



## Editors' Introduction

# Activism, Resistance and Presence: Exploring Disabled Children's Childhood Studies in Canada

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The idea for this special issue on disabled children's activism, resistance, and presence in social justice movements came from a deep commitment to spotlighting disabled young people's justice-seeking action in the northern part of Turtle Island colonially known as Canada. Currently, Canada is buzzing with cross-movement activism that features young people's crip wisdom. To name only a few actions unfolding as we release this special issue: high school students in New Brunswick are protesting a review of policy that allows students to use their choice of personal pronouns without schools notifying their parents (Sweet, 2023); teen water protector Autumn Peltier continues making global headlines as she pushes for policies to preserve clean water across the country (Slack, 2023); and a group of 15 youth climate activists has mobilized a lawsuit against the federal government, arguing that they are disproportionately affected by climate change (David Suzuki Foundation, 2023). We feel resonances between this cross-movement activism and multiple theoretical frameworks that attend to disabled children and youth, including disabled children's childhood studies. Amid this crosshatching of activism and intellectual work, we issued a call for papers in 2021 inviting scholars, activists, and artists to share how and where young disabled folks are making waves. Now, we offer this special issue as a partial snapshot of disabled children's childhoods in Canada.

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By “disabled” children we mean those whose myriad of bodymind differences are not restricted to age or developmental status, including mad, Deaf, neurodivergent, sick, and spoonie folks of many stages and ages of life whose fluid experiences of childhood are complex, intersectional, and evolving. As Akemi Nishida writes in *Just Care: Messy Entanglements of Disability, Dependency and Desire* (2022, p. 27):

Disability is a name given to particular bodyminds, their conditions, and their visceral and sensual experiences in a dynamic assemblage of political and economic forces, the medical industrial complex, legal recognition, capitalist investment or divestment, interlocking systems of social injustices, cultural setup, and disability community formation, among others.

In positioning disability as a complexly political assemblage and cultural phenomenon, we, the editors, nod to our respective fields of critical disability studies (Jones), child and youth studies (Atwal), and Deaf education (Weber); we represent a transdisciplinary collaboration taking signals from many directions about disability’s role in culture. We work, live, and create alongside disabled young people, including in our roles affiliated with Canadian universities, whose investment in disability is often coded in buzzword-laden promises of inclusion as academic ableism abounds (Ahmed, 2012; Dolmage, 2017). As Mel Y. Chen, Alison Kafer, Eunjung Kim, and Julie Avril Minich explain, “academia, ableist to its core, rejects *disability* in its love for *abilities* (read: merit, excellence, rigor, achievement, productivity, and so on), a preference so strong that disability is lost, and, with it, sick and disabled people” (2023, p. 4; emphasis in original). We notice how disability is *lost* in our own scholarly domains, where even the politicization of disability tends to be made legible through adultism. Meanwhile, we witness young disabled people enacting radical forms of kinship, mobilizing care work, reforming the systems in which they are bound, resisting trans/institutionalization, and engaging in cultural creation, including in the arts and digital worldmaking. We also learn from disabled elders, and from conversations such as those between disability justice activists Stacey Park Milbern and Leah Lakshmi Piepzna-Samarasinha (2018a), that because disabled aging does not always follow normative timelines, ideas of childhood, youth, and eldership are not straightforward. For these reasons, we consider disabled childhoods as specific intersectional locations that influence critical analysis.

In taking disabled childhoods as embodied, epistemological, and socio-cultural, we root this collection in activist-driven resistance to the disability-normalcy binary so often imposed on young people, framing disability as deficit and normalcy as desirable. This eugenic binary has deep roots in Canada and is an extension of colonization, cis-heteropatriarchy, and white supremacy enacted through violent state policies of sterilization, institutionalization, and segregation that haunt the current ethos of disability culture in this country (Burghardt, 2018; davis halifax et al., 2018 Kelly et al., 2021; Kuri et al., 2022; Malacrida, 2015). One example is the Canadian Parliament’s current

considerations around extending Medical Assistance in Dying (MAiD) to infants and “mature minors” (Cullen & Zabjek, 2022; Wright, 2023) – a firm reminder that eugenics is not only an issue of the past (Malacrida, 2020). Disabled children’s very existence in Canada is called into question when disability cannot easily be cured or eradicated through medical, developmental logics. We do not align ourselves with such deficit-oriented modes of engaging with difference. Nor are we interested in contributing to the ongoing reproduction of normative life trajectories, diagnoses, bureaucratic classification, government investment and divestment, and broader systems of social injustices that benefit from pathologization. When cure-seeking discourses are applied to children without the balance of critical thought, the child is objectified, routed toward a non-disabled adulthood – a future where disability is *lost*. We are, however, interested in disabled young people’s work resisting these frameworks; it is through anti-eugenic activism, resistance, and presence that disabled children and youth assert themselves now and into the future.

We recognize that disabled children and disabled childhoods bring to social justice action a breadth and depth of crip community knowledges. Such wisdom is based on crip epistemologies – vibrant and varied modes of knowledge creation stemming from Black, Brown, Indigenous, trans and queer people fed up with the limits of white-dominant rights-based action, including that traditionally espoused by the field of critical disability studies (Chen et al., 2023; Piepzna-Samarasinha, 2018b; Kafai, 2021). We might also term this thinking “cripistemologies” as David Mitchell, Sharon Snyder, and Linda Ware explain in their germane argument for crip and queer childhood failure in classrooms (2014). Terminology aside, one of our motivations for this collection was to attend to the ways in which disabled children’s childhoods are a vital part of expansive and ever-changing traditions of crip-related knowledge production. By mapping the knowledge and creativity of disabled, mad, crip, Deaf, sick, debilitated, neurodivergent, queercrip, and spoonie young people, among others, children’s *cripping* becomes extremely meaningful and sparks a new dream for the future. We bring up future dreams not to parrot conventional views of childhood and futurity (e.g., the children are our future), but to nod to what Piepzna-Samarasinha (2018b) refers to as *dreaming* social justice by refining our ambitions toward “a movement-building framework that would center the lives, needs, and organizing strategies of disabled queer and trans and/or Black and brown people marginalized from mainstream disability rights organizing’s white-dominated, single-issue focus” (p. 15). Disabled childhoods offer important contributions to such dreams. So, in our 2021 call for papers, we left the idea of what “counts” as disabled children’s activism, resistance, and presence quite open-ended, hoping to gain insight into a myriad of dreams intertwined with social justice.

In tandem with crip theory and emergent crip epistemologies, our scholarly interest in young disabled people’s social justice investments is rooted in Tillie

Curran and Katherine Runswick-Cole’s crucial, United Kingdom-based work in disabled children’s childhood studies. In 2013, Curran and Runswick-Cole introduced the domain of disabled children’s childhood studies through three principles: moving beyond discussions of impairment and inequality “to enable disabled children to step out from under the shadows of normative expectations that have clouded their lives”; demanding ethical research design that centres disabled children; and troubling these practices in local, historical, and transnational contexts (Liddiard et al., 2018, p. xxii). In the spirit of a disabled children’s childhood studies that centres children’s experiences and assumes their agency as knowledge producers, thereby asserting children’s legitimacy as authors and knowledge creators, we sought submissions other than adult-led scholarship (Curran & Runswick-Cole, 2013; 2014), many of which are available in the “Dispatches” section of this special issue.

In the years following their inaugural work on disabled children’s childhood studies Kirsty Liddiard, Curran, and Runswick-Cole edited *The Palgrave Handbook of Disabled Children’s Childhood Studies* (2018), the contributions of which include the intersectional facets of children’s lives, which also informed our call for submissions. Recently, researchers have dipped into this intersectional domain, emphasizing the need to account for broad understandings of childhood and its socio-political contexts in disabled children’s childhood studies’ knowledge production (Balter et al., 2023; Eilers, 2023; Tiefenbacher, 2023). In Canada, Kristen Tollan, Rita Jezrawi, Kathryn Underwood, and Magdalena Janus (2023) report on recent shifts in thinking around early intervention that include social factors that shape disabled people’s experiences. Even so, the impact of ableism and other social injustices have compounded service changes for disabled children, and something needs to give. Partly drawing on disabled children’s childhood studies to frame their institutional ethnography of the ways that families and children are organized around disability before and during the COVID-19 pandemic, Alice-Simone Balter, Laura E. Feltham, Gillian Parekh, Patty Douglas, Kathryn Underwood, and Tricia van Rhijn (2023, p. 55) make a bid for disability justice to be part of service systems:

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 knowledges families hold and enhances families’ authentic choice over how they access support while overall reducing safety risks for disabled children.

The widely available tenets of disability justice are outlined by U.S.-based performance group Sins Invalid and have become staples in intersectional disability-related theorizing (Sins Invalid, 2015), so the overlap with disabled children’s childhood studies is fitting. Meanwhile, departures from traditional ontologies toward Black feminist theorizing and Indigenous resurgence support new articulations of how settler colonialism and white European conceptions of children/childhood difference impact children (Saraceno, 2012;

Spencer & Sinclair, 2017; Perez, 2017). Like these authors, we too consider vital the socio-political contours around race, disability, and childhood as significant challenges to scholarly colonialism.

In response to our call for papers, we received a swath of scholarly writing as well as a small collection of creative works, including an interview, a book list, and a video available in the “Dispatches” section of this special issue. Some pieces are written by adults, others are produced by young people. In some instances, authors reflect on their own experiences of disabled childhoods; in other cases, authors are co-creating alongside, interviewing, or parenting with disabled children and childhoods in mind. Our call evoked a collection of research accounts that teach us much about how disabled children’s lives are currently regulated, represented, and expressed. We recognize the importance of focusing on young people’s own already-established activities (Jones et al., 2023); this, as Rebecka Tiefenbacher (2023) points out, is the difference between doing research *with* disabled children rather than *about* them, solely on adult terms. In this vein, we received artful contributions that emphasize interdependence, collaboration, assemblages, and space-making for many at once. With the aim of putting forward a slice of disabled children’s childhood studies in Canada, we conceptualize this special issue through three overlapping themes: deaf and disabled young people’s activism and art; representations of disabled childhoods (mainly through literature); and the regulation of disabled childhoods.

The section opens with a 19-minute video titled “Deaf to Deaf” (2024) to kick off the theme of disabled young people’s activism and art. This video forefronts American Sign Language and is offered without an introduction or accompanying text. Made in consultation with video producers for the Saskatchewan-based performance group Deaf Crows Collective, the decision to frame this video without much context for hearing audiences is quite intentional; this move is about intelligibility. Although the video is captioned so non-ASL speakers who see can read along, the producers expressed that the inclusion of a written summary of the video would continue to exclude deaf young people from spaces such as academic journals. Due to the language deprivation experienced by many deaf young people, a video submission should be seen as the equivalent to a written text-based submission. Intelligibility is a theme running through Joanne Weber’s accompanying article, “Making Multiple Deaf Worlds Intelligible: A Posthumanist Arts-based Cartography of *Apple Time*” (2024). Considering intelligibility as a methodological and representational problem sparked by deficit-driven understandings of deafness, Weber offers an insider account of the performance *Apple Time* by members of Deaf Crows Collective. The Collective includes eight deaf high school students who are also newcomers to Canada. Through the co-construction of *Apple Time*, they operate in what Weber describes as deaf epistemology, a positioning that makes legible the ways in which deaf youth build and represent multiple worlds beyond those of the hearing audience’s audism. Weber explains:

The framing of the world according to sound does, in many ways, render the realities of deaf lives unintelligible and therefore exacerbates the abyssal line between hearing and deaf. Deaf people have developed a remarkable astuteness concerning the ways they are perceived by hearing people and continue to challenge hearing people's perceptions of deaf experience. (2024, p. 31)

Through *Apple Time*, deaf young people engage in activism via the arts by “remixing cultural references” and commenting on issues of language deprivation, phonocentric assumptions about themselves, and difficulties connected to hearing others—including, at times, their own families.

The next Dispatches contribution is an exchange between autistic advocate Lulu Larcenciel and autistic poet Imane Boukaila. In “Tilting Still Thinking: A Dialogue of Autistic Youth Advocacy and Nonspeaking Truths” (2024), Larcenciel poses questions to Boukaila in a back-and-forth sprinkled with poetry, with the intent to honour nonspeakers' and Spellers' accounts of the world. This dialogue has not been heavily edited as we wish to respect the integrity of Boukaila's words; we share the authors' view that tampering with Boukaila's non-normative communication style would risk losing her nonspeaking, artful presence as it emerges on the pages of this short account. Through these stories created by deaf and neurodiverse young people, we recognize that their authorship supports a wider re-imagining world-making that is already led by young activists, often outside the confines of traditional, adult-led scholarship and its overreliance on normative modes of communication.

Then, in a cluster of pieces that point to cultural representations of disabled childhoods, primarily through literature, we notice that disability is merely tolerated in young people's literature, even as buzzwords like “diversity” trend through publishing mandates. Kimberlee Collins and Julie McGonegal turn their attention toward the sticky issue of inclusion as it appears in some Canadian children's literature via “dangerous representational repertoires” of intellectual disability in the second article of this collection, “Persistent Narratives: Intellectual Disability in Canadian Children's Literature” (2024). The authors zoom in on Lorna Schultz Nicholson's One-2-One series of young adult fictional novels based on the real-life Best Buddies programs that operate in and beyond Canada. In a Canadian literary ethos that has yet to forge strong critiques about representations of disabled children and youth, Collins and McGonegal cast a sharp gaze toward the novels' palatability of difference via overcoming that match Best Buddies' mandates for inclusion. These myths are made possible through adjacent cis-heteropatriarchy, adultism, and whiteness inlaying so many stories of disabled children. What is needed instead, Collins and McGonegal suggest, is a publishing model that “critiques the hegemony of normalcy rather than trying to make intellectually disabled characters more normal and thereby included” (2024, p. 56)

We follow this call for anti-ableist publishing with suggestions for anti-ableist and mad-positive stories. In the third Dispatches piece, the authors and

illustrator of the award-winning picture book *We Move Together* compile a visual essay that takes readers behind the scenes of this storybook. Through reflecting on their process of creating and sharing the story with people of all ages, Anne McGuire, Kelly Fritsch, and Eduardo Trejos (2024) share a critical account of crip storytelling praxis, immersing themselves, readers, and their audiences in new modes of reading that value interdependence, crip wisdom, and disability justice. Then, in the fourth Dispatches installment, mad-identified scholar and parent Danielle Landry (2024) offers a list of recommended children's books on madness. Understanding madness as a reclaimed mode of being that intersects with childhood (Douglas et al., 2021), and with recognition that mental health discourses circulating through childhood are often a culmination of ableism, colonialism, and psy-discipline dominance (Mills & LeFrancois, 2018), we feel an urgency to circulate Landry's first-of-its-kind list. Pioneering work in this area by Brenda LeFrancois (2007, 2008, 2012) teaches us that children experience madness, and this experience involves agency and resistance, especially in trans/institutional contexts (LeBlanc Haley & Jones, 2020). Yet, as Landry points out, madness is too often hidden from children by adults. By contrast, Landry's book list situates children and youth as part of the movement's history and community.

Despite the vibrant examples of children's presence in cultural production that constitute the first two parts of this special issue, contributing authors also concretize the reality of disabled children's socio-political context in Canada. That is, they repeat the message that disabled children's childhoods have long been – and still are – entrenched in policies and regulation that favour inclusion into dominant norms. In “Children of Bill 82: Reflective Histories of Disability and Childhood in Ontario, Canada” (2024), Kathryn Underwood and Ayshia Musleh challenge disability discourses in education from the viewpoints of a child of a disabled person and a disabled person herself, respectively. Now adult education researchers, Underwood and Musleh observe that past thinking about disability and inclusion persists despite advances in theory. Adding to disabled children's childhood studies' valuing of childhood memories that honour social experiences (Curran & Runswick-Cole, 2013) and its critiques of solely rights-based disability activism (Schneider, 2017), childhood innocence (Dyer, 2019), and citizenship (Srisikandarajah, 2017), Underwood and Musleh offer a chronology of disability activism paired with educational reform that points to a split between theory and practice in institutional spaces. By centring the experiences of themselves as people who lived through disabled childhoods in Canada, the authors acknowledge disabled children's childhood studies' emphasis on the importance of the heterogeneity and diverse experiences of their families. This emphasis, too, follows disabled children's childhood studies' broad understanding that kin is formed in a multitude of ways and that people in these networks – particularly (m)others and siblings – experience disablism due to the liminal space they occupy

(Abbas, 2017; Douglas et al., 2021; Lalvani, 2019; Runswick-Cole & Ryan, 2019).

Relatedly, intersecting fields of critical race, queer, and crip theory recognize and challenge “normal” and “inclusive” independence-driven frameworks imposed on children, including disabled children (Karmiris, 2020; Watson, 2018). Maria Karmiris and Adam Davies pick up on this richly blended critique of normalcy, inclusion, and independence in “Crippling the Story of Overcoming: An Analysis of the Discourses and Practices of Self-Regulation in Early Childhood Education and Care” (2024). Arguing that narratives of overcoming in neoliberal schooling contexts are entrenched in teaching and learning of self-regulation practices for (or on) disabled kids in Canada, Karmiris and Davies use crip theory to invite disruptions of these normative frameworks – the kind of disruptions that “refuse to be overcome by demands to self-regulate”(p. 93) and speak instead to the interrelatedness of children, families, peers, and systems. The emphasis on kinship is also brought to the fore in Fiona Moola, Nivatha Moothathamby, and Methuna Naganathan’s article focused on the experiences of racialized parents of autistic children. In “Portraits of Resistance: Exploring Intra-personal, Social, and Institutional Resistances through the Use of Arts-Based Research among Racialized Parents of Autistic Children and Youth” (2024), the authors draw on DisCrit and arts-based methodologies to make legible stories that are often hidden about how racialized parents of autistic children demonstrate resistance. In their stories of resistance, racialized parents resist the ableism embedded in the Canadian health-care system, including by naming the hurdles in this system, such as anti-Black racism. The work of Moola, Moothathamby, and Naganathan opens a space for further scholarship at the intersection of race and disability in childhood studies.

In all, this special issue is a slice of the current ethos of disabled childhoods in Canada with sometimes overlapping content from deaf children, autistic advocates, nonspeakers, a mad-identified parent, families whose lives include neurodivergence, and racialized experiences of disability and childhood. Still, there remain overwhelming connections between race, gender, class, and sexuality to explore. We note the abundance of work in this area elsewhere, including Liat Ben-Moshe and Sandy Magana’s 2014 special issue of *Women, Gender, and Families of Colour* focused on race, gender, and disability; the collection *DisCrit: Disability Studies and Critical Race Theory in Education* (2016) edited by David J. Connor, Beth A. Ferri, and Subini A. Anamma and their accompanying *DisCrit Expanded: Reverberations, Ruptures, and Inquiries* (2022); and Nirmala Erevelles’ repertoire of work around disability and education (including the aptly titled “Scenes of Subjection in Public Education: Thinking Intersectionally as if Disability Matters,” 2019). Further, missing from this collection are experiences of Indigenous childhoods and content about disabled children’s climate activism. We did not receive submissions to this end, and we attribute this at least in part to our call’s connection to disability studies which, as a field of study, is entrenched in

whiteness (Bell, 2018; Miles et al., 2017; Redikopp, 2021). For more on Indigenous childhoods and their relation to bodymind difference, we direct readers to a 2021 special issue of *Disability Studies Quarterly* themed “Indigeneity & Disability: Kinship, Place, and Knowledge-Making” (Larkin-Gilmore et al., 2021). For recent scholarship at the intersection of Indigeneity and disability that is based in Canada, we recommend writing by Nicole Ineese-Nash (2020a; 2020b) and Pearl Yellow Old Woman (2020), as well as the feminist, decolonial scholarship centred in the museum exhibition, “Into the Light” (Kelly et al., 2021).

For now, with a focus on young disabled people’s art and activism, their representation in literature, and the binding inclusionist policies under which they live, we put up this collection as a partial but productive glimpse into the ways in which disabled childhoods are experienced in Canada through the critical, expansive lens of disabled children’s childhood studies. The purpose of this special issue is to honour young people’s place in, and contributions to, social justice work. In so doing, we bid for a significant shift away from deficit-fuelled and risk-averse discussions that too often claim (and make claims for) disabled children’s lives, including in scholarly journals (Liddiard et al., 2018). Instead, in the interest of attending to disabled childhood-related action in Canada, we invite readers to consider this collection an invitation toward broader discussions about the many ways that children’s activism, resistance, and presence contribute to social justice movements – conversations we hope will advance alongside crip epistemologies, intersectionality, and other accounts of bodymind difference that invariably involve children and youth in this place.

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