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Re-Imagining Inclusion Through the Lens of Disabled Childhoods

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Abstract

The purpose of this article is to contribute new insights to critical disability and disabled children’s childhood studies that center on the valuing of disabled children’s lives—a guiding purpose in the disability justice movement. We use published findings from the Inclusive Early Childhood Service System project, a longitudinal, institutional ethnography of the ways that families and children are organized around categories of disability, which show social inclusions and exclusions before and during the pandemic. These findings illuminate: (a) institutional flexibility for the purpose of social inclusion and isolation during the pandemic as a result of institutional organization; (b) the impact of institutional decisions around closures, remote programs, and support on families’ choices and self-determination; and (3) the ways safety is differently applied and rationalized for disabled children allowing institutions to exclude disabled children and families. We use critical disability studies and disabled children’s childhood studies to interpret these findings and position the valuing of disabled children’s lives with a call for disability justice actions.

Keywords

critical disability studies; disability justice; disabled children’s childhood studies; pandemic; social exclusion

Issue

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1. Introduction

This article uses critical disability studies (e.g., Goodley, 2016) and disabled children’s childhood studies (e.g., Curran & Runswick-Cole, 2014) to theorize social inclusion and exclusion for families and disabled children during the Covid-19 pandemic. We present new theoretical insights about social inclusion and exclusion gleaned from previously published work from the Inclusive Early Childhood Service System (IECSS) project, as well as other literature, which underscores how pandemic responses to early childhood education and care services impacted families’ access to services and the choices

they could make with what was on offer (Underwood, Frankel, et al., 2019; Underwood et al., 2021). We first explore institutional flexibility, which relates to how organizations structure the menu of services for families. Institutional flexibility impacts how families access, navigate, and choose services for their disabled children. We then address the “fallacy of choice,” which refers to an illusion of authentic choice around accessing early childhood service systems that institutions present to parents/caregivers (Underwood, Frankel, et al., 2019, p. 146). Finally, we examine safety, whereby disabled children are both simultaneously constructed as needing enhanced protection for their own safety as well

as constructed as threats to the safety of others (see Ivery & Endicott, 2018; Stoughton, 2006). We use critical disability and disabled children's childhood studies to interpret these findings, which pushes the paradigms of early childhood service systems in ways that affirm value and inclusion of disabled children and their families. We turn to disability justice (e.g., Mingus, 2011; Piepzna-Samarashinha, 2018; Sins Invalid, 2019), a movement that is implicit in its inclusion of disabled children and aims to center the valuing of disabled children's lives.

The IECSS project is a longitudinal, institutional ethnography of the ways that families and children are organized around categories of disability. Our previous findings show that exclusions through the pandemic did not account for the complexity of the closure of early childhood service systems for disabled children (Underwood et al., 2021). Rather, how early childhood service systems are structured and how they have responded to the pandemic illuminate existing ableism and other injustices. Yates and Dickenson (2021, p. 1) state that "underlying social structures and systems mean some groups are more at risk in a pandemic context and are therefore more affected [in all aspects of their health, physical, emotional, social, spiritual] than others." Specifically, our previous findings on pandemic-imposed changes to how early childhood service systems organize and deliver services to disabled children demonstrate that institutional responses led to exclusions for many families, while other institutional adaptations to the pandemic demonstrated opportunities for connection and inclusion (Underwood et al., 2021).

We begin this article by discussing critical disability and disabled children's childhood studies and describe tenets of the disability justice movement. We then offer a general description of pre-pandemic disability services in Canada and show how ableism is at the center of pandemic discourse and service changes. We hold the complexity of institutional flexibility, fallacy of choice, and safety as intricate concepts dependent on how disability is constructed and interpret these from the lens of critical disability and disabled children's childhood studies. We highlight disability justice actions for institutional responses that are more inclusive and affirming of difference with an emphasis on the implications of pushing this paradigm forward in early childhood service systems.

2. Theoretical Frameworks: Critical Disability and Disabled Children's Childhood Studies

Critical disability and disabled children's childhood studies offer rich theoretical and political resources to explore tensions around disability, normalcy, and social inclusions/exclusions made visible by institutional responses during the pandemic. Critical disability studies is an interdisciplinary field that rethinks impairment and disability beyond a western medical model of deficit and its emphasis on fixing or remediating indi-

viduals (Garland-Thomson, 2013; Goodley et al., 2019). Instead, critical disability studies make a "paradigm shift" (Goodley, 2011, p. xi), troubling normative conceptions of the human and re-orienting to disability as a fundamental way of being with something of value to contribute to our human life together (see also Michalko, 2002; Titchkosky, 2003). Human complexity and disability are constituted by material, socio-political, socio-cultural, discursive, geopolitical, historical, and other processes (Garland-Thomson, 2013; Goodley et al., 2019). Critical disability studies present alternatives to deficit and medical views, including more affirming ontologies and representations of disability (Douglas, Rice, et al., 2021), intersectional, global, and post-colonial analyses of disability along multiple axes (race, class, gender, sexuality geopolitics, and others (see, for example, Erevelles, 2011; Puar, 2017), interventions in exclusionary policy and practice, and the valuing of disabled childhoods (Underwood et al., 2021).

Critical disability studies thus critique and contest *ableism*—the assemblage of institutions, knowledges, discourses, policies, practices, and relationships that systemically advantage and value able-bodied/minded individuals (Campbell, 2009; Goodley, 2014; Goodley et al., 2019)—and *disablism* the systemic devaluing, stigmatizing, marginalizing, and disadvantaging of disabled people (Abberley, 1987; Thomas, 2007, pp. 13–14). Within our contemporary moment of advanced capitalism, understanding neoliberal ableism, or what Goodley et al. (2019, p. 981) term "neoliberal ableist capitalism" is particularly salient for theorizing pandemic responses to disability. Neoliberalism is the marketization of all of life through ideology, policy, and forms of governance that simultaneously compel hyper-individualism, choice, and self-reliance within ever-expanding markets, shrinking public support and increasing demands for hyper-productive, competitive, and adaptable workers (Goodley, 2014; Larner, 2000). Neoliberal ableism means austerity rules the day, casting disability as devalued, a potential drain on systems in need of a solution in which the labor of parents and custodial adults, and particularly mothers, is implicated (Douglas, Runswick-Cole, et al., 2021).

The field of critical disability studies is tied to a rich legacy of critical scholarship and activism. During the 1970s in the UK, a group of disability activists and Marxist sociologists put forward the social model of disability as a radical contention that disability is a social rather than individual or medical phenomenon: "Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society" (UPIAS, 1975, p. 14; see also, among others, Oliver, 1996). It is not individual impairments that disable, exclude, and stigmatize people, but inaccessible physical and ideological environments. Fueled by the Black Power, feminist, Marxist, queer, and other political and academic movements of the 1960s and 1970s, proponents of the social model of disability made strategic

interventions into exclusionary policies and advanced disability rights in education, accessibility, independent living, and more. This mushroomed into a vibrant field of critical work and disability models (cultural, social, relational, feminist, minority) with broad academic and political influence (e.g., Goodley et al., 2019; see also Davis, 1995; Garland-Thomson, 1997; Morris, 1991; Snyder & Mitchell, 2006; Wendell, 1989).

Critical disability studies emerged over the past decade in response to provocations (Goodley et al., 2019) by feminist, queer, crip, feminist of colour, Global South, and other scholars and activists whose work illuminates some of the limitations of the social and other disability models to substantively take up intersectionality and decenter white, male, physically disabled experiences (Bell, 2006; Erevelles, 2011; Garland-Thomson, 2013; Kafer, 2013; Schalk, 2018; Sins Invalid, 2019). It also developed to theorize impairment and lived experiences of impairment (including painful or difficult ones; see Douglas, et al., 2020; Patsavas, 2014; Tremain, 2015), decentre Global North experiences of disability, take up provocations from decolonial, post-colonial, and Global South disability studies (Erevelles, 2011; Ineese-Nash, 2020; Nguyen, 2018; Puar, 2017); and move beyond western Enlightenment ontologies centered on a humanist perspective (as opposed to relationality or the non-human; see Braidotti, 2013; Rice et al., 2021).

Disabled children's childhood studies (Curran & Runswick-Cole, 2013, 2014; Runswick-Cole et al., 2018) extends critical disability studies by centering the experiences and perspectives of disabled children and the role of (m)others, families, kin, and care, aspects of disability experience typically associated with the devalued feminine and missing within critical disability studies (Douglas, Runswick-Cole, et al., 2021; Underwood, Angarita Moreno, et al., 2020). Curran and Runswick-Cole (2014) describe the emergence of disabled children's childhood studies stemming also from childhood studies that challenge, among other things, normative assumptions of the child and human development as a universal progression toward identity with the economically productive, non-disabled, self-fashioning, autonomous individual (Curran & Runswick-Cole, 2013). The "normative" child is based on assumptions that are moored in western "psy" disciplines (i.e., developmental psychology, childhood psychiatry) and Global North deficit models of disability that also underpin institutions of early childhood including education, service systems, and care (Douglas, Runswick-Cole, et al., 2021). Ableism affects both disabled children and their families, who often experience systemic discrimination along with their children (Douglas, Runswick-Cole, et al., 2021).

According to Curran and Runswick-Cole (2014), disabled children's childhood studies have three main tenets: a conscious repositioning of disability discourse "about' disabled children, which is so often conflated with talk of impairment, inequality, and abuse" (p. 1618); it centers disabled children's narratives and experiences

in research; and it seeks to "trouble the hegemony of the 'norm'" (p. 1618). Together, these principles:

[Create] an agenda for change [which] rejects the mythical status of the "normal" child as an end point and instead promotes ongoing action against poverty, and a recognition of the distinction between disabled children's "ordinary" and productive childhoods and their experiences of inequality, and attempts to widen understandings of children's identities in a global context. (Curran & Runswick-Cole, 2014, p. 1622)

In the next section, we use both critical disability and disabled children's childhood studies to interpret the reoccurring findings of institutional flexibility, the fallacy of choice, and safety within the IECSS project to help us understand social inclusions and exclusions during the pandemic and question whether disabled children's lives were valued. We use our new theoretical insights to contribute to disability justice in childhood, a focus that has not yet been taken up in the literature.

3. Arriving at Disability Justice in Childhood

Disability justice is an intellectual, political, and artistic movement that pushes beyond the whiteness of disability studies and activism, centering the experiences of Black, Brown, queer, sick, and disabled people. As such, disability justice also collectively creates worlds that affirm the difference between disability and other non-normative bodyminds alongside the right to care as a fundamental part of being human together (Mingus, 2011; Piepzna-Samarashinha, 2018). Sins Invalid (2019), a performance group that forwards disability justice states:

Disability justice is not yet a broad based popular movement. Disability justice is a vision and practice of what is yet-to-be, a map that we create with our ancestors and our great-grandchildren onward, in the width and depth of our multiplicities and histories, a movement towards a world in which every body and mind is known as beautiful. (para 11)

Of the 10 key principles identified that shape a commitment to disability justice work, prioritizing the following is pertinent in putting forth disability justice in childhood: (a) intersectionality, a term coined by Crenshaw (1989) that speaks to the multiplicity of individual identities that result in unearned privileges and oppressions in socio-political and socio-cultural contexts; (b) resisting capitalist notions of work and production (Sins Invalid, 2019); (c) valuing disabled individuals as a whole, and recognizing many facets to one's life; and (d) interdependence, which captures the necessity of togetherness and inclusion to value all lives (Mingus, 2022) and is contrary to concepts of independence, which on a systemic level

works to maintain the status quo of ableism, disablism, and neoliberal ableism and other dominant oppressions (e.g., racism, classism, sexism). We come back to these principles in our interpretation of the findings and advocate for disability justice in childhood.

We recognize the inclusivity of the disability justice movement with its strong focus on collective liberation, its cross-movement nature, and cross-disability solidarity (Sins Invalid, 2019). We use this opportunity in theorizing about pandemic responses to disabled children resulting in social inclusions and exclusions to tie in ideas from critical disability and disabled children's childhood studies, to bring forth disability justice in childhood. We do this by first describing, albeit briefly, the pre-pandemic experience of accessing disability services in Canada to set the stage that institutions are embedded within ableist, disablist, and normative constructions of childhood. We then discuss our findings from previous IECSS work (Underwood, Frankel, et al., 2019; Underwood et al., 2021), and illuminate how the concepts of institutional flexibility, fallacy of choice, and safety are understood through the lens of critical disability and disabled children's childhood studies which informs new insights into disability justice in childhood.

4. Pre-Pandemic Disability Services

There is a multitude of pathways from which families access disability services which vary between provinces and territories across Canada. We present a generalized picture of pre-pandemic organizational structures of disability services in early childhood which situates the context from which changes were made during the pandemic. This organization of disability services is based on families' experiences shared in the IECSS project (e.g., Underwood, Frankel, et al., 2019; Underwood, Ineese-Nash & Haché, 2019; Underwood et al., 2021; van Rhijn et al., 2021).

Disability services are accessed through multiple sites including therapeutic services, childhood care and education, and school systems, although they are largely triggered through health services. Some families are referred to services as early as pregnancy, while others inherit service relationships from before a child was in their care in the case of adoption, fostering, or change of custody. Some families are connected with disability services later in the child's life through referrals to health or therapeutic services, early learning settings, childcare, and/or school. Some families already have experience of disability services with another child in their family and may make self-referrals to early intervention or advocate for a referral from a health care provider. Early childhood services can also connect families to developmental services. For example, "drop-in" and childcare centers can often be one of the first places where families interact with early learning professionals (e.g., Underwood et al., 2018; Underwood, Frankel, et al., 2019).

Waitlists to access early intervention and disability services are common. There is often a transition process between services for pre-school and school-aged children who access developmental services, with some families experiencing long waitlists for assessments or severance in services once they enter the school system. The IECSS project has heard from many families that services in schools look significantly different from the early years (Underwood, Frankel, et al., 2019).

Families' access to early intervention is impacted by many factors including income, geographic location, race, culture and language, housing status, disability, and the approach of service providers (e.g., Underwood et al., 2021). There are both public and private early intervention services. Some families access one or the other, while some use a combination, and many are funded through workplace benefits. Many families living outside of large metropolitan areas travel to access services. For some families, traveling to access services can involve time away from their community and can include traveling to a different province, all of which involves work for families to access travel grants, or other funds, and to coordinate care between communities. Families' initial connection with developmental services, their experiences with waitlists, and transitions between services are often shaped by external factors. In early March 2020, the Covid-19 pandemic resulted in unprecedented worldwide closures of public and social service spaces and specifically impacted how early childhood service systems responded to public health measures to mitigate the effects of Covid-19 transmission. These changes dramatically shifted which services were deemed essential and how services were accessed.

The Covid-19 pandemic has resulted in new public discourses on health care, which have illuminated inequities in our society (e.g., Mingus, 2022), but were evident prior to the pandemic. There are countless examples of blatant ableism evident throughout the pandemic discourse and response. For example, Abrams and Abbott (2020) share that, at the beginning of the pandemic, Covid-19-related deaths in care homes in the UK were not reported; Parekh and Underwood (2020) describe the long-standing systemic issues in long-term care facilities in Canada for both its residents and workers, which were and continue to be at the heart of Covid-19 outbreaks; and media reports frame deaths resulting from Covid-19 within the rhetoric of "underlying and pre-existing health conditions" (Abrams & Abbott, 2020, p. 169) as an excuse in the deaths of disabled individuals (Mingus, 2022). These examples and more simultaneously dismiss, devalue, and "other" disabled individuals and feed the socio-political context of how disability is understood and constructed, which extends to the response of early childhood service systems in the pandemic.

Throughout the pandemic, childcare and school closures and the suspension of essential services for disabled children revealed the inequitable structure of

Canadian's lives and those all over the world. In our previous work (Underwood et al., 2021), we document institutional responses to the pandemic and share the standpoint of families with disabled children navigating and accessing early childhood services since March 2020. The pandemic has accentuated how institutional decisions to delay or omit disability-specific early childhood services are rooted in ableism and constitutive, at least in part, of exclusion (Underwood et al., 2021).

5. Institutional Flexibility: Meeting the Needs of Families With Disabled Children

Institutional procedures are exposed when we look to the everyday experiences of individuals who navigate these systems (Smith, 2005) which reveals how institutions are organized and impact access and interactions with services for families with disabled children. The tenants of critical disability studies invite a view of disabled children's childhoods beyond services poised to normalize disabled children (Goodley et al., 2019). The expanding view of disabled children often calls for malleable approaches to supporting children to be included in ways where they are valued. As such, we see families of disabled children advocate for institutional flexibility to support their children's inclusion, recognizing the complexity, variety, and value of their children's and families' experiences (Underwood, Frankel, et al., 2019; Underwood et al., 2020; Wright & Taylor, 2014).

In our findings previous to Covid-19, institutional flexibility was needed for "programs to adapt needs to be in response to children, but also to their families" (Underwood, Frankel, et al., 2019, p. 148). Throughout the pandemic, there have been examples of greater inclusion for disabled children that "are situated primarily in interactions that are outside of the typical institutional conceptualizations of inclusion" (Underwood et al., 2021, p. 20). Inclusion often happens outside of systems working to have "normative" or non-disabled experiences, which is often the experience institutions are aiming to create through their medicalized view of disability. This undermines disabled identity which is central to critical disability studies (Curran & Runswick-Cole, 2013) and necessary in how we understand the institutional flexibility needed for disabled children's inclusion. Institutional flexibility moves inclusion beyond what Mitchell and Snyder (2020) and other disability scholars (see, e.g., Collins et al., 2022; Jones et al., 2022) have called "neoliberal inclusionism," an institutionalized, ableist, and functionalist response to disability that "tends to reify the value of normative modes of being developed with respect to able-bodiedness, rationality and heteronormativity" (Mitchell & Snyder, 2020, p. 179) and, we would add, in relation to western individualist, capitalist, and colonialist ways of being. In our previous work, we describe the role imposed on families as being "responsible for normal" (Underwood, Church, & van Rhijn, 2020, p. 89).

Families have always had to maneuver early childhood systems; however, new protocols initiated in response to the pandemic created opportunities for greater inclusion, for some families. Before the Covid-19 pandemic, many families and kin, in more rural and northern communities, were required to travel to access services. When closures occurred as a response to the pandemic, many health services moved online or to phone appointments, and some therapeutic services offered virtual services, while some private providers continued to offer in-home in-person services (Underwood et al., 2021). Through the lens of disabled children's childhood studies, these changes align with valuing families' time, safety, other services, and relationships, both in valuing disabled children and their families' experiences (Curran & Runswick-Cole, 2013; Runswick-Cole et al., 2018). These remote options, pulled forward by the Covid-19 pandemic, act as an example which demonstrate how flexibility in accessing services is in accordance with valuing all the other activities, services, relationships, joy, work, pace, etc., that are involved in disabled children and their families' lives, recognizing the wholeness of disabled children and their families and pushing inclusion beyond inclusionism (Sins Invalid, 2019).

Though some institutions have adapted and offered flexibility within services during the pandemic, it has not necessarily resulted in greater inclusion for all children. For example, flexible learning is a concept that requires individual students to be more adaptable to environmental changes (Huang et al., 2020). Increased learning flexibility can mean less structured routines which blurs work and leisure and can put more work on individuals to create the structure for themselves. Removing structure and access to people outside of homes does not prioritize the interdependence that can exist for disabled children. Many parents took on additional roles in remote settings, including creating routines and supporting children to participate in online schooling and therapy programs (Underwood et al., 2021). The expectation that families (predominately mothers) take up work in supporting children's participation in school and therapy has long existed and is something disabled children's childhood studies have highlighted (Curran & Runswick-Cole, 2013; Runswick-Cole et al., 2018). The closures resulting from the Covid-19 pandemic exasperated the demands and workload placed on families for their disabled children to connect with school and therapies. The anti-capitalist political principle of disability justice values the often invisible work families (predominately mothers) carry out on behalf of institutions, while current capitalist values exploit them (Sins Invalid, 2019). The pandemic brought the hidden labor of inclusionism and frictions around access to the surface.

Participants in the IECSS project living with disabled children during the pandemic describe rigid institutional policies that exclude them from a variety of programs and services (Underwood et al., 2021). For example,

remote options were not offered to everyone, leading to exclusion from programs, including school, early years programs, early intervention services, recreation programs, etc., meaning that some programs were paused and did not offer services for a time, while other programs closed (Underwood et al., 2021). Disabled children's lives and experiences were not centered. Disability justice calls for justice for all and recognizes that any exclusion is injustice (Sins Invalid, 2019). We hold onto the glimpses of institutional flexibility during the pandemic that moved inclusion beyond inclusionism and in so doing, value disabled children and families. The result is altered ways of being, through interdependence, relational autonomy, and flexibility. We see possibility in applying disability justice to the programs that children and families are accessing and recognize how flexibility is needed for their inclusion. We contend that flexibility can be carried out at various levels, including institutional levels that can facilitate access and inclusion (Gordon, 2014) in a way that values disabled children and their families.

6. Is there Authentic Choice in Accessing Early Childhood Services for Disabled Children?

The structure of early childhood services is limited in scope—families are required to fit into a pre-determined menu of available services. We coined the term “fallacy of choice” in our previous work, where our research findings illuminate a “fallacy in the claim of choice[s] that families have” (Underwood, Frankel, et al., 2019, p. 146). In reference to accessing disability services in schools, “parents are able to gain access to services if they comply with the procedural aspects of the system, which often requires multiple forms of privilege” (Underwood, Frankel, et al., 2019, p. 146). Indeed, while choice is forwarded as a site of freedom within neoliberal discourse and capitalist education and service systems, critical disability studies scholars (among many others) have shown how choice operates instead as an instrument of ableism and inclusionism (Mitchell & Snyder, 2020; Underwood, Frankel, et al., 2019). Conforming with the expectations of service systems to gain access to pre-set offerings hinders choice and highlights “conflicts that can arise for parents who are forced to make a choice, given the dilemma of [often choosing between] two [or more] less than desirable options” (Bartlett & Rice, 2019, p. 56).

Thus, institutions set the stage and create the structures that shape early childhood services. Early childhood services are informed by “ableism [which is] inherent in [institutional] decisions that lead to disabled children being pushed out of the institutions of childhood” (Underwood et al., 2021, p. 25). Institutional structures also impact and constrain how families can make choices for their disabled children. The reality of constrained choice precedes the pandemic, and families and disabled children have had to contend with the outcome of such choices made in accessing developmental services including learning loss, school disruption, as well

as cross-sectoral barriers and integration in a way that the rest of society is only adjusting to as a result of the pandemic.

Institutional responses to the pandemic have further constrained choice and self-determination for families with disabled children. For example, the choice to send children to school or early intervention programs was limited during the closures of services deemed non-essential by governments, which provided evidence of a false narrative of self-determination around accessing services and programs for disabled children. The limitations in the options that were available from the pre-determined menu of early childhood services during the pandemic led to social exclusions within organized programs (Underwood et al., 2021). The choice to send disabled children to school was, in many cases, not a choice at all as disabled children's realities were not considered in plans for school re-openings. Restricting school and the very act of deeming services for disabled children as non-essential magnifies both ableism (Campbell, 2009; Goodley, 2014; Goodley et al., 2019) and disablism (Abberley, 1987; Thomas, 2007). This devaluing of disabled lives as discardable is a point disability activists have long articulated and fought against (see, for example, Church et al., 2016), and we extend this point to pandemic disabled childhoods here. During the pandemic, non-disabled children were advantaged and disabled children were disadvantaged in accessing educational and developmental services.

Additionally, an intersectional framework is needed in discussing social inclusions and exclusions as “disability cuts across and is at times indistinguishable from age, gender, race, mortality, class, trauma or sexuality [which] are ripe for cross-movement building work and has the potential to deepen and expand our understanding of oppression and violence like never before” (Withers et al., 2019, p. 182). In our previous research findings, it was noted that privately funded services, including schools, saw less disruptions and were largely accessed by middle- to high-income families (Underwood et al., 2021). This example ties in with how multiple oppressions work together to marginalize individuals, which was evident during the pandemic. Taking power and privilege into consideration and using an intersectional framework in understanding the institutional design of accessing and choosing early childhood services is an important part of disability justice in childhood. Mingus (2011) states:

We need to think of access with an understanding of disability justice, moving away from an equality-based model of sameness and “we are just like you” to a model of disability that embraces difference, confronts privilege and challenges what is considered “normal” on every front. (para. 5)

Furthermore, in thinking with Mingus (2011) it is evident that choices concerning access in the pandemic follow

the same pattern of “institutional control over development, social participation, family engagement, and accommodation or adaptation” (Underwood, Frankel, et al., 2019, p. 149) where government allocations of “essential” and “non-essential” presented a landscape of unequal and unfair choices. Disability justice challenges inclusionism, or access, and focuses on justice and valuing disabled children’s childhoods.

7. Navigating Safety: Whose Safety Matters?

Disabled children are persistently centered in debates around safety. Disabled children’s childhood studies provide theoretical resources to explore how pandemic responses have been shaped. Normative understandings position the disabled child as simultaneously vulnerable (to disordered development, for example) and in need of support, and dangerous (a threat to already scarce resources within a neoliberal context of austerity; see Curran & Runswick-Cole, 2013; Douglas, Runswick-Cole, et al., 2021; Underwood et al., 2020). For instance, the calls for greater resources in schools to support student safety with eating, mobility, and personal care is often juxtaposed against the calls for greater resources to protect staff from their students (see Miller, 2019). Although Stoughton (2006, p. 147) was referring to children identified with “emotional disturbance,” their observation that such children “can become the focus of fear and moral concern” could be applied to the experience of many disabled children in school. The perception of threats to safety and well-being also extends to the threat to normative school programming, where disabled students are often removed to reduce their perceived impediment to the success of their peers (Danforth et al., 2006; Erevelles et al., 2006). Concerning Covid-19, disabled children have been identified to be at increased risk of serious health outcomes, while at the same time being positioned as contributing to the increased risk of transmission to school staff (Viau, 2022). Throughout the pandemic, policymakers have been attempting to respond to the evolving science and rhetoric around safety—what constitutes safety, whose safety should be prioritized, and how.

For many disabled school-aged children, services and therapies are accessed through special education programming in school. Over the pandemic, schools across Canada have been frequently shuttered due to rolling lockdowns. For example, schools in Ontario were closed for 20 weeks between March 2020 and May 2021 (Gallagher-MacKay et al., 2021) while other early childhood services were closed for an even longer period. Even when schools re-opened, there were continued interruptions and limitations in early childhood and school-related activities.

At the same time families were asking for authentic choice, the discourse around the reopening of schools in Ontario in September 2020 was driven, to some extent, by an equity-based discourse. The narrative sug-

gested that in-school learning was key to the equalization of learning opportunities, particularly for historically marginalized communities. Yet, when the demographic data were reviewed within Ontario’s largest public board of education, the Toronto District School Board (TDSB), communities that were largely racialized, lower-income, and had been impacted more significantly by Covid-19 (for more on the intersection of race, class, gender, and precarity of work during the pandemic see Kantamneni, 2020) were the least likely to opt for in-person schooling (Crawley, 2020; TDSB, 2020). Withers et al. (2019) remind us that “systems of oppression come into existence in and through one another” (Fellows & Razack, 1997, p. 335, as cited in Withers et al., 2019, p. 180) and “ableism [specifically] is both dependent on and necessary for every other oppression to exist” (Withers et al., 2019, p. 183). Intersectionality (Crenshaw, 1989; Sins Invalid, 2019) helps us see why the return to school privileged abled, white, wealthier families who lived in communities that were more protected from infection (Timmons et al., 2021). Families with privilege were more likely to manage and keep up with the demands of online learning, such as having devices for every child, separate spaces where each family member could work flexible work schedules to accommodate supporting children during remote learning, their own computer literacy and the uploading and printing demands that were put on many families during remote learning, thus even in remote settings online school was inequitable (Timmons et al., 2021).

Additional concerns around the implications on children’s health and safety because of extended school closures (SickKids, 2020) emerged from concerns around school safety and the conditions in classrooms that were exacerbating Covid-19 transmission (Fox, 2021). Questions raised around learning loss, the implications on child development and socialization as well as mental health arose, with some analyses including particular attention to disabled children (Engzell et al., 2021; Gallagher-MacKay et al., 2021; Whitley et al., 2021). Examinations of what disabled children have lost over the pandemic have been well documented and demonstrate the significant disruption in and loss of programming and services (Underwood et al., 2021). However, the risk of contracting Covid-19 within schools was and remains an important safety consideration. For many disabled children, who access self-contained special education programming or schools, consistent masking and social distancing may not be possible. Therefore, policymakers have had much to consider in weighing the safety risks of facing the heightened risk of transmission of a potentially fatal virus with the ongoing risks associated with interruptions of service, support, and programming. As such, even when schools were closed to the general population, many continued to offer in-person, self-contained, special education programming (Bowden, 2021), in part because there was no mechanism to provide the range of services in online environments.

Maintaining in-person learning for disabled children, when deemed too dangerous for the general population, was a strategy aimed to mitigate the risk of delays or interruptions in development and socialization. Conversely, disabled children accessing in-person learning were simultaneously positioned as contributing to the heightened risk of Covid-19 transmission, particularly to the teaching team and their classmates (Sharpe, 2021; Wong, 2021). The narrative of returning to in-person learning also positioned the return to school as necessary for the families of disabled children who may be in a heightened need of respite (SickKids, 2020). However, in many discussions around the return to school, disabled children are positioned as the locus of risk to families' well-being as opposed to advocating for the reorganization of a care system that ensures families are adequately supported. Despite this push, when TDSB families were asked to indicate whether their children would return to in-person schooling, special education schools had, overall, notably lower response rates with lower proportions of students confirmed returning compared to the system average (TDSB, 2020b, 2020c). As the section addressing the fallacy of choice argues, this finding suggests that families were not really presented with an authentic choice; instead, families whose children could not participate virtually were often presented with two options—in school or no school—neither of which offered support and protection for their children. The false choice presented to families in the form of binary options for school results in exclusion. It also undervalues the work that families are doing in assessing risk for their children, family, and communities, while they imagine, create, and advocate for something outside of the binary options they are presented with. If systems adopted the tenets of disability justice, particularly anti-capitalist principles and principles of interdependence, support would be organized in a way that recognizes the critical knowledge families hold and enhances families' authentic choice over how they access support while overall reducing safety risks for disabled children.

An examination of how capitalist values intercede and hinder disabled children is illuminated by Hall's (2022) observations of schooling during the pandemic: "the problem of sending some disabled students into schools at this time is a similar problem to long term care homes—an inability and/or unwillingness to imagine something different for disabled people that doesn't use cost as an excuse." In addition, a return to school also alleviates systems of educational governance from having to ensure access to support disabled children and their families through other, arguably more responsive, means. For instance, tying access to supports and services to in-person attendance in congregated care or classroom settings at the height of a viral pandemic results in three key outcomes and considerations: The responsibility to conceptualize, evaluate, and navigate all "safety" considerations related to in-person learning is placed onto the

families of disabled children, creating a false sense of choice for families coupled with less than ideal options; attitudes of ableism and the devaluing of disabled lives emerge, where safety appears to play into the "unwillingness [of systems] to imagine something different" (Hall, 2022); the positioning of disabled children as both vulnerable and in need of protection, as well as contributors to risk and unsafe conditions both at home and school continues to be reflected through the return-to-school approach. Either way, Covid-19 responses have not and do not center disability or disabled children.

8. Concluding Thoughts: Re-Imaging Inclusion and Moving Towards Disability Justice

As highlighted by many disabled advocates and researchers, disabled lives, including disabled children's lives, were not considered essential during the pandemic (Gurza, n.d.; Mingus, 2022; Parekh & Underwood, 2020; Thorneycroft & Asquith, 2021). The devaluing of disabled lives has also persisted in the wake of ending the pandemic and the narratives around the economic toll the pandemic has had and continues to have. Capitalist neoliberalism is continued through the demands that are placed on disabled children and their families during the pandemic and in the broad call for "a return to normalcy" to end the pandemic. In all, critical disability studies and disabled children's childhood studies help us theorize (a) the ableism and disablism of pandemic responses to disability, (b) the intersectionality of disabled childhoods and how this played out in pandemic responses, (c) the implication of institutions in maintaining systemic discrimination through recruiting parent/family labor to "solve the problem" of disability, (d) the fallacy of choice produced through neoliberal ableist discourse and policy, and alter conceptions of the child beyond vulnerability and danger. Disability justice calls for the re-imagining of inclusion throughout all systems and emphasizes valuing disabled children and their families

Adopting the principles of disability justice in childhood means challenging the sense of neutrality through which policies and practices around care and access to services are delivered and urges us to recognize and reconcile the underlying ableism, racism, and colonialism in shaping our early childhood services and the rigidity of our institutional practices. In forwarding disability justice in childhood, we have shown how understanding intersectionality (Crenshaw, 1989), resisting neoliberal capitalism, and implementing concepts of interdependence (Mingus, 2011; Piepzna-Samarashinha, 2018; Sins Invalid, 2019) creates the opportunity to re-imagine dismantling early childhood systems that place explicit value on disabled children's childhoods.

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Conflict of Interests

The authors declare no conflict of interests.

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