**(Re)Imagining inclusion in ways that foster belonging in the lives of disabled children and youth**

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***Comment***

For the greater part of the twentieth century, thanks in part to disability rights movements around the world, disableda children and youth have increasingly been afforded access to community spaces, such as schools and classrooms; and activities, such as inclusive recreation programs, alongside their non-disabled peers. However, despite increased access, disabled children report ongoing experiences of exclusion in spaces labelled as ‘inclusive’.1—3 Disabled children continue to be more likely than their non-disabled peers to experience bullying, discrimination, loneliness, and accessibility barriers that negatively impact their health and well-being.4 Evidently, there is a fundamental gap between how inclusion is theorized in practice and how inclusion is experienced in the everyday lives of disabled children.

Recent global events have instigated a shift in priorities towards equity, diversity, and inclusion, positioning inclusion at the forefront of national and international policies and reports, including initiatives related to disabled children’s health and well-being. The COVID 19 pandemic has and continues to negatively impact disabled children’s access to play, activity, and education, as well as, social connectedness, and overall mental health and well-being (see the Council of Europe report on the COVID 19 Pandemic and Children and the American Academy of Pediatrics report on The Impact of the Pandemic on Households with Children and Youth with Special Health Care Needs). Limited opportunities for inclusion in child-driven culture, the culture produced between children without mediation of adults,5 may have negative effects on identity, resiliency, relationships, and feelings of connectedness with one’s peers and community.3 The collateral effects of the pandemic have amplified these inequities and now, more than ever, it is essential to support disabled children’s inclusion and belonging.

Critical disability scholars have problematized the ways inclusion theories and practices are often imbued with normative, ableist, assumptions2. Many inclusion initiatives, policies, and conventions around the world are informed by the United Nations Convention on the Rights of Persons with Disabilities, placing the emphasis on political and material aspects of inclusion, rooted in rights and citizenship. Although necessary, this approach fails to address the normative underpinnings of inclusion theories and practices, creating a “facade of inclusion”.2 For example, inclusion for children and youth has been operationalized predominantly in education and recreation contexts. These initiatives create spaces for inclusion in the physical sense, in hopes that the intersubjective and relational aspects of belonging and community will intuitively follow as natural effects. Leaving this to chance has resulted in the exclusionary effects of inclusion today; disabled children continue to report feeling lonely, excluded, and have limited social relationships outside of the home.3,4 Other critical disability scholars shed light on the ways inclusion theories and practices affecting disabled children have primarily been directed by non-disabled and neurotypical adults. Further, others illuminate the unpaid, hidden labor of disabled children and their families in pursuit of inclusion.6

We, along with other critical scholars, call for a radical shift in how we envision and enact inclusion, one that moves beyond rhetoric towards an actualization of belonging. What if inclusion was radicalized as an approach that maintains political recognition and protection of human rights, but also disrupts and (re)negotiates ableist assumptions and norms that maintain an “in” and an “out”? We suggest the following radical shifts as strong starting places for beginning to (re)imagine inclusion:

*Blurring the boundaries of normative expectations.*Blurring the boundaries of inclusion means acknowledging meaningful and non-normative participation in activities and relationships.7,8 A radical inclusion subverts inclusion as assimilation. Instead, it values variation – celebrating disability identity and harnessing its generative potential. This includes valuing both mainstream and congregated spaces as possibilities for cultivating inclusion and belonging. It also calls for reciprocity and collective responsibility in the (re)negotiation of norms in the community.

*Recognizing disabled children’s agency.* Instead of understanding inclusion as a discrete or fixed state, we advocate for the recognition of inclusion as a fluid, dynamic, temporal, relative, (inter)subjective experience.8 This disrupts the assumption that inclusion can be ‘achieved’, ‘counted’, or is unequivocally ‘desired’. This also recognizes children’s agency in directing, shaping, and negotiating their inclusion and belonging experiences with their peers. Further, it recognizes the negotiation of inclusion in child(-driven) culture. Inclusion as a (re)negotiation holds space for a continuum of belonging and recognizes there are various degrees to which one is, or desires to be, included or to belong. Inclusion is therefore ‘measured’ not only by the quantity or nature of relationships or activities, but also by their ascribed meaning and experiences of them.

*Centering belonging as fundamental.* We argue that cultivating a felt sense of belonging—an intimate and emotional experience of being safe, known, respected, and ‘at home’; a rooted connectedness to a group(s), space(s) or place(s), is fundamental to inclusion.7,9 Human beings have an innate need to belong and people with a strong sense of community belonging typically perceive life to be more meaningful and experience better physical and mental health outcomes.10 For disabled children and youth, belonging has been understood as protective of well-being; despite experiences of discrimination, disabled youth do not report low levels of life satisfaction when they experience a sense of belonging to the community.11 If we recognize belonging as central to inclusion it is possible to envision an inclusion framework that attends to the dialectical relationship between the social and the individual, contributes to healthy populations, and full participation in cultural life.

A paradigm shift that responds to the evolving socio-cultural conditions that underpin inclusion theories and practices is essential if we wish to better the health and well-being outcomes for disabled children and youth. Meaningful involvement of disabled children’s voices and experiences in the development of (*radical)* inclusion policies and practices that place belonging at the centre would be foundational. Acknowledging its intersubjective and embodied nature, radical inclusion is rooted in the voices and experiences of those who pursue it. This radical shift moves beyond the material aspects of inclusion towards acknowledging inclusion as a negotiated, relational, social, cultural, and political experience.

**Footnote**

1. The authors have used the term ‘disabled’ to bring attention to the ways in which disability is culturally constructed through inaccessible spaces, medicalization, systemic constraints, discriminatory policies, stigma, and ableist attitudes. The effects of deficit-oriented discourses disable children and their childhoods, limiting full participation and inclusion in cultural life.

**Declaration of Interests**

The authors have no conflicts of interest to disclose.

**References**

1. Spencer-Cavaliere N, Watkinson EJ. Inclusion understood from the perspectives of children with disability. *Adapt Phys Activ Q*. 2010;**27**(4):275—293. DOI: 10.1123/apaq.27.4.275
2. Graham LJ, Slee R. An illusory interiority: interrogating the discourse/s of inclusion. *Educ Philos and Theory*. 2008;**40**(2):277—293. DOI: 10.1111/j.1469-5812.2007.00331.x
3. Reeves P, Ng SL, Harris M. Phelan SK. The exclusionary effects of inclusion today: (re)production of disability in inclusive education settings. *Disabil Soc*. 2020:1—26. DOI: 10.1080/09687599.2020.1828042
4. Woodgate RL, Gonzalez M, Demczuk L, Snow WM, Barriage S, Kirk S. How do peers promote social inclusion of children with disabilities? A mixed-methods systematic review. *Disabil Rehabil*. 2020;**42**(18):2553—2579. DOI: 10.1080/09638288.2018.1561955
5. Mouritsen F. Child culture-play culture. In: Mouritsen F, Qvortrup J, editors. Childhood and children’s culture. Denmark: University Press of Southern Denmark; 2002. p. 14—42.
6. Goodwin DL, Ebert A. Physical activity for disabled youth: hidden parental labor. *Adapt Phys Activ Q*. 2018;**35**(4):342—360. DOI: <https://doi.org/10.1123/apaq.2017-0110>
7. Cobigo V, Ouellette-Kuntz H, Lysaght R, Martin L. Shifting our conceptualization of social inclusion. *Stigma Res Action*. 2012;**2**(2):75—84.
8. Simplican SC, Leader G. Counting inclusion with Chantal Mouffe: a radical democratic approach to intellectual disability research. *Disabil Soc*. 2015;**30**(5):717—730. DOI: 10.1080/09687599.2015.1021763
9. Antonsich M. Searching for belonging – an analytical framework. *Geogr Compass*. 2010;**4**(6):644—659. DOI: <https://doi.org/10.1111/j.1749-8198.2009.00317.x>
10. Lambert NM, Stillman TF, Hicks JA, Kamble S, Baumeister RF, Finchman FD. To belong is to matter: sense of belonging enhances meaning in life. *Pers Soc Psychol Bull*. 2013;**39**(11):1418—1427. DOI: <https://doi.org/10.1177/0146167213499186>
11. Daley A, Phipps S, Branscombe NR. The social complexities of disability: discrimination, belonging and life satisfaction among Canadian youth. *SSM Popul Health*. 2018;**5**:55—63. DOI: <https://doi.org/10.1016/j.ssmph.2018.05.003>

**Resources to include in the margin:**

For more information on the **United Nations Convention on the Rights of Persons with Disabilities** see <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

For more information on the **Council of Europe report on the COVID 19 Pandemic and Children** see <https://rm.coe.int/final-covid19-factsheet-pandemic-and-children-web/16809f8031>

For more information on the **American Academy of Pediatrics report on The Impact of the Pandemic on Households with Children and Youth with Special Health Care Needs** see <https://www.aap.org/en/patient-care/family-snapshot-during-the-covid-19-pandemic/the-impact-of-the-pandemic-on-households-with-cyshcn/>