

Dis/Abling States, Dis/Abling Citizenship: Young Aboriginal Mothers and the Medicalization of Fetal Alcohol Syndrome

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Abstract

This article draws on data collected in group interviews with six young, urban Aboriginal mothers whose lives have included substance use and Fetal Alcohol Syndrome/ Fetal Alcohol Effects (hereafter FAS/FAE) to highlight the multiple and often contradictory ways in which disability as a constituent of social relations is defined in public policy and experiences of people's everyday lives. The findings of this research demonstrate that the process of medicalization acts in both enabling and disabling ways to inform the women's experiences of substantive citizenship in their everyday lives and the lives of their children. Young Aboriginal mothers simultaneously reify and resist medicalization in diagnosis of and interventions for FAS/FAE, in order to support advocacy efforts on behalf of their children to access a range of educational, health, and social services. "Labeling" a child's struggles in medicalized terms through a diagnosis of FAS or FAE was useful for some mothers because it enabled access to supports that would otherwise have been unavailable and provided a way to resist racist, sexist, and class-ist representations of Aboriginal women as "bad mothers". At the same time, the women who participated in this research found that the processes of disclosing that a child's impairments were the result of prenatal alcohol exposure and of having her child labeled as a "special needs placement" could also frustrate attempts to advocate for supports and access some types of community services. Accordingly, I argue that medicalization acts as both a site of oppression when institutionalized through education, health, and welfare policies, and as a site for advancing claims to knowledge and social justice in a neo-colonial context.

Introduction

In this article, I draw on the experiences shared with me by six young urban Aboriginal[1] mothers whose lives have included substance use and Fetal Alcohol Syndrome/ Fetal Alcohol Effects (hereafter FAS/FAE) to examine the relationship between the constructions of young Aboriginal mothers and their children articulated in the FAS/ FAE prevention policies and projects of nation-building. These interviews were conducted as part of a larger study of a Canadian public health education initiative on the prevention of FAS/FAE[2], which targeted young Aboriginal women and Aboriginal communities. The purpose of this research was to develop an understanding of the ways in which competing and highly politicized conception of the needs, interests, concerns, and experiences of Aboriginal communities, and young Aboriginal mothers in particular, affects Canadian public discourses, policy, pedagogies, and social service provision in relation to FAS/FAE. In so doing, I wanted to understand how a group of young Aboriginal mothers who were accessing a program for FAS/FAE "prevention" articulate their own needs, interests, concerns, and experiences, and how these may be similar to or different from the ways they are constructed in policy texts. Accordingly, I examined how young Aboriginal mothers affected by these policies (and the service environments these policies create), negotiate and challenge the conventions, relevancies, and hegemony of education and social service provision related to FAS/FAE "prevention" and "support". This analysis points to important implications as to how "public" institutions serving young Aboriginal mothers and their children might amend their practices to be better reflective of their needs, interests, concerns, and experiences.

As Taylor et al (1997) have demonstrated, public policies- including those related to public health and education- are fundamentally ideological texts, and can be understood as a terrain in which the State is continually contested and renewed (Taylor et al 1997). As products achieved through the negotiation of hegemonic and counter-hegemonic ideologies and interests, policy texts are directly implicated in practices of nation-building (see also Hall 1988, Torres 1995, Luke 1997). In this article, I examine these practices in relation to two recurring themes: a) the representation of FAS/FAE, and substance-using Aboriginal mothers who give birth to children affected by FAS/FAE, as a "risk" and a "threat" to First Nations and the

Canadian Nation-State; and b) Aboriginal women's lived experiences of "citizenship" in the context of their daily lives, and the implications of public discourses about FAS/FAE for advancing social justice for Aboriginal women and people with disabilities on the basis of their rights and entitlements as "citizens".

Mothers in Canada have been subject to on-going "public education" and "public health" campaigns instigated by various branches of the federal government for almost 100 years. As has been noted by feminist historians, such initiatives have been strongly rooted in projects of Nation-building, in which women (by virtue of their reproductive capacity to produce future citizens and soldiers) have been simultaneously praised and vilified as both "guardians" and "threats" to the Nation and its institutions (Arnup 1994, Davin 1978). While many of these public health and maternal education campaigns were undertaken for the seemingly philanthropic purpose of decreasing infant mortality and providing access to health and education services for women and children, it remains that many were also fueled by eugenic concerns for the perceived need among those in middle and upper classes to undertake measures to prevent "race suicide" by "preventing births" of people with disabilities, people living in poverty, and racialized minorities (Mitchell and Snyder 2002, 2003). Marlee Kline (1993), Jo-Anne Fiske (1992, 1993), Karen Swift (1995), Kim Anderson (2000), and others have further demonstrated how Aboriginal women in Canada have been marginalized by European ideologies of motherhood in general and in child welfare legislation in particular. However, very little scholarly work combines a feminist, anti-racist, and anti-colonial critique of contemporary public health education or FAS/FAE prevention campaigns aimed at Aboriginal women in Canada. Moreover, young Aboriginal women's voices, perspectives, and priorities have been largely neglected in this analysis, and in the development of policies and programs addressing this topic.

In this article, I reflect on how the "medicalization" of FAS/FAE informs the women's experiences of substantive citizenship in their everyday lives and the lives of their children. Far from being an unyieldingly monolithic construct and process, I show how the process of medicalization in the diagnosis of and interventions for FAS/FAE is simultaneously imposed, upheld, resisted, and transformed by young Aboriginal mothers. I argue that the hegemonic discursive and material practices of

medicalization are one means through which the substantive citizenship interests of Aboriginal Peoples affected by FAS/FAE are both differentiated and contested, simultaneously enabling and disabling. As such, medicalization offers both a site of oppression and a site for advancing claims to knowledge and social justice. The discursive and material practices of medicalization in turn place substantive limits on what Roman (2001) has called the "epistemic space" available to young Aboriginal women and people with disabilities to articulate claims to specific rights and entitlements as "citizens" via the welfare state (Meekosha and Dowse 1997). I conclude by exploring the implications for social justice and substantive citizenship, and the use of medical models of disability in education which are raised for marginalized groups when the languages and mechanisms for identifying knowledge claims and oppressive material conditions requires the reification of oppressive mechanisms.

"Citizenship" and Social Justice in a Gendered, Racialized, and Ableist Context

In Western democratic Nation-States, individuals and groups organizing to ameliorate social inequalities for marginalized groups frequently articulate their demands for change in claims to rights and entitlements people have as "citizens". In some instances, these claims call attention to the need for Nation-States and their institutions, including educational institutions, to such to expand the rights and entitlements accompanying "citizenship". In other instances, such claims highlight pre-existing rights and entitlements that are being neglected.

Feminist anti-racist scholars of nation-building practices in and outside of education have noted that differentially-located groups experience two distinct dimension of "citizenship" as an organizing constituent of social, political, and economic relations: formal citizenship and substantive citizenship (Fraser 1997a, 1997b, Ng 1993, Sharma 2000, Young 1990). Formal citizenship is best understood as the rights or entitlements afforded to individuals as "citizens", as described or guaranteed in formal declarations, legislation, policies, or statutes of the Nation-State. In Canada, these include the rights to vote, own property, enter and leave the country, or attend public school. While significant for protecting citizens' human rights, this legal-juridical conception of citizenship has been criticized as inadequate for understanding the perpetuation of social inequalities between and among groups identified as "citizens"

(and "non-citizens"). This is because this dimension of citizenship is "abstracted" from the conditions of people's everyday lives (Ng 1993, Roman 2004, Young 1990). Lived experiences of citizenship as an organizing constituent of social, political, and economic relations often exceed the formal legal-judicial aspects of citizenship. These include those aspects of citizenship found in the recognition of individual and collective experience, knowledge, and material conditions, as well as efforts toward the redistribution of state resources to improve the situations of marginalized groups (Fraser 1997b).

Held and Abu-Laban have referred to these dimensions of citizenship as "substantive citizenship". In distinguishing between formal and substantive citizenship, Held (1989:22) argues that although citizens must "formally enjoy 'equality before the law'", it is equally important that citizens have "the material and cultural resources to choose between differing courses of action in practice". Held underscores that contemporary social inequalities, including those of gender, class, race, and ethnicity, render it difficult for some individuals and groups to "allow citizenship to become a reality in practice" (ibid). Similarly, Abu-Laban (1998:70) differentiates the domain of substantive citizenship as including "pressing issues related to the equality of rights and opportunities, treatment and life conditions, and, not least, participatory involvement that ought to come from holding formal citizenship". As such, substantive citizenship rights and interests are evident in the recognition of individual and collective lived experiences and circumstances. This includes the presence of structural supports that make formal rights and entitlements present and meaningful in people's everyday lives. Substantive citizenship interests are also evident in efforts to ensure that all groups have equal enjoyment of their formal rights and entitlements, including the redistribution of state resources to enable enfranchisement of marginalized groups through the improvement of their material conditions (Fraser 1997a, Young 1990). To illustrate, advocates lobbying for access to state resources to support the inclusion of students with disabilities in public schools often do so on the basis of their "rights" as "citizens" to an education.

As a colonial state, the institutional practices of Canadian nation-building have been founded upon the social, political, economic, and cultural domination of Aboriginal Peoples and explicit efforts to limit or exclude Aboriginal Peoples from both rights

and recognition as "citizens". As official "wards of the Crown", Aboriginal Peoples remain formally disenfranchised in their relations with the Canadian state through the contemporary administration of the Indian Act. Current struggles by Indigenous Peoples in Canada to achieve self-government and settle land claims are fueled by the continuing impact of the loss of traditional lands and access to resources, the enactment of policies aimed at the assimilation of Aboriginal Peoples and communities, and the eradication of indigenous languages, spiritualities, cultures, pedagogies and traditional social, political, educational and kinship structures (Royal Commission on Aboriginal Peoples 1996). The on-going colonial relations between the Canadian state and Aboriginal Peoples mediate the unique position of Aboriginal women in their struggles to secure rights and entitlements as citizens in and of the Canadian Nation-State.

As Fiske (1992) has highlighted, the gendered and racialized legacy of colonial nation-building has resulted in the paradoxical positioning of Aboriginal mothers as both "children of the state" and "mothers of the nation", and informs the disenfranchisement and marginalization of Aboriginal women within and outside of First Nations governance structures (see also Acoose 1995, Anderson 2000, Fiske 1993, Silman 1987). The formal and informal disenfranchisement of Aboriginal mothers as "non-citizens" organizes the material conditions under which the overwhelming majority of Aboriginal women in Canada live.

Disability theorists have argued that the discursive, symbolic, and material practices of medicalization are also crucial mediators of substantive citizenship interests. Specifically, disability rights activists have argued that the discourses and practices of medicalization define individuals with disabilities as inferior "Others" with needs and interests that are contrary and threatening to those of "society" and the Nation-State (c.f. Gabel and Peters 2005, Meekosha and Dowse 1997, Mitchell and Snyder 1997, Oliver 1996, Pfeiffer 2003, Salmon 2004, Shakespeare and Watson 1997, Wendell 1996). Indeed, medicalized conceptions of disability are frequently at the core of conflicting policies, programs, laws, and advocacy which challenge entitlements to citizenship, as medicalization is often understood to undermine the efforts of people with disabilities to achieve equality in social, political, economic, cultural, and educational domains.

An integral factor in this process is the discourse of "productive citizenship". As Meekosha and Jakubowicz (1996) have argued, the discursive and material practices that construct ideologies of productive citizenship are enabled and inscribed by capitalist modes of production. According to the ideology of productive citizenship, the "ideal citizen" is seen as one who is economically self-sufficient, and for whom membership in the nation is contingent upon an ability to be seen as a "productive" and "contributing" member supporting the political economy of nation-building (see also Roman and Christian-Smith 1988). According to productive citizenship discourses, those who are constructed in hegemonic institutions and popular imaginations as unable, unwilling, or unsuited to participate in capitalist modes of production, including women, Indigenous Peoples, racialized migrant populations, and people with disabilities, are construed as "burdens" on the institutions and citizenry of the nation (see also Meekosha and Dowse 2002, Meekosha and Dowse 1997, and Meekosha 1999).

The reproduction and circulation of discursive and material practices that inscribe physical, cognitive, and behavioural difference as "limitations, dependencies, and abnormalities" have been used to "define disabled people as excessive to traditional circuits of interaction and as the objects of institutionalized discourses" (Mitchell and Snyder 1997:3). The economic relations of industrial and global corporate capitalisms absent people with impairments, (as well as Indigenous Peoples) from circuits of production, as "burdens", "drains", and even "threats" to the institutions of the Nation-State (Meekosha and Dowse 2002, Meekosha and Dowse 1997, Meekosha 1999). To illustrate, it is increasingly common in neo-liberal "public" education agendas to view the pressure (and expense) of providing supports to students with disabilities as taking away from the rights and resources that are available and necessary for "typical" students to succeed in classrooms, and as placing overwhelming (and unjustifiable) demands on teachers (Troyna and Vincent 1996, Erevelles 2000). In Canada, similar discourses are also invoked in arguments against providing "special" supports or entitlements to Aboriginal students in school settings, as representing an "undue burden" on individual teachers and on the "public" purse. As such, people with disabilities, Aboriginal Peoples, and others come to be seen not only as having interests that do not contribute to building and maintaining State institutions, but as having interests that are antithetical to the needs and priorities of those institutions

(and by extension, to the State itself). Historically, these conceptions of citizenship, dependency, and nation-building have informed a variety of eugenic programs, including the forced confinement, sterilization, and extermination of people with disabilities. Similar conceptions of citizenship, dependency, and nation-building have also informed projects of colonization. Moreover, they are enshrined in contemporary policies resulting in the segregation of people with disabilities and Aboriginal Peoples in schooling and housing, employment discrimination, institutionalized poverty, lack of access to public spaces and services, social and political isolation, and harassment by public and private sector bureaucracies (Browne, Connors, and Stern 1985, French 1996, Meekosha and Dowse 2002, Morris 1996, Rizvi and Lingard 1996, Wendell 1996).

Productivist concepts of citizenship also obscure the fact that it is often not the existence of impairment per se, but structural, institutional, and environmental factors that create and mediate disabilities. For educators, these assumptions are readily apparent in arguments that individual students with "special needs" require "accommodations" because a *student* is disabled, not because a *building, pedagogy, or curriculum* is inaccessible for students with diverse needs. As a result, medicalized conceptions of disability are (re)produced by practices used to regulate the use of public space as well as institutional and structural relations that exclude people with impairments.

Constructing the "Problem": FAS/FAE in Aboriginal Communities

In Canada, the power, influence, and authority to define and position FAS/FAE as a disabling condition for individuals and a "social problem" for the State and its citizens emerges from a broader social context, in which epistemic power and privilege are differentially conferred on the basis of "race", culture, nation, gender, class, sexuality, and dis/ability (c.f. Edelman 1988, Tait 2003). From its first emergence in public discourse as a "social problem", special attention has been paid to the effect of FAS/FAE on Aboriginal Peoples and communities. In Canada, Aboriginal Peoples and communities have been over-represented in diagnoses of FAS/FAE and have been identified as being particularly "at risk" for the condition. Indeed, while most estimates of incidence of FAS/FAE place rates at about 3 for every 1000 births, it is believed that rates of FAS/FAE among Aboriginal Peoples are as high as ten times

this figure (Boland, Burrill, Duwyn, and Karp 1998, Ennis 2001, Square 1997).[3] However, Tait (2002) observes that many methodological problems exist in epidemiological studies that isolate Aboriginal heritage as a risk factor for FAS/FAE. Rather, she emphasises that

... chronic poverty and social marginalization appear to variables more important to identifying women at risk than ethnic identity. Because Aboriginal women are the poorest and most marginalized group in Canada these factors, rather than their Aboriginal culture or heritage, situate them among women at risk (174).

For Aboriginal women, who have for generations struggled against the forced removal of their children by various agencies of the State under the auspices of assimilationist and "child protection" policies, the discourse of Aboriginal mothers as "dangerous" to the health and wellbeing of their children remains particularly salient. As Kline has observed, socially, culturally, politically, and historically mediated ideologies of "good" motherhood have had significant impacts on First Nations women, in that what is often considered evidence of "bad mothering" (i.e. maternal alcohol use or drug addiction) is frequently isolated by agents of the State as individual behavioural "choices", rather than locating them within the broader contexts and lived experiences of on-going colonial and racialized oppressions of First Nations Peoples (Kline 1993; see also Boyd 2004, Robertson and Culhane 2005, Tait 2003). This is particularly apparent in the case of alcohol use, in that the introduction of alcohol to First Nations has been specifically acknowledged as a tool of colonialism (Anderson 2000, York 1990). As Swift (1995) has demonstrated, the presentation of alcoholism as a "disease" to which First Nations Peoples are particularly inclined continues to pathologize individual Aboriginal mothers as "sick", and Aboriginal families and communities as unconscious and uncritical perpetrators of "disease". Indeed, Stange (1994) argues "the growing alarm over FAS- an alarm whose context includes devastating impairment of Native Americans- has meant that Native American women are often singled out for scrutiny and condemnation". She cautions that racialized and gendered constructions of FAS as a social problem 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" (ibid). In this context, it is not surprising that young Aboriginal mothers whose lived experiences include substance use and FAS/FAE are both over-represented in

pathologizing terms in academic literature and public policy on FAS/FAE prevention, and under-represented as "experts" with valuable contributions to make, on their own terms, to public discourse and debates about solutions to problematic substance use and FAS/FAE in their communities.

Description of Research Methodology and Participants

The data presented in this paper were gathered as part of a larger research project, in which the voices, insights, and analysis of six young Aboriginal women guided an examination of a contemporary Canadian policy for the prevention of FAS/FAE in Aboriginal communities. One of the primary objectives of this research was to examine the relationship between constructions of young Aboriginal mothers and their children articulated in a Canadian public health education initiative to prevent FAS/FAE and projects of nation-building. This research employed methodologies informed by Dorothy Smith's (1987) institutional ethnography, using group interviews with six Aboriginal women accessing a "model" FAS/FAE education program (whose lives have included mothering, substance use, and FAS/FAE) to ground policy analysis[4]. Throughout the research process, the focus of the critique was an official policy of the Canadian state, and not the behaviours or practices of the women themselves. However, situating the policy analysis within the context of the voices, understandings, and relevancies of young Aboriginal mothers who negotiate the complexities of FAS/FAE, substance use, and mothering in their daily lives provided an opportunity to examine how young Aboriginal mothers affected by these policies negotiate and challenge the conventions, relevancies, and hegemony of policy and service provision related to FAS/FAE "prevention", "education" and "support".

All women who participated in this research were self-identified Aboriginal mothers who volunteered to participate in the research because the topic was of interest to them. Given that women, and particularly Aboriginal mothers, who admit to substance use in pregnancy can be vulnerable to significant repercussions from state authorities (i.e. child protection, social welfare, and criminal-legal systems) when their experiences are made public, every effort was made in the research process to protect participants' confidentiality and anonymity. The methodology employed in this study did not allow for representative sampling schemes or generalizability of findings. Nonetheless, the women's testimonies and analysis offer important and often

neglected insights into the context and experiences of FAS/FAE in their communities. At the time of the interviews, all women were in their early to late 20s, and had given birth to between 1 and 5 children. The age of the women at the birth of their first child ranged from 15 to 26. One woman was partnered, the others were single mothers. All of the women admitted to drinking alcohol and/or using drugs with teratogenic[5] effects .during a pregnancy. Some of the women have family members, partners, or other significant persons in their life who live with FAS or FAE, and some are concerned that they themselves might have FAE. 5 of the 6 participants held "Registered Indian" status[6]. Like many urban Aboriginal women in Canada , half of the participants reported that they regularly moved back and forth between the city and their reserve community, while others who did not regularly live in their reserve communities retained a significant connection to their Band.

Offered the choice of individual or group interviews, the women all chose to participate in two semi-structured group interviews. During the first interview, the women were asked to reflect on their understandings of FAS/FAE, and what FAS/FAE has meant to them in their daily lives in their community. With their full consent, this interview was tape-recorded and transcribed. I then analyzed this data using a coding schedule consistent with qualitative, inductive research methods and principles of emergent research design (c.f. Luttrell 2003, Pillow 2004). At the second interview, I presented the women with a copy of the interview transcript and a summary of my preliminary analysis of the transcript in relation to the policy texts. During this interview, I asked the women questions to solicit their own analysis of the transcribed data, and to examine whether or not my preliminary findings resonated with their own analysis of their experiences. Their feedback was then incorporated into the findings presented in this article.

Dis/abling citizenship: negotiating citizenship in the home, in the streets, and on the margins

Not surprisingly, the young Aboriginal mothers I interviewed did not directly use the word "citizenship", whether in its formal or substantive terms, to describe dimensions of their lived experiences or grounds for securing their individual and collective rights, entitlements, and interests in their daily lives. However, all of the women shared experiences that illustrate one of the most salient indicators of substantive

citizenship as a mediator of their well-being: the ability to successfully advance claims on the institutions of the Nation-State (Young 1990). For example, Super Woman[7] shared the following experience of advocating for her daughter at school:

I was struggling for a long time with my daughter, trying to get support for her, and we needed help. And then, in grade 1, she finally started getting some help, and we had a big meeting of occupational therapists, speech therapists, ... her teacher, her resource teacher, and even the school principal who doesn't usually attend these meetings stepped in. And they were really supportive and they listened to my concerns ... We were supported and therefore I'm keeping my daughter in the school.

Tricksey shared an instance of successfully laying claim to state resources to secure entitlements to financial support as an illustration of a time when her "voice was heard".

[M]y voice was heard when I had my son and I was living in the Downtown Eastside ... Anyways, the social worker was not answering phone calls, because I wanted an emergency allowance, where they give you \$100 for your son, or for your baby, newborn babies. So I asked for that, and I needed that money. For a whole week I was phoning, phoning, phoning every day. So, no response. So I finally called the last call. I said "If I don't hear from you within an hour, I will phone your supervisor and I will tell them how many phone calls I've been calling you, and you're not responding". And sure enough, who calls a half hour later? "Don't call my supervisor! Don't call my supervisor! What do you want? How much?" And I was like, "Yeah, I want a hundred dollar cheque!" (all laugh). So that was my voice.

However, these experiences of substantive citizenship were not universal, even when considered in the context of an individual woman's life. Their experiences of having voices that were "heard" or "counted" in one context were accompanied just as often (if not more often) by experiences of being silenced, disenfranchised, ignored, or marginalized in another. Each woman in turn readily identified times in which they felt they had not "been heard" by individuals and institutions representing the interests of the Nation-State, or when they felt their voices did not count in interactions with these agents. Their lived experiences of substantive citizenship varied greatly between and among institutions of the Nation-State, in some cases protecting their entitlements to resources, recognition, and support, and in others ignoring these entitlements in ways that compromised their well-being. Cheryl's experience of being pushed out of

an education program offered by a community organization for Aboriginal mothers provides an example:

I had a problem with ... the [Aboriginal program]. I went there and I didn't know anybody. And I took a little class ... I had no problem with the teacher, but the main boss there, she has ... a daughter that volunteers there. And her daughter ended up sleeping with my baby's dad. ... She told me [about it] in the Aboriginal Centre, in the kids' area, so I couldn't say anything or do anything. That's probably why she told me there. And then I was taking the [adult education] class, and I finished it and did all my subjects on it, and I ended up getting into an argument with the main boss. And she told me to go somewhere else... And I made complaints about it and I was never dealt with. (pause) Oh, and another thing was that, because of her daughter working, or volunteering there, I wasn't allowed to graduate with my class. I wasn't allowed to be there anymore, even though I'd finished the class.

Numerous interactions with authority figures who were dismissive, unresponsive and in some cases blatantly cruel provided evidence that women's voices had been silenced or marginalized. One of the most salient examples of violations of women's substantive citizenship interests can be found in women's descriptions of interactions with police officers. Five of the six women I interviewed reported negative experiences with police officers which directly compromised their safety, sense of belonging in their communities, and abilities to advocate to protect their own and their children's interests. For example, Jo-Anne describes an experience of being attacked by her ex-partner:

I was with my ex, and he started really using drugs and he got really abusive. And, um, one day I decided I was going to call ... 911, and walk down to the police station there, and tell them what happened. So I called 911, and I realized I was standing in front of where the [police department's] Native Liaison Office used to be. And I told her, " I see him!" ... And then he just came out of nowhere. So in the last minute I said to her 'He's right here!' You know, like, I'd told her he could be armed, but he'd been gone for ten or fifteen minutes. And, um, he came at me and smashed my phone. And she could have got somebody to come out. Nobody came out. I had to go inside the police station and get help. And I had my son in the stroller, and I was really upset, because, you know, I'm standing out front, and he's trying to attack me and smash my phone. ... And she never sent anyone out. And I know that they can. She could have sent someone out, and at least got him. Because for all I know, he's still wandering out there somewhere, you know? And he was right out front, and he still got away. They came up after I went inside. I went inside and waited 20 minutes before the police helped me. I didn't really feel I was heard then either. And the last time I saw him at my house, I waited for over 4 hours for the police to come.

(unknown speaker): I waited six once.

Jo-Anne: And it was really disgusting. The cop had the nerve to sit there and say "Oh, you don't bruise easy, hey?" cause he was looking at my face ... I had a huge bruise on my stomach, under my shirt and all over my arm. And he didn't ask me that. He didn't ask me anything. He didn't even go look to where he could see that the door was kicked in, and he'd smashed stuff. And I told him, and he just brushed it off like it was nothing.

Super Woman, a former sex-trade worker who struggled with addiction, observed that working in the sex trade leaves many women in her community vulnerable to violence as well as disenfranchisement. This vulnerability is compounded when unresponsive law enforcement officials compromise a woman's safety. She described the following experience:

Before I had my kids, I was involved in the sex trade, and I was almost raped by this guy in the park. ... And I was yelling for help and stuff, 'cause then I realized that I had a knife in my purse and he had found that before I could get into it. So now he had it. And this other guy walking through the park heard me scream and he came over and he managed to scare the guy off. And then, I guess, another apartment in the area heard all the commotion and called the police. And the police came, and it was, um ... Well, they saw the way I was dressed, with the high heels and the clothes. And just ... at first they thought it was the guy I was with, and I was, like, "No! It's not him!". They had him up against the car and everything. And I was, "It had nothing to do with him!". So then they were searching us both for drug paraphernalia, and, um ... I wasn't even known to police, and they just did all this stuff that made it seem like I was asking for it. Like, "well, you were out on the street".

Super Woman further emphasized the consequences of being "discounted" for women who experience violence in this way:

I know this isn't just my problem alone, because I've read reports from sex trade workers and stuff. And that's probably one of the biggest times you feel unheard, when you're in that type of situation. Whether it's for survival, or addiction, or whatever, your way of life, or whatever reasons you're in there. You know? You're not heard by police and you've been discounted. And it's really painful, because it makes you feel that you can never go to the police if you have something bad happen to you. So, I don't have a whole lot of trust in the police officers down here.

As has been noted in multiple studies of "risk" factors associated with having a child with fetal alcohol spectrum disorders, the experiences of violence and trauma are closely connected both to increased use of drugs and alcohol in pregnancy and to

numerous barriers to accessing a wide health care and social supports necessary for supporting the well-being of pregnant women, mothers, and children (e.g. Astley et al 2000, United Nations 2004, Zweig, Schlichter, and Burt 2002). However, women's experiences of violence, trauma, and marginalization are frequently absent from public discourses about FAS/FAE prevention. Instead, the responsibility for ensuring the health and well-being of children is usually placed solely on the shoulders of women who are often least able to ensure their own safety. The women who participated in this study repeatedly emphasized that these punitive approaches to FAS/FAE have ramifications that pathologize the contexts in which they raise their families and place firm limits on their advocacy work to secure the supports that their children need.

Claiming Dis/Ability: Medicalization as a Mechanism for Securing Substantive Citizenship

In a context of overwhelming marginalization and disenfranchisement, the women who participated in this study repeatedly emphasized the ways that medicalized understandings about the causes and consequences of FAS/FAE helped them to access State resources and community support. The women I interviewed were well versed in medicalized discourses about FAS and FAE. To illustrate, in response to my question "In your daily life and experiences, what has FAS or FAE meant to you?", Tricksey replied:

FAS is Fetal Alcohol Syndrome and FAE is Fetal Alcohol Effects. FAS is a full-blown syndrome, where you might see the facial characteristics, where they might have a thinner upper lip, and their eyes are beady, and then they're born, it's a low birth weight. And it's just how it is. And of course on the inside, their body, their brain, it's dysfunctional ... Yeah, and FAE, they have just a normal look, but sometimes they might have the hyper ... like a child that's really hyper ... [O]ne of the things that FAS will have is a loss of memory. You have to tell them something constantly. Like, you have to repeat something to the FAS person over and over. And, um, they constantly lose time, and they don't know the cause and the effect when they get older.

Wonder Woman's response to this question indicated a similar medicalized understanding of the causes and consequences of FAS/FAE:

I know some adults, but I know some kids who are, well, I shouldn't say 'full-blown', I guess it's not 'full-blown', but they have almost all the characteristics of FAS. And that's what I think of when I think of FAS. The kids that are short, eyes that are small, that have learning disabilities, that don't understand the consequences, that are born with multiple birth defects. You can ... that's what I see FAS is.

However, while some of the women accepted a medicalized understanding of FAS and FAE, it is important to note that they also contested medicalized discourses that position individuals with FAS/FAE as overwhelmingly "different" from "normal" people. For example, Super Woman cautioned:

[T]he thing to remember about this is that a lot of regular kids without FAS are gonna have these characteristics. They're gonna have these traits. But the thing to remember is the difference ... It's more the build-up. When you compare, when you compare each child, the FAS child will have more severe. The other kids might have tendencies to be like that, but they're not always like that. So that's one thing I like to remember. When people, like, jump, "Oh, my child has this and this and this, they must be FAS". And I'm like, slow down first.

Similarly rejecting understandings of children with FAS/FAE as overwhelmingly "different" from children without FAS/FAE, Shannon emphasized that the techniques she had learned to educate and parent one of her children who has FAS were equally useful in parenting and educating her children who do not have FAS. She stated:

[I]t's helped to learn about it and have the information [about FAS and FAE] to be able to do that [parent her children]. And it helps dealing with children without FAS as well, you know? Like, just the way you would teach a child with FAS, you have to spend more time, and repeat over and over again.

In the interviews, the women repeatedly underscored the importance of medicalization for supporting the well-being and enfranchisement of their children, families, and communities. Specifically, getting a diagnosis of FAS was, in some contexts, the key to accessing much needed supports that would otherwise have been unavailable.

Super Woman's experience provides an example:

In my pregnancy with my son, I went to do an assessment with my daughter for FAS and ... I was about half way through my pregnancy and I was pretty stressed out I was highly still involved with drugs and alcohol at this part of my

pregnancy and ... [My doctor] shifted the focus and realized what was happening, and tried to change it around to getting supports for my pregnancy with my son, which was great.

Indeed, for many women, the fact that their children had not been able to access appropriate diagnostic and early intervention support services for FAS/FAE was a substantial barrier to securing recognition and supports for their struggles as mothers, as well as resources for their children at school. Shannon's struggle to access resources for her son, who has been diagnosed with FAS, was shared by most of the women:

When I was pregnant with [my son], I came to [a pregnancy outreach program]. And they said I couldn't get in because I didn't live close enough to them...And out of all my kids, I think he was the one who would have really benefited from the program, because he has health problems and speech delays, and all the delays that he has had. You know, I'm getting help with him now from [the program], but when he was an infant ... it's when he really could have used that help.

For many of the women, having accurate medical information about the causes and consequences of substance use during pregnancy and about the diagnostic criteria for FAS/FAE provided grounds for exercising their substantive citizenship interests, in that the information created some of the conditions that enabled them to make choices that improved their health and the health of their children. However, although women identified that public health education initiatives about the effects of substance use in pregnancy were an important, they repeatedly emphasized that without accompanying structural and personal supports that made it possible to make change, such initiatives were not enough . Jo-Anne explained:

They definitely need a lot more support. Because from the women I've talked to in the groups, they drank and stuff, and they obviously needed support. Like some people said they were angry with the baby's dad taking off on them. Or just dealing with the pressures of friends who weren't being supportive, and instead of saying "you're not supposed to drink", saying "who cares? Let's go out to the club!", and you're going to burst any second ... You need support systems. Like, I know it's hard trying to find new friends when you're pregnant and stuff, but that's a thing too. If you're so used to clubbing, you need something to do other than going out clubbing and drinking. There's lots of stuff that needs to be done. ... There's not a lot of information out there, other than "here's a pamphlet, here's why you shouldn't drink". Because nobody sits there and tells you unless you get involved in a program.

The medicalization of FAS/FAE also proved supportive of Aboriginal mothers and children in indirect ways. For example, some women spoke of the ways in which applying the "labels" of FAS or FAE helped them to make sense of their experiences with children, families, or partners that had been confusing or painful for them. This is well illustrated by Jo-Anne's comments regarding the value of the FAS/FAE education program she attended:

I've learned more about the people around me. Like, why they're like this, why my family is messed up, or why people I've been with are messed up. That it's not just them. It's issues that are out of your control. And I think with parenting, if there's ever any issues, it's that it helps you not to think you just have a "bad kid". You know? It helps, the labels. You know, finding out the source issues.

On multiple occasions, women also spoke of how viewing the "problems" of FAS/FAE through a medicalized lens lead to an improved understanding of the challenges faced by their loved ones. In fact, without a diagnosis of FAS or FAE, the women noted that some people with FAS or FAE come to be viewed as hopeless or disposable to their families and communities. Jo-Anne explains:

I think that happens, well, it's like what happened with me growing up. Like, they're not really aware of the effects, so then, you know, they think that they have bad kids, and they treat them as bad, and then they give up on them. You know, because they're kids who can't stay out of trouble, or kids who can't learn, you know, more drop outs. It's nice to see now more understanding. They understand now that these kids aren't just bad. They're not just stupid. They're not just lazy. Like, it's the same with grown-ups. Why can't you hold a job? Why are you such a deadbeat? You know, it helps.

In the passage above, Jo-Anne also invokes and troubles familiar stereotypes frequently used to characterize Aboriginal Peoples in Canada (i.e. those "who can't stay out of trouble", "can't learn", are "lazy", who "can't hold a job", or are "deadbeats"). Accordingly, the medicalization of FAS/FAE may also be seen as a vehicle for challenging to popular racisms and colonialism that provide a hegemonic rationale for the marginalization and exclusion of Aboriginal peoples.

Dis/abling States: The Contestations and Contradictions of Medicalization for Substantive Citizenship and Social Justice

In relating their experiences, the women I interviewed identified challenges they face in the fundamental domain of substantive citizenship: the structuring of discursive and material practices that position young Aboriginal mothers and their children as worthy and deserving of help when in need. For example, Jo-Anne stated that racist stereotypes of Aboriginal Peoples needing specialized services to prevent maternal substance use leave many Aboriginal women feeling like " they don't deserve help" when they want or need to access supports related to substance use or FAS/FAE. She explains:

To just focus on Aboriginals, it makes you feel more ... what's the word? I don't know if stigmata is really applicable, but there's a lot all ready. Like, people talk about treaties, and people already think badly about Aboriginal people ... I think, too, it limits when you say Aboriginals and people who aren't. Or people who aren't aware they are. You know? Then they don't want to go. You know, like they feel they don't deserve help. And then people who are racially biased, they'll be, "see look." There are people who complain about "oh, they get all these things. You can see why they need it. They can't not drink when they're pregnant". That what I mean about stigmata, like, the bad label.

Institutionalized racism, sexism, and ableism experienced by Aboriginal mothers can present barriers to accessing the services and care they want and need for themselves and for their children. This in turn can result in negative consequences for Aboriginal mothers and children who have FAS /FAE.

The process of medicalization was one that the women I interviewed identified as important for helping them to secure both recognition of the realities of their and their children's lives and access to the medical, financial, educational, and other supports that are critical to their well-being. A diagnosis of FAS or FAE can also enhance women's well-being by providing them an opportunity to reconsider experiences in their families and communities that have been confusing or painful to them. Furthermore, discourses of medicalization may provide avenues for resisting naturalized and racialized stereotypes of Aboriginal Peoples as "lazy" and "deadbeats" who "can't hold a job".

In the current relevancies of the Canadian welfare state (and other national contexts), people with disabilities must medicalize themselves in order to successfully advance claims for the recognition of their status as a differentiated, marginalized group and for the redistribution of resources that will enable them to improve their material conditions (Fraser 1997b, Meekosha and Jakubowicz 1996). For example, the funding of some school-based supports for children with disabilities is dependent on the student having a medical diagnosis that supports the need for the requested accommodation. Indeed, in the province where this research was conducted, the amount of money school districts receive for providing educational services to a "special needs" student varies considerably depending on the medical or psycho-educational diagnosis of the student in question. Thus medicalization of impairments would seem to be a process for enabling the substantive citizenship of people with disabilities, in that medicalization (in the form of diagnosis) provides access to State resources. However, given the productivist notions of citizenship that are salient in capitalist Nation-States, medicalization also positions people with disabilities in biologically determinist terms as "burdens" on the resources of national economies and institutions. These realities were familiar to Wonder Woman, who recalled the impact these discourses have on her mothering experiences:

So now I'm seen as the disabled mom who went and had a kid that's disabled. A couple of times. Emily was revived when she was born, so I suspect, and that's what the neurologist suspects, that there's a lesion on her brain as well as a cyst, that the epilepsy, at least, comes from her traumatic birth. Lisa, um, her hips come from sitting upside down inside of me ... But I've been medicalized for all my births, except for the miscarriages. I'm seen as disabled. I can walk, but I'm still seen as the mom with the disabled child. And now that she's got a seating device, and it's like, "oh, she's a burden on our government, and now her child's going to be."

Without access to medical testing, diagnosis, and treatment Wonder Woman and her children would not have received many of the supports that have been crucial to their health and well being. However, Wonder Woman notes that being "seen as the disabled mom who went and had a kid that's disabled" and receiving the supports they require (such as the seating device for Lisa) also positions them as "burdens" on "our government". The effect of this discourse is to undermine the substantive citizenship interests of people like Wonder Woman and her children, and to place significant

limits on the ways they can articulate their experiences and mobilize for social, political, and economic justice.

These experiences point to a need for a highly nuanced analysis of the complexities and contradictions in the relationship between medicalization and the citizenship interests of young Aboriginal mothers and individuals affected by FAS/FAE. Medicalization simultaneously enfranchises and disenfranchises people with disabilities as "deserving citizens" and "non-citizens". These contradictory effects are not easily reconciled, and are significant in shaping and mediating Aboriginal mothers' interactions with state institutions. These contradictions are evident in the exchange below, in which the women and I were developing an analysis of their experiences:

AS: I was left scratching my head, because it seems like then the relationship between being medicalized ...

Wonder Woman: Everything's medicalized!

AS: Yeah, it's kind of double-edged. Because on one hand, it was seeming from the interviews that it's important to get the diagnosis, to do all those things, because that gives you access to the supports.

Shannon: But then you're labeled.

Super Woman: You're labeled. Like my daughter had an issue at school, ... and the principal told me I should go back to [a centre specializing in diagnosing fetal alcohol spectrum disorders]. And I told him she doesn't have FAS or FAE, like, there's issues with her, yeah, but why would I go back there? She was diagnosed with *not having it*. But that's the first place he wanted to send me. And because she has all these reports and stuff. And now, I don't know. I'm feeling ... well, I was the one that was advocating to get her all these supports. I'm the one that put her on all the waiting lists, and signed her up, and filled out all the paperwork, and asked for and advocated for myself. And now, because she's having problems, the principal is telling me it's coming from home. Like, that's where all the problems stem from. And I told him, "no, there's stuff going on at school, too". And I'll take my blame, or my responsibility part of it, but there's stuff going on at school. And he's like, "no, I don't think that's the case" ...

Wonder Woman: The nurse at the hospital thinks that my house is a mess, that my kids aren't well fed, because I'm disabled. My house is spotless! I'm a neat freak! ... But I've got all the supports in place. Lisa was a preemie, and I was still in the hospital, phoning Infant Development ... going "OK, we're going to need follow-up, she's preemie, she's got these problems". I was on the ball, two days

after she was born, saying "can I make the first appointment?", because I knew there was a wait list. So I've gotten all the supports in place. If I needed something, I stood up.

The women I interviewed taught me that the substantive citizenship interests of young Aboriginal mothers and their children are frequently disregarded on multiple levels in their interactions with institutions, including those related to education, health care, social services, and policing. As Super Woman and Wonder Woman explain above, this often requires that mothers advocate on their own behalf and on their children's behalf for access to supports and services on the basis of a medicalized "label". Indeed, receiving access to diagnostic and other services that result in "labeling" of people with disability is not easy or guaranteed. As Super Woman and Wonder Woman note, the supports their daughters have been able to access are the direct result of their advocacy work. The importance of these mothers' efforts in supporting the health and education of their children cannot be overemphasized or underestimated.

However, these women's experiences also show that advocacy on the basis of medicalization can have multiple, sometimes unintended, consequences for mothers and children. For Super Woman, the result of her daughter being "labeled" has required the recognition that some of her daughter's "issues" at school may be related to prenatal alcohol and drug exposure. However, this has enabled school administrators to pathologize Super Woman's parenting and living conditions as well as her daughter's behaviour. In this instance, medicalization allowed school administrators to emphasize that "the problem is at home", and consequently limit the epistemic space from which Super Woman can articulate her and her daughter's lived experiences. The consequences of these limits are to eclipse the ways schooling practices themselves impact children's ability to learn and thrive in those environments.

Similarly, Wonder Woman notes she has had to advocate to ensure that she and her daughter will receive appropriate care in and outside of hospitals, which requires a recognition by medical and social service staff that both she and her children have disabilities and need specific kinds of supports. While this advocacy has resulted in Wonder Woman and her daughters receiving the support they need, the effect of

advocating using discourses of medicalization has also been to invoke stereotypes of mothers with disabilities as unable to care for their children, including keeping a "messy house" with "kids [that] aren't well fed".

Wonder Woman's experience of medicalization in relation to her daughter's disabilities has also presented significant barriers to her ability to return to university and to her daughter's access to childcare. She explains:

Even I ... I hate being called "disabled" ... There's other issues. Like, if there were more accesses for me to go to school, or more programs and services. Not just, oh you're disabled, let's get you more money, it's ... I want to get back to school. I want to finish. And even with Lisa, [one local daycare] has a 30 percent load of special needs kids in the daycare, and I went to the other two [local] daycares, and they refused to take special needs. So this one [local] daycare has to take up the load from the others. Well, she's special needs, and I called up a few other daycares and they're, "oh, our special needs placements are full". I said, "well, could you put her in a regular spot?", and [they said] "well, we can't".

In sharing this experience, Wonder Woman underscores the ways in which using medicalized discourses of disability obscure the social, political, and economic conditions that contribute to the marginalization of people with disabilities in and outside of education. Indeed, by emphasizing the lack of resources available to her in her community that would support her return to school, Wonder Woman reminds us that the impact of a disability on a person's life is mediated considerably by the availability of structural supports that some people with disabilities require to access public institutions (in this case, post-secondary education institutions) and services (such as child-care). These conditions must also be understood in gendered terms, in that as a single mother, Wonder Woman's ability to access post-secondary education is limited much more significantly by her lack of access to childcare than by the effects of her disability.

Moreover, Wonder Woman's experiences of attempting to access childcare demonstrates the ways in which medicalization, indicated by the description of Lisa and other children with disabilities as "special needs", can be experienced as both enabling and disabling. In some circumstances, the process and discourse of medicalization enabled Wonder Woman and her children to access the health care and social services they needed, including access to infant development workers, specialist physicians, and assistive devices. However, medicalization also proves

disabling to Wonder Woman and her children, in that designating her daughter as "special needs" rendered her ineligible for a "regular spot" in the childcare centres in her community. As such, the practice of labeling Lisa a "special needs placement" meant that childcare centres could position her as having needs and abilities that are fundamentally different from, and perhaps in conflict with, the needs of "regular" children. Moreover, the practice of limiting the number of "special needs placements" in childcare centres further reifies the differentiated subject positions of disabled and non-disabled children, to result in "special needs" children having less access to childcare centres than "regular" children. These contradictions and contestations of medicalization and citizenship prompt the question: how social justice and substantive citizenship for marginalized groups be secured when the languages and mechanisms for identifying knowledge claims and oppressive material conditions requires the reification of the mechanism of oppression?

Conclusions and Implications

The findings presented in this paper highlight the complexities and nuances found in role of medicalization in public policy, education, and citizenship practices. For the Aboriginal mothers I interviewed who were negotiating the challenges of FAS/FAE (and other impairments) on a daily basis, medicalization proved to be a simultaneously enfranchising and disenfranchising process. The women described the process and consequence of receiving a diagnosis of FAS/FAE as beneficial, as it enabled them to access resources and services that were necessary for supporting their well-being and the well-being of their children and families. Because the availability of these resources and services is limited in their community (and, in the case of "special" education services, required a diagnosis), most of the women were required to engage in an enormous amount of advocacy work in order to access them. These difficulties are compounded by both systemic and "common sense" racisms that inform the social, political, and economic marginalization experiences by Aboriginal Peoples in their daily lives. Indeed, as Jo-Anne indicates, appeals to medicalized understandings about the causes and consequences of FAS/FAE can be one way in which Aboriginal mothers and communities can resist "common-sense" racisms in representations of Aboriginal peoples. At the same time, the medicalized "labeling" through assessments and diagnosis of FAS/FAE proved disenfranchising for the

women and their children in other respects. For example, Super Woman noted that "labeling" her daughter has required school administrators to recognize that some of her daughter's "issues" at school may be related to prenatal alcohol and drug exposure. School administrators used this information to pathologize her child's behaviour as well as Super Woman's parenting skills and living conditions. Arguing that "the problem is at home", the use of medicalized discourse enabled school administrators to limit the epistemic space from which Super Woman could advocate for changes in the way her daughter was being schooled and to eclipse the effects of socially organized schooling practices inform the schooling experiences of marginalized children with and without FAS/FAE. Similarly, Wonder Woman's analysis of her experience of medicalization in relation to her daughter's disabilities, which resulted in the labeling of her child as a "special needs placement", has been that this "label" disqualified her daughter from being placed in a daycare space reserved for "normal" children. In a community with few daycare centres offering a very limited number of "special needs placements", Wonder Woman describes an unintended consequence of using medicalization to support her advocacy: her daughter has less access to daycare centres (and the early childhood educational opportunities that they provide) than non-disabled children in her community. Moreover, lack of access to child care appropriate for her daughter's needs was identified as a major barrier to Wonder Woman's abilities to pursue her own post-secondary educational aspirations.

These findings have significant implications for the development of the social model of disability, which has been the cornerstone of critical disability studies in and beyond educational praxis. Specifically, these findings lend complexity to the implications of medicalization for compromising or advancing the substantive citizenship interests of people with disabilities. One of the defining features of critical disability scholarship and disability rights movements has been the "wholesale resistance of the functionalism of the medical model" (Gabel and Peters 2005:20). The process of medicalization (as articulated in the medical model of disability) has been problematized by contemporary disability theorists on the grounds that medicalization attributes all aspects of disability, and disabled experiences, to the presence of pathologized, biologized, and objectified "defects", "diseases", or "deformities" (Barton 2001, Oliver 1990). These ideologies support structural, institutional, and material practices that marginalize people with disabilities as "non

citizens" and mediate the consequences of impairment or bodily difference in people's everyday lives (Shakespeare and Watson 1997).

However, Gabel and Peters (2004:20) have argued that within disability studies and disability rights movements, "resistance exists within and around the medical model". Accordingly, they argue for an expansion of social models of disability, to recognize the important role that medicalization can have in improving the health and well-being of some people with disabilities (for example, by supporting access to much needed health, social, and educational services or "accommodations") without negating the importance of resisting those aspects and consequences of medical models that marginalize and disenfranchise people with disabilities and their struggles for social justice through state institutions, including schools.

To deny the challenges presented by FAS/FAE as only or primarily effects of discourse or oppressive institutional practices does little to support the daily struggles experienced by Aboriginal mothers, children, families, and communities who regularly negotiate the physical, cognitive, and behavioural dimensions of their impairments. However, embracing those aspects of medicalization that have instrumental value for supporting the health and education of those affected by FAS/FAE (for example, by enabling access to "special education" services) must not preclude critical examination and transformation of institutionalized policies, practices, and pedagogies that employ medicalized discourse to marginalize and disenfranchise people with disabilities and position them as "burdens", "drains", or "threats" to their communities and to the Nation-State.

Abstracted notions of "citizenship" appear to have questionable utility when decontextualized from the relations between marginalized Peoples and institutions of Nation-States. In order to effectively lay claims to status as "citizens", individuals or groups must first be recognized as "citizens" in both the formal and substantive senses of the term, with voices that count and interests that matter in their daily interactions with the members and institutions of their communities and nations (Young 1990). The experiences of young Aboriginal mothers whose lives have been impacted by substance use and FAS/FAE, which include experiences of violence, insensitive and unresponsive treatment by people in positions of authority, lack of access to appropriate medical care and parenting supports, and encounters informed by racism,

sexism, and ableism, confirm that many women and children who are marginalized by gender, race, class, nation, and dis/ability still await this recognition. Abstracted notions of citizenship, as defined in and through the formal recognition of rites and entitlements, mask the means by which substantive citizenship is negotiated and contested in people's everyday lived experiences. Abstracted notions of citizenship are further entrenched by rendering citizenship in monolithic terms, as something an individual or group does or does not have in all contexts, at all times. Supporting the substantive citizenship interests of marginalized women and children requires recognition of the ways these interests are mediated and differentiated in and through their interactions with various institutional policies and practices at the local and national levels. These findings demonstrate that efforts to support marginalized groups in their struggles to secure rights and entitlements as "citizens" cannot ignore the structurally and contextually dependant domains of formal and substantive citizenship that shape the lived experiences of marginalized women and children.

These findings suggest a need for new ways of thinking and teaching about FAS/FAE, and ways of supporting children and families who are affected by FAS/FAE, that extend beyond an individualized "shame and blame" approach to acknowledge the conditions in which women negotiate and experience substance use, pregnancy, and mothering. This approach would allow for the development of educational programs, resources, and policy responses that more closely reflect the realities of Aboriginal (and non-Aboriginal) mothers lives and the lives of their children who have FAS/FAE. The mothers who participated in this research taught me that such a shift is much needed, because existing programs and services often attempt to isolate substance use and FAS/FAE from other facets of Aboriginal mothers' and childrens' lives. For the women who I interviewed, the result of these exclusions is that they often have encounters with service providers (including educators) that are unhelpful, unproductive, and in some cases traumatic. As a result, many Aboriginal mothers who want to receive help in parenting their children who have FAS/FAE are not getting the supports they want and need.

The women I interviewed agreed that all mothers (including Aboriginal mothers) need accurate information about FAS/FAE. This includes information about the defining characteristics of FAS/FAE, information about the consequences of FAS/FAE, and

accurate, reliable information about the effects of alcohol and drug use during pregnancy. In order to be meaningful and useful to mothers, the women argued that public education about FAS/FAE must be more detailed than simplistic and reductive messages such as "just say no" or "don't drink or use drugs if you are pregnant". Focusing only on alcohol and drug use also ignores other factors that influence whether a person will develop FAS/FAE, as well as other consequences for women's and children's health and well being that are related to prenatal drug or alcohol exposure. Having this information is important for supporting women's substantive citizenship interests because it allows women to make independent, informed decisions that support their health and well-being as well as the health and well-being of their children. As Jo-Anne and Tricksey noted, this information also helps them to make sense of life experiences in their families, intimate relationships, and communities that have been painful, confusing, or traumatic. In the interviews, the women also suggested that access to information about the effects of alcohol on her fetus may support women in their relations with friends and intimate partners who may influence or pressure women into drinking during pregnancy. Given that women's decisions about alcohol and drug use are made in the context of unequal gender relations, and that male partners often use alcohol or drugs to maintain power or influence a woman's behaviour in these relationships (Astley et al 2000), public education and policy efforts that support women who wish to abstain from substance use during pregnancy clearly have a key role to play.

According to Ward and Bouvier (2001:5), "Understanding the context of Aboriginal peoples' experiences ... is crucial to determining the strategies that might be employed through education systems that are devoted to the 'public common good'". As educators, the policies that we create and implement, the pedagogies we develop and enact, and the interactions we have with those who live with FAS/FAE are not of passing significance. They provide us opportunities to create conditions that welcome Aboriginal women, families, and communities to work with us in respectful, collaborative ways, that are grounded in a shared commitment to provide women, men, families, and communities with the best education possible. This means approaching people diagnosed with FAS/FAE, and the mothers who give birth to and care for them, as sources of knowledge, experience, and strength. It means greeting the person with FAS/FAE as a person first, who has a variety of needs, interests, and

challenges. It means working with a person who has FAS/FAE and her/his support network to find the best method for meeting their needs in a positive, encouraging way. It also means rethinking the source of the "risks" and "problems" of FAS/FAE as located in the policies and practices of state institutions, including schools, not just in Aboriginal families and communities. Most of all, it means working to identify and transform those institutions and practices from ones that disable and marginalize to ones that offer compassion, respect, and empowerment.

Notes

[1] In Canada, the term "Aboriginal" is the preferred term used to collectively describe Indigenous Peoples of First Nations, Metis, or Inuit ancestry.

[2] Recently, the term *fetal alcohol spectrum disorder* has been adopted in medical discourse to refer to a continuum of physiological and psychological characteristics associated with fetal exposure to alcohol during gestation, including conditions such as fetal alcohol syndrome (FAS) and those previously referred to as fetal alcohol effects (FAE). In this article, I retain the use of the earlier terms FAS and FAE in keeping with the terminology used in Canadian federal policy texts I was studying and by the participants at the time of the interviews.

[3] This assumption is based on data from the United States, as no epidemiological studies have yet been completed in Canada to determine rates of FAS or FAE among First Nations.

[4] For a detailed discussion of the methodological dimensions of this study, see Salmon (in press).

[5] Teratogenic agents are substances cause adverse effects on the development of a fetus during gestation.

[6] The term "Registered Indian Status" is an administrative category used by the Government of Canada to recognize rights and entitlements afforded to persons registered under the *Indian Act*. The *Act* defines an "Indian" as "a person who, pursuant to this *Act*, is registered as an Indian or is entitled to be registered as an Indian." To be eligible to receive benefits under the *Indian Act*, individuals must be

registered in the Indian Register, which is maintained by the Department of Indian Affairs and Northern Development (DIAND). Generally, persons are eligible to register if one or both of their parents are registered (for exceptions, see Cornet 2001). In Canada, Aboriginal people (which includes Peoples who identify as First Nations, Metis, or Inuit) who are non-registered (or "non-status") may not have access to certain rights and entitlements (i.e. to on-reserve housing, education, non-insured health benefits, etc.) afforded to "Registered" or "Status Indians".

[7] To protect their anonymity, I refer to each participant and their children using a pseudonym. Most women chose their own pseudonyms, although some women preferred to conduct the interviews using their own names, and noted "you'll need to change the names on the transcript". In these cases, I have assigned the pseudonyms.

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