

# FETAL ALCOHOL SPECTRUM DISORDERS (FASD) IN ANCHORAGE, ALASKA, AND THE RACIALIZATION OF A DIAGNOSIS

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## ABSTRACT

This research examines the racial and cultural politics that shape diagnostic encounters and outcomes of fetal alcohol spectrum disorders (FASD) in Alaska. Utilizing ethnographic data collected in a variety of foster and extended family settings, the lived experiences of individuals with FASD and their families will be highlighted in an effort to understand and document how diagnosis disrupts connection to family, kinship, and community; structures access to health, education, housing, employment, and disability resources; and hinders opportunities for meaningful community inclusion across the lifespan. Collected family stories speak to a broad set of interrelated concerns within anthropology and public health, including settler colonialism and the racialization of medical knowledge, political accusations of risk and blame associated with alcohol use and pregnancy, and the pathologization of contemporary Indigenous identity.

## INTRODUCTION

Fetal alcohol spectrum disorders (FASD) is an umbrella term that encompasses the range of diagnoses and effects associated with prenatal alcohol exposure (Jones and Streissguth 2010; Sokol et al. 2003).<sup>1</sup> Alcohol is a teratogen that can readily pass to an unborn child through the placenta, interfering with embryonic progression and resulting in damage to the brain and other organs of the developing fetus (Popova et al. 2018). The effects are permanent, lifelong, and include physical, behavioral, and developmental disabilities in various combinations and degrees of severity. Recent nationwide estimates suggest prevalence rates as high as one in 20 (May et al. 2018), and Alaska has the highest reported rate of FASD in the United States (Burd et al. 2010; Centers for Disease Control and Prevention 2021; Schoellhorn et al. 2008). According to a recent summary report, there are 47,860 people living with FASD in Alaska (McDowell Group 2020). With a total statewide population of 728,903, prevalence estimates for Alaska are significantly higher than the national average at approximately 1 in 15 (Alaska Department of Labor and

Workforce Development 2021). This is nearly three times the national prevalence estimates for autism (Centers for Disease Control and Prevention 2020). Rates for Alaska Native populations are reported to be significantly higher than other racial/ethnic groups in Alaska, but less often discussed are the inequalities in diagnostic access and the racial and gendered politics of risk and blame that create the conditions and institutional relationships whereby Alaska Natives are more likely to be diagnosed.

While FASD is considered an “equal opportunity affliction,” in that drinking during pregnancy can cause birth defects, it is not an equal opportunity diagnosis (Armstrong 2003; Choate and Badry 2019; Golden 2006; Salmon 2007, 2011). Rooted in paternalistic attitudes and ethnocentric assumptions about Indigenous peoples and alcohol use, FASD is directly linked to settler-colonial regimes and is part of a long history of racial othering in medicine (Gampa et al. 2020). The institutions created and charged with health management, education, and social services are borne out of settler-colonial policies

and power structures, and they are actively reinforced in the present through everyday forms of clinical practice. Since its emergence as a medical category or diagnosis, Alaska Natives have had far greater access to surveillance and diagnostic services as the primary diagnostic teams have been housed at federally funded Indian Health Service clinics. While legislation has affirmed Indigenous self-determination and facilitated a transition to tribally owned and operated delivery systems for healthcare services (Gottlieb 2013), disparities in access to diagnosis remain and reflect enduring legacies of colonialism. This fuels public misperception, shapes clinical interactions and predispositions, and reinforces the positioning of FASD as an Indigenous pathology despite continued efforts by federal, state, and tribal health partners to promote a message of universal risk and prevention (Yousefi and Chauhan 2021).

In Alaska, the four-digit diagnostic system developed at the University of Washington is used to diagnose FASD (Astley 2014; Astley and Clarren 2000). Diagnosis is time-intensive and expensive, requiring use of highly specialized multidisciplinary treatment teams that generally include a care coordinator or case manager, psychologist or licensed mental health professional, speech language pathologist, occupational therapist, physician or advanced nurse practitioner, and family navigator. Individuals are scored based on the presence or absence of four “conditions”: (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 gain 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 (e.g., learning disabilities); and (4) documented drinking during pregnancy.

The stories presented below offer a critical perspective on existing gaps and inequalities in systems of care across the lifespan for individuals who experience FASD and their families. They offer important glimpses into the ongoing role of colonialism in racializing medical knowledge about FASD, but they also illustrate everyday forms of resilience practiced by individuals and families as they navigate complex legal, educational, health, and social service landscapes.

## METHODS

A primary goal of this research was to examine racial and cultural assumptions that shape knowledge and medical practice about FASD and structure outcomes for individuals and families in Alaska. During the period from August 6, 2010, through August 5, 2011, I worked with foster families and extended families living with and supporting individuals diagnosed with FASD (Hedwig 2013). Documenting the experiences of families in their interactions with clinical, state, tribal, and nonprofit institutions offered opportunities to understand inequalities in the diagnostic landscape and exposed vulnerabilities across systems of care, including health, education, child welfare, housing, employment, and community living. I interviewed 43 people, including 18 foster or adoptive parents; 10 extended family members (i.e., grandparents, aunts, or uncles); 10 direct service professionals, including program administrators and parent support professionals in state, tribal, and nonprofit organizations; and five adults over the age of 18 who have a diagnosis of FASD. Because of the family focus of the organizations I was working with (e.g., Volunteers of America, Stone Soup Group, and Hope Community Resources), many of the relationships I formed with families extended beyond interview settings and created additional opportunities for participation in community events and activities. My social location as a white, cis-gendered male from suburban New York shaped my interactions with people and limited what I could ever know or understand about someone else’s everyday lived experience. The point of entry into the work was through direct care in the field of developmental disabilities, which provided a unique opportunity to listen to challenges in navigating complex institutions and managing everyday care needs for families. Many of the families I interacted with appreciated my background in direct care and welcomed me into some of the informal support groups that exist. For example, Volunteers of America, which houses the Grandfamilies Support Network, consists of grandparents raising individuals with FASD. The support network was an invaluable resource for meeting families and understanding the role of extended kinship caregiving as a response to perceived imposition of state institutions, including the Office of Children’s Services (OCS). Similarly, Stone Soup Group, which houses a statewide FASD Family Support Network, was a critical source of information and networking with families. Hope Community Resources, a nonprofit community organization and the largest ser-

vice provider for people who experience developmental disabilities in Alaska, provided the opportunity to speak with care coordinators and share opportunities for participation. In addition to monthly support group meetings, I met and interacted with many families at FASD-related community functions, including the Fascinating Families Camp hosted by Volunteers of America, Family Stories workgroup sessions hosted by Stone Soup Group, and family picnics hosted by the Alaska Center for Resource Families. 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 the complexities of accessing support services. All research activities were reviewed and approved by the Institutional Review Board at the University of Kentucky (Protocol #10-0457-F4S).

### MOVED BY THE STATE: HOW DIAGNOSIS SHAPES FAMILY FORMS

Diagnosis of FASD (in some cases, even the suspicion of diagnosis) has a profound influence on patterns of residence, family forms, and disability outcomes. It sets in motion particular sets of 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 (Choate and Lindstrom 2017; Rockhill 2010; Schulz and Mullings 2006). Several people interviewed for this work described family disruption and relocation as prominent themes in their everyday experience. 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), an Alaska Native grandparent I spoke with explained:

Until I came back up here to Anchorage, my son's kids were in OCS custody. I turned around and they said, that was the first thing that came out of the OCS's mouth, "Well, she is considered an unfit mother."

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. They further explained:

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 [in Juneau]. 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.

The experiences of this grandparent reflect how racial (or in some cases racist) clinical discourse and practice shape family interactions with state institutions. Discourses of risk, blame, and moral responsibility become pretexts that justify a variety of interventions, including removal of children from their home families and communities. In response to these pressures, families deploy a variety of strategies to resist these kinds of impositions. For example, as one extended 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.

Her daughter, adopted from a family within her tribal affiliation, struggles with mental health problems, including depression, and experiences learning disabilities. After the birth of her son, she experienced severe postpartum 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 on this initial interaction, the home visiting nurse reported the family to the Office of Children's Services.

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 or mental health issues, then a nurse has to do a home visit.

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. Their struggle raised several fundamental issues of sovereignty and authority to decide what is in the "best interests" of an Alaska Native child. A grandmother and caregiver 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.

This narrative speaks to several important issues, including the racial and cultural assumptions made based on 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.

In failing to comply with a regulatory 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 colonialist perception of cultural difference and otherness, which assumed her lack of parental capability and fitness, was used as justification for removal (Choate and Lindstrom 2017). 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 described further:

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.



This narrative speaks to the great lengths this grandparent was willing to go in order to retain custody of her grandson. It also demonstrates her resilience in navigating an unfamiliar 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 important questions of equity for those who may not have access to such resources. It is easy to see how someone at the initial point of entry 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 outside of family and community if not for their diligence, knowledge, and desire to have their family remain with them. What is more, individual family struggles were seen and readily identified as a part of a broader struggle for equity and justice within a framework of colonial imposition and cultural judgment that continues to this day. 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.

While this was a common theme among grandparents with respect to the centrality of family and the importance of community preservation and (re)unification, it stood out as an important way of engaging the community in broader discussion about history, colonialism, and systemic racism in our systems of care. Listening to the stories of families, it becomes clear that many of these encounters are shaped before they occur. Racial bias is reinforced through clinical practice and shapes public attitudes toward Alaska Native women, alcohol use, and the need for intervention. This disparity is most notable in Anchorage, where the only diagnostic clinic is housed within the tribal health system, currently has a six-month waiting list at a minimum to see a diagnostic team, and only serves Indian Health Service beneficiaries.

### SOVEREIGNTY, HEALTH GOVERNANCE, AND “INDIAN” CHILD WELFARE

The apparent and understandable distrust many families feel with regards to state channels for resolving legal custody disputes is rooted in colonial mentalities and re-

inforced in the present in a number of ways. Such interactions are perhaps most concerning in the area of child welfare, where overrepresentation of Indigenous women and children is explicitly linked to histories of colonialism, dispossession, and ongoing disempowerment (Choate and Badry 2019; Yousefi and Chaufan 2021). While the federal Indian Child Welfare Act (ICWA) requires that “active efforts” be made at the onset of interactions with child welfare systems to keep families intact, this does not happen continually across all cases, resulting in structural inequalities that perpetuate disparities in rates of Alaska Native children in OCS custody (Lucero et al. 2020). For example, one grandparent, in describing her struggles in finding and transferring a custody case to tribal court, described a tumultuous legal battle over jurisdiction, which lasted more than 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.”

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 and her creativity in engaging a variety of channels and locating the appropriate resources to resolve her grievances. In addition, the legal and jurisdictional issues that 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 that research participants would draw on to inform their experience and 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 (e.g., “the state stole my child”), the state also had its perceptions of difference and cultural misunderstanding that influenced

family outcomes in profound ways. Within tribal court settings, this was further explained by a grandparent:

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 firsthand 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.

The perceived urgency and necessity of staying with family and community was communicated by several people. As another grandparent raising her grandchild related:

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.

These sentiments were reiterated by a tribal leader and child welfare advocate who, in discussing the importance of keeping children in their home communities and learning new ways of accommodating individuals who experience impairment or disability, stated:

One of the most important things that needs to happen is to keep children in their home communities. Instead of saying, “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, 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.

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 to support people with FASD at home. The comments also highlight increased recognition of the need for racial and cultural reconciliation to eliminate long-standing patterns of injustice directed toward Alaska Native families and communities. This was reiterated by another 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.

Sovereignty and the issue of jurisdiction was a central theme that emerged in collected interviews. Interactions with state entities, which are shaped in part by 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 families interviewed, relationships and interactions with state, nonprofit, 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 institu-

tional practices is largely a cultural consideration. Such interactions serve to alienate Alaska Native families from the very institutions that have been set up to provide assistance. This also has a polarizing effect on how FASD is constructed and understood publicly. 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, 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, there was almost a knee-jerk reaction assuming that Alaska Native families and communities were inherently “unfit,” incarcerated by culture, and otherwise incapable of keeping their children and of being “good” parents, even when family history and alcohol exposure was unknown. While distrust tended to characterize the perceptions that extended 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.

This narrative is revealing in a number of ways. First, it contains elements of common (mis)representations of contemporary Indigenous life, including social dysfunction, mental illness, alcoholism, and homelessness. This kind of “stereotyping logic” (Prussing 2011:9) is a product of settler-colonial mindsets that 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 culture (Choate and Lindstrom 2017). This positioning is particularly problematic in light of

the fact that middle-aged, educated white women are the demographic most likely to report drinking while pregnant (Centers for Disease Control and Prevention 2012) despite continued public emphasis on and linkage to Indigenous pathology.

The collected narratives 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 nonprofit entities. For example, as one 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 or 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.

These comments similarly reflect an awareness of how competing 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 construct a sense of “best interest” culturally necessitates a shift in thinking and a recognition of ongoing injustices at the systems level. It is also an invitation to broaden the conversation and involve all community members in building an environment of support. 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.

Listening to the perspectives of community leaders as well as family members who live with and have experienced the stigma that can accompany a label of FASD is a critical step toward understanding how difference is culturally constructed and how it constrains everyday life possibilities for families and communities. It also offers an opportunity to reflect on the many ways in which historic injustices rooted in colonialism are actively replicated in our current systems of care.

## **PATHOLOGIZING NATIVENESS**

Within the professional and community contexts studied, the collected discourses about FASD frequently position and pathologize Alaska Native peoples and communities as risk factors, which can fuel suspicion and cultural judgment. For example, several professionals interviewed readily admitted that a child (and that child's home family and community) is generally looked at with additional scrutiny if Alaska Native. Additionally, several professionals referenced the phrase "What part of town are you from?" This became an informal indicator of diagnosis in some clinical contexts. Lower-income neighborhoods were more readily associated with relatively higher rates of FASD. In one instance, in response to learning of the neighborhood where a recently referred Alaska Native family resided, a professional case manager stated, "Must be an FASD kid." This type of nonclinical, nonmedical 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, ADHD, or other impairments unrelated to FASD. These kinds of situated professional reactions reflect racial, cultural, gendered, and class-based assumptions about FASD and risk that lead to accusation, moral judgment, and inequities in clinical interactions and outcomes.

Normalization of a disabling language that refers 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 or adoptive parents were generally more critical of rural or "village life" and associated it with general safety concerns for children. In contrast, extended families tended to contest this narrative by focusing on family connections, historical injustice, and the need for tribal sovereignty over custody-related issues and community placement. The phrase "Must

be an FASD kid" indicated a particular framing loaded with negative assumptions and perceptions both of the impairment or disability associated with FASD and of 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" Alaska Native mother from a family, community, and culture assumed to be unfit. 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 a 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 (or even the suspicion of diagnosis) evokes negative stereotypes that prefigure clinical encounters and leads to profound disparities in outcomes for individuals, families, and communities.

## **DISABLING WORLDS: IMPLICATIONS FOR FAMILY AND COMMUNITY**

Living with and supporting a person with FASD can be challenging, stressful, and 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 relatively recent history 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 disabilities and mild cognitive impairments) are not easily noticeable and express themselves in a variety of ways across individuals. As a result, many families have difficulty obtaining the individualized supports they need in areas of education, healthcare, employment, and community living. Such realities highlight the need for increased federal, state, and tribal cooperation in expanding access to community-based services for people living with FASD and their families.

Policies and practices with respect to FASD in Alaska have undergone substantial changes over the last few decades. This tenuous history has been marked by expansion in diagnostic access as well as expansion of surveillance practices to monitor risk factors associated with FASD. While many improvements have been made at the systems level, inequalities persist in the present and continue to shape a variety of institutional settings and relationships.



These settings are powerful vehicles for the reproduction of colonial mentalities and must be destabilized as part of broader efforts to achieve health equity and justice. In this regard, FASD diagnosis itself can be a double-edged sword. In many instances, individuals and families reported that diagnosis does not necessarily help in terms of getting access to needed services and supports. In fact, it may hinder efforts to reunify families and serve as a further marker of stigma and social difference for both the person diagnosed and their family. Since FASD is essentially a diagnosis for two (Armstrong 2003), loaded with accusation and moral judgment that has profound consequences for entire families and communities, we must work to build more FASD-informed institutions across the board and recognize the ongoing role of colonialism in contributing to health inequalities.

Equally, families who “had a diagnosis to work with” also found that understanding the challenges their loved ones were experiencing and learning about possible accommodations to support everyday community living 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 did so in order to learn more about her son’s care needs. With increasing awareness at the policy level coupled with initiatives to improve equity in diagnostic access and improve community-based services and supports, the rights of individuals with FASD and their families to live and work in their communities of choice is being maintained and expanded. As a result, historic injustices and the ongoing disparities in health outcomes they have created can potentially be eliminated.

## CONCLUSIONS

Much of the literature on FASD intentionally disassociates factors such as race, class, gender, and culture in order to make universalist claims about risk (Armstrong 2003; Golden 1999, 2006). Insisting that FASD “crosses all lines” masks historic injustices and perpetuates racism in Western biomedical institutions. Such considerations are generally missing from biomedical and epidemiological reports showing disproportionate rates of FASD prevalence in Alaska Native communities. Anthropological

perspectives offer an opportunity to critically interrogate racial and gendered accusations of maternal alcohol consumption and situate the conversation historically. While the literature continues to position FASD as “100% preventable,” in that minimizing or eliminating alcohol exposure continues to be a major focus of intervention, such a framing ignores broader social determinants, including histories of colonialism, systemic racism, discrimination, and naturalized inequality (Stewart 2016).

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 on in the form of clinical and state intervention. Diagnosis is therefore just as much a moral judgment as it is a medical determination, and social location figures centrally in how such interactions unfold. Overrepresentation of American Indian and Alaska Natives with FASD in the child welfare system (Choate and Lindstrom 2017; Woods et al. 2011), criminal justice system (Jeffery 2010; Tait et al. 2017), and foster care system (Tait 2000, 2008) are all powerful examples of the broader structures of inequality that shape disparities in health outcomes. In this regard, FASD serves as a powerful example of how implicit cultural bias and systemic racism can become normalized in our medical, educational, and legal institutions. Bringing into conversation critical understandings of FASD in both research and everyday practice will serve to expose the structures of inequality that create health disparities in the first place, while working to build culturally informed and responsive programs to better serve families and communities across Alaska.

## ENDNOTE

1. Please note that use of FASD as an umbrella category reflects the four-digit diagnostic code used by the State of Alaska. In both Canada and Australia, FASD is a diagnosis, a more recent innovation that simplifies the terminology and places primary emphasis on the neurodevelopmental impairments that can result from prenatal alcohol exposure (Bower and Elliott 2016; Cook et al. 2016).

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