struggles and successes.

### **New Social Networks and Movements**

Many of the parents I worked with participated in a variety of both formal and informal organizations to network with other parents in similar situations, share experiences, develop additional activities to get families together and raise community awareness, etc. Most parents reported both enjoying and gaining a lot from these kinds of gatherings, both in terms of getting out and meeting other families as well as learning specific skills and ideas to try at home to help manage the impairments of everyday life for their children. However, oftentimes these efforts created additional strains in terms of time burden and unpaid effort. As one parent described,

“I was so frustrated. I was getting nowhere with the school and there just didn't seem to be anyone out there to help. And so, I started challenging the school district on all these things and I started doing advocacy through the parent support groups like Stone Soup Group. I started meeting other families that were experiencing similar things and it was almost like you start seeing this bigger

picture. I was there for my son, but I was also there for everyone else that lives with this, you know? It was encouraging. It was also a distraction from all the other things that were going on in his (my son's) life at that time. The two sort of complemented each other. It started to become a way of life almost" (CM-001-013).

Many parents describe their participation in community organizations and support groups in a similarly positive way. One parent, for example, described the overwhelming feeling she had when she first began interacting with state and non-profit service delivery institutions. She explained,

"As far as services go, it's really really hard. Even before I knew my son was FASD, just having a special needs child period. It's difficult to know where to go, who to turn to, or what to do and there are not enough people employed by the state or anywhere else to help. Like there's Stone Soup Group and that's it, but they're not really providers, you know. They are good at connecting people and pointing them in the right direction. But if you are referred to Stone Soup Group and you are somebody like me who doesn't know who to trust and is afraid to go and ask them for any help then it doesn't do me any good. I think they need more people who are available to help children when they are diagnosed with special needs to reach out to the families and help the families" (OA-001-014).

Simply having somebody to talk to who understands was frequently mentioned as a helpful resource for families. One grandparent I interviewed, for example, stated,

“Everyone needs a good person to talk to who can help them and keep them strong when they need someone to lean on. There was a person, I think she was a caseworker, who really helped me out a lot. She helps people. She really goes out of her way to listen and to help. She helped me deal with OCS when I didn’t understand what was going on. Sometimes I feel like I have to work twice as hard to balance it all out and to be there for my grandkids so they get what they need. Having people like that around, I just can’t say enough how important that is” (SL-001-006).

Another grandparent reiterated the value and importance of support networks for connecting with other families, taking a break and just getting out and socializing. As she described,

“I really think the grandparents network is awesome. I get invited. They send out invitations to everyone in the network. We got invited for breakfast last month, but I was off at school. It’s really a great opportunity to connect with other families and I know it means a lot to families. My sister-in-law also goes. She is also raising a child with FASD” (LA-001-009).

For some families, these kinds of support networks represented the only social activities they participated in. They were also critical sources of information and other resources that proved helpful in locating services and supports and interacting with providers. For example, as another parent described,



I wouldn't even have a clue if it wasn't for Stone Soup Group. Not a clue. I didn't know what to do. I'm frustrated, really frustrated with the state. It's a waiting game, I know, but I'm mad, I am frustrated because of the fact that the waiting game hasn't even started yet. They haven't even signed the stupid paperwork to get the eligibility process going. It's like a pre-waiting game waiting game. And all they have to do is sign the paperwork and the ball starts rolling. Well, we can't even get the ball rolling yet. Somebody is overworked, I guess. It's all just really stressful. Sometimes I beat myself up and wonder if I can do more. Have I checked this or that out? Have I kicked over this rock? Those are some of the hardest times. You just want to make sure he's getting the help he needs, you know? It helps to talk to somebody that knows what I'm going through when I feel like that" (OA-001-014).

Having access to friends, family and others to help manage the stigma of disability and the everyday life challenges of impairment was important for all families. For some, however, access to support networks was one of the only outlets they had. One grandparent, in describing just how important these networks are for her and her family, explained,

"I've thought about going home many times. I came here to help my son and to keep my family together. OCS tried to break up my family. I came here to make sure that didn't happen. I know I have other grandkids down there. I miss them very much. But they aren't in trouble. They are all doing what they are supposed to be doing and my son needs me. Sometimes it's really hard, but the

grandparents raising grandchildren group is really helping me. I really enjoy going. It's a good outlet for me when I need it (SL-001-006).

When advocating for their children, families often feel that they simply want to have a voice in decisions that are made with respect to their lives and everyday care needs. Community organizations and networks are also a useful tool in this regard. As one foster parent explained,

“If they can speak up without being labeled, they should be heard. I think that's the way it should be. There are a lot of things I'd like to put in OCS's face and have them address. There are a lot of things I'd like to put in the school's face. The providers. The parents support group has really helped me learn to choose my battles. It usually doesn't help you get very far going in and screaming and yelling all over the place. I can vent with other parents and strategize and plan my next move. It's helpful for me” (MD-001-022).

Strategies of community making and organizing are effective tools that families utilize in their everyday lives to learn, share, advocate, connect, and formulate plans of action. They also serve as important social venues where families can take a temporary break from the constraints of everyday life. In an urban context such as Anchorage, these organizations represent important grassroots efforts that provide a powerful voice and unite families across a diversity of life experiences and serve as a critical site of meaning making and exchange.

In the next section, I examine how such exchanges can serve as a vehicle for the negotiation of identity through the creation of new kinds of community and new opportunities to redraw the boundaries of inclusion and belonging. For individuals removed from their home communities and relocated to family settings in Anchorage, these negotiations are important sites of investigation.

### **Locations and Negotiations of Indigenous Identity**

For many of the families I interviewed, diagnosis of FASD was often associated with profound dislocations of family, kinship and indigenous identity. How the experience of relocation, family dislocation and/or living with impairment/disability in an urban area influences the experience of indigenous identity was an important topic of consideration for families. What these negotiations mean and under what circumstances they occur for individuals who find themselves removed from family and community varies considerably.

For example as one adoptive parent of three daughters with FASD described, “For one of my daughters, since we were having some difficulties with her behaviors, we were always looking for things to keep her hands busy. She is very artistic and while she doesn’t have contact with her natural family, she has always been drawn to Native art. We wanted to funnel her energies into something constructive and so we always just encouraged her with art. We started getting her involved in some extra classes. She is always doing artwork, working with her hands and doing amazing beaded jewelry or crochet. It is amazing to watch her because her hands are constantly moving. She could do like 20 scarves in a

week. It helped her to focus. Her work is amazing. In fact, she does commissioned pieces and one-of-a-kind pieces and sells them on a regular basis. She hasn't done anything online yet and we may explore that at some point, but she has done a lot of the art fairs around town and she works at one of the bead shops part time and they are very, very understanding and know that sometimes she just can't come in. She has been really lucky in that way. She got some great accommodations in place and she works really hard. She's got this dress she has been beading for about three years. She hauls it around with her. It's a white dress and it's covered with beads. It's for her wedding, which she's been planning for about six years" (WJ-001-002).

While one her daughters has utilized artwork as a way of making meaning and exploring her indigenous heritage, she is also renegotiating her identity and sense of self in the world in an urban context and utilizing her experience to connect with people. She participates in Inupiaq dance and "she's very, very into her culture". Her sister, on the other hand, adopted from another family but raised in the same adoptive setting, has not expressed the same level of interest in learning about her past or engaging in Native cultural activities. According to her mother, "she doesn't want to be Alaska Native. Very actively doesn't".

One foster parent, in supporting her daughter's interest in learning about her past, explained,

"We do as much as we can to get her involved. We have a relationship with the natural family. I've actually been out to the village with her several times and the

family sometimes calls us when they are in town. I have videos and books of Native peoples and cultures of Alaska and she loves to look at them. My two oldest are Yup'ik and my two youngest are Tlingit-Haida. We just went to the Alaska Native Heritage Center on mother's day. They loved it. Everyone had a really good time. They are Native. One of the kids, their aunt, I talk to her on text almost everyday. When she comes to town, we all go out. We do things with the kids. I learn a lot from her. We taste a lot of foods. It's really cool. And the kids just love it and I'm so glad they have that connection" (PM-001-011).

Cultural connections and locations of indigeneity provide a context for meaning making and negotiation of identity in urban spaces. As one tribal leader and grandparent described,

"Education in places like Anchorage is so important. Anchorage is different from the village and people need those opportunities to connect. So education is so important. I push that all the time. To learn about their culture and not only their culture but who they are. I know where I come from. I can trace myself back over 100 years. We have no recording but through the hearing from some elders saying you are related to me and I say we're related. And they say, 'Yes, through your aunt, through your grandfather'. So there's stories and there's books and there's documentation that is finally coming out and I have a lot of relatives up north that I didn't realize I had. So now I am realizing who I am. And it is even more important to know who your grandparents were. Because we have that connection to our land and to each other. People need this" (LA-001-009).

Understanding the ways in which identity, being and belonging are constantly negotiated and renegotiated for individuals moved by the state and relocated to Anchorage is of critical importance in building more inclusive communities and supporting people where there are in their everyday lives. Documenting everyday life strategies, experiences and practices of identity and belonging offers a unique opportunity to contribute to understandings of how difference is constructed and inscribed onto impaired bodies of difference. It also provides a unique vantage to explore the fluid and diverse articulations of identity people experience, negotiate, practice and perform in the context of everyday life.

In the last chapter I will offer summary and analysis of the research experience and situate collected data within current anthropological theory to highlight broader issues of relevance and concern for both the discipline of anthropology and humanity more generally.

# The Cultural Politics of Fetal Alcohol Spectrum Disorders and the Diagnosis of Difference

## Chapter Seven: Analysis, Summary and Findings

### **FASD at the Intersections of Gender, Race, Class, and Health**

Throughout the process of research and data collection, I was struck by how aware participants were of the broader racial and cultural politics surrounding both popular and professional framings of FASD. Across collected interviews, perceptions of FASD and the role of the state in intervening in the lives of families were strongly influenced by the positionality of research participants. Adoptive parents, for example, invoked representations of degradation and dysfunction and positioned intervention as a moral imperative. Similarly, many of the extended natural families I worked with described a deep sense of distrust towards state institutions and a lack of cultural understanding afforded to them in their interactions with professionals. There appeared to be strong stereotyping logics at play that were fueled by misperceptions and contradictory messages about risk, blame and the perceived need for state intervention. This was particularly pronounced across rural and urban patterns of residence. I struggled with this throughout the research period, as the more I spoke with people, the more I saw the perpetuation and reproduction of inequality. It was difficult for me to understand how people, especially in professional circles, could be so complicit in perpetuating the very disparities they allegedly work to alleviate. The more I probed, the more I began to see how raced, classed and gendered constructions of risk prefigured FASD as a problem more likely to affect certain kinds of people. As such, the public health message of universal risk is a powerful discourse that diverts attention away from

the deeper historical, economic, political, social and environmental conditions that provide the context for diagnostic visibility and state intervention.

Risk is best understood in the context of a larger structure of constraints and social choices conditioned by race, class and gender (Collins 2000; Krieger 1999; Mullings and Wali 2001; Schulz and Mullings 2006). Within medical anthropology, intersectional approaches to health inequalities have shifted attention to situating individual behaviors within the broader social contexts and hierarchies in which they are produced. From this perspective, the biomedical focus on controlling and managing individual behaviors overlooks the broader circumstances that shape those behaviors. Lynn Weber (2006) argues, for example, that while white mothers are significantly more likely to smoke than black mothers during pregnancy, the most negative social associations are made with regards to single, young, black mothers. The same phenomenon holds true with regards to the associations of drinking with Nativeness and risk of FASD. While white, non-Hispanic women were more likely to drink during pregnancy (Armstrong and Abel 2000; Centers for Disease Control 2012; Floyd et al. 1999), dominant cultural conceptions recirculate the image and representation of Native peoples as poor, dysfunctional, lacking self-control and inherently more likely to be drawn to alcohol use (Prussing 2011; Martin 2006).

The historical depth and extent of these representations informs both public and professional attitudes about FASD risk. Several scholars have examined raced-based bias in physician and other medical professional decision-making (Geiger 2003; Kaufert and O'Neil 1993; Mwaria 2001; van Ryn and Fu 2003) and found it to have a significant effect on health outcomes and the perpetuation of health inequalities. Historical



discrimination in medicine shapes attitudes and perspectives of minoritized patients in the present and creates a context of distrust. Mwaria argues that, “race and class are intertwined in this complex web of mistrust” (2006:305) with regard to perceptions of bias, fair treatment, and even choices as to whether or not and how to utilize health services. My own findings revealed competing and contradictory discourses between professionals, foster/adoptive parents and extended natural kin surrounding proper motherhood and child rearing. Perceived negative bias on the basis of race/ethnicity, pattern of residence and family status were reported by several research participants. These perceptions, in turn, fostered feelings of distrust and constrained relationships with professionals in a variety of institutional and community settings, including health clinics, schools, and courts. This made it even more difficult for families, particularly natural grandparents, to navigate through already overwhelming, burdensome and complex service delivery bureaucracies in managing the everyday care needs of their loved ones. Their experiences speak to the ways in which subtle biases in perception can shape clinical outcomes.

Alaska Native families are more likely to come into contact with state surveillance mechanisms by way of the tribal health system and are as a result more likely to bear the brunt of state interventions once labeled as “unfit” (Weber 2006). Since alcohol use during pregnancy is such a highly stigmatized issue, the focus on “treatment” of individual behaviors of minoritized groups already perceived to be at risk overlooks a much deeper set of concerns with respect to the structural causes of health inequality and the role of social norms in shaping perceptions of deviance, normalcy and risk. At the same time, it deflects blame off of other groups who may be even more likely to be

consuming alcohol during pregnancy. As a result, inequities in screening and surveillance may be contributing to a substantial level of undiagnosed FASD in non-Native populations in Alaska and elsewhere. However, due to a relative lack of attention to FASD in non-Native populations (despite universal messages risk), it is not being diagnosed to the same degree.

This represents a significant dilemma with respect to public health and biomedical responses to FASD. On the one hand, racial/ethnic bias in public and professional constructions of risk may be inadvertently reinforcing disparities by focusing uneven effort and resources towards a prefigured target population. Coupled with the stigma associated with maternal alcohol consumption during pregnancy, Alaska Native families are more likely to encounter multiple lenses of state surveillance. Compounding this problem, lack of available resources, services and supports for families create severe structural constraints that affect the health and well being of individuals, families and communities in profound ways.

In Anchorage, families are more likely to be flagged as “at risk” on the basis of their social and structural locations, including race/ethnicity, pattern of residence and family/kinship status. The consequences of this can be far reaching, as my findings indicate significant levels of family disruption and removal of children from home communities in favor of foster or adoptive placements in Anchorage. In this regard, the state can be viewed as a powerful vehicle for the control and regulation of the family (Das and Poole 2004; Lodd-Taylor and Umansky 1998; Rockhill 2010). Legal definitions concerning normalcy and deviance with respect to the “best interests” of a child are shaped in large part within the authoritative contexts of state courts and other

institutional settings such as medical clinics. Rockhill argues, for example, that courts provide a critical context where moral judgments are made with respect to parents and family life and expected norms are outlined. However, as this expected norm is outlined, “so inevitably is a deviance zone, expressed as a non-correspondence to this norm (Rockhill 2010:135-136). Many families described such encounters with the legal system as being fraught with miscommunication, unfair treatment and moral judgment. Positioned as poor parents from inherently unfit families and communities, several research participants, particularly grandparents, described struggles to maintain custody of their kids and have cases moved into tribal courts, where they felt they were treated more fairly and had more likelihood of having their voices heard. In the context of my research, several participants described negative experiences in managing their interactions with state legal institutions. Perceptions of cultural difference and otherness were especially visible in cases where the child was from a rural part of the state. Tribal courts represented critical spaces where families contested dominant cultural norms and asserted creative agency in maintaining natural kinship networks and advocating for their children.

Other modes of state intervention that contribute to disturbances in family and kinship forms include placement in out-of-state institutional facilities. The high rate of Alaska Native children with FASD sent to out of state Residential Psychiatric Treatment Centers (RPTC’s) are a powerful example of the role of state intervention as a vector of migration and relocation (Fournier and Crey 1997; Rockhill 2010; Smith 2005; Tait 2003). Of the 28 (foster/adoptive and extended natural) parent interviews conducted, 23 were raising American Indian/Alaska Native children. In approximately 21 of 23 of these

families, the child was from elsewhere in the state. These numbers speak to the ways in which cultural politics shape perceptions, attitudes and meanings about FASD and disproportionately affect Alaska Native families and communities. In this regard, my findings parallel Kaufert and O'Neil's work (1990; 1993) concerning cultural constructions of Inuit childbirth and the competing and often contradictory discourses concerning pregnancy and its administrative and medical management. The languages in which people spoke about risk and intervention "reflected who was speaking, to whom they were speaking, and the historical and political context of what they were saying" (Kaufert and O'Neil 1993:43). Their positionality embodied sets of differences and hierarchies of power and authority that influenced how they were treated by state and clinical institutions. Cultural assumptions regarding village life and family and community capacity for care constrained individual choices for women and led to increased surveillance and management of their pregnancies, including coerced relocation to urban areas away from families and communities. A similar cultural politics are at work in the framing of FASD in Alaska. Researchers, professionals and the public generally must necessarily take historical, cultural and structural factors into account in understanding how cultural constructions of FASD shape perceptions of risk, blame and appropriate intervention.

Eliminating health inequalities requires attention to the circumstances that shape and constrain the behaviors in question, including historical, economic, social, political and environmental. Insisting that FASD "crosses all lines" (Armstrong 1998; 2003; Armstrong and Abel 2000; Golden 2005; Salmon 2007; Tait 2003; Vedder 2005) serves to mask the ways in which one's social location prefigures their level of "risk". Such

considerations are generally missing from biomedical and epidemiological reports showing disproportionate rates of FASD prevalence in Native communities. I have provided numerous examples to show that raced, classed and gendered assumptions that shape authoritative discourses about FASD are conveniently disguised and attention is effectively diverted away from deep inequities in diagnostic practice. In this regard, FASD serves as a powerful example of how biomedical knowledge reflects social and cultural norms about gender, class, citizenship, inclusion and belonging. Bringing into conversation critical understandings of FASD with research being done by engaged scholars of health inequality from multiple disciplinary contexts will serve to expose current (and historical) structures of inequality and assist in building more responsive programs with the explicit goal of eliminating rather than busily reinforcing disparities in health outcomes.

### **Disabling Impairment/Disability: Anthropological Contributions**

Everyday life practices of impairment/disability are places or sites, operated on by the body, where the uncertainties of impairment and social otherness can find expression through the active and strategic insertion of the disabled body into a world of non-disabled others (Butler 1997; Koppers 2004; Snyder and Mitchell 2006). These everyday “performances” of disability have the potential to rupture the normative alignments of public space and expand the cultural boundaries of inclusion, belonging and group membership (Rapp and Ginsburg 2001).

By redrawing the space of possibility in which relationships can be imagined, Rayna Rapp and Faye Ginsburg argue that the experience of disability becomes an

occasion for meaning making for both parents and their children, where “unanticipated cultural future(s)” are imagined that could “give meaning and possibility to the reshaped habitus of daily life with a disabled family member” (2001:534). In this context, Anchorage can be viewed as an important site of new community making where Alaska Natives actively create meaning and negotiate identities as urban citizens struggling with the stigmatizing consequences of disability.

Due to the complexities of mobilizing resources and supports to manage disability, individuals experiencing FASD and their families “rewrite kinship in ways that circulate within larger discursive fields of representation and activism” (Rapp and Ginsburg 2001:541). Many families I interviewed explained how advocacy efforts and participation in community support networks represented additional but necessary burdens on their everyday lives. Participation offered opportunities to learn from other families, share experiences, or simply vent to an understanding audience. In several instances, families reported learning strategies for negotiating complex service delivery systems, interacting with school officials with respect to their child’s education, and exploring creative and accommodating employment opportunities. Expanded kinship networks included other natural or foster parents, caregivers, various community-based organizations and support groups. They became critical sites of community making, networking and advocacy, and important strategies used by individuals with FASD and their families to meet everyday care needs and facilitate community inclusion.

My research links anthropologies of impairment-disability with a range of other theoretical concerns in medical anthropology, including kinship, citizenship, difference, inclusion and otherness. Ablon argues that difference is profoundly felt through

diagnostic encounters that brand human beings as “other” and that the effects of this are felt throughout the lifetimes of both parents and their children (1988:2). I have argued that families of individuals with FASD had mixed feelings about diagnosis.

On the one hand, it offered a way to better understand the specific care needs of family members and offered possible access to services and supports (provided an individual was deemed “disabled enough” to meet federal and state eligibility requirements for community-based services). On the other hand, due to the stigma associated with drinking during pregnancy (and Native drinking in particular), the label also has a variety of consequences on family forms, patterns of residence and sense of identity, inclusion and belonging. Families explained how with a relative lack of services available they perceived a certain futility in diagnosis.

While some new programs have emerged to help fill the service delivery gap to this population, strict eligibility requirement and limited funding have prevented widespread access. Specifically, the state’s newly piloted Medicaid Home and Community-Based “3M” waiver, while promising as a possible source of long-term, community-based supports for family members experiencing disability, has yet to grow large enough to meet demand. Furthermore, problems in defining and standardizing level of care requirements for a disability as complex and variable as FASD has proven challenging (Vedder 2005). Parents in many cases have reported that their family members simple aren’t considered “disabled enough” to receive services under this funding stream and that current definitions prevent most families from accessing needed supports.

The many narratives of parents that have been included in this study help identify critical service delivery gaps and offer an opportunity to reflect on the effects of everyday policy and practice on the lives of families. My findings reveal several areas in need of further research and attention with respect to FASD in Alaska and elsewhere in the world. Expanded diagnostic access to people of all social locations is primary among them.

While the earliest targeted interventions were led by tribal health institutions and have been instrumental in raising awareness of FASD, they have also played a role in reproducing the perception of FASD as a “Native problem” (Maternowska 2006; Salmon 2007; Snyder 2006; Tait 2003). This perception has deep historical roots (Frank et al. 2000; Prussing 2011; Smith 2005; Tait 2003) and feeds “culture of poverty” discourses (Lewis 1966; Martin 2006) that position Alaska Native families, communities and cultures as dysfunctional, deviant, and inherently “at risk” of FASD. Anthropological critiques of culture of poverty discourses emphasize the need for greater understanding of the structural constraints that shape everyday life from the perspective of those who live it. This study exemplifies how anthropologists can play a role in articulating, through observation and ethnographic analysis, how cultural assumptions shape professional and lay understandings of risk and further entrench inequalities and contribute to disparities in FASD rates and outcomes.

In addition, findings reveal an overall lack of continuity of services and supports for families in transition. This includes supports for families that have just relocated to Anchorage and need assistance navigating service delivery bureaucracies as well as supports through different life transitions for individuals with FASD. Specifically,



transitions into adult life after secondary school were challenging for families and represented times of vulnerability and uncertainty. With a lack of resources, services and information about where families can go for help, many research participants expressed fear for the future safety and security of loved ones. Ethnographic research is thus critical to understanding the everyday life challenges of families and individuals experiencing FASD. These data can then be shared with community leaders and policy makers and integrated into everyday clinical practice. By focusing on impairment-disability as a critical aspect of one's social location, anthropologists can examine the stigmatizing consequences of FASD diagnosis as it intersects with several overlapping fields of difference.

### **Deconstructing Difference**

All interpretations are necessarily provisional, partial, and incomplete. As anthropologists, we must actively reflect upon who we are as human beings and how our own power and presence shapes "the field". The "false air of security" and "authoritative claims to certitude" that bounded disciplinary preparedness often brings has been destabilized and we must now focus our attention on how meaning is contested by people from multiple social locations (Rosaldo 1989:8). Through active consideration and reflection, we can destabilize essentialist depictions linking poverty with indigenous identity and risk of FASD. We must also highlight processes of change and internal inconsistencies, conflicts and contradictions into our analysis so as to more accurately capture the diversity of everyday life circumstances for urban Alaska Natives experiencing disability. Cultural borderlands have now moved from a marginal to a

central place in social analysis, and “encounters with cultural and related differences belong to all of us in our most mundane experiences” (Rosaldo 1989:30). Arthur Kleinman argues that,

“It is within the margin of disability that therapeutic change may make a small difference that becomes all the difference in a person’s life, a small importance that repairs, rebuilds, reinvigorates, reinvents. Healing usually is transformative at this margin of small yet crucial changes in bodily processes that have social effects. Experience too is about small, local things: including edges and brinks. Unlike depth psychology, the phenomenology of social experience is about surfaces and boundaries, many small importances” (1995:10-11).

We encounter difference in our everyday lives all the time, as we pass through the interstices of myriad social worlds and constantly carve out new spaces of being and belonging. Turning to borderlands and margins is important for ethnography as it offers an opportunity to articulate the ways in which people cope and “contend with the structural and psycho-cultural dimensions of racism, sexism, and the other myriad forms that social inequality can assume in people’s lives” (McClaurin 2001:15; Mwaria 1995; Page and Thomas 1994). Das and Poole argue that margins are spaces between bodies, law and discipline, spaces where life itself is put into question (2004:10). Individuals occupying marginal spaces, in these terms, “are reconstituted through special laws as populations on whom new forms of regulation can be exercised” (Das and Poole 2004:12). Alaska Native families struggling to maintain family and kinship ties occupied several spaces of marginality with respect to their interactions with state legal systems and clinics. The pedagogic or disciplinary aspects of the state in this light are manifested

through practices, techniques and technologies of everyday life, where subjects are “made to learn the gap between membership and belonging” (Das and Poole 2004:17)

As anthropologists, it is critical to engage the terrain of human emotion as experienced in everyday life by those we work with and attempt to bring those experiences to the forefront of our analysis through reflexive ethnography. Emotions, for Rosaldo, “entail both feelings and cognitive orientations, public morality, and cultural ideology...they provide a ‘missing link’ capable of bridging mind and body, individual, society and body politic” (1989:219). The people that shared their lives and stories with me during research did so with the hope that they might help raise awareness of the broader cultural politics that shape perceptions of FASD and bring improvements to existing ways of thinking about FASD as a public health problem. Listening to family stories, we can learn how to expand available resources and supports into peoples’ home communities of choice. Critical insights from anthropology can thus become important points of engagement and collaboration with other researchers, state officials, program administrators, families, and professionals from a variety of backgrounds who are interested in eliminating health inequalities and improving health outcomes across social location.

The ways in which cultural constructions of difference are contested, affirmed and negotiated in the context of everyday life is a critical consideration. Through ethnography, we can document changing and fluid locations of difference as experienced in everyday life by those we work with. Rather than looking for consensus or uniformity, the focus should be on those very inconsistencies that challenge taken for granted assumptions by researchers. This shift in focus is necessary in order to understand and

destabilize the structures of power, privilege and authority that constrain everyday life choices for bodies in the margins. Critical dialogue with a variety of related disciplines has significantly shifted the ethnographic project and inspired a flowering of recent scholarship on relations of inequality, forms of domination, political mobilization, resistance movements, and the practices of everyday life. How we write and represent these phenomena have implications far beyond research. As history shows, if not engaged in carefully, honestly and reflexively, our work can become the very fuel for the continued marginalization of those we wish to understand.

Ultimately, if the structures of inequality that generate multiple layers of human difference, suffering, health and illness are to be contested, a more nuanced set of understandings need to be integrated into both popular and academic discourses. Learning how to articulate the ways in which these structures constrain the lives of people in diverse social locations without busily reinforcing them represents an ongoing challenge for anthropology and other scholars working on health inequalities. While significant theoretical improvements have been advanced through intersectional and critical public health approaches, clearly more work needs to be done to bring these perspectives into interdisciplinary conversation with scholars who share an interest in eliminating health inequalities. FASD in Alaska provides a critical context to examine how researchers need to dig deeper for solutions to health inequalities. By expanding our willingness to work alongside scholars from other disciplines, new spaces of collaboration will emerge. As serious and committed scholars, we have a responsibility to faithfully and dutifully engage this new terrain.

## **Policy Implications**

There are several important policy implications that emerge from this research:

(1) First and foremost, *expansion of diagnostic access* to families of all social locations will reduce the perception of FASD as a Native problem and assist in developing a more accurate understanding of the scope and distribution of FASD in Alaska. There is already work being done in this area with the creation of a diagnostic team at the non-profit disability service delivery agency known as Assets, but the clinic has only just started making diagnoses and few have been made to date; (2) *Coordination of existing programs, state surveillance systems and diagnostic clinics* is needed to ensure families do not slip through the cracks or get endlessly referred from one agency to the next. This was referred to me by one professional I spoke with as the “silo effect”, where programs get mired in their own everyday operations to the point where they become unaware of other programs and initiatives that may be available and of benefit to families (SC-002-003). With a lack of coordination and inter-agency communication, it is difficult to identify and respond to gaps in service delivery and build systems of care across critical life domains. Furthermore, because of the range of impairments associated with FASD, an individual may have interactions with a number of different institutions, including tribal health, state behavioral health, state intellectual and developmental disabilities systems, criminal justice systems and a variety of other entities, all of which can complicate service delivery and create additional constraints on individuals and families. (3) *Improve Behavioral Health Care Systems in Alaska* to avoid costly out-of-state placements in residential facilities. While the Bring the Kids Home Initiative has made great strides towards allowing individuals with complex behavioral health challenges to

return to Alaska to live in their communities of choice, there are still 400-500 kids receiving care out of state. In order to facilitate this transition, capacity to provide care, including identifying and training more providers, needs to be greatly expanded. While it is widely recognized that the criminal justice system is filling this gap in the meantime (Burd et al. 2011; Jeffery 2011; Thiel et al. 2011), improvements to behavioral health care systems in Alaska will alleviate this burden. (4) *Expand access to tribal courts* in ICWA cases by developing information and referral hubs to connect families with tribal court liaisons. This would be a form of parent navigation not unlike that offered by Stone Soup Group, but staff would be there specifically to help navigate tribal court cases. This would be of tremendous benefit to families who reported having great difficulty accessing tribal court. (5) *Expand cultural sensitivity trainings* for all levels of state government and actively work to develop open and honest dialogue with communities. This will help reduce negative perceptions of state employees, validate community concerns by providing opportunities to listen to one another and reduce perceptions of distrust. (6) *Recruit Alaska Natives into the foster parenting system* to provide more options for families in community settings that are comfortable for them and develop a sense of cultural continuity for individuals in the system. By developing networks of care and expanding them into communities throughout Alaska, the historical trope of removal of individuals with FASD from families and communities can be challenged and the stigma associated with FASD eliminated. (7) *Integrate educational and counseling services into all prenatal and primary health care settings*. This will work to balance the relative lack of attention given to FASD in non-tribal health care contexts and help educate the public about the risk of fetal harm associated with alcohol consumption

during pregnancy. By expanding the dialogue into broader community settings, public misperceptions about FASD can be addressed, resulting in new opportunities for community learning and problem solving. (8) Finally, it is critical to *find new and creative ways to get communities more actively involved in developing solutions*. Getting people to talk about the problems that exist in their communities is important. Many communities have identified alcohol consumption and by extension FASD as among the most serious problems they face. Focusing the conversation only on those individuals and families struggling does not help build community capacity for care and inclusion. Dialogue at the community level will create a broader awareness of the scope of the problem and get communities more deeply invested in developing locally appropriate responses.

It is my sincere hope that this dissertation will serve as a catalyst for a new kind of dialogue about FASD as a community health problem in Alaska and elsewhere. While this study has revealed some of the historical structures of inequality that continue to shape the meanings of FASD for families and communities in Alaska, I have also provided practical recommendations for how these might be eliminated. While there have been vast improvements made within the last decade with regards to the recommendations I have suggested, there is still a great deal of work to be done. It is my intention to expand this work and continue to build collaborative research relationships with those who share the same goal of improving human health outcomes for all.

## **Limitations of Research**

This study has several limitations. As discussed in chapter 1, the exclusion of voices of birth mothers and individuals with FASD can have the unintended consequence of perpetuating the very stereotypes this research seeks to address. It is my hope that this work will serve as a starting point for a broader conversation about FASD that includes and figures centrally the voices of mothers and their children. More importantly, a critical space of dialogue where mothers and their children can play a more central role in narrating their own life stories is needed. Future studies need to highlight these voices and mediate the many exchanges that occur between state, tribal and non-profit organizations and the varieties of families they serve, including foster families and extended natural families. Many of the perspectives included in this study involved assumptions that were made about someone else's motherhood. Similarly, conversations about the "best interests" of children were conducted with those voices conspicuously absent. Future research must be careful to move beyond these limitations and build a more inclusive dialogue where mothers and their children are encouraged to speak in a forum that is safe, accepting and understanding.

Another limitation includes the relatively small sample size of research participants. Future studies could build on existing networks to find more families interested in sharing their stories. Continued involvement with community-based organizations will allow for opportunities to learn of new programs and initiatives being designed to help families in Anchorage and elsewhere in Alaska and the United States. Additional studies might incorporate diagnostic clinics in hub communities in Alaska, which would provide the opportunity to meet more families and trace individual and



family histories and migrations within the state in response to family and community disruptions. There are a number of important research directions and this study represents one piece of what I hope to be a career of long-term community engagement and dedication to the improvement of human health.

Appendix A: Table of Research Participants

<b>Interview code</b>	<b>Interview type</b>	<b>Gender</b>	<b>Ethnicity</b>
BD-001-001	Adoptive parent	Female	Euro-American
WJ-001-002	Adoptive parent	Female	Euro-American
LR-001-003	Adoptive parent	Female	Euro-American
SC-001-004	Adoptive parent	Female	Euro-American
OT-001-005	Adoptive parent	Male	Euro-American
SL-001-006	Natural grandparent	Female	Alaska Native
HJ-001-007	Natural grandparent	Female	Alaska Native
KR-001-008	Natural grandparent	Female	Alaska Native
LA-001-009	Natural grandparent	Female	Alaska Native
SA-001-010	Adoptive parent	Male	Euro-American
PM-001-011	Adoptive parent	Female	Euro-American
MS-001-012	Natural parent	Male	Alaska Native
MT-003-001	Adult with FASD	Male	Alaska Native
CM-001-013	Adoptive parent	Female	Euro-American
RF-003-002	Adult with FASD	Female	Alaska Native
BM-002-001	Professional	Male	Euro-American
CS-002-002	Professional	Female	Euro-American
SC-002-003	Professional	Female	Euro-American
HS-003-003	Adult with FASD	Male	Euro-American
HA-002-004	Professional	Female	Alaska Native
OA-001-014	Natural parent	Female	African-American
TE-002-005	Professional	Female	Euro-American
ET-003-004	Adult with FASD	Female	Euro-American
DB-002-006	Professional	Female	Euro-American
AL-002-007	Professional	Female	Alaska Native
BM-001-015	Natural relative	Female	Alaska Native
MR-001-016	Adoptive parent	Female	Euro-American
TA-001-017	Natural relative	Female	Alaska Native
ST-001-018	Adoptive parent	Female	Euro-American
MT-003-005	Adult with FASD	Male	Alaska Native
SD-001-019	Adoptive parent	Female	Euro-American
AC-001-020	Natural relative	Female	Alaska Native
GJ-001-021	Adoptive parent	Female	Euro-American
MD-001-022	Adoptive parent	Female	Euro-American
NB-001-023	Adoptive parent	Female	Euro-American
CA-001-024	Natural parent	Male	Alaska Native
PC-002-008	Professional	Female	Euro-American
PL-002-009	Professional	Female	Euro-American
BH-002-010	Professional	Male	Euro-American
KT-001-025	Adoptive parent	Female	Euro-American
BA-001-026	Adoptive parent	Female	Euro-American
BJ-001-027	Adoptive parent	Male	Euro-American
BG-001-028	Adoptive parent	Female	Euro-American

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