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Mothering Disabled Children in Early Childhood: Institutional Reproduction of the Standard North American Family

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Abstract

This paper considers Smith's 'standard North American family' (SNAF; 2005; 1999; 1993) to understand how early childhood systems uphold and reproduce gendered spaces of care for disabled children that also reify ableist, racist, and classist constructions of family and mothering. We present findings from an analysis of 25 mother and caregiver interviews over a 6–9 year time period, through which we have mapped the interactions that families have in the context of seeking support, education, and care for their disabled children. We draw on the scholarship of Black feminism and Critical Disability studies to shape our analysis of the gendered, raced, and classed work of families, and the institutional expectation on mothers to do the work of gaining access, and the lack of collective responsibility for all young children.

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In this paper, we look to Smith's 'standard North American family' (Smith, 1993, 1996, 1999) as 'ideological code' (Smith, 1993, p. 51) to understand how early childhood systems uphold and reproduce gendered spaces of care for disabled children that also reify ableist, racist, and classist constructions of family and mothering. Moreso, we examine social constructions of mothering, which relies on the professionalization of child development (Griffith & Smith, 2005) and creates 'good mothering' and 'intensive mothering' (Hays, 1996; Wilkinson et al., 2021) ideologies implicit within SNAF. We turn to critical disability theory (Goodley, 2016; Goodly et al., 2019) to challenge the normative nature of SNAF and expose its implicit sexist, ableist, racist, and classist ideologies present in what is required of mothers' work in accessing services for their disabled children. We extend this analysis through Black feminist scholarship that has documented the ways that Black mothers respond to systemic barriers for their children. We see parallels in the scholarship of disabled and Black mothering in which systems impose norms upon women to engage in activities, relationships and processes that situate them as outside. These responses of parental advocacy are classed, gendered, and raced, with a mould that mothers must adhere to, in order to gain acceptance to the resources of institutions. By adhering to the system's values around communicating, navigating, and advocating, we bear witness to the pressure to fit a white and ableist norm of behaviours deemed as neutral. There are disproportionate impacts from these norms on Black, Indigenous, and racialized mothers, particularly in the ways that systems respond to parental advocacy which subvert ableist and raced norms. Critical disability studies and Black feminist scholarship are aligned in this project to act in solidarity with the intention of uncovering bureaucratic and structural constructions of disabled childhoods that draw some mothers in, and simultaneously push others out. Further, the family is then blamed for limits that are constructed within the systems that claim to care for their children (Carey et al., 2020). The analysis presented in this article aims to identify and name these processes with the goal of disrupting current systems and moving toward a relational and equitable system of care.

Organization of Gender and Care Within SNAF

Care work is synonymous with women's work and is a gendered phenomenon that is experienced worldwide (e.g. Este, 2011; Ferrant et al., 2014, 2019;

Guppy et al., 2019). Experience and research demonstrates that the SNAF ideology is visible within the 'breadwinner/homemaker' economy where men participate for pay in public domains of the market economy and women take care of children and the house in the private economy (Este, 2011). The gendered nature of childcare is insidious:

> Though this model ['breadwinner/homemaker'] has not been equally represented among families of different economic, racial, and ethnic backgrounds, it has nonetheless resulted in the ideological, if not actual, association of men with waged labor and women with domestic labor. (Este, 2011, p. 234)

Further, Este (2011) describes new institutionalism, an approach to understanding gender disparities by examining how gender is 'done' in different cultural and socio-political contexts, and specifically examining 'work-family policies to the division of domestic labo[u]r' (p. 236). Este (2011) examines cross-cultural research on work-family policies and its effects on gendered divisions of child care and housework which finds differences based on whether countries are classified as liberal (e.g. US), social democratic (e.g. Denmark), or conservative (e.g. Germany). In social democratic countries work-family policies such as parental leave are not dependant on the employer (as they are in Canada and the United States), but rather are paid for by the government and both parents are encouraged to go on leave. More egalitarian divisions of labour are found in social democratic countries in comparison with those from both liberal and conservative countries. Este (2011) concludes her paper by stating

> Depending on how it is structured, parental leave has the power to intensify or mitigate the gendered division of domestic labor. If men are encouraged to take leave, parental leave offers an avenue through which the allocation of market labor and domestic work along entrenched gender lines may be subverted. (p. 241)

We note the relationship between socio-political context and the reproduction of gendered work in accessing disability services is key to transforming oppressive care arrangements for all families (Underwood, Church & Van Rhijn, 2020). This led us to the SNAF literature, which provides an entry into our analysis of the gendered work of families in their interactions with early childhood and children's disability services. Through this lens we analysed the institutional interactions through the following questions: How do early childhood service systems reinforce the 'standard North American family' and 'reproduces injustices of [ableism] class, race, and gender' (Griffith & Smith, 2005, p. 9)? How are ideologies of 'good mothering' and intensive mothering' reinforced in the 'standard North American family'?

How do early childhood service systems perpetuate a gendered expectation for care of disabled children? How do early childhood service systems organize mothers and those doing parenting work?

Using an Institutional Ethnography Lens

Our work on the Inclusive Early Childhood Service System (IECSS) project, an institutional ethnography which examines how early childhood systems define disability and organize families, informs this paper which examines how early childhood service systems reproduce gendered work in accessing disability services. Our research demonstrates that this work is primarily done by mothers (e.g. Frankel et al., 2019; Ineese-Nash et al., 2018; Underwood, Frankel et al., 2019; Underwood, Moreno Angarita et al., 2020). Early childhood service systems require parents to 'comply with the procedural aspects of the system' (Underwood, Frankel et al., 2019, p. 146) in order to access disability services, work that largely falls to women.

For this paper, we began with an interest in the work that mothers, and those who have taken up the work of primary carer, have done in their engagements with institutions. We have reported elsewhere on the work of mothers, the need for them to comply with institutional requirements, making connections and gaining access to interventions in what we have called the responsibility to make their children 'normal' (Underwood, Church & Van Rhijn, 2020). We have noted the tensions in their acts of resistance and their compliance at each interaction, with deep knowledge of institutional processes while also maintaining their focus on the humanity of their children despite the endless bureaucratic documentation of their development (Church et al., 2020). We have also noted that overwhelmingly this work is done by women (Church et al., 2020; Underwood et al., 2018; Underwood, Angarita Moreno et al., 2020, Underwood et al., 2018). This article arises from our curiosity to understand the gendered nature of this labour in the context of childhood disability, early childhood education and care, and the ways that this positioning of gendered work is implicated in how families are organized into this system. This is what we call the problematic. In institutional ethnography 'analysis is anchored in relation to the problematic(s)' (Rankin, 2017, p. 7), where 'learning how the standpoint of informants' experiences are being coordinated is the *purpose* of the analysis' (Rankin, 2017, p. 3, emphasis in original). In this case, we were interested in how institutions rely on women to do the work of the institution, and the organization of families within early childhood systems (see Underwood, Angarita Moreno et al., 2020, Underwood et al., 2018; Underwood et al., 2019).

Standard North American Family (SNAF)

The Standard North American Family (SNAF; Smith, 1993; 1999) is construed as an *ideological code* (Smith, 1993, p. 51) that reinforces a 'normative' family as white, heterosexual, cis-gender, able minded/bodied, and middle-classed which is perpetuated in laws and policies throughout North America (Letiecq, 2019). Smith (1993) stated that

> the term *ideological code* [is used] as an analogy to *genetic code*. Genetic codes are orderings of the chemical constituents to DNA molecules that transmits genetic information to cells, reproducing in the cells the original ordering. By analogy, an ideological code is a schema that replicates its organization in multiple and various sites. (pp. 51-52, emphasis in original)

In the SNAF blueprint married, heterosexual, and cis-gender couples play out gendered work regulations structured for middle-class, non-disabled, and white families (Brady, 2022; Lightman & Kevins, 2021) which dictate that the primary financial responsibilities belong to men, and child care and housework are exclusively a woman's domain. This, despite the fact that many women, and particularly working-class, and racialized women have always worked outside of the home in part-time or full-time employment. This division of labour is exclusive to middle-class white, global north families which separates men and women into public and private spheres (Smith, 1993) as working-class, Black, Indigenous and racialized, poor, and immigrant families who rarely experience work and home as separate entities (Bush, 2010; Douglas, 2024). This means that the work of mothering is contained within norms that are not universally relevant. Closely tied with the middle-class status is the 'script … that nuclear families (i.e. married couples and their [able-bodied and minded, heterosexual, and cis-gender] children) should be self-sufficient and should not rely on anyone else for help' (Sarkisian, 2006, p. 808). Thus, implicit within the SNAF ideology are the notions of independence and self-reliance within family life.

> 'the overwhelming whiteness of the "special needs" parental memoir genre is enabled by the material and discursive privileges of white settler colonialism and, in particular, a white supremacist sense of entitlement to belonging. This conclusion proceeds from a disability justice framework that understands that "able-bodied supremacy has been formed in relation to intersecting systems of domination and exploitation' (Apgar, 2023, p. 107).

Ideas of independence and self-sufficiency are rooted in ableism and disablism. Mingus (2017) shares

> the myth of independence reflects such a deep level of privilege, especially in this rugged individualistic capitalist society and produced the very idea that we could even mildly conceive of our lives or our accomplishments as solely our own. … the Myth of Independence is not just about the truth of being connected and interdependent on one another; it is also about the high value that gets placed on buying into the myth and believing that you are independent; and the high value placed on striving to be independent, another corner stone of the ableist culture we live in. (para 36)

Interdependence, a critical tenant of the disability justice movement, a movement founded and led by Indigenous, Black, queer and other multiply marginalized disabled folks, focuses on the fact that we are in relation with and need one another for our collective well-being (Sins Invalid, 2019). Interdependence is central to all disability movements, in the form of families being in relation with – extended family and kin, social networks, community and educational services, and more – is critical to family and child health. Interdependence is central to disabled organizing and disrupting discourses of independence as the ideal, which is often used to situate disabled people as in need, and requiring labour on the part of those who care for them. Further, Beneke et al. (2021) mirror Mingus' (2017) and other disabled scholars and activists, within the context of early childhood education and care for disabled Black children:

> to authentically enact care, early childhood education can re-imagine competence through the lens of interdependence. … educators and leaders must dismantle the myth that any learner moves through the world without support… —and instead frame young children, educators, and knowledge itself as interrelated, supportive entities. (p. 341)

Every family that does not fit within the confines of the SNAF paradigm, and many that do fit within it, struggle with the implicit ideology of self-sufficiency and independence. Additionally, children often do not fit into the norms that are established for mothers, particularly with regards to the timeline and outcomes of their development. As Kafer (2013) points out, we live in a society that sees disability as a life without a future, and our systems are designed to ameliorate disability and normalize children at every turn. In their notion of *crip time* Kafer (2013) suggests that our temporal realities, including the structures of childhood that strictly adhere to birthdates as an organizing category, limit the possibilities for disabled futures.

Research on racialized (Black, Asian, & Latina) mothers (Collins, 1997), single mothers (Griffith & Smith, 2005; Nelson, 2006; Sarkisian, 2006), Asian immigrant mothers (Grahame, 2003), and mothers with disabled children (Douglas et al., 2021, 2022; Chiaraluce, 2018; Runswick-Cole & Goodley,

2018) illustrate the necessity of interdependence in raising children. Further, Black feminist scholars have long described *othermothering* which is mothering and providing care for children extending biological children and family configurations (Brady, 2022; Collins, 1987; Wane, 2000). Hooks (2015) describes the ways that Black women provide community-based childcare when limited social systems and supports are afforded. Othermothering and interdependence assist in raising disabled children. Marginalized groups are required to navigate 'doing family' (Letiecq, 2019) within oppressive systems and find numerous opportunities to develop 'new ideological codes' (Chiaraluce, 2018, p. 2902) that value disabled children's childhoods (Curran & Runswick-Cole, 2014) and diverse family structures.

Despite the fact that family diversity is the norm, the structure of SNAF remains the ideal (Van Eeden-Moorefield & Demo, 2007; Van Eeden-Moorefield & Shih, 2015) and is a 'reference point and center through which both individuals and institutions conceptualize and "do family"' (Letiecq, 2019, p. 2885). Ruling relations, which refers to the organization of people's lives through institutional complexes (Smith, 1996), impose expectations of SNAF as a universal reality which protects hierarchies of power through laws and policies invisible to everyday experiences (Kushner et al., 2014; Nelson, 2006; Smith, 1993; Weigt, 2006). For example, maternity and parental leave policies in the US (e.g. Grahame, 2003) and Canada (Sakaluk et al., 2022) are based on the SNAF paradigm which centres middle-class family privilege, where one parent's income (fathers) is enough for the entire family to subsist on while mothers take maternity and parental leave to raise children. Taking leave from work is not a given and often times not a possibility for working-class, poor, and/or single parent families where women have always had to work, taking on multiple, often domestic, jobs to support the survival of their families (Ehrenreich & Hochschild, 2002; Lightman & Kevins, 2021). Often the flexibility required by the system, favours white middle-class families based on lopsided arrangements of care work which disproportionately affects Black and racialized women. This can be understood through domestic work schemes which brought Black women into the Global North while fragmenting their own families back home and offering little to no migration status stability (Henry, 1968; Lawson, 2013). Through gendered anti-Black racism, these domestic work schemes later shifted to non-Black racialized women who came from countries such as the Philippines (Pratt, 2012). In all, these systems continue to perpetuate white supremacy and lead to the survival of some families at the expense of racialized families. The experience of domestic workers is reflected in the organization of early childhood disability services, where the labour for mothers is an expectation devoid of recognition of the impacts on families, communities and social participation of the carer and the children. Yet the foundations of the SNAF ideology are insidiously engrained in policies, institutions, and work settings, favouring families that are willing, able and invited into the relationships of these service systems.

Employers hold much power over the possibility of work-family balance. Blair Loy et al. (2015) discuss *work inflexibility*, where employers do not accommodate schedules that are adaptive to family life, and *flexibility stigma*, where parents can flex their workdays to accommodate family life. Both work inflexibility and flexibility stigma are related to dominant notions of masculinity and class where men cannot access flexible work schedules, as these are seen as a solution for women who are responsible for child care (Burnett et al., 2010). Further, as Burnett et al. (2010) highlight the very idea of work flexibility 'is loaded with gendered assumptions' (p. 540). However, the use of gender neutral language in work-family policies hides that these policies were created for women and are primarily used by middle-class women who opt to work 'part-time, flexible hours, job sharing and working from home' (p. 539) in order to balance child care with paid employment. As dual-income families have become a norm among middle-class families in North America, the globalization of feminized domestic care work resolves the problem of child care (Ehrenreich & Hochschild, 2002; Lightman & Kevins, 2021).

The SNAF framework for dual-income families is maintained as child care and domestic work is outsourced from developing countries (Ehrenreich & Hochschild, 2002; Lightman & Kevins, 2021). As discussed earlier, child care and domestic work is usually filled by poor, immigrant, and racialized women who have no choice but to leave their families to take care of more privileged families abroad (Lightman & Kevins, 2021). This pattern of racialized and poor women taking care of white women's families and children is not new (Hays, 1996) and serves the SNAF by maintaining class, gender, and race hierarchies. As Ehrenreich and Hochschild (2002) share, 'the presence of immigrant nannies does not enable affluent women to enter the workforce; it enables affluent *men* to continue avoiding the second shift' (p. 30). Even within the licensed childcare and school settings, lower-paid care positions tend to be overrepresented by racialized women (Abawi, 2021). The SNAF ideology conflates the term family with mother (Smith, 1993) or mothering work which is commonly performed by immigrant, racialized, and working poor domestic help in middle-class families. This impacts the mothering discourse which 'is through and through SNAF ordered' (Smith, 1993, p. 55).

Mothering Discourse: The Good Mother and Intensive Mothering

Intensive mothering was coined by Hays (1996) and consists of three principles: (1) 'child rearing is synonymous with mothering' (p. 29), mothers are *the* primary caregiver; (2) mothers, as 'natural' caregivers, self-sacrifice themselves for the care of their children which is '*child centered, expert* *guided, emotionally absorbing, labor intensive,* and *financially expensive*' (p. 8); and (3) mothering work is prioritized over paid work (Hays, 1996). These functions are within the confines of the SNAF and reinforces white, middle-class, able-bodied/minded family values. Intensive mothering does not apply to *all* mothers. Women are valued based on their mothering contributions regardless of their access to resources, time or energy (Brown, 2022). Family diversity in its make-up and cultural structure is not valued by the SNAF ideology but the ideology is so insidious that mothers of every background are measured by their mothering work, and in some cases, seek to adhere to its impossible expectations (e.g. Elliot et al., 2015). Intensive mothering also runs contrary to other forms of mothering such as *othermothering* in Black communities and community-parenting models in Indigenous communities (Watts, 2021) because of its emphasis on individual nuclear parenting. There is little work done to understand how disability services in early childhood are implicated in the individual responsibility placed on mothers, and the resulting discourses of dependence (not interdependence) imposed on children.

The intensive mothering ideology extends, in particular, to mothers with disabled children who are also positioned as 'natural' caregivers with endless reserves for intense emotional, physical, and financial labour (Douglas et al., 2021, 2022; Brock, 2014). Mothers with disabled children are under greater surveillance (Ryan & Runswick-Cole, 2008) as their interactions with various disability service systems are constantly evaluated. In light of an early childhood service system that is inequitable in providing disability related services for young children, Nichols et al. (2020) suggest that the intensive mothering ideology 'reflects role and gender inequities, including imposed work demands and potential role tensions. This positioning of motherhood in mitigating system inadequacies, amplifies tensions and a lack of other choices for mothers in their life path' (p. 8). The 'good mother' becomes synonymous with white, middle-class intensive mothering making up for the work of inadequate systems within the SNAF configuration. This excludes working-class, Black, Indigenous, single and other mothers who do not fit the norm from the category of the 'good mother', subjecting them to heightened surveillance. The 'good mother' trope is, however, an almost impossible role for all mothers, particularly in the context of work, care for other family members, and the normative mothering that excludes disabled children in all facets of community life. This reflects the entanglement of the SNAF and intensive mothering ideologies, which through institutional policies enact power over mothering work in accessing services for disabled children.

We know that families must either comply with a system, which positions disabled children as in need and a burden, or they will be excluded through a multitude of processes including expulsion, removal of supports, reductions in funding, among others. This results in routine decisions about whether to participate or to resist (Underwood, Angarita Moreno et al., 2020; Underwood et al., 2018). The mothers themselves are subject to this ableist independence discourse that values abilities attributed to the good mother, and which are necessary for the child to gain access. In another study, 33 Black mother participants describe their role in navigating anti-Black racism in the school system for their children while also experiencing systemic racism through their own social-locations, and the significance of knowing your rights and adhering to white norms to navigate the system (Brady, 2022). These prior studies inform our analysis of the SNAF concept in early childhood.

Method

The analysis presented in this paper was developed as part of the IECSS project. IECSS is a partnership that has been conducting informant interviews with families who have disabled children since 2014, with families in 3 provinces and 1 territory in Canada. With 153 informants (at the time of this analysis), who have participated in up to nine interviews, the IECSS project holds a large qualitative dataset of attributes tables that document the characteristics (waitlists, number of engagements, assessment requirements, number of visits, length of visits, etc.) of each institutional interaction reported in the interviews. From the attributes tables we have generated maps of the institutional engagements from prenatal through late elementary school. These maps include the referral pathways, length of time in a service, the texts that are generated through referral and intake processes, and the context for interactions with the services along a timeline.

Using the maps, we identified those informants who presented as deeply involved in the institutional process. We operationalized this by counting the number of self-referrals made by the family member(s) being interviewed. Of the 156 families in the study, we identified 25 informants who had made more than 4 self-referrals over the period of time that we had been interviewing them. Our focus on families who have made substantial self-referrals allowed us to understand the systems from the standpoint of those who had the most access to those systems. This meant that they had been able to self-refer to a number of services, by identifying, contacting and activating the processes that led to participation in a service for their child. This high number of self-referrals indicated to us that they were highly assimilated into the system as it is designed, and, we were interested in better understanding what was happening for those families.

There were a total of 25 informants who fit the criteria for inclusion, with $N = 7$ informants from our first study cohort (recruitment beginning in 2014), who had up to eight interviews, and $N = 18$ informants from our second cohort (recruitment beginning in 2018) who had up to five interviews. All of the informants were mothers. There were two foster mothers included in the sample, and one informant couple where the father was present at each interview. We refer to them collectively as informants in the tradition of Institutional Ethnography, which views workers as holding knowledge of institutions.

Following identification of the problematic, and an in-depth review of the literature on SNAF, the first two authors read through the transcripts to identify the deep descriptions of institutional engagements from these informants. All transcripts from each year of interviews with the 25 informants were reviewed. Attention to how informants interacted with professionals and services was a primary focus to better understand what early childhood service systems require of families to access and maintain services.

Findings

The informants in this study were able to activate services by first finding them, via searches, relationships with professionals, and advocating for their children, and then engaging in the procedural and relational activities needed to participate. These are described in more detail below. We are interested in who fits into this model and our findings indicate that there is a complex integration of characteristics of families who we identified as highly active in these systems. These mothers and foster mothers were primarily white (n = 16), although there were also Indigenous (n = 3), and other racialized informants (n = 5). The 25 mothers reported that their families had a range of incomes, with 13 of them having high income ($100, 000+ per annum), 8 having middle income ($40–100,000), and 4 having low income ($15–40,000). This group of mothers were well educated, with all of them having at least high school education, and 23 of them with post-secondary education. The children of these mothers were described as neurodiverse (n = 12), having speech or language delays (n = 3), having low vision, being hard of hearing, and having multiple genetic differences. These diagnostic characteristics were described as valued parts of who children are, but also as categories that generate different institutional responses. The mothers from Cohort 1 (n = 7), who we began interviewing in 2014, had fewer self-referrals than their counterparts in Cohort 2 who we began interviewing in 2018 (n = 18). This may be a result of changes to how funding is allocated, particularly with the Ontario Autism program (OAP), which moved to a direct funding model. Direct funding has flexibility for families to decide how funding is spent, but it is more work for families.

There are many barriers to accessing services during the workday which is an activity dependent on class, work structure and employment (in)flexibility. Every mother described the barriers in accessing services for their children while being employed full-time. Mothers who work full-time hours shared with us that they need to take time off work to attend meetings or take children to services. In some cases, mothers were able to take time off, and in others they were not, which resulted in missed services for their children. One mother shared that weekday evenings or weekend appointments could not be accessed because the waitlist for these appointments was more than one year. This resulted in the mother needing to take unpaid time off of work. She shared 'I had just gone back to work so I didn't have accumulated vacation or any time that I could use paid. So I had to take an un-paid leave during marked work time to do this session'. Another mother described the inflexibility within her work to take her child to a specialized service outside of school, 'I've started working again (after mat leave) and I can't take time off to do that…I feel guilty I can't take time off of work to access services'. Many mothers expressed guilt as a result of not being able to meet the expectations of the early childhood service system. Mothers were not able to take time away from work (without consequence of being unpaid or viewed unfavourably), access more services, and afford private services. One mother stressed how finances impact her access to services, 'if I had more money coming or if I was able to work and coordinate with all those activities I probably would put him in so many things. Music or sports or whatever makes him happy. But I think the financial is a heavy weight'.

Many mothers shared that accessing particular services could only be done in a location outside of the child's school, which also resulted in missed services and employment changes or job losses. Mothers described service delivery that split up the day with paid childcare or school attendance in the morning and therapy sessions in the afternoon, which required mothers to drop children at childcare, pick them up either before or after lunch, and then take them to their afternoon therapeutic services. This schedule is not feasible for working mothers, or mothers with multiple children (pick-up and drop-off is often required at the same time at different locations), as the entire workday is taken up driving children to and from services. In one case, an autistic child wasn't allowed to travel on the bus with their siblings because they were deemed too young. One year later they were approved for bus transportation; however, the mother describes frequent instances where she had to call the school to check whether the child was coming home on the bus or she needed to pick him up. This example of unreliable transportation and the frequency of pick-ups and drop-offs illuminate that mothers must be available at all times. The requirement to be available is only available to those who can afford to hire a caregiver and/or whose jobs are flexible. In many cases mothers experienced job changes or losses as a result of trying to access services.

Ten of the 25 informants discussed the challenges of juggling work, caregiving, and accessing services for their children. One informant shared how her experience of having an autistic child prompted a career change into the autism field; however, the demands of accessing services for her child put a pause on starting school. Eight of the informants shared that the demands of accessing services interfered with their employment to the point where they were either let go or forced to resign. One mother's words capture the frustrating defeat that all of the informants shared: 'I can't work, I can't really do anything because I'm constantly picking kids up from school so its been a struggle for sure with the school this year in trying to get these kids the supports that they need'. Another mother shared her hesitation of going back to full-time work and the implications it has on accessing services: 'I went back to school about 3 years ago so I've been very flexible in my schedule in terms of being able to do meetings with the school at 3:30 or being able to take her to most appointments, those sorts of things so I've finished my studies and I'm going back to full time work next week for the first time since before [child] was born … [this] means there will be less of my time to put towards supporting and advocating for [child] which has been really easy if I was just at home'. These experiences shed insight into the structures and expectations of early childhood systems, which require mothers to be available at all times of the workday to take children to services.

The reliance on mothers to access and navigate early childhood service systems is done with an insular approach that does not take family systems into consideration. One mother discussed her experience meeting the expectations of service providers to be available and present at whichever referral is arranged without being asked if it works for her schedule. She shares '[pediatrician stated] I'm going to refer you here, I'm going to refer you here…with no conversation about what do you have time for? What do you do? Are you home with your daughter'? This is a shared experience among informants that illustrates the expectations of the SNAF ideology, where one parent has paid employment, and the other (mothers) are responsible for the care work of children. The expectation of availability is both classed and gendered with implications for mothers from all class backgrounds.

The early childhood service system is ruled by a parental advocacy model. Parents are pushed into advocacy roles in attempts to speed up both diagnosis and access to services. This creates an inequitable and inconsistent service system for parents who have different axes of privilege (e.g. time, knowledge, finances, connections, availability). Mothers described their experiences advocating for services with sentiments of combat. Mothers proclaimed to 'fight' with the system, 'leave no stone unturned', 'have loud voices' or be 'aggressive' in their attempts to access diagnosis or services that their children required. Two foster mothers had to fight school systems that rely on the privilege of mothers being available for fragmented schedules. Both mothers had multiple children at the same school and met resistance in the schedules that schools offered or even registering children to begin school. Both mothers had to 'fight' for equitable school schedules and entry. One mother details how she escalated her position to have her foster-child registered for school by suggesting a meeting with Child and Family Services and the School Board, which was met with the school allowing registration. She shares her frustration and the implications of the school's resistance on her life: 'Because it's not possible for me to do 3 drop-offs and pickups every morning, and every evening, and get to work on time. I don't have a teleporter machine…we had to fight hard and long just to get him to start JK'. Another mother was told that the school had limited EA support and offered a fragmented half-day school schedule. This mother had two other children at the same school and adding mid-day pick-ups interfered with her ability to work. She fought with the school to implement more full school days for her child, which is also a more sustainable schedule for her ability to work. Three mothers faced challenges with accessing diagnosis and changing diagnosis when professionals didn't agree with them, which was a risk to the service delivery their children were already receiving. One mother whose child had an autism diagnosis and was receiving services was required to get re-assessed when moving to another province. The wait time for diagnosis appointments was close to 2 years, so this mother used social media outlets to plead for access to a developmental physician to confirm her child's autism diagnosis in order to continue services. Another mother shared how an apraxia of speech diagnosis was reversed for her child when a new speech and language pathologist didn't agree with the initial diagnosis, putting the services the child was already accessing at risk. This mother shared how she navigated getting her child re-assessed, 'so we kind of had to fight – to get more assessments so that it would be sent to the right people [for evaluation]'. One mother shared how the waitlists for a developmental physician were so long in her community that she accessed a walk-in clinic where a doctor who does diagnosis worked in order to access a diagnosis could then provide the referral needed for services.

Discussion

Our analysis is situated in early childhood where systems require mother work in order to gain access. Our findings indicate ongoing production of SNAF in the earliest years of children's lives. Findings suggest that this work has impacts on the lives of mothers.

Our analysis illustrate that our systems are accessible to mothers who have access to the resources to participate. These resources, as the system is currently structured are primarily linked to social and economic privilege. What is not valued is the relational practices of *othermothering* that have long been valued by Black mothers. Further, the attributes of those families who have the most access are focused on individuals rather than the lack of systemic support for families, which not only reproduces ableism through classed and gendered lines, but also results in a lopsided arrangement that impacts mothers. Through a SNAF model, the complex realities of mothers from multiple social-locations is ignored and results in multiple outcomes such as assuming guilt and responsibility for difficult scheduling which in turn effects employment as well as sustains a parental advocacy model. The parental advocacy model perpetuates what Black women scholars have described as the superstrong Black mother trope (Collins, 2000). Though the superstrong Black mother trope is often used to describe Black women's system navigation experience, it can be extended here to mothers who navigate complex early childhood service systems for disabled children. As Brady (2022) has documented, Black mothers avoid the risk of countering systemic roadblocks for fear of coming off as confrontational because of the angry Black racism trope. This trope demonstrates the ways that white supremacy, and disabled children as other, are embedded within systems that privilege dominant white middle-class women, and non-disabled children. The strong mothers are denied access or access is limited to structural supports for their children. The intergenerational impacts of this arrangement mean that access for children is situated within the work of mothers and families, which is in turn situated in existing inequity, and creates the conditions for marginalization.

Mothers describe the barriers faced when they do not have access to flexible work schedules reproducing classed privilege. This further perpetuates an intensive mothering role whereby work is gendered and classed. The intensive mothering trope exacerbates whiteness, classism, and ableist norms, which is representative of SNAF families. A central concern that has not been taken up across the literature is that the inequity is most likely to cross from the mother to the disabled child. As described earlier, Black and Indigenous families often rely on *othermothering* and or community-parenting models to provide care for families and communities beyond SNAF configurations. Othermothering runs parallel to the experiences of informants in this study who describe the many ways in which they create support systems within their own communities. As such, these families transgress the boundaries of normativity where intensive mothering is maintained and often positioned as neutral or the norm. The system navigation for all mothers imparts a difficult expectation whereby only a select few can successfully meet such drastic intensive mothering expectations. And those who do, such as the informants in this study, are overwhelmed with the effort to participate, creating further inequality between disabled and non-disabled families.

As demonstrated in the findings, mothers faced system navigational barriers when service providers assumed that they were '*home with their children all day*'. Mothers with access to class, ability, race, and gender privilege are better able to fit within a SNAF model, and are more readily able to meet such strenuous requirements as systems are set up in ways that support them in doing so – but the cost of participating is high. All of the families describe exclusion from community as a result of this labour. We selected those informants who appeared to have the most privilege within this system. It is immediately apparent that such dynamics are classed – through access to time – and gendered through the role mothers are assigned as the natural caregivers. At the same time, it is also clear that such dynamics of complex system navigation and parental advocacy are embedded in the value of independence, with families doing the work to gain access and positioning disabled children as outside the norm. As a result, mothers respond and react to systems that disenfranchise their disabled children. Overwhelmingly, mothers in the study assume parental advocacy roles as described in the findings, which is often a response to limited socio-political systems. Mothers then assume the roles of 'fighting', 'having loud voices', and 'being aggressive' in order to access services and supports for their disabled children at an individual level. As noted earlier, this role of advocate is not neutral and presents greater risk for Black mothers (Brady, 2022), and with greater risk of exclusions for low income families in our findings who do not have the degree of control over private services which is afforded to the families in this analysis. Learning how to navigate such complex systems tends to reward those with greater cultural capital and privilege than others. This is particularly salient in the early years as this analysis indicates. Early childhood services are dispersed across service systems such as childcare, family support, early intervention, healthcare, family courts, and recreation. This both allows for greater control for mothers who have the resources, but those mothers then must do the labour of multiple systems. Most mothers must make decisions about where their efforts will be focused. The Black mothering concept of othermothering holds promise to share the labour, as does the disability discourse of interdependence, with both concepts disrupting what work is valued. In both constructs, value is placed on relationship with children and their communities, over institutional processes. While this analysis resonates with previous scholarship in Critical Disability Studies (Kafer, 2013; Runswick-Cole & Goodley, 2018), and in the scholarship of Black mothering (Beneke et al., 2021), our study contributes understanding of the multiply situated locations of power that are held in the years prior to and at the onset of schooling, that are implicated in how we as a society understand childhood, disability, and mothering.

Through their institutional navigation mothers assume the role of advocates. The expectations imparted on mothers are ableist, classed, and raced. Further, there are implications of what it means to be a 'good mom'. The SNAF model is therefore embedded in individualism whereby individuals are required to address deeply ableist structural gaps. Such gaps produce and reproduce structural barriers. Mothers in the study supplement what is missing as they navigate complex systems for their children. Hence, there is a reliance on families as an institution rather than robust social systems. This model is rooted in ableism, whiteness, capitalism, and heteropatriarchy. Further, the SNAF model perpetuates ideals of sameness, which is fundamentally ableist. All the while, through institution navigation, mothers learn that 'knowing your rights' becomes a primary orientation to program and service access. Mothers in the study describe how they became their disabled child's advocate.

Smith's 'standard North American family' (SNAF) first published in 1993, in this journal, provides a relevant frame to understand how the procedural, social policy, and practice of providing early childhood services for disabled children positions mothers. These systems, we have argued uphold and reproduce gendered spaces of care for disabled children that also reify ableist, racist, and classist constructions of family and mothering. Our findings indicate that it is possible to gain access to a wide range of services, but this requires active labour on the part of mothers, who use social capital in the form of education, income, and race. Critical Disability studies and Black feminist scholarship shaped our analysis of the gendered, raced, and classed work of families, and the institutional expectation on mothers to do the work of gaining access, and the lack of collective responsibility for all young children. Ultimately, the perpetuation and normalization of a SNAF model further marginalizes mothers and their disabled children.

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