

Research with Children with Disabilities: Ethics, Queries, and Activism

When designing methodology for the examination of the perspectives, experiences, or needs of individuals with disabilities (IwD), often, the voice of the individual is absent or circumvented (e.g., Bremmer et al., 2021). A few researchers have considered issues in music education from the disabled individual's perspective (Blair, 2009; Draper, 2022; Haywood, 2006; Rathgeber, 2019). Blair (2009) and Haywood (2006) explored the perspectives of individuals with disabilities in secondary settings. Rathgeber (2019) shared the perspectives of adult musicians with disabilities. Draper (2022) examined the perspectives of two children on the autism spectrum to see if their perspectives aligned with those of educational stakeholders (i.e., parents and teachers).

Scholars who employ the cultural model of disability (CMD) are asked to consider representations of disability historically and within literature, film, media, and cultures (Snyder & Mitchell, 2005; Waldschmidt, 2018). Proponents for critical disability theory (CDT) ask researchers to “compare liberalism’s norms and values with their actualization in the daily life of disabled people,” while also considering intersections of identity and positions of power (Devlin & Pothier, 2006; Hosking, 2008, p.5). Laes & Westerlund (2018) posited teaching *with* or *by* rather than about IwD. Therefore, how do we, as music education researchers, ethically design and conduct research *with* rather than *on* or *about* disabled children to challenge the representation of disability within music education research and curricula while advocating for systemic change? I assert that by applying the lenses of the CMD and CDT to historical (i.e., traditional) and current accepted norms of research design we can advocate for systemic change in research practice and praxis.

Between October 2022 and January 2023, I engaged three children with disabilities in participatory research (Cain, 2008; Montreuil, et al., 2021, Seale et al., 2015) seeking to better understand their perspective of musicking and music education. The purpose of this paper is to critically examine my experience in designing, conducting, analyzing, and writing research with disabled children through the lenses of CMD and CDT. After sharing current research on participatory research with IwD, I will outline my experience of designing and conducting research with children with disabilities who dismantled and reassembled research expectations and norms to meet their individual access points and interests. I will then share what those children taught me regarding research and teaching praxis. Finally, I hope to engage conference attendees in conversations about the implications of these experiences for future research and teaching practices.

Word count: 400

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