

## Pandemic Effects: Ableism, Exclusion, and Procedural Bias

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*The COVID-19 pandemic has changed social organizations and altered children's worlds. As part of an ongoing longitudinal study of the institutional organization of disabled children's lives, since March 2020 we have conducted interviews with families in rural and urban communities across Canada (65 families at the time of writing). The narrow focus of governments on the economy, childcare, and schooling does not reflect the scope of experiences of families and disabled children. We describe emerging findings about what the effects of the pandemic closures demonstrate about the social valuing of childhood, disability, and diverse family lives in early childhood education and care. Our research makes the case that ableism, exclusion, and procedural bias are the products of cumulative experiences across institutional sites and that it is critical we understand disabled childhoods more broadly if we are to return to more inclusive early childhood education and care.*

**Key words:** disabled children's childhood studies; COVID-19; inclusion; early childhood education and care; family support

The COVID-19 pandemic is having catastrophic effects on people globally and disproportionately impacting marginalized people and communities through inequality and discrimination (Brennan, 2020). Substantial social changes are occurring due to government responses to the public health crisis, but we do not yet know the long-term, pandemic-related outcomes for disabled children and families. Governments and media have focused almost exclusively on getting childcare and schools reopened because of their impact on the economy. In this article, we present emerging findings from the Inclusive Early Childhood Service System (IECSS) project in which disabled<sup>1</sup> children's family experiences inform us about institutional power, its demands on people, and the values it lays bare. This longitudinal study began in 2014, with 133 family members (to date) participating in annual interviews. This article focuses on interviews conducted between March 13, 2020, when lockdowns were declared throughout Canada, and November 30, 2020. Focused on institutional responses to disability in childhood, our research positions us to understand how institutions have responded to the pandemic and where closures and restructuring have illuminated mechanisms that organize disabled childhoods.

We draw on disabled children's childhood studies and international research on disability rights and inclusion (Runswick-Cole & Curran, 2013; Underwood et al., 2021) to situate our findings. Our purpose in centering disabled childhoods is to highlight how disabled children and their families are often asked to interact with many services, professionals, and procedures and therefore offer a unique standpoint from which to examine early childhood institutions. Disability in this theoretical tradition is a sociological categorization used to organize children for the purposes of services. Disability is also a part of children's identity and a valued way in which children may understand the world (Runswick-Cole & Curran, 2013; Underwood et al., 2021).

## **Pandemic effects across Canada and the world**

The closure, reopening, and further closures of services for children give us a rare opportunity to study which services are considered to be essential and most valued by government. This time is also, however, an opportunity to better understand what children's and families' daily experiences can tell us about Canadian societal values. Governments have made pandemic-related decisions advertised as supporting collective well-being but have "magnified the [social inequities] for persons with disabilities" (UNICEF, 2020, p. 5). Following the World Health Organization's global pandemic declaration on March 11, 2020, states of emergency were declared in every Canadian province and territory (Bronca, 2020). Within a few weeks, gradually increasing restrictions and closures of nonessential businesses and services resulted in the loss of physical access to childcare, schools, "nonessential" health care, early intervention, and most family support programs. Our research indicates that exclusions take place in many settings in the early years (van Rhijn et al., 2021). Examining pandemic closures from the standpoint of family experience leads us to recognize that exclusion and inclusion in childcare are affected by many sites of related participation for young children, including health care, recreation, family support, and other social and educational settings. These sites form an interconnected network of institutional procedures and power that affect each site of participation, as we have seen in our research to date and present in our findings specific to the pandemic in this article.

The Canadian government has focused on childcare throughout the pandemic response as an economic strategy. Childcare has been a focus of public discourse about which services are deemed essential for our economy (Stanford, 2020). For this reason, it was one of the first services to be reopened (see Childcare Resource and Research Unit [CRRU], 2020a, for a detailed overview of childcare reopenings in each province and territory). School reopenings were also prioritized in some provinces but not others. The switch to online learning in spring 2020 was quick and unplanned and, arguably, not implemented in consideration of disabled children (Baker, 2020; Jeste et al., 2020; Patel, 2020). Of the 3,028 Ontario kindergarten teacher participants in a COVID-19 impacts study, almost 80%

reported that disabled children had difficulty with online learning (Janus et al., 2020). The public discourse was preoccupied with public health measures to ensure schools reopened safely—a critical conversation—but lacked focus on what disabled children needed in order to fully participate in childcare and other early years education and care sites (Brandenburg et al., 2020; Thomas & Lopez-Martinez, 2020). This omission, combined with concerns that disabled children might be at higher risk of severe COVID-19 infection, forced some families to keep their children (and the children's siblings) at home rather than attending school or accessing childcare (Plante, 2020).

In many jurisdictions, school closures began with announcements of extended March breaks with schools remaining closed to in-person learning in almost all provinces and territories for the remainder of the 2019–2020 school year. Exceptions included Quebec, where schools reopened in all areas except for Montreal in mid-May 2019, and British Columbia, where schools reopened on June 1, 2019, on a part-time, voluntary basis, both with strict public health guidelines. For the 2020–2021 school year, all provinces and territories planned to reopen schools with in-person learning, except where there was a documented health risk to children or staff, with the exception of Ontario, which offered parents the choice between in-person and online learning (see CRRU, 2020b for a detailed overview of school reopenings in each province and territory). In-person learning included varying public health requirements such as cohorting, physical distancing, reduced classroom size, and mask mandates. As the pandemic progresses, individual schools have temporarily moved back to online learning when outbreaks occur and enforced remote learning during periods of provincial lockdowns (e.g., Ontario Ministry of Education, 2021). While this special issue is focused on childcare, in order to understand the scope of decisions made that centered nondisabled experiences (i.e., ableism) and to illuminate the scope of exclusions for disabled children through the pandemic, it is necessary to also examine schooling and other settings as noted by global disability scholars and discussed throughout this article.

Childcare responses have been more varied than schools', with some jurisdictions not mandating closures at any point to our knowledge (e.g., Northwest Territories, Yukon, and British Columbia, although many still chose to close in BC; CRRU, 2020a). In many provinces and territories, childcare centres were not initially considered essential services and were required to close along with all businesses and services that were deemed nonessential. Most areas reopened a limited number of centres to provide emergency childcare for essential workers, with the exception of Nova Scotia and Nunavut (Northwest Territories and Yukon did not provide emergency childcare; however, their centres were not mandated to close; CRRU, 2020a). Childcare centres in other provinces reopened between May 11, 2020 (i.e., Quebec; Newfoundland & Labrador) and June 12, 2020 (i.e., Ontario). Nunavut reclosed childcare centres to all families except essential workers on November 18, 2020, due to increased cases (Nunavut Department of Education, 2020). Public health guidelines in place for childcare are similar to those for schools (CRRU, 2020a).

These local restrictions are situated within a global concern on the part of disability advocacy groups about the effects of pandemic closures on disabled people. The COVID-19 disability rights monitor has declared a global “catastrophic failure” to protect the rights of disabled people through the pandemic (Brennan, 2020). Documented human rights violations include dismal protection for persons with disabilities in residential institutional settings, loss of community supports, and inaccessibility to healthcare. These rights violations are rooted in an ableist and systemic disregard of disabled people in every country in the world (Brennan, 2020). For disabled children specifically,

stigma and discrimination against [disabled children] often lead to increased exposure to abuse and neglect, reduced access to services, and general lack of recognition. Moreover, children with disabilities and their families are more likely to live in poverty, and they are overrepresented among the homeless population and those living in residential care and shelters, which further exacerbates their

marginalization. (UNICEF, 2020, p. 5)

Disability's effects intersect with "gender identity, age, ethnicity, race, sexual orientation, origin, location and legal status, among other factors, [and persons with disabilities] carry a heavier burden of the immediate and long-term economic and social consequences of the pandemic" (UNESCO, 2020, p. 8; see A. Smith, 2020 and Underwood, Ineese-Nash, & Haché, 2019 for analysis of intersectionality in the IECSS project). The UN has pushed for disaggregated data to identify COVID-19 rates in disabled populations, which would better inform responses to the pandemic and future planning (UNESCO, 2020). We are concerned with disability-specific effects of the pandemic and ongoing references to risk and vulnerability for those with "underlying medical conditions" (Statistics Canada, 2020). These discourses allow paternalistic protections, as well as the possibility of deeming some lives as essential and limiting whose participation is valued. Under the guise of safety, many disabled children experienced exclusion from childcare before the pandemic. This ableism has created procedural biases that risk being exacerbated by the pandemic.

### **Preexisting systemic barriers going into the pandemic**

Our analysis of the initial pandemic effects on disabled children is situated within our pre-pandemic knowledge of the procedural and policy contexts experienced by children and their families from the IECSS project. We have identified some key features of early childhood education, care, intervention, healthcare, family support, and social services that are structural barriers to inclusion. We have documented that families do a lot of work to gain access to services including childcare and other early childhood settings, especially when they have a disabled child (Underwood et al., 2020). This work involves time, money, emotional energy, and ongoing monitoring. We have found that the more services a family accesses, the more the system needs from them. This is particularly true at transition times, such as entering kindergarten, transitioning home from hospital, when referred to a new program, and moving or other family changes that lead to changes in services (Underwood, Frankel, et al., 2019).

We have seen that institutions hold power through procedures, policies, and qualifying criteria for services (Church et al., 2020; van Rhijn et al., 2021). This power comes through professionals' decisions, as well as requirements for families and frontline workers to comply with policies and procedures in order to gain and maintain access to programs and services. We have found that this compliance requires families to conform to Western medicalized values of early childhood education and care, such as autonomy over relationships, as well as health care services (Underwood et al., 2020). The accessibility of early years services is impacted by geography, financial resources of families and programs, staffing, and alignment between the worldview of families and programs (Frankel et al., 2019; Ineese-Nash et al., 2017). Inclusion requires social policy, support for families, and professional collaboration (Frankel et al., 2020).

We have shown that the responses in the system are generic, meaning they do not necessarily fit the families' circumstances or the children's individual characteristics. Instead, systems respond to standardized categorizations of child development and family circumstances (Frankel et al., 2019; Ineese-Nash et al., 2017). Attending to preexisting systemic barriers matters for institutional responses to childhood disability during the pandemic because it allows us to see what needs to be carried forward to achieve more inclusive childcare and early childhood settings.

### **Research approach**

The IECSS project is a longitudinal study employing an institutional ethnographic approach (e.g., D. E. Smith, 2006, 2009). Institutional ethnography (IE) seeks to ground research in the everyday experiences of people, not to

give them voice, but to consider how people are ruled through their interactions with institutions. Descriptions of people's everyday lives provide an entry point into the institutional ruling relations that govern people's work—including unpaid labour such as parenting (Kearney et al., 2019; Ng et al., 2017).

Since 2014, the IECSS project has conducted annual interviews with families whose children were between infancy and two years old at the first interview. The interviews ask participants about institutional responses to disabled childhoods and families in order to map the regulatory and conceptual power of institutions. The annual interviews—typically in person—are extensive, lasting up to two hours and asking about the processes and procedures required to gain access to all programs and services for their disabled child and other family members. After March 13, 2020, we shifted to conducting shorter interviews (45–60 minutes) by telephone. As of November 30, 2020, we had conducted 65 interviews with participants living in New Brunswick, Quebec, Ontario, Manitoba, Northwest Territories, and British Columbia. These interviews have been dominated by family experiences during the COVID-19 pandemic. These 65 interviews are a snapshot taken within a particular time during the pandemic.

These are not the first interviews conducted with many of the families, who were participants in the study prior to the pandemic. The interviews analyzed for this paper range from the first to sixth annual interview. Our analysis focuses on how the effects of the pandemic have altered the organization of children and families in institutions. We are aware that services differ in response to income inequality, and that income inequality has been a factor in pandemic effects (Oronce et al., 2020; Wherry, 2020; Wildman, 2021). For this reason, we begin with an analysis of differences in how services are organized around family income. We then examine other ways in which families are generalized by service systems. Our analysis focuses on income; however, we know that income is linked to race and that racial inequality has had a direct effect on everyday experiences of the pandemic. The city of Toronto has been publishing data that documents these linkages throughout the pandemic (City of Toronto, n.d.). Focused on institutional responses to disability in childhood, our research positions us to see how institutions have responded to the pandemic and to understand its organizing effects on families.

## **Pandemic effects: Our findings**

Our findings are organized into examples of inclusion and exclusion. Interestingly, the examples of inclusion are situated primarily in interactions that are outside of the typical institutional conceptualizations of inclusion. These examples may not have been as well understood or illuminated had the pandemic not happened. The examples of exclusion highlight several structural barriers in early childhood institutions. IE uses description of the everyday activities of individuals to build understanding of the institution. The unit of analysis is the institution itself not individual interview participants. As Ng et al. (2017) note, “[Dorothy] Smith proposed IE partially in response to grand theorising in sociology, which, she argued, abstracted and objectified people's everyday experiences and living conditions” (p. 53). IE seeks to see the theory that is entrenched in institutional processes and that emerges in the descriptions of how everyday activities work. As such, we divide the subsections within our exclusions section below into key sites of power that organize people, including disability-specific programs and services, childcare and respite services, family employment and work, and both children's and families' relationships.

### *Inclusion*

The pace of each day, the physical spaces in which children and families spend time, and relationships have all changed as a direct effect of the pandemic. Many examples of deeply inclusive interactions between people were described in our interviews as the result of individuals making decisions outside of the typical rules and regulations of institutions, which was possible during these unusual times. In our examples of inclusion, which we touch on in this section, it was human actions rather than policy that facilitated the inclusion of disabled children in their

communities.

The policies and procedures families had been navigating pre-pandemic were altered by the new reality. Some families during this time describe benefits from the lockdown. These include children making gains in language, academics, and development. Other children appear calmer and happier because they are home with family, particularly the youngest children. Families also mentioned support individuals who are important contacts for families, for example, an educational assistant in the Northwest Territories who made physically distanced home visits. In Peel Region, a speech pathologist created engaging activities tailored to the interests of two children in the program, with one mother noting how engaged her 2-year-old son was in the therapy. In New Brunswick, a parent described the importance of being in a small community where the school guidance counsellor, a social worker, and teachers were regularly checking in and sending home weekly activity packages. In Toronto, we heard about a family who struggled pre-pandemic with communication between private therapists and the school improving the communication links and finding value in improved coordination. In Brandon, we heard about a grade 1 teacher who sent home a school welcome package, had regular telephone meetings to coordinate development of the individual education plan (IEP), and helped the family to find a tutor. In Hamilton, a parent reported that their child felt abandoned during the pandemic, but they were able to get friends and family to share photos of themselves. In Quebec, a mother noted the stronger relationship her child had with cousins because of daily virtual communication. These specific examples of individuals acting outside of the typical rules of institutions were found in every community, which tells us that this type of “pandemic” inclusion is happening across different localized policy contexts.

Families also noted the structured or unstructured schedules that emerged from pandemic living. Some families created routines that included connection with services; others created their own structure, or limited the amount of structure in their schedule. One participant identified that positives have emerged from having less structure:

I've seen the benefits of unstructured time for both my kids. They play together in a really nice way.... For a few years now, all these different programs [gave] us a bit of a breather, but through this pandemic I've realized actually those programs just bring more stress to our lives.

These examples of inclusion are characterized by being outside of the regulations that typically governed institutions before the pandemic lockdowns. Overall, the loosening or removal of procedures that were required prior to the pandemic created the conditions for some of the examples of inclusion, indicating pre-pandemic procedural bias toward exclusion.

### *Exclusion*

Our findings around pandemic exclusions, in contrast to those on inclusions described above, are situated within institutional structures and processes. While there have been positive changes in children's routines and activities, we have also heard about significant losses of services and supports throughout the pandemic.

***Economic inequality.*** Our research on pre-pandemic conditions that lead to inequality in early years systems has directed us to consider differences in how institutions interact with people based on their economic circumstances (Underwood et al., 2020). We began our analysis by organizing the data into three family net annual income categories—low ( $n=15$ , \$34,999), middle ( $n=19$ , \$40-99,999), and high ( $n=25$ , above \$100,000)—with  $n=6$  not reporting. These categories allowed us to identify differences in how services govern families, or generalize their needs, in income groupings. In this way, we were able to see that the number of private services that were part of the early childhood service system prior to the pandemic has exacerbated inequality among disabled children post-pandemic. In the low-income group of families, many lost all the support services that they had pre-pandemic.

For example, one child's transition plan to move from three days per week to full-time attendance was interrupted. In addition, there were disruptions in application processes and assessments for subsidy and other monetary supports for low-income families.

Several middle- or high-income participants reported that their privately funded services were not interrupted during the pandemic restrictions. Some private schools provided families access to both hardware and software that facilitated instruction and participation as a standard part of their programs. Several families had private therapists (some of whom continued to attend family homes throughout the lockdown) who helped with schoolwork and communication with educators and provided families with activities to do with their children.

This analysis demonstrates a significant disparity in how services are organized for families at different income levels. As the pandemic has evolved, families have experienced disparate access to critical services for their children, revealing a lack of prioritization for family and disability services. The impact of the pandemic on disabled children, economically diverse families, and access to inclusive childcare and school must be understood within this larger institutional context.

***Disability-specific programs and services.*** Some services are specific to disabled children, organizing these children and their families into a particular category. We found that most disability-specific early childhood programs were not considered to be essential during the various pandemic-related closures, with some moving online or being cancelled. Our findings indicate that many services that were critical for gaining entry into institutions pre-pandemic (e.g., assessments, assistants, adaptations; Underwood et al., 2018) were no longer classified as essential. Families experienced significant disruptions in existing policies and procedures, which affected intake processes and mechanisms to qualify for services. Some children waiting for meetings about developmental assessments, IEPs, or individual support plans (ISPs) in childcare or school had them delayed or cancelled altogether.

Participants across all communities where we conducted interviews described the cancellation of disability-specific services in speech and language, occupational therapy, mental health services, and resource consultation in childcare. In addition, children who outgrew adaptive equipment could not get new assessments or fittings. Children who previously had regular contact with principals, social workers, and other school staff often had none of these due to physical distancing and maintaining "bubbles" in some provinces. The redeployment of frontline staff, either to reduce group sizes in childcare and school or to other essential programs, resulted in the loss of entitlements for disabled children. Similarly, resources to support educators (early childhood educators and teachers) to create inclusive environments were also lost or reduced. For example, families reported that assessments or visits from resource consultants in childcare and schools intended to support staff have not occurred or have been substantially delayed.

Activities in online learning environments were often described by families as not suitable, too difficult, or not engaging. Some families noted online work was too easy because the teachers did not know about gains children had made during the initial lockdown and the summer. Some parents were adapting the work themselves. For example, one mother downloaded the grade 1 curriculum to adapt material for her child in grade 2. Other families simply did not engage with the materials. Some parents who previously provided in-school support for their child found that they could no longer do so with COVID-19 restrictions. For example, one parent had been attending her child's school to teach classmates American sign language and, despite their child being back in school full time, the parent could no longer enter the school.

***Childcare and respite.*** Many families rely on institutional support to care for young children either through childcare (both paid and unpaid) or through disability-specific care support, often called respite. Regardless of

whether care was paid or unpaid, we saw disruptions to the support that families received due to the pandemic, which also interrupted their interactions with institutions. During spring 2020, every IECSS family who had access to childcare lost that service. Some childcare centres continued to provide connection through virtual meetings, but these connections were sporadic and did not serve the same purposes for children's development, social participation, and support for employment, studying, or other family activities. Childcare was not inclusive to many families in our study prior to the pandemic (van Rhijn et al., 2021). Several families had relied on grandparents for childcare pre-pandemic, in part because childcare centres were not inclusive. With older adults considered high risk for COVID-19 infection, these families lost this important support. In addition, some families relied on respite services which were lost and, for some, have yet to be reinstated.

Care of children was affected by family circumstances. The ability of parents to care for their own children was impacted by the support services they previously accessed, with some losing *all* their support services due to the pandemic. One participant who had a baby during the pandemic could no longer advocate for services for her other child. Another participant, whose child lost their place on several waitlists for assessment and services, had three other children who also lost services. This participant moved one of her children to a group home, relinquishing custody in order to have the capacity to support her other three children. Access to services was also affected by family economic status. Families who paid for private services, in general, had more communication with them, and these services seemed to be less affected by pandemic restrictions.

**Family employment and work.** Differences between families are often connected to their work arrangements, including whether they work shifts or are on salary, have flexible or fixed hours, and whether their work is considered essential or not. Work arrangements had a significant impact on how families cared for their children during the pandemic and, in turn, their interactions with early childhood education and care institutions. We heard from families where one or more parent had lost their job, some of whom qualified for the Canadian Emergency Response Benefit (CERB) while others did not. A central finding of the IECSS project to-date is that early childhood services require work by families of disabled children (Underwood et al., 2020). The current analysis indicates that this work has been amplified by the pandemic. Therapists, educators, and other professionals rely on families to implement therapies, adapt curricula, and help children to access online programs. Our participants report a high degree of exclusion of disabled children, particularly from school programs where children and/or their families need skills to physically operate a computer and knowledge of programs to help children participate. Providing this support requires families to be physically, emotionally, and intellectually able and available. Some families have engaged in this work, but others have given up.

The work that has been downloaded to parents has impacted their own lives, including their employment and mental health. Several parents also found it difficult to find employment because they had lost childcare or because the support their children needed at home required at least one parent to be available. One participant said:

We were basically working three jobs at a time: We were doing our full-time work that we needed to do to afford all the masks and food and the toilet paper. And then we had to do the parenting and then all of sudden we became special needs educators. So that four months, middle of March to middle of July, that was the worse part of the year for me. Thankfully, none of us got affected by COVID health-wise, but in terms of our mental health, that was an absolute nightmare.

Families' employment circumstances, including job loss, whether they were frontline workers, and flexibility in working, and their income have led to differences in whether families could continue to participate in early childhood education and care, as well as disability services. Employment differences among families in our study have led to disproportionate negative effects of the pandemic.

**Relationships.** Family relationships impact the support they get to participate in institutional processes and relationships and have impacted whether their children have had social interactions throughout the pandemic. In addition, social relationships are one of the most important aspects of children's participation in early childhood education and care, as well as other early years environments. An important site for community participation is recreational activities (e.g., swimming, soccer, gymnastics, arts programs, clubs), one of the most common losses for social participation during the pandemic. Some children lost access due to restrictions to adaptive programs. For the majority of these families, the closure of recreational programs resulted in the loss of an important place where their children had been active members of their community, as well as the loss of a space for children to practice their gross motor, social, language, and communication skills. We noted that discussion of recreational activities was more prominent in interviews during the pandemic than in pre-pandemic interviews.

Relationships within the household have also been impacted by the extended period of time that households are spending together. Multiple participants had children join or rejoin their household through birth, fostering, or older children coming home. Some families reported improvements in sibling relationships while others described tensions. Parent-child relationships also shifted, with many parents taking on new roles, including educator and therapist, during the pandemic. One father working from home now spent more time with his children; another father learned more about the mother's work supporting their child because of working from home.

Family support groups were also interrupted. Some, but not all, groups went online. Some parents reported that face-to-face meetings were vital for their well-being and for both children's and parents' opportunities for social relationships. Most of these services have not yet returned to face-to-face activities.

Many families reported that their children were experiencing extreme social isolation. One participant noted that her child saw only their immediate family from March until September 2020. In one case, a child was exhibiting concerning anxiety symptoms, becoming fearful of situations not previously feared. Other children in foster care or shared custody arrangements were not allowed in-person visits with biological parents. Yet, for some children, staying at home and not engaging with peers was a relief. In either case, families expressed concerns about their children's emotional well-being, social skill regression, and the impact of isolation resulting from childcare and school closures.

Many families commented that communication with professionals they previously worked with was sporadic and in many cases nonexistent during the spring closure of childcare centres and schools. As the fall approached, many participants had yet to hear from their children's teachers, special education staff, or resource consultants. Families did not know who their children's teachers would be, what supports would be in place, and whether agreements established pre-pandemic would be honoured. Finally, other systems interrupted by the pandemic have also impacted disabled children and their families, such as the court system, with one family's adoption interrupted and their child's custodial status in limbo. The effects of closures and exclusions underscore how disability services and supports in addition to childcare, school, and recreation programs for disabled children have been (de)valued as essential services, and how disruption in social relationships has led to isolation of children and families in our study.

## Conclusions

While some families may be satisfied with the tele-education and medical services they accessed during the pandemic (Espinosa et al., 2020; Jeste et al., 2020; Provenzi et al., 2020), our study indicates variable experiences, with many children disengaging from learning, finding work to be too difficult, and struggling without adapted supports. Designating disability-specific services as nonessential is a reflection of the lack of value placed on

disabled lives.

Emerging research on the pandemic demonstrates that families of disabled children are concerned about their children's loneliness or isolation, mental health, academic success, behaviours, stress levels, and emotions (Arim et al., 2020). Our research finds families of disabled children experiencing similar stresses related to economic well-being, employment security and benefits, and concerns about health, especially for older relatives. Their experiences of stresses, however, are compounded by services families describe as critical for inclusion in communities, as well as for children's social and emotional well-being, being deemed nonessential.

There has been a lack of disability-specific considerations during the COVID-19 pandemic on the part of governments. The choices made by public health officials and governments illuminate tensions that have always existed for disabled children—tensions that appear heightened during the pandemic for disabled children and their families—laying bare their vulnerability to the disabling effects of ableist values held by early childhood systems. As one of the participants stated, "I'm already seeing examples of how COVID is being used as sort of an excuse for rolling back rights and access for disabled people."

Closures of "nonessential" health care and early intervention services are pushing families of disabled children into the role of therapist or early interventionist. Strong social and education institutions should ameliorate inequality. However, many of the entitlements that parents fought hard for pre-pandemic have not been reinstated at the same level or at all. This is a concerning development in the historical struggle for inclusive early childhood services. Nevertheless, services alone will not address the ableism inherent in decisions that lead to disabled children being pushed out of the institutions of childhood.

Inclusion is a moral and pedagogical principle that involves recognition and valuing of differences, leading to respect and trust, social participation and relationships, and learning and development. International conventions, including the Convention on the Rights of Persons with Disabilities (United Nations General Assembly, 2007) and the Convention on the Rights of the Child (United Nations General Assembly, 1989) declare that childcare, education, and inclusion are all inalienable rights. These rights require a wider view of childhood than that which is represented in childcare and education alone. We must recognize that disabled children's childhoods are experienced in diverse economic and geographic circumstances, as evidenced by the families in this study. We conclude by noting the urgency for a response to the pandemic that enshrines the right to "equally access services and ensure that *all* people are treated with dignity and respect" (Schariti, 2020, p. 661, italics in original). This right will only be upheld if the childcare and early years community recognizes and values disabled childhoods, the work of families, and the policy and procedural contexts that placed a burden of work on families and which the effects of the pandemic demonstrate to be ableist and exclusionary. The examples of inclusion that emerged from the pandemic provide a starting point for better serving families and for designing inclusive early childhood education and care that centers disabled children's experiences rather than treating them as "special" or having "additional" needs. Instead, childcare will recognize the need for meaningful relationships and will advocate for disabled children across the many important sites of institutional participation that support inclusion, including school, recreation, and family support, rather than approaching disability as an "extra" to be referred out to specialists.

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<sup>1</sup> Our use of the term disabled (rather than the more common institutional "person first" language) is the preferred term in disabled children's childhood studies. This term puts identify first rather than the person first and is largely accepted by disabled activists. Early childhood and education programs at universities have long encouraged language that is considered in disability theory and by disabled people's

organizations to be informed by medicalized understandings of disability, which are driven by institutional interests in categorizing people for the purpose of service delivery. Further reading on this can be found in the style guide of the U.S.-based National Center on Disability Journalism (<https://ncdj.org/style-guide/>) and in a recent article on disability terminology (McColl, 2019).



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