

CANADIAN JOURNAL OF

# Disability Studies

Published by the Canadian Disability Studies Association · Association Canadienne des Études sur l'Incapacité

*Canadian Journal of Disability Studies*

**Published by the Canadian Disability Studies Association**

**Association Canadienne des Études sur l'Incapacité**

**Hosted by The University of Waterloo**

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**Absence and epidemic:  
Autism and fetal alcohol spectrum disorder in Indigenous populations in Canada**

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**Abstract:** This paper contemplates the absence of Indigenous perspectives within autism discourse in Canada, despite increasing concern and surveillance over a growing autism 'epidemic.' I posit that the simultaneous production of a fetal alcohol spectrum disorder (FASD) 'epidemic' among Indigenous populations contributes to this absence. Taking a genealogical approach to the emergence of FASD as a diagnostic framework, I situate the FASD 'epidemic' and subsequent prevention campaigns within a lineage of biopolitical strategies aimed at limiting the reproductive agency of Indigenous women. I argue that this phenomenon has two main consequences: first, the erasure of Indigenous autistics and a homogenization of Indigenous neurodiversity; and second, I claim that the association of FASD with Indigeneity converts the violent outcomes of settler colonialism into an embodied pathology, working to justify ongoing dispossession of land and resources from Indigenous people.

**Keywords:** fetal alcohol spectrum disorder, autism, Indigenous, trauma, settler-colonialism

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**Introduction**

“[Neurodiversity] is an element they tried to disappear when villages were burned, when ships came and dead-eyed lies were told to us and promises were broken. This is colonialism brain-drain and what environmentalists might call a drastic reduction in biodiversity culminating in a dangerous reliance on destructive production. That is how they laid waste to the land and water; how they laid waste to we symbiotic creatures who live here and whose minds and spirits are created joyfully and powerfully neurodiverse” (Jen Meunier [Gzhibaeassigaekwe], 2017, p. 428).

This paper began with an inquiry into the way autism diagnoses and interventions manifest amongst Indigenous communities in Canada. However, it did not take long to notice that autism and Indigeneity rarely intersect within Disability or Indigenous Studies scholarship, media discourse, or Canadian health policy. One of the few documents that discusses autism and Indigenous communities in the Canadian context is a federal government response to a Senate Committee report on autism in Canada entitled *Pay Now or Pay Later: Autism Families in Crisis*. The report, published in 2007, offers a series of recommendations to the Canadian government regarding the autism ‘crisis’ in Canada. The Government of Canada responded to the report with their own document which specifically referenced autism among Indigenous peoples:

The Government of Canada supports the provision of health services and programs, as well as social and other services, to First Nations living on reserve and to Inuit communities. First Nations and Inuit children represent the fastest growing segment of the population in Canada. The First Nations birth rate is more than twice that of the Canadian population at large, contributing to a population that is much younger in comparison to the general Canadian population. Notwithstanding this high proportion of First Nations and Inuit youth, there are no known statistics on the number of First Nations and Inuit individuals with ASD. (Government of Canada, 2007, p. 2)

Noting that the Indigenous population has a greater proportion of youth than the rest of Canada and given the preponderance of autism diagnoses across the population, we might expect Indigenous youth to be carefully monitored. However, as the document points out, there is no statistical data on the prevalence of autism amongst Indigenous people in Canada. Later, the document goes on to describe several government programs that address, "the unique challenges faced by children with special needs in First Nations and Inuit communities," including The Fetal Alcohol Spectrum disorder program (Government of Canada, 2007, p. 4). The program is described as follows:

The Fetal Alcohol Spectrum Disorder (FASD) program promotes early diagnosis and intervention for First Nations pre-school aged children with FASD. Multi-disciplinary teams provide holistic, family-centered support before, during and after diagnosis. These teams incorporate a wide variety of expertise including doctors, social workers, psychologists, elders, and educators. The program supports community coordinator positions in some areas, with a focus on improving access to multi-disciplinary teams. Although the program is focused on children with FASD, it may also provide increased

opportunities to children with other special needs, such as those with ASD, through the assessment and diagnosis process. (Government of Canada, 2007, p. 4)

Here, the document introduces a different diagnosis: fetal alcohol spectrum disorder (FASD). While the two diagnoses are not conflated (i.e. ASD and FASD), it is implied that autistic Indigenous children will be able to find resources and support within FASD programming.

In Canada, autism is often represented as an epidemic. It is estimate that one in sixty-six children and youth in Canada have been diagnosed with ASD (Government of Canada, 2016). There is not enough historical data on ASD diagnosis in Canada to estimate changes in ASD prevalence, however, drawing on data from the US-based Centers for Disease Control and Prevention, Autism Canada claims that prevalence increased by thirty percent between 2000 and 2012. The production of autism as an epidemic has led to a proliferation of etiological studies and advocacy organizations, which work to 'solve' the supposed problem of autism (McGuire, 2016). Yet, there have been limited to no studies on the prevalence of autism amongst Indigenous peoples in Canada; several researchers suspect that autism is either under-detected or under-represented in Indigenous populations (Lindblom, 2014; Ouellette-Kuntz et al., 2006; Burstyn, Sithole, & Zwaigenbaum, 2010). Australian researchers have had similar findings among Indigenous people in that country (Leonard et al, 2011; Roy & Balaratnasingam, 2010). With no specific data on Indigenous populations it is impossible to effectively compare diagnostic rates. However, as Lindblom (2014) points out, there is a distinct absence of information about Indigenous children in available literature on autism in Canada and in other Western settler-colonial countries, and likely lower rates of ASD diagnoses in these groups.

Lindblom concludes that under-diagnosis will result in Indigenous children lacking access to services and supports which are available to non-Indigenous children.

I argue that a factor in Indigenous peoples' absence in autism discourse is that there is a discursive preoccupation with the production of an Indigenous fetal alcohol spectrum disorder (FASD) 'epidemic.' The outcomes of this phenomenon are twofold: first, it contributes to the erasure of Indigenous autistics. Second, I claim that the association of FASD with Indigeneity converts the violent outcomes of settler colonialism into an embodied pathology, working to justify ongoing dispossession of land and resources from Indigenous people. I begin with a discussion of the emergence of FASD as a diagnostic framework, and situate the production of the FASD 'epidemic' within a lineage of biopolitical tools deployed by the state to control Indigenous reproduction. Next, I compare the diagnostic criteria of FASD and ASD, underlining the slippery nature of these classifications and exploring how mothers of children diagnosed with ASD and FASD are uniquely subjectivized. This leads into a discussion of how diagnosis frames futurity, and the ways gradations and spectrums within diagnostic categories demarcate bodies worthy of care. The final section argues that the FASD 'epidemic' discursively flattens Indigenous neurodiversity, while sustaining the perception that Indigenous people are not fit to govern themselves, and therefore need to be 'saved from themselves' through assimilation into the Canadian neoliberal state.

I write this paper from the position of a white settler of Irish and English ancestry, born and raised on unceded territory of the Lekwungen (Songhees) First Nation. Currently, I live and work in Tkaronto, territory of the Wendat, Petun, Seneca, and the Mississagua of the Credit River. I write with a deep commitment to both disability justice and decolonization movements, and a desire to further understand their intersections. Drawing on the foundational intersectional

frameworks within the work of Erevelles and Minear (2010) and Connor, Ferri, and Annamma (2016), I understand disability and race as co-constitutive social categories, and frame my analysis as such. Most importantly, I feel that 'doing' disability studies in Canada requires paying attention to and revealing the way ableism functions within the confines of a settler-colonial state. I hope to draw attention to the connections seemingly disconnected processes – dispossession of Indigenous lands and medicalization.

This paper, while rooted in theories of critical disability studies, is necessarily interdisciplinary. I draw heavily on the work of Métis medical anthropologist Caroline Tait, who has written extensively on the production of the FASD epidemic in Canada. I also draw upon autistic scholars and advocates including Mel Baggs, Lydia X. Z. Brown, and Jen Meunier to inform my framing of autism as both a diagnostic category and a lived experience, and to highlight the erasure of autistic people of colour. The work of Eve Tuck, Unangax scholar of Indigenous and Critical Race Studies, has informed my understandings of connections between gender, heteropatriarchy, settler-colonialism and decolonization. The theoretical frameworks used by Anne McGuire in her 2016 book *War on Autism* have helped to ground my analysis. Finally, I engage with Tanana Athabascan scholar Dian Million's work on the medicalization of colonial trauma, Indigenous healing, and self-determination. It is important to note that I also reference medical discourses and statistics throughout this paper. Rather than employing these discourses as natural or neutral truths, I use them to highlight the ways in which the (medicalized) classifications of race and disability intersect, producing material realities (Annamma, Connor, & Ferri, 2016. p. 17). When referring to medical diagnostic literature, I use diagnostic labels, including autism spectrum disorder (ASD), fetal alcohol syndrome (FAS), fetal alcohol effect (FAE) and fetal alcohol spectrum disorder (FASD).

## I. The production of an Indigenous epidemic

"The introduction of a new diagnostic category brings with it the power to reshape our understandings of individuals and populations." (Tait, 2009, p. 202).

Fetal alcohol spectrum disorder (FASD) is an umbrella term for a variety of impairments experienced by individuals who are exposed to alcohol in utero (Shankar, 2016). FASD is often further categorized into diagnostic labels including fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), and alcohol related birth defects (ARBD). These terms are sometimes used to indicate varying levels of severity, however their use has shifted over time and they are sometimes used interchangeably. Following McGuire's (2016) genealogical approach to the emergence of autism as a diagnostic category, I seek to understand the emergence of FASD not to investigate what FASD *is*, but rather how the category itself has come into being and changed over time (p. 28). To understand the production of a FASD epidemic amongst Indigenous populations in Canada, we must look to the specific context in which the diagnostic category emerged.

Fetal alcohol syndrome was first named as a diagnosis in 1973, when Washington-based pediatricians Kenneth L. Jones and David W. Smith published their article "Recognition of the Fetal Alcohol Syndrome in Early Infancy" (Tait, 2009, p. 203). David W. Smith and Kenneth L. Jones were pediatric researchers in the field of dysmorphology – "the study of congenital abnormalities that arise during development" (O'Neil, 2011, para. 7). Smith is celebrated as the "father of dysmorphology," publishing his manifesto on the subject in 1966 (Frias, 2015, p. 4). This foundational text in the field shows Smith's deep investment in both understanding the cause of various 'congenital abnormalities' as well as creating a classificatory schema to define and name them (Smith, 1966). Jones and Smith's 1973 study of FAS gives detailed descriptions



of physical, physiological, and developmental characteristics of three American Indian infants born to "chronic alcoholic mothers" (Jones & Smith, 1973, p. 999). Their study built on their own previous research of eight other infants – three American Indian, three Black and two White. The subsequent publication categorized "abnormalities" amongst the eleven infants, noting characteristics such as pre- and post-natal growth deficiency, developmental delay, microcephaly (small head size), and short palpebral fissures (horizontal opening of the eyelid), and fine motor dysfunction (Jones & Smith, 1973, p. 999). While Jones and Smith do not discuss race as a factor in diagnosis, it is important to note that nine of the eleven infants studied were not white, with over half being Indigenous (American Indian).

Early studies of FAS in Canada echoed the over representation of Indigenous children found in Jones and Smith's (1973) work. The first major Canadian study of FAS was carried out by pediatrician K. O. Asante and published in 1981 (Tait, 2003, p. 94). Researching children who had been clinically assessed for developmental issues in Northwest British Columbia and the Yukon between 1972 and 1980, Asante found that 95% of the children diagnosed with FAS were Indigenous (Tait, 2003, p. 95). However, as Caroline Tait (2003) points out, Asante's publication does not note the overall proportion of Indigenous children in the study, nor the fact that the geographical area of research had a large Indigenous population, likely leading to an overrepresentation of Indigenous children in the study. Despite these issues, Asante concludes that FAS is likely a major health issue for Indigenous communities (Tait, 2003, p. 95). Methodological flaws plague early FAS research in Canada. Most studies that indicate higher prevalence of FAS amongst Indigenous people were carried out in remote Indigenous

communities or areas with a large population of Indigenous people, all but guaranteeing disproportionate representation of Indigenous children in their findings (Tait, 2003).<sup>1</sup>

In addition to focusing largely on Indigenous communities, FASD research lacks consistency across diagnostic criteria (Tait, 2009, p. 203). FASD is believed to manifest differently amongst individuals, existing, like ASD, on a 'spectrum', as a clustering of characteristics, some or all of which may be present to varying degrees of severity, and which may change or disappear with age. None of the defining characteristics are unique to FASD (Tait, 2003, p. 203). Defining facial characteristics (which may or may not be present) have been noted to be problematic as a diagnostic tool among Indigenous people, as they may overlap with facial phenotypes of some Indigenous groups, reflecting a bias against these facial phenotypes. The idea of a 'standard' white face seems likely to be a contributing factor in over-diagnosis (Tait, 2003, p. 11). Another difficulty in diagnosis is ascertaining confirmation of maternal alcohol use during pregnancy, which, as it usually depends on self-disclosure, is impossible to consistently determine. Tait (2009) argues that the Canadian imaginary of FASD as an 'Indigenous problem' is a result of the false assumption that, "Aboriginal women are at significantly higher risk than any other group of women to give birth to an alcohol-affected child" (p. 196). This belief is derived from the longstanding stereotype of widespread alcoholism amongst Indigenous communities, despite research which indicates that Indigenous women drink no more during pregnancy than their non-Indigenous counterparts (Stange, 1997; Razack 2013; Tait, 2003; 2009; Salmon, 2011). Legitimizing this dubious body of outdated research, a 2006 Health Canada report on FASD

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<sup>1</sup> For more examples, see: Godel, Pabst et. al., 1992; Robinson, Conry et. al., 1987; Asante and Robinson, 1990; Habbick, Nanson et. al., 1997; Smith, Sandor et. al., 1981; Asante and Nelms-Matzke, 1985; Williams and Gloster, 1999.

states that "research suggests that the occurrence of FASD is significantly greater in Aboriginal populations, and in rural, remote and northern communities" (p. 1).

Discursive links between FASD and Indigenous communities are pervasive, in the medical literature and elsewhere. A 1997 article in the *Canadian Medical Association Journal*, entitled "Fetal alcohol syndrome epidemic on Manitoba reserve" states that one in ten children on the reserve are victims of FASD, and speculates that the number is likely two to three times that in reality (Square, 1997). In 2000, the *Globe and Mail* published an article by Margaret Wentz entitled, "Our poor ruined babies: the hidden epidemic," wherein she calls FAS "a devastating, but preventable birth defect," and claims that "virtually every native child adopted over the past 20 years has some degree of alcohol damage" (Wentz, 2000, para. 2; para. 9). A year later, Wentz penned an article which claimed "FAS and FAE are six times more common in Canada than AIDS. They are the leading known cause of mental retardation. And they are the common denominator for many of the plagues of native communities" (Wentz, 2001, para. 6). Sweeping generalizations like these bolster the idea of an Indigenous FASD epidemic in the Canadian imaginary. Furthermore, media sources frequently associate FASD with violence, in effect arguing that the disproportionate rates of Indigenous incarceration are a result of widespread rates of FASD.<sup>2</sup>

As FASD comes to be represented as an Indigenous epidemic, a multitude of state sponsored FASD prevention campaigns are directed at Indigenous communities, and more specifically, Indigenous women. In 2011, feminist health researcher Amy Salmon wrote that there have been over 350 FASD prevention campaigns in Western Canada and territories alone

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<sup>2</sup> For example, see: Malone, 2018; Blake, 2018; Craig, 2018; Grant, 2017; Graham, 2017; Morin, 2017.

in the previous twenty years (p. 168). This phenomenon must be situated in a history of state surveillance and control of Indigenous women. Indigenous feminist scholars have argued that the management of Indigenous gender and sexuality is a cornerstone of the settler-colonial project in North America (Arvin, Tuck & Morrill, 2013). Settler-colonialism is built upon the assumption of physical and intellectual superiority of European settlers, their political systems, and ways of life. Complex and far-reaching systems were put in place by settlers with the goal of Indigenous elimination, largely through the regulation of Indigenous reproduction. The interlocking structures of ableism, racism and heteropatriarchy inform these systems of reproductive surveillance and control.

Although an overview of these systems is beyond the scope of this paper, it is important to identify some of their manifestations. Their immense scope and interconnectedness is made manifest in: the imposition of heteropatriarchy and nuclear family structures onto sovereign Indigenous nations with complex and varied systems of kinship and social organization (Arvin, Tuck & Morrill, 2013; Million, 2013); the Indian Act, which in its much amended version continues to govern the lives of Indigenous people in Canada, including the ways in which Indian status is passed down (Barker, 2008; Lawrence, 2009; Million, 2013; ); the Indian Residential School system; official sterilization programs in Alberta and British Columbia, as well as non-official sterilization practices in other provinces (Stote, 2012); widespread sexual violence which continues to the present day (Million, 2013); and lastly (although the list could continue) the child welfare system, which in the nineteen sixties began to remove children from Indigenous families in huge numbers, a phenomenon known as the 'sixties scoop' (Salmon, 2011).

The production of the FASD epidemic is a newer, more insidious iteration of these systems, which have already identified Indigenous mothers as incompetent, neglectful, irresponsible, genetically predisposed to alcoholism, and overall unfit for motherhood (Salmon, 2011; Salmon, 2004; Hunting & Browne, 2012; Shankar, 2016). As Salmon (2011) writes, "campaigns to prevent FASD must be understood as emerging from a social, political and historical context in which Aboriginal mothers and their children have been constructed repeatedly as objects for State intervention..." (p. 170). Poor and racialized women in the US and Canada (including Indigenous women) are increasingly being criminally charged for using drugs or alcohol during pregnancy (Shankar, 2016; Tait, 2009). Despite known links between FASD and lower socio-economic status, prevention efforts remain focused on the behavior of individual mothers rather than structural concerns (Shankar, 2016; Salmon, 2011; Salmon, 2004; Hunting & Browne, 2012; Jones, 2011).

FASD prevention campaigns are expressions of biopower; the theory of power developed by Michel Foucault (1978/1990) concerned with the management of life, at both the level of the individual body and at the level of population. Rabinow and Rose (2006) describe biopower as being categorized by three key elements: "one or more truth discourses about the 'vital' character of living human beings, and an array of authorities considered competent to speak that truth;" "strategies for intervention upon collective existence in the name of life and health;" and "modes of subjectification, through which individuals are brought to work on themselves, under certain forms of authority, in relation truth discourses, by means of practices of the self" (p. 197). Biomedical FASD research, some of which I have detailed earlier, produces authoritative truth discourses, the legitimacy of which is reinforced by governmental health agencies. Truth discourses are reflected and reinforced by media representations of the FASD 'epidemic.'

Strategies for intervention also include surveillance; prevention campaigns, which warn prospective parents of the risks associated with drinking and attempt to prevent the occurrence of FASD through education of said risks; the child welfare system, which frequently removes children from parents deemed 'unfit;' and, increasingly, criminalization of mothers who drink alcohol or use other substances during pregnancy. The goal of these strategies is to create self-responsibilized subjects, who, made aware of the consequences of alcohol use during pregnancy, will abstain on their own accord or else risk social shame and ostracization.

## **II. Comparing diagnoses, contrasting motherhood**

"Racial and disability categories can be quite slippery, with the specific characteristics and types of people put in one category or kept from another shifting by time period or cultural context" (Lydia X. Z. Brown, 2018, p. 5).

Autism and FASD are both diagnoses that lack biological diagnostic markers. This is not to say that other disabilities, which do rely on more concrete biological diagnoses, function within a neutral and unbiased framework, but instead to highlight the ways in which behavioural and developmental 'disorders' are especially at risk of diagnostic bias (Connor, Ferri, and Annamma, 2016, p. 10). Biomedical autism researchers Thomas et al. (2012) write, "since autism is a clinical diagnosis for which there is no reliable diagnostic marker, it is likely that conditions considered in ASD represent similar phenotypic signs and symptoms of mixed underlying etiologies" (p. 202). In other words, diagnostic criteria for ASD includes characteristics which are applicable to other diagnostic categories. Likewise, regarding FASD, Salmon (2004) writes "it is important to note that, as current diagnostic criteria for FAS/FAE are highly subjective and open to misapplication" (p. 117). There are significant overlaps in the

diagnostic criteria of ASD and FASD, some of which have been acknowledged within the biomedical literature. For example, autism researchers Bishop et al. (2007) write that "...research suggests that children with FASD exhibit some of the same difficulties as children with ASD, including strong sensory interests and aversions, cognitive delays, deficits in executive function, and poor adaptive skills" (p. 1112). Researchers Stevens et al. (2013) also identify overlaps in diagnostic criteria, writing that "...children with FASD are also reported to display a number of autistic like characteristics and to be at increased risk for autism" (p. 580). Another study of twenty-one individuals diagnosed with FASD showed that 72% of the participants also fit diagnostic criteria of ASD (Mukherjee et al., 2011). Both ASD and FASD are in part identified by "socially inappropriate behaviors" (Bishop et al., 2007, p. 1111). However, the nature of these behaviors has been identified differently: while autistic people have been characterized as uninterested in social interaction, people diagnosed with FASD have been characterized as inappropriately friendly and affectionate (Stevens et al., 2013). Bishop et al. emphasize that FASD and ASD are not interchangeable diagnoses. To be diagnosed with FASD there must be a confirmed history of prenatal alcohol exposure. This criterion is in itself convoluted, as it requires the mother to self-disclose her pre-natal alcohol use. For Indigenous mother, the assumption of pre-natal alcohol consumption is much more likely than among non-Indigenous mothers, likely resulting in increased diagnoses rates (Tait, 2008). Conversely, Tait (2009) writes that "labelling non-Aboriginal people with FAS/FAE does not happen to any significant degree" (p. 204). This presumption assumes a biological cause to behaviors identified as disruptive among Indigenous youth, while ignoring other environmental possibilities for non-normative behavior. For example, as Salmon (2004) argues:

[...]it has been repeatedly demonstrated that Aboriginal children and youth frequently find mainstream public school curricula irrelevant, biased, and exclusive of Aboriginal peoples. Thus, it is curious that issues such as "disrupted school experience" are never considered in the texts of [public health documents relating to FASD in Indigenous communities] to be possible manifestations of resistance to the curriculum and institutional practices of non-Aboriginal, middle-class education, rather than evidence of a significant psychosocial disturbance. (p. 117)

The purpose of comparing diagnostic criteria is not to reaffirm medical model understandings of autism nor FASD. Instead, it is to highlight the instability of the categories themselves. More importantly, it shows how these categories, despite their instability, are not arbitrary: they have purpose, and they are biopolitical. Alexis Shotwell (2016) suggests that classification – which, I argue, medical diagnoses are instances of – is intimately tied to the Canadian settler colonial project. She writes, "when classifications work well, they become infrastructure – they fade out, we cannot easily perceive them, and the social relations they shape become commonsensical" (p. 26). To illustrate Shotwell's argument, I explore the ways in which embedded classification schemes produce differing levels of state surveillance between mothers of children with FASD and autism.

While the mother of the child diagnosed with FASD is supposedly racialized and poor, the mother of the child labelled with autism frequently seems to be white, well educated, and middle to upper class (McGuire, 2016). Thomas et al. (2012) have noted that ASD diagnoses appear to be associated with higher socio-economic status, although the reasons behind this remain speculative. This is not to say that mothers of autistic children—who appear to enjoy a higher level of privilege than mothers of children with FASD—are not also under surveillance.



However, as McGuire (2016) points out, historically, a certain level of privilege was necessary for a mother to be seen as producing an autistic child. Early investigators of autism observed that mothers of autistic children were cold and non-nurturing, and had often 'abandoned' their mothering responsibilities in order to work outside of the home (McGuire, 2016). McGuire writes: these subject positions [mothers of autistic children] were often only available to those parents perceived to be intelligent, educated, successful in the workplace, and so economically privileged. In this way, the organization of the subject position of parent of an autistic person—and by extension the subject position of the autistic person—worked to exclude, for example, people of color from participation. (p. 40)

While both the mother of the autistic person and the mother of the person labelled with FASD are identified as not mothering 'right,' their deviance is constructed differently, and in turn so is the deviance of their children. Interestingly, the characteristics of the two diagnoses also mirror the ways in which mothers of the diagnosed person are respectively (historically) subjectivized: people diagnosed with ASD are characterized as anti-social, reflecting their mothers' supposed lack of affection, whereas people diagnosed with FASD are characterized as lacking social control, reflecting their mothers' supposed inability to control her drinking habits (Stevens et al., 2013).

Contemporary research has shifted the mainstream understanding of the etiology of autism away from the behavior of the mother, and into the pathologically-labelled body of the autistic person (McGuire, 2016, p. 44). While mothers of autistic children continue to be scrutinized, their subjectivity also shifts into the "paternalistic position of surveiller" (McGuire, 2016, p. 54). The mother of a person with FASD is subjectivized distinctly. Shankar (2016) cites an FASD researcher identified as Cindy: "'there is no other disability [like FASD] that directly

implicates a birth mother as being solely responsible for the cause of [her] child's disease or disorder" (p. 166). As noted above, FASD is more likely to be diagnosed among populations of lower socio-economic status and racialized populations *despite* the fact that there is no significant data in Canada showing those populations are more likely to consume alcohol during pregnancy (Jones, 2011; Salmon, 2011). Autism, while similarly understood as disorder or "embodied pathology," is more likely to appear in populations which are white and of higher socio-economic status *despite* the fact that its "etiological origins remain unknown" (McGuire, 2016, p. 54).

This differentiation has strong implications for the ways risk and responsibility are understood amongst parents of people diagnosed with autism or FAS, respectively, particularly in the context of neoliberal governmentality. In this social, cultural, and economic context of neoliberalism, autism is figured as "risk which may—in the absence of biomedical control—potentially divert the normative productive course" of childhood (McGuire, 2016, p. 132). This risk is figured, in part, due to a perceived strain on resources both due to the cost of caring for and rehabilitating the autistic child as well as the potential lack of productivity the autistic child represents. FASD is similarly figured as a risk, both to the individual and to the state (Salmon, 2007a; Shankar, 2016). Shankar (2016) writes that in public health campaigns, "provision of risk is premised upon a distinct allocation of responsibility," and that through the individualized nature of the medical model, risk and responsibility are contained in the same body (p. 153). Individual people are required to take responsibility in managing health-related risks (Shankar, 2016). "Accordingly, individuals whose behaviours and actions are deemed risky are seen as lacking self-control and are understood to be irresponsible citizens" (Shankar, 2016, p. 153). According to Shankar, public health messaging around FASD differs from this figuration of risk

and responsibility, as it locates the "risk" and the "responsibilities" across two different bodies. "Women who give birth to children diagnosed with FASD are seen as making deliberate choices during pregnancy that placed their unborn child at risk" (Shankar, 2016, p. 158). I would argue that risk and responsibility are also separated between parents of autistic children and autistic children themselves, albeit in a different way. In this case, the responsibility is not so much in the actual production of the autistic child, but more so in their management—through psychiatric and behavioural interventions. However, the direct causal link between the behavior of the mother and the diagnoses of FASD puts a particularly potent rendering of responsibility onto the mother who is perceived as likely to produce an FASD-labelled child—to the point at which "...the woman becomes constructed as a dangerous object" (Shankar, 2016, p. 157). The focus of intervention here remains on the mother, as her actions literally *produce* the deviant child, thus purportedly perpetuating her community and nation's marginalization (Shankar, 2016, p. 158).

### **III. Dis/advantages of diagnoses**

"Hundreds of forces swirl through diagnoses, each with its own balance of utility and risk. Some carry almost no stigma; others come freighted with discrimination and self-loathing; still other bring both relief and sorrow. I want to read diagnosis in all its incarnations" (Clare, 2017, p. 42).

The intersections of diagnosis, race and class lead to differential access to resources and supports, and differential outcomes in long term wellbeing. An Ontario study which compared perceptions of the future amongst parents of children diagnosed with autism and FASD showed that parents of children diagnosed with FASD perceived unemployment, institutionalization, or incarceration as likely futures for their children; families of children diagnosed with autism were

much more optimistic, believing "their children could live fully independently, hold meaningful employment, and have their own families in the future" (Watson et al., 2013, p. 89). Several parents of children diagnosed with FASD noted the disparity of resources available for autism and FASD, and commented that there is a sense that children diagnosed with FASD have been "forgotten" (Watson et al., 2013, p. 89). While this study does not take into account socio-economic differences, we know that autism diagnoses are positively associated with higher socio-economic status, whereas FASD diagnoses are positively associated with lower socio-economic status, a factor which mitigates access to services, including diagnostic screening (Leonard et al., 2011; Thomas et al., 2011; Jones, 2011; Salmon, 2011). For Indigenous people living on reserves, this is further exacerbated by greatly inferior service provision and unequal funding for children on reserve compared to the rest of the population (Blackstock, 2016). In addition, research has indicated that suicide rates may be higher among populations labelled with FASD (O'Malley & Huggins, 2005).

My point is not to argue that an autism diagnosis is inherently more advantageous, or that the resources available for autistic people are not in themselves oppressive: many mainstream autism interventions (Applied Behavioural Analysis, Intensive Behavioural Intervention, and institutionalization, for example) have been deemed assimilatory, oppressive and violent by autistic people and their allies,<sup>3</sup> yet, having no access to resources is also deeply troubling. Eli Clare (2017), commenting on the complexities of diagnosis, writes "diagnosis wields immense power. It can provide us access to vital medical technology or shame us, reveal a path toward less pain or get us locked up. It opens doors and slams them shut" (p. 41). Rather than pitting diagnostic categories against one another, I strive to understand how they work to create "gradations of capacity and debility" (Puar, cited in Fritsch, 2015, p. 37).

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<sup>3</sup> See, for example: Bascom, 2011; Yergeau, 2013; Brown, 2014; Gruson-Wood, 2016

Gradations exist between and within diagnostic categories. Both autism and FASD are understood as spectrums, existing on linear planes of severity (see McGuire, 2016, p. 51). Autistic people are often sub-categorized into groups of 'high-functioning' and 'low functioning' and FASD is variously categorized into labels such as fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), alcohol related birth defects (ARBD), among others. While acknowledging a diversity of experience within diagnostic categories is important, disability studies scholar Kelly Fritsch argues that gradations work to mark bodies which are more or less able to be "capacitated" into the norms of a neoliberal society (Fritsch, 2015, p. 36). Those deemed too disabled for capacitation are "left to wither" (Fritsch, 2015, p. 38).

Links can be made between Fritsch's formulation of capacity/debility and Sherene Razack's (2011) discussion of Indigenous deaths in custody. As Fritsch has noted, disability and race are frequently conflated through practices which demarcate racialized and/or disabled bodies as expendable. Investigating the disturbing rates of Indigenous deaths in police custody, Razack argues that, within settler-colonial societies, Indigenous bodies are seen as irreparably damaged, to the point of being beyond care. Razack refers to this as the "killing indifference [...] of settler societies towards Aboriginal people" (p. 353). In her formulation, Indigenous people in custody can be neither harmed nor helped, and are therefore left to wither, or worse, are subjected to acute violence. Razack writes: "the Aboriginal body is considered by health care professionals as so deeply destroyed by alcoholism that nothing else can destroy it, a situation that renders the body one that is not worth caring for, and one that can be violated with impunity" (p. 354). With alcoholism seen as the source of Indigenous pathology, not only is the body beyond capacitation, but is also understood to "contain within it the poisonous seeds of its own demise" (Razack, 2011, p. 365). In other words, responsibility lies squarely within the pathologized body, and

outside the realm of the state. This is where the relationship between diagnosis and dispossession becomes painfully clear: it is through medicalized classification that ongoing seizure of lands and resources is not only legitimized, but also deemed to be in the best interest of Indigenous peoples.

#### **IV. Self-management and/or self-determination**

"The space of our medicalized diagnosis as victims of trauma is not a site wherein self-determination is practiced or defined" (Million, 2013, p. 150).

The predominant critique of state responses to FASD prevention campaigns has been to shift the focus from individual mothers' behavior towards examining social determinants of health (Salmon, 2004, 2007a, 2007b, 2011; Tait, 2003, 2008; Hunting & Browne, 2012; Shankar, 2016). This shift would redirect prevention efforts towards structural issues, including poverty, education, and access to health care services. These critiques often identify settler-colonialism, or more specifically, the resulting trauma of settler-colonial violence, as the 'source' of FASD (Salmon, 2004, 2007a, 2007b, 2011; Tait, 2003; Hunting & Browne, 2012). In her book *Therapeutic Nations*, Indigenous feminist scholar Dian Million (2013) argues that Canada's current relationship with Indigenous peoples is characterized by 'healing' (p. 5). She writes: Healing highlights Canada's historical legacy of colonization as it became linked in a direct causal relationship to Indigenous people's contemporary poor health, both physical and mental, substance abuse, suicide risk, and early death understood as a holistic, tightly intertwined effect. The colonized subject became a trauma victim. (p. 5-6)

Million describes how the move from colonized subject to trauma victim occurs in tandem with the North American shift towards neoliberal governmentality. More expansive than

an economic system, Million (2013) describes neoliberalism as a "way of life," wherein individualism underlines all aspects of society (p. 18). It is in this context that Indigenous trauma is articulated by the state, and becomes a quasi-medicalized diagnosis, encompassing conditions such as diabetes, alcoholism, FASD, suicide, abuse, and so on. Trauma represents an obstacle to economic growth (Million, 2013, p. 19).

State-sponsored healing practices are presented as solutions to Indigenous distress. Practices such as the Truth and Reconciliation Commission (TRC) and currently, the floundering Inquiry into Missing and Murdered Indigenous Women and Girls, "call on [Indigenous peoples] to witness to and to define ourselves as the product of the state's violence as it presents in a rising tidal wave of self-immolating behaviors," as a form of corroboration with the state narrative (Million, 2013, p. 149). Million urges us to resist the "medicalized discourse of trauma" (p. 20). In this discourse, healing from trauma is the pathway to self-determination. However, as Million argues, the form of self-determination articulated by the state is antithetical to Indigenous notions of self-determination. She writes: "nations like Canada often pose self-determination as self-management in adaptation to capitalist realities" (p. 150). Thus, achieving self-determination as presented by the state requires one to take up biopolitical practices of self-management, ultimately working towards reducing one's burden on the state.

While absolved of overt racism, the discourse of medicalized colonial trauma continues to locate distress and disorder *within the body*, and by extension, within the Indigenous communities at large. Eve Tuck's (2009) concept of "damage centered research" is an accurate assessment of the bulk of published literature on FASD (p. 413). I quote Tuck at length to describe the dangers of this research framework:

In damaged-centered research, one of the major activities is to document pain or loss in an individual, community, or tribe. Though connected to deficit models—frameworks that emphasize what a particular student, family, or community is lacking to explain underachievement or failure—damage-centered research is distinct in being more socially and historically situated. It looks to historical exploitation, domination, and colonization to explain contemporary brokenness, such as poverty, poor health, and low literacy. Common sense tells us this is a good thing, but the danger in damage-centered research is that it is a pathologizing approach in which the oppression singularly defines a community. (p. 413)

The discourse of medicalized colonial trauma is produced by and through damaged-centered research (Million, 2013; Tuck, 2009).

Our contemporary imaginary of FASD is produced is as a site of physical evidence through which colonial trauma is embodied. Because FASD is understood as an embodied pathology (McGuire, 2016), it invokes an almost genetic understanding of intergenerational trauma: “this notion of alcoholic disease as a legacy passed on by female bearers of children has enabled an etiology of Native American distress in which woman is both the medium of infection and, through her sexuality and fertility, an infectious agent in her own right” (Stange, 1997, p. 127). The diagnosis of FASD confirms to the state the very need to surveil and contain the ‘contagion’ of the Indigenous mother, which in turn feeds the production of an epidemic. Once an epidemic is discursively established, surveillance is normalized. In the context of colonial trauma, FASD, rather than autism, more easily conforms to a narrative of intergenerational trauma, upon which Indigenous people are encouraged to identify with in order to access healing services (Million, 2013). Thus, to remind us of the implications of the Health Canada (2007) statement cited in the



introduction of this essay, parents of potentially autistic Indigenous children are encouraged to rely upon resources provided for FASD, asserting that Indigenous 'disorder' is always and only a result of colonial trauma – erasing other expressions of embodied difference and neuro-divergence.

Drawing on Lauren Berlant, Million (2013) argues that through biopolitical mechanisms, Indigenous people are posed as as incapable of self-management, their “agency is deemed to be fundamentally destructive” (Berlant, qtd. in Million, 2013, p. 151). Refusing to “adapt to capitalist realities” is understood as an expression of Indigenous pathology, which, once rehabilitated, will fade away. The production of the FASD epidemic is a method through which Canada has attempted to prove this claim, discrediting Indigenous demands/desires by marking bodies with disability. Furthermore, as the source/cause/root of FASD, the epidemic “affectively positions Indigenous women at the figurative center of any Indigenous nation’s inability to govern” (Million, 2013, p. 7). Accordingly, Indigenous demands for decolonization, “the repatriation of Indigenous land and life” (Tuck & Yang, 2012, p. 21), are symptomatic of colonial trauma. While our current administration identifies itself as more sympathetic to Indigenous demands, concessions are made at the symbolic and therapeutic level, whilst continuing to exploit Indigenous lands and resources. As Million puts it, “this healing would occur while capitalist development might still displace one or require one's land - a little like accepting being bandaged by your armed assailant while he is still ransacking your house” (p. 106).

Racialized diagnostic classification schemes, as they fade into “commonsensical background knowledge,” go unquestioned, legitimizing the settler colonial project and allowing white settlers to take on the subjectivity of innocent bystanders (Shotwell, 2017, p. 24). As

Razack has described aphoristic nature of this argument, "it goes without saying that a damaged and dying people cannot be entrusted with self-governance and stewardship over the land" (p. 353). As FASD is produced as a "catchall category for Aboriginal distress" (Tait, 2009, p. 208), disability (instead of Indigeneity) is the means through which self-determination is denied.

## Conclusions

In *War on Autism*, McGuire (2016) details the ways in which 'autism advocacy' primarily works to advocate *against* autism, whether through preventing autism in the first place, or rehabilitating – assimilating – autistic people to fit the contours of dominant society. Because, as some autistic self-advocates have argued, autism is not a 'thing' which can be separated from a person (Sinclair, 1993/2012; Baggs, 2010), advocating against autism means advocating against autistic people. In response, there is a vast and growing movement of autistic self-advocacy, centering the voices of autistic people and valuing neurodiversity as a site of generative difference.

The overwhelming majority of research on FASD focusses on its prevention – in essence, advocating against FASD, and thus positioning FASD-diagnosed bodies as undesirable to inhabit. Because FASD is often conceived of as a consequence of settler colonialism, it can easily come to stand in for the violent disruption of ongoing colonial practices. Preventing colonial violence *is* urgent. Nonetheless, for those diagnosed with FASD, prevention is not an option. Recalling Eve Tuck's provocation to suspend damage, I wonder how the singular rhetoric of prevention could contribute to understanding oneself – and being understood – as irreparably damaged.

Prevention occupies a liminal space within disability studies. Rosmarie Garland-Thomson (2012), for example, has contested the dominant notion that a better world would be one without disability, arguing that this belief is rooted in eugenic logic. If the goal of prevention is the elimination of disability, we must resist this impetus, working instead to conserve disability, the argument goes. This argument does important work in highlighting the ways disabled life is so frequently conceived of as life not-worth-living. And yet, this argument tends to flatten the experience of disability to an identity that can – and should – always be celebrated. Complicating this narrative, Nirmala Erevelles (2011) asks “how can acquiring a disability be celebrated as ‘the most universal of human conditions’ if it is acquired under the oppressive conditions of poverty, economic exploitation, police brutality, neocolonial violence, and lack of access to adequate health care and education?” (p. 119). The etiological linking of FASD and colonialism – both rhetorically and materially – brings forth challenges in taking up disability pride, and complicates a wholesale rejection of prevention. Many Indigenous communities have identified preventing FASD as a goal. It is seemingly in stride with colonial logics to impose the Eurocentric subjectivity of a ‘properly politicized disabled subject’ onto Indigenous peoples engaged in struggles for sovereignty and self-determination.

Attending to disability in the settler colonial context requires us to dwell in sites of tension.

Disability studies scholar and activist Eli Clare (2017) addresses this tension in his book *Brilliant Imperfection: Grappling with Cure*: “how do we witness, name, and resist the injustices that reshape and damage all kinds of body-minds – plant and animal, organic and inorganic, nonhuman and human – while not equating disability with injustice?” (p. 56). While he does not offer an answer, the question itself provides insight. Our movements must be built to at once

reject settler-colonial violence *and* embrace neurodiversity, in all its forms. We must create spaces that acknowledge those who are diagnosed with FASD and their families as worthy, welcome, and wanted in this world – spaces that do not exist within the rallying cry of ‘100% preventable.’

Since colonization, Indigenous peoples have always engaged in interruptions to colonial normativity. In response to queer theorist Lee Edelman’s call for queers to take up a politics of “no future,” Native studies theorist and activist Andrea Smith (2010) writes that “Edelman makes an important critique of how the investment in the future justifies contemporary oppression” (p. 46). Indigenous mothers are frequently monitored and policed under the assumption that they pose a dangerous threat to the future of their unborn child. However, as Smith goes on to argue, Edelman’s response to contemporary oppression does not hold up well in the context of colonial genocide. “If the goal of queerness is to challenge the reproduction of the social order, then the Native child may already be queered. [...] In this context, the Native Child is not the guarantor of the reproductive future of white supremacy; it is the nit that undoes it” (p. 48). Smith considers the very survival, through reproduction, of Indigenous people to be an interruption in normative colonial space. In this figuration, the hierarchy between the oppression of the mother and the child is removed, as the co-constitutive bodies of mother and child are of equal importance to Indigenous futurity. In the context of the settler-colonial neoliberal nation-state of Canada, Indigenous children pose a disruption to the normalizing logics of the state on multiple fronts, embodying the failure of the settler-colonial project.

Contesting medical/individual models of disability, scholars have argued that disability is a relational phenomenon (Titchkosky, 2007; Kafer, 2013; McGuire, 2016). “Disability – its meaning and thus its very materiality – is made and remade, rhetorically and interactionally,

between all of us who have a body, all of us who live and participate in the making of culture,” writes McGuire (2016, p. 18). Ironically, both autism and FASD are commonly characterized as *relational* disorders, understood as a lack of ‘proper,’ ‘normal,’ and ‘appropriate’ ways of relating to other people and the world. Thus, these diagnostic categories only come into being in relation to others – through contact with those of us deemed to relate in normative ways. This notion highlights the responsibility of all of us to consider of the ways in which we are implicated in the production and maintenance of racist, ableist, and colonial classificatory mechanisms.

In this paper, I have shown how the cultural meanings made around FASD draw one to the conclusion that it is a life less worth living, a failed potential, and a risk to society at large. In order to meaningfully engage in decolonial praxis, we must work towards undoing the ableist notions upon which settler-colonialism thrives. I invite us to take accountability to how we participate in producing cultural meanings of FASD and autism, and take efforts to re-configure them: considering neurodiversity, regardless of its source, as valuable both inherently but also in the generative ‘risk’ it poses, that continuously threatens to disrupt the normative logics of the settler-colonial state.

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