

Disability Studies and Occupational Therapy: Renewing the Call for Change

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Disability studies (DS) is an interdisciplinary field grounded in a minority studies philosophy that approaches disability as a socially constructed phenomenon. The first special issue of the *American Journal of Occupational Therapy* on DS was published in 2005. The present issue serves as a follow-up to highlight opportunities for and examples of DS integration into occupational therapy education, research, and practice. Studies in this special issue reflect a DS approach to research that prioritizes lived experiences, critical approaches, and participatory methodologies. Reported interventions focus on changing societal barriers rather than remediating individual impairments and acknowledge instrumental activities of daily living often neglected by traditional research. Studies on educational practices in occupational therapy have found persistent issues around negative attitudes toward disability and many opportunities to better infuse disabilities studies into curricula. Revisiting DS as it applies to occupational therapy has shown that many of the issues and considerations raised in 2005 remain in the field today. Recommendations across articles in this special issue highlight that advocacy and working for broader social change are essential for occupational therapy practitioners, given ongoing occupational injustices for people with disabilities. Infusing DS ideas into occupational therapy can promote greater alignment with priorities of disability communities and spur professional change to dismantle oppressive structures and ideologies.

Disability studies (DS) is an interdisciplinary field dedicated to the critical study of disability. Similar to women and gender studies or African American studies, DS is grounded in a minority studies philosophy that views disabled people¹ as a minority group with unique culture, community, and experiences of systemic oppression (Linton, 1998; Siebers, 2008). Whereas medical and rehabilitative professions tend to consider disability as an objective medical defect, DS approaches disability as a socially constructed phenomenon, meaning that the diverse and complex meanings of disability are informed by cultural representations, society, and politics (Linton, 1998; Siebers, 2008).

One of the foundational theories of DS is the *social model of disability*, which explains that people with impairments are disabled by an inaccessible society that is not designed for people whose bodies or minds differ from the expected norm (Oliver, 1990). Rather than stemming from people's faulty bodies (medical model of disability), DS approaches disability as the result of societal ableism and sanism (i.e., the social model of disability). *Ableism* refers to a widespread societal preference for nondisabled ways of being that contributes to bias and discrimination against disabled people (Campbell, 2014). *Sanism* is the societal power structure that privileges normative mood, behavior, and thinking and marginalizes people with mental differences, creating structural oppression of mad² and neuro-atypical people (Wolframe, 2013). Siebers (2008) wrote,

Unlike the medical approach, the emerging field of disability studies defines disability not as an individual defect but as the product of social injustice, one that requires not the cure or elimination of the defective person but significant changes in the social and built environment. (p. 3)

¹This article uses identity-first language (*disabled people*) rather than person-first language, in keeping with the social model of disability and the disability studies approach to disability as a minority identity.

²*Mad* (from the British slang for *crazy*) is a reclaimed slur used as an identity label by people labelled *mentally ill* by mental health systems. It denotes a political and cultural identity that frequently includes taking pride in one's mental difference or critiquing the oppression of mad people in the mental health system and broader society.

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Disability Studies and Occupational Therapy: 15 Years Later

This is the second special issue on DS to appear in the *American Journal of Occupational Therapy* (AJOT). The first was published in 2005 and was guest edited by Gary Kielhofner. The intention of the original special issue was to examine the critique of rehabilitation by DS and to expand the profession's understandings of disability. In the introduction to that special issue, [Kielhofner \(2005\)](#) highlighted ways in which occupational therapy perpetuated disability oppression—a new concept for many practitioners at the time.

With this special issue, the guest editors felt that a second look at this topic was warranted to reinitiate discussion of how occupational therapy has and, more important, has not reckoned with the implications of DS. The original special issue highlighted opportunities for and examples of the integration of DS into occupational therapy education, research, and practice. However, when interviewed in 2019, the authors of the 2005 special issue reflected that more work needs to be done to infuse DS principles into occupational therapy, including developing authentic partnerships with disability communities, facilitating critical discourse, and moving from impairment- to societal-level intervention approaches ([Sheth et al., 2021](#)). In the interests of (re)opening the door for reflection on the profession, we ground this editorial in critical questions: How must the profession change so that we are not writing the same demand to engage with DS in another 15 years? How can occupational therapy practitioners better align with disability communities now?

Infusing Disability Studies Into Occupational Therapy: Lessons From This Special Issue

Simi Linton, in her 1998 field-defining piece “Disability Studies/Not Disability Studies,” argued that applied fields (such as occupational therapy) “would benefit from an infusion of disability studies scholarship and Disability Rights perspectives in their work” (p. 533). The articles in this special issue sketch out possibilities for occupational therapy to infuse DS into research, practice, education, and advocacy.

Research

The articles in this issue differ from the majority of existing research in occupational therapy by illustrating a DS-informed approach to research. Not all research on disabled people is DS. DS research acknowledges disabled people (rather than practitioners or researchers) as the disability experts. Many articles in this special issue prioritize the first-hand lived experiences of disabled people in different areas ([Bathje et al., 2021](#); [Njelesani et al., 2021](#); [Rabaey et al., 2021](#); [Stasell & Bathje, 2021](#); [VanPuymbrouck et al., 2021](#); [Wasmuth et al., 2021](#)). Articles also demonstrate participatory research methodologies that center community priorities through Photovoice ([Rabaey et al., 2021](#)) and share power with those most affected by the research by partnering with community members as co-researchers ([Magasi et al., 2021](#)) or co-creators of the studied intervention ([Wasmuth et al., 2021](#)).

Another aspect that differentiates DS research from typical occupational therapy research is the critical lens. Critical theories used in research turn the gaze from the individual to society, thereby illuminating social structures that “maintain a status quo of power” ([Scotland, 2012](#), p. 13). Studies in this special issue take a critical approach that interrogates broadly accepted concepts or practices in the field or acknowledges power structures, such as ableism and sanism, that oppress disabled people ([Bathje et al., 2021](#); [Holler et al., 2021](#); [Magasi et al., 2021](#); [McArthur & Gill, 2021](#); [Rabaey et al., 2021](#); [Sheth et al., 2021](#); [VanPuymbrouck et al., 2021](#); [Washington et al., 2021](#)).

DS scholars point out that applied fields do not focus enough on “solutions that the disabled community has asked for” ([Linton, 1998](#), p. 527). Occupational therapy researchers can better align with the disability community by requiring leadership and representation of disabled people in all realms of our research. Collaborative research approaches and advisory boards that include disabled advocates can ensure that research reflects the priorities of the disability community. Such collaboration may be part of ethics reviews to ensure that disabled people have a say in research that will affect their lives and communities. Disability advocates must be equitably paid for this work.

Occupational therapy could also strive to increase understanding and acceptance of humanities and critical theory research. Articles using humanities research approaches, such as discourse analysis, historical document analysis, or media studies, are infrequently published in occupational therapy journals. Although empirical research from human participants is crucial to evidence-based practice, humanities perspectives from critical fields such as DS are also vital to understanding power structures such as ableism and sanism and promoting critical reflection on the profession. Qualitative and participatory research approaches are also valuable in offering nuanced and rich descriptions of disabled people's priorities in their own words. Occupational therapy researchers, educators, and practitioners could sharpen their skills for reading and analyzing humanities, critical, qualitative, and participatory research and allow for greater publication and dissemination of such works in our profession.

Practice

Several articles in this special issue offer alternatives to conventional medical model approaches to occupational therapy practice and interventions. Whereas the medical model of disability demands intervention at the individual level to change the disabled person's body or bring their functioning closer to the expected norm, the social model of disability focuses on societal change that improves accessibility and reduces structural bias against disabled people. Some articles highlight "context-changing" versus "person-fixing" approaches (Trickett, 1994, cited in Linton, 1998, p. 527) that are in line with a social model of disability. Wasmuth et al. (2021) focus on improving transgender and gender-nonconforming (TGNC) community health by addressing transphobic attitudes in broader society around TGNC clients rather than intervening at the individual level. McArthur and Gill (2021) demonstrate how occupational therapy practitioners can use disability ethics in practice. Their approach to disability ethics can aid the practitioner in better considering environmental factors, including critical reflection on social attitudes and disability rights policies. Njelesani et al. (2021) also recommend that practitioners advocate and collaborate with disabled women to access community services to meet their occupational needs and that programs targeting economic development strengthen their inclusivity of disabled women. Despite such opportunities for using the social model of disability in occupational therapy practice, Holler et al. (2021) found that most occupational therapy practitioners still adhere to the medical model in both theory and practice, placing less emphasis on social barriers to participation.

Previous research has demonstrated that interventions that focus on changing contexts, rather than individuals, can be effective in improving outcomes on traditional occupational therapy assessments in a pediatric context (Law et al., 2011). Interventions that target environmental or social contexts align with the social model of disability by shifting the "problem" of disability away from the individual and toward the inequitable environmental conditions in which they live. Occupational therapy practitioners who align their practice with the social model of disability by changing ableist structures and inaccessible environments can achieve meaningful participation outcomes for their clients.

Although not specifically intervention focused, several articles in the special issue use a DS approach to explore instrumental activities of daily living often neglected by mainstream research, such as sexuality (Bathje et al., 2021), intimate partner roles (Njelesani et al., 2021), navigation of health care systems (Magasi et al., 2021; VanPuymbrouck et al., 2021), and travel (Stasell & Bathje, 2021). This work challenges assumptions of what disabled people prioritize in their routines and roles and broadens the view of which occupations interventions should address.

Education

Several articles in this issue highlight opportunities to infuse DS into occupational therapy curricula (Holler et al., 2021; McArthur & Gill, 2021). Although many of the articles in the special issue do not discuss education explicitly, their content highlights areas that are often missing from traditional coursework. Other studies specifically examine current aspects of occupational therapy education in the United States. In their study on the impact of occupational therapy education on students' attitudes toward disability, Friedman and VanPuymbrouck (2021) found that although explicit attitudes

toward disability became more positive over time, implicit biases increased. These authors raise important questions about how occupational therapy education may actually increase ableist biases among future practitioners. Occupational therapy educators interviewed by [Sheth et al. \(2021\)](#) also noted that students often do not engage in reflection about their own disability attitudes, nor do they critically examine educational materials and practices that may be rooted in ableism or other oppressive power dynamics. Although the shift to doctoral-level education is a prime opportunity to increase exposure to DS within occupational therapy curricula, current accreditation standards often make it challenging to address this sort of content ([Sheth et al., 2021](#)).

Educating students about DS and strategies for practicing in allyship with disability communities is vital to laying groundwork for systemic change in our profession. Educators should mindfully educate about DS, disability rights, disability justice, and disability culture in occupational therapy programs. Critical reflection on ableism and sanism at all levels should be encouraged as part of curricula, including reflection upon implicit biases, power structures within the profession, and disability oppression in broader society. To further promote DS incorporation into all occupational therapy education, future Accreditation Council for Occupational Therapy Education standards could require education about critical DS, disability rights, disability justice, and disability culture. Hiring disabled people with politicized disability identities as lecturers and instructors throughout the educational curriculum can help balance medicalized approaches and disrupt the traditional power dynamic that upholds medical providers as the sole disability experts.

Advocacy

Implications for occupational therapy outlined across the articles in this special issue call on the profession and individual practitioners to engage in advocacy. The authors recommend facilitating the development of client self-advocacy ([Bathje et al., 2021](#); [Rabaey et al., 2021](#); [Stasell & Bathje, 2021](#)), collaborating with and referring to programs and organizations that support community participation and occupational justice ([Bathje et al., 2021](#); [Sheth et al., 2021](#); [Wasmuth et al., 2021](#)), and advocating for disability benefits, accessible community and health care services, and equitable policies ([McArthur & Gill, 2021](#); [Njelesani et al., 2021](#); [Stasell & Bathje, 2021](#); [VanPuymbrouck et al., 2021](#); [Washington et al., 2021](#)). In addition, some authors call for the profession and its educators, researchers, practitioners, and students to confront implicit bias ([Friedman & VanPuymbrouck, 2021](#)) and power dynamics ([Magasi et al., 2021](#)) to more authentically infuse DS priorities into practice.

A full reckoning with the insights of DS requires structural change to both our profession and our broader society. Within the profession and the health care system, reimbursement requirements can make it difficult for practitioners to bill for advocacy and context-changing approaches, and practitioners doing DS-aligned work often have to do this as “underground practice” ([Dhillon et al. 2010](#); [Heffron et al., 2019](#)). Occupational therapy practitioners who engage in advocacy also may encounter resistance from coworkers and workplaces ([Dhillon et al., 2010](#)). The American Occupational Therapy Association’s (AOTA’s) *Vision 2025* calls occupational therapy practitioners to work to change “policies, environments, and complex systems” ([AOTA, 2019](#), p. 1). Future advocacy should work to modify reimbursement structures to allow practitioners to better align with values of DS, including improving reimbursement options for context-changing interventions such as advocacy.

Given that people with disabilities experience occupational injustices in broader society, working for broader social change is also essential for occupational therapy practitioners. The *Occupational Therapy Practice Framework: Domain and Process* (4th ed.) names advocacy, including “efforts directed toward promoting occupational justice” ([AOTA, 2020](#), p. 61), as a key occupational therapy intervention, and it includes examples of disability rights advocacy such as “talking with legislators about improving transportation for older adults, developing services for people with disabilities to support their living and working in the community of their choice, . . . and assisting in the development of policies that address inequities in access to health care” ([AOTA, 2020](#), p. 19). Despite being prioritized in our foundational documents, we do not see such advocacy on a broad scale in the occupational therapy profession. Moving

forward, the profession should aim to set advocacy priorities with disabled leaders of disability rights and/or disability justice organizations. As a starting point, occupational therapy practitioners could engage in advocacy in support for the Disability Integration Act, a centerpiece of current DR advocacy that would uphold the right of disabled people to live in the community (ADAPT, n.d.).

Conclusion

The implications of DS for occupational therapy are urgent, vital, and immense. The articles in this special issue present strategies for infusing DS into occupational therapy research, practice, education, and advocacy. These strategies can be used to spur professional change to dismantle ableist structures and ideologies and more authentically serve disabled communities. Fifteen years from now, perhaps there will be another special issue on DS. We hope that—unlike this issue, which returns to many of the same issues that were discussed in 2005—a future issue will reflect on sweeping changes that have been made to better align occupational therapy with disability communities and prioritize working for social change. We hope that DS, ableism, sanism, and the social model will be part of every occupational therapy practitioner’s awareness, and we hope that those in the profession will more actively advocate for the rights and inclusion of disabled people in all spheres. We hope that you will be part of creating this more just future. Will you join us? 🍷

References

- ADAPT. (n.d.). *ADAPT calls on Congress to pass the Disability Integration Act (S.117/HR.555) and stop the needless deaths of disabled and elderly people in nursing facilities and other institutions*. <https://adapt.org/adapt-calls-on-congress-to-pass-the-disability-integration-act-s-117-hr-555-and-stop-the-needless-deaths-of-disabled-and-elderly-people-in-nursing-facilities-and-other-institutions/>
- American Occupational Therapy Association. (2019). AOTA board expands *Vision 2025*. *American Journal of Occupational Therapy*, 73, 7303420010. <https://doi.org/10.5014/ajot.2019.733002>
- American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy*, 74(Suppl. 2), 7412410010. <https://doi.org/10.5014/ajot.2020.74S2001>
- Bathje, M., Schrier, M., Williams, K., & Olson, L. (2021). The lived experience of sexuality among adults with intellectual and developmental disabilities: A scoping review. *American Journal of Occupational Therapy*, 75, 7504180070. <https://doi.org/10.5014.ajot.2021.045005>
- Campbell, F. K. (2014, June 6–8). *Ableism: A theory of everything?* [Paper presentation]. International Conference: Ableism, Racism and Conflicts of Participation & Inclusion in Society and the Labour Market, Hamburg, Germany. <https://youtu.be/dY3EMNaB5p0>
- Dhillon, S. K., Wilkins, S., Law, M. C., Stewart, D. A., & Tremblay, M. (2010). Advocacy in occupational therapy: Exploring clinicians' reasons and experiences of advocacy. *Canadian Journal of Occupational Therapy*, 77, 241–248. <https://doi.org/10.2182/cjot.2010.77.4.6>
- Friedman, C., & VanPuymbrouck, L. (2021). Impact of occupational therapy education on students' disability attitudes: A longitudinal study. *American Journal of Occupational Therapy*, 75, 7504180090. <https://doi.org/10.5014/ajot.2021.047423>
- Heffron, J. L., Lee, D., VanPuymbrouck, L., Sheth, A. J., & Kish, J. (2019). "The bigger picture": Occupational therapy practitioners' perspectives on disability studies. *American Journal of Occupational Therapy*, 73, 7302205100. <https://doi.org/10.5014/ajot.2019.030163>
- Holler, R., Chemla, I., & Maier, A. (2021). Disability orientation of occupational therapy practitioners in physical rehabilitation settings: Tension between medical and social models in theory and practice. *American Journal of Occupational Therapy*, 75, 7504180010. <https://doi.org/10.5014/ajot.2021.042986>
- Kielhofner, G. (2005). Rethinking disability and what to do about it: Disability studies and its implications for occupational therapy. *American Journal of Occupational Therapy*, 59, 487–496. <https://doi.org/10.5014/ajot.59.5.487>
- Law, M. C., Darrah, J., Pollock, N., Wilson, B., Russell, D. J., Walter, S. D., . . . Galuppi, B. (2011). Focus on function: A cluster, randomized controlled trial comparing child- versus context-focused intervention for young children with cerebral palsy. *Developmental Medicine and Child Neurology*, 53, 621–629. <https://doi.org/10.1111/j.1469-8749.2011.03962.x>
- Linton, S. (1998). Disability studies/not disability studies. *Disability and Society*, 13, 525–539. <https://doi.org/10.1080/09687599826588>
- Magasi, S., Angell, A. M., Papadimitriou, C., Ramirez, R. D., Ferlin, A., Reis, J. P., & Wilson, T. (2021). Inside an occupational therapy–disability community partnership to promote health management: Ethnography of a research collaboration. *American Journal of Occupational Therapy*, 75, 7504180050. <https://doi.org/10.5015/ajot/2021.045468>
- McArthur, A. R., & Gill, C. J. (2021). The Issue Is—Building bridges: Integrating disability ethics into occupational therapy practice. *American Journal of Occupational Therapy*, 75, 7504347010. <https://doi.org/10.5014/ajot.2021>
- Njelesani, J., Teachman, G., & Bangura, I. R. (2021). "The strength to leave": Women with disabilities navigating violent relationships and occupational identities. *American Journal of Occupational Therapy*, 75, 7504180040. <https://doi.org/10.5014/ajot.2021.045542>

- Oliver, M. (1990). *The politics of disablement*. Macmillan Press.
- Rabaey, P., Hepperlen, R., Manley, H., & Ament-Lemke, A. (2021). Empowering caregivers of children with disabilities in Zambia: A Photovoice study. *American Journal of Occupational Therapy, 75*, 7504180030. <https://doi.org/10.5014/ajot.2021.045526>
- Scotland, J. (2012). Exploring the philosophical underpinnings of research: Relating ontology and epistemology to the methodology and methods of the scientific, interpretive, and critical research paradigms. *English Language Teaching, 5*(9), 9–16. <https://doi.org/10.5539/elt.v5n9p9>
- Sheth, A. J., Kish, J., VanPuymbrouck, L. H., Heffron, J. L., Lee, D., & Mahaffey, L. (2021). "A legitimate place in the profession": Author reflections on the 2005 disability studies special issue. *American Journal of Occupational Therapy, 75*, 7504180005. <https://doi.org/10.5014/ajot.2021.045294>
- Siebers, T. (2008). *Disability theory*. University of Michigan Press. <https://doi.org/10.3998/mpub.309723>
- Stasell, M. R., & Bathje, M. M. (2021). Hotel experiences of people with physical and sensory disabilities: A qualitative study. *American Journal of Occupational Therapy, 75*, 7504180020. <https://doi.org/10.5014/ajot.2021>
- VanPuymbrouck, L., Carey, J., Draper, A., & Follansbee, L. (2021). Recognizing inequity: A critical step of health literacy for people with disability. *American Journal of Occupational Therapy, 75*, 7504180100. <https://doi.org/10.5014/ajot.2021.045492>
- Washington, S. E., Johnson, K. R., & Hollenbeck, J. M. (2021). Environmental supports for participation among adults aging with intellectual and developmental disabilities: A scoping review. *American Journal of Occupational Therapy, 75*, 7504180060. <https://doi.org/10.5014/ajot.2021.045336>
- Wasmuth, S., Leonhardt, B., Pritchard, K., Li, C.-Y., DeRolf, A., & Mahaffey, L. (2021). Supporting occupational justice for transgender and gender-nonconforming people through narrative-informed theater: A mixed-methods feasibility study. *American Journal of Occupational Therapy, 75*, 7504180080. <https://doi.org/10.5014/ajot.2021>
- Wolframe, P. M. (2013). The madwoman in the academy, or, revealing the invisible straightjacket: Theorizing and teaching saneism and same privilege. *Disability Studies Quarterly, 33*(1). <http://dsq-sds.org/article/view/3425>