Critical pedagogy and disability in participatory research: a review

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Abstract

Purpose – The literature review explores how multidisciplinary approaches based on critical pedagogy and participatory research can provide frameworks for equitable partnerships and genuine participation in educational design and research practices. Additionally, the essay aims to expand understandings of equitable engagement within educational research and design based on principles from critical pedagogy.

Design/methodology/approach – The essay draws from diverse literature in the learning sciences, health informatics, industrial design, disability studies, ethnic studies, rehabilitation science, and to a lesser extent HCI research to understand how critical pedagogy and participatory research methods can provide useful frameworks for disabled peoples' equitable engagement and genuine participation in educational research and design. The literature reviewed in the paper concern topics such as participatory approaches to community development with disabled adults, the implementation of university-initiated community partnerships, participatory research with students and disabled people, and the importance of culturally-responsive research practices. The design literature in this review explores various arenas such as the co-design of assistive technologies with disabled children and adults and the design of curricula for students with and without disabilities. This review focuses on research practices that engender disabled peoples' participation in educational research and design, with focus on developing multidisciplinary frameworks for such research.

Findings – The literature review concludes that participatory research methods and critical pedagogy provide useful frameworks for disabled peoples' participation in educational design and research practices. Critical pedagogy and participatory design allow for the genuine participation of disabled people in the research process.

Social implications – Emphases on collaboration and collective knowledge-building in social transformation are present in scholarship concerning critical pedagogy, participatory research, and disability studies. However, these connections have been routinely underexplored in the literature. This paper aims to underscore these integral connections as a means to build solidarity between disabled and other marginalized people.

Originality/value – The connections between participatory research methods, critical pedagogy, and disability studies have been previously underexplored. The literature review proposes a combined approach, which has the potential to radically transform multiple realms of research beyond the learning and information sciences.

Keywords Knowledge production, Participatory research, Disability studies, Critical pedagogy, Design-based research, Community-based research

Paper type Viewpoint

1. Introduction

Disabled people [1] have notoriously been excluded from design, research, and development processes, which has furthered inaccessibility in many realms of everyday life. In response, there has been a growing body of research across disciplines that concerns participatory and community-engaged methods of research with disabled people. However, this research frequently operates from deficit-based frameworks. Additionally, it often furthers extractive design and research practices, defined by Costanza-Chock (2020) as those that obtain input

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from users who do not receive direct benefits from the product or from the design process itself.

The aims of this literature review are twofold. First, this literature review aims to understand how critical pedagogy approaches which center disabled peoples' situated knowledge can lead to the formation of equitable partnerships in educational design and research practices. Second, this essay aims to expand understandings of equitable engagement in design and research contexts through critical pedagogical perspectives. Drawing upon multidisciplinary literature and insights from critical pedagogy, this review offers the framework of transformative collaboration. This framework centers disabled people's knowledge in the collective formation of a critical consciousness toward social change.

In the inaugural issue of the *Information and Learning Sciences* journal, Reynolds *et al.* (2019, p. 3) define learning sciences as an "inter-disciplinary scholarly domain" that examines:

> Teaching and learning in both formal and informal settings, and which draws on knowledge from fields including cognitive science, sociocultural theory and social constructivism, educational psychology, computer science, information sciences, and design studies among others.

The Learning Sciences provide a unique focus on design-based approaches and the everyday implications of research. The authors define Information Science as:

> The science and practice of effective collection, storage, retrieval, and use of information, concerned with recordable information and knowledge and the technologies and related services that facilitate their management and use (Reynolds *et al.*, 2019, p. 3).

The two fields share a similar focus on examining systems design and theories of knowledge. Additionally, both disciplines' research practices emphasize the importance of technological and pedagogical innovations, as well as the connections between research and practice. This literature review will explore the shared aspects of Information Science and Learning Sciences research. More specifically, this literature review will focus on design-based research approaches in the field of education that support collaborations that center participants' experiential knowledge.

This literature review responds to the ethical issues of design-based research, with a focus on research within education. The transformative collaboration framework developed in this review addresses these concerns. Extending concepts from critical pedagogy and participatory research, the intervention underscores the importance of cross-disciplinary perspectives on collaborative research. The review employs a multidisciplinary approach to underscoring the connections between community-engaged research, design-based research, critical pedagogical perspectives, and research with disabled populations. Moreover, it draws from the literature of health informatics, industrial design, disability studies, public health, ethnic studies, rehabilitation science, and learning sciences. The literature reviewed in this paper concerns a wide array of topics such as participatory approaches to community development with disabled adults, the implementation of university-initiated community partnerships, participatory research with students and disabled people, and the importance of culturally-responsive research practices, among other subjects. The design literature in this review explores various arenas such as the curriculum design for students with and without disabilities, co-design of assistive technologies with disabled adults, and design within mixed-ability groups. This review does not focus on a particular design domain or product type. Rather, it focuses on the research *practices* that engender or inhibit disabled peoples' participation in community-based research. Echoing Miskovic and Hoop (2006, p. 269), the framing of this literature review resists the "university and funding agency–

driven push for a 'product,'" and instead gives attention to the collaborative processes that foster genuine participation, garner community engagement, and most crucially center disabled people's experiential knowledge.

2. Research questions

This review focuses on how critical pedagogy and participatory research methods can provide useful frameworks for disabled peoples' equitable engagement and genuine participation in educational research and design. The first research question examines how critical pedagogy centers disabled peoples' knowledge and leads to equitable partnerships in educational design and research practice. The second research question aims to understand how researchers and practitioners can foster equitable partnerships in practice:

RQ1. How does critical pedagogy provide frameworks for equitable partnerships?

RQ2. How can community-engaged and participatory education and design practices help build and sustain equitable partnerships that center disabled peoples' knowledge?

3. Methods

This paper utilizes the scoping review method to explore the connections between topics of disability in design research, community-engaged and participatory research approaches and critical pedagogy, with focus on research that centers marginalized populations (i.e. populations who are marginalized due to race, gender, class and disability). Following Arksey and O'Malley (2005) five-stage scoping review framework, the author first formulated the guiding research questions included in Section II. In the second stage, the author identified relevant studies using relevant electronic databases such as Proquest Library and Information Science Collection and Education Collection. Additionally, the author hand-searched the titles and abstracts of articles in peer-reviewed journals in the Learning Sciences published between 2016 and 2022, with attention to articles that discuss the topics of disability, community-engaged research, participatory research approaches, and critical pedagogy [2]. The author also performed a keyword search on Google Scholar for articles that explore the connections between disability and critical pedagogy as well as community-engaged research and critical pedagogy. The search terms included those that describe critical pedagogy (e.g. "critical pedagog*", "critical education*", social justice education*"), disability (e.g. "disab*", "disability studies", "disability justice"), community-based research (e.g, "CBPR", "community-based", "community-engaged", "community engaged", "community partnered", "action research", "partner*") and participatory research ("paticip*", "participatory research", "participatory design"). Lastly, the author performed keyword searches on Google Scholar and the ACM Digital Library for articles in the critical HCI literature that discuss disabled people's participation in research and design, to supplement the literature on critical pedagogy, community-based research, and participatory research. The author utilized keywords such as "disab*", "disabled design", "disabilities design", and "critical design". To locate literature on neurodivergent communities, the author utilized keywords including "neurodiv*", "autis*", "ADD" and "ADHD". The aforementioned keywords were chosen as literature on neurodiverse individuals may not include disability as a keyword.

In the third stage, the author developed two inclusion criteria for all literature consulted:

(1) articles written in English, and

(2) focus on research partnerships with marginalized populations

For literature on community-engaged partnerships, the author focused on research utilizing social justice or critical pedagogical perspectives. Four articles were excluded from the study because they concerned topics such as design with caregivers, lacked explanation of study design, focused on co-design with educators, and utilized community-engaged research methods without a specific social justice- or critical pedagogy-informed outlook. In the fourth stage, the author created a review matrix on Excel that included key terms, research questions, theoretical paradigms, sampling and population, methodology, and results of the articles. This was done in order to provide a uniform analytical framework across all consulted literature. Lastly, in the fifth stage, the results of the scoping review were summarized and synthesized to provide an overview of literature that responds to the research questions.

4. Multidisciplinary theories of knowledge and marginalization

Drawing from diverse research in inclusive education, HCI, disability studies, university-community partnerships, and occupational therapy, this literature review attempts to outline multidisciplinary frameworks for conducting participatory, design-based research with disabled people. One of the primary goals of this synthesis is to generate best practices for conducting research that centers disabled people's perspectives on their own experiences and provides equitable access to opportunities. Moreover, scholars can look toward research on inclusive education for means to challenge the ways in which educational institutions and structures reproduce inequality for marginalized students of various identities and experiences (Liasidou, 2012). Inclusive education refers to the movement regarding the inclusion of disabled students in mainstream classrooms. The aim of the inclusive education movement is to provide equal educational opportunities for disabled students (Bentley, 2008; De Schauwer *et al.*, 2009; Liasidou, 2012). Despite the gradual increase in educational opportunities for disabled people, disabled students' perspectives have been continually overlooked in integral decision-making processes regarding their education. Bentley (2008, p. 546) writes:

> The voices of children with labels of severe disabilities are missing from the important epistemological, political, pedagogical, and pragmatic currents that will shape their future [. . .] even within the field of inclusive education research, their voices have been virtually silenced.

Research on inclusive education and educational access can provide context for best practices of inclusion in mixed-ability groups.

In order to highlight students' own perspectives on such issues, De Schauwer *et al.*, 2009 conducted interviews with disabled students about their individual experiences in inclusive education settings. The findings revealed that disabled students have valuable insights about their education. Additionally, interviews underscored the importance of focusing on disabled students' often-overlooked capabilities. The authors noted that children are able to communicate about their educational experiences. Therefore, educational personnel and parents should consult disabled students about them. Moreover, disabled students have valuable opinions about their educational trajectories and the types of support they need. The study concluded that disabled students are well-equipped to speak about their own experiences. De Schauwer *et al.* also note the importance of focusing on disabled students' strengths rather than their limitations. The authors note that there are few opportunities to focus on disabled students' capabilities. Rather than reproduce rigid labels of disability, De Schauwer *et al.* reveal the possibilities of educational research that highlights disabled students' capacities. The suggestion to focus on disabled people's capacities rather than their limitations is reflected in the literatures of various disciplines.

Within the field of health information and design, Chinn and Pelletier (2020) examine the tensions between "expert" and "experiential" knowledge within a mixed-ability group engaged in the co-design of an accessible text format for people with intellectual disabilities. However, the article is focused on the perspectives of the facilitators of the co-design sessions. The facilitators of the co-design sessions were salaried employees of organizations that utilized the accessible text format. Participants included individuals with intellectual disabilities, organizational staff members, and university students. Chinn and Pelletier (2020, pp. 333–334) note that "the role of those with intellectual disabilities was largely confined to that of reviewers or quality checkers, with limited influence on the final form of the [accessible text format]". Although the roles of disabled participants in the study are limited, the authors' extension of "embodied insights" (Martin, 2008) provides a guiding concept for conducting research with disabled people that centers and builds from their knowledge. Embodied insights are more than simply experiential knowledge. Rather, they are complex and critical understandings of one's condition, which one formulates as a result of one's lived experience and the torrent of information they encounter and sort through on a daily basis (Chinn and Pelletier, 2020; Martin, 2008). Chinn and Pelletier conclude that drawing from participants' embodied insights might disrupt epistemological inequalities within the co-design process, such as facilitators taking on the role of "expert" and disregarding the inputs of disabled participants.

Similar insights have been drawn in education literature, particularly within social justice-oriented work. This can be seen in the growing literature that critiques deficit thinking in educational research and practice. In the context of education, deficit thinking views the academic struggle of low-income students of color as a result of their families and upbringings. It is based on racist falsities regarding the alleged cultural, and environmental deficits of marginalized students (Valencia and Solórzano, 1997). Deficit thinking also affects disabled students' experiences. Disabled people's perspectives—even those concerning their own experiences—are often ignored due to ableist conceptualizations of knowledge. Deficit thinking not only harms disabled students, it can also negatively affect parental involvement in their children's education (Aceves, 2014). Moreover, research in critical disability pedagogies have begun to make the crucial connections between systems of oppression, deficit thinking, binary categories of disabled/non-disabled learners, and pathologizing logics (Castrodale, 2017). While studies of deficit thinking do not frequently intersect with the topic of disabled students, their similarities can provide a preliminary foundation for mapping the connections between ableism and racism in education and conceptualizations of knowledge more broadly.

Alemán *et al.* (2017) examine the effects of a community-based partnership program on educators' patterns of deficit thinking. Despite the program's success in securing funding, engaging parents, and expanding offerings, organizers nonetheless struggled to combat educators' rampant deficit thinking and establish a robust partnership with many of the educators. The authors reflect that the interviews with educators revealed their disregard for "students' funds of knowledge and other assets they bring to the classroom" (Alemán *et al.*, 2017, p. 867). Funds of knowledge refers to the culturally-embedded knowledge that arises from the daily routine practices and social experiences of children and their families (Moll *et al.*, 1992). The concept can be utilized as an approach to implementing participatory research in education. Moreover, it not only validates marginalized students' experiences as sources of knowledge, but provides them opportunities to transform—and make vital connections between—their realities both inside and outside of the classroom (Cammarota and Romero, 2009). While funds of knowledge has been primarily utilized in

contexts regarding the educational experiences of low-income students of color, the concept nonetheless provides a useful framework that highlights disabled people's often overlooked knowledge. Moreover, an engagement with funds of knowledge approaches, which counter deficit thinking, establishes crucial connections between the longstanding lineage of anti-racist and social justice-oriented research in education and emergent research on critical disability pedagogies.

5. Participatory research methods

Participatory research includes methods, design processes and frameworks that are based upon direct collaboration with those affected by the issue being studied to promote change (Vaughn and Jacquez, 2020). While it is not always political in nature, participatory research is frequently implemented by researchers who are invested in social transformation (Hayes, 2011; Vaughn and Jacquez, 2020). Participatory action research (PAR) is an approach to action research (AR) that considers participants as integral collaborators in the research process. AR requires that researchers do not distance themselves from the issues and communities that ground their research. Rather, researchers should work collaboratively with communities to not only plan and implement research, but also share and discuss results (Hayes, 2011). PAR is a specific approach to action research that involves those who are directly affected by research as collaborators in the research process (Cammarota and Romero, 2009; Duncan-Andrade and Morrell, 2008; Minkler *et al.*, 2002). Similar to other participatory methods, PAR is invested in egalitarian principles and the inclusion of participants in the research process.

Participatory design methods include end-users as collaborators and designers in the design process. Participatory design is based on the understanding that end-users' knowledge and participation is important throughout the design process. Originating in the 1970s within Scandinavian trade unions, the ethical underpinnings of participatory design research include the importance of democratizing the design process, equitable collaboration, and empowering end-users (Kensing and Blomberg, 1998; Kuhn and Muller, 1993). With its underlying premise of inclusivity and emphasis on design as a situated and collaborative activity, participatory design has the potential to "desettle" the power imbalances, dominant ideologies and restrictive assumptions embedded in normative research practices (Bang *et al.*, 2013, as cited in Zavala, 2016). There have been a number of critiques of participatory design, including questions concerning the efficacy of involving stakeholders in the design process and the overall benefits of participation for end users. Costanza-Chock (2020) notes that while participatory design is conducted with good intentions, it is often the professional designers, researchers, and institutions who reap the material benefits of the collaboration. It is important to note the differences between participatory design and PAR. While they are both grounded in principles of democracy and inclusion, the scope of each respective approach is quite different. For instance, participatory design is limited to the design of a specific product. On the other hand, PAR is concerned with the learning and transformations that occur as a result of participant involvement in research, which Hayes (2011) describes as "learning through action" (Foth and Axup, 2006; Hayes, 2011). Similar to the objectives that underlie this review, participatory research challenges the normative and exclusionary ideas surrounding knowledge production by involving those affected by research as integral collaborators.

There is a vast, multidisciplinary literature that concerns participatory research with disabled people. The literature explored in this review spans community-based participatory research (CBPR), PAR, and participatory design. A recurrent theme in the literature are the multiple barriers to participation. In the implementation of CBPR,

participatory design, and PAR projects alike, this includes inaccessible and imbalanced communication wherein participants felt they were not listened to or could not understand others (McDonald and Stack, 2016; Minkler *et al.*, 2002; Stack and McDonald, 2018). Additionally, participants of such projects have voiced concerns about a lack of ownership of the projects and their findings (Minkler *et al.*, 2002; Stack and McDonald, 2018). In international contexts, challenges of participatory research with disabled participants include the "cultural translation" of language, practices, and norms into local environments (Sharma *et al.*, 2022). Researchers have also found that implementing participatory design in non-Western contexts with disabled children in particular has been difficult due to researchers' misunderstandings about strict hierarchies between children and adults, which affect children's participation in the design process. In a study of the participatory design of prosthetics with disabled children in Cambodia, researchers found that cultural mores concerning age and disability impacted their willingness to collaborate and share ideas with adult co-designers (Hussain *et al.*, 2012).

In response to these challenges, the literature has also produced a number of recommendations and best practices for conducting participatory research with disabled participants. To foster opportunities for equitable partnerships, the literature includes recommendations that researchers practice self-reflection about power imbalances in the research process (Stack and McDonald, 2018), develop participants' capacities to participate in the project (Hussain *et al.*, 2012), and provide necessary accommodations (McDonald and Stack, 2016; Schwartz *et al.*, 2020). Additionally, some participatory research studies also include community advisory boards with leaders of the disability community, disabled researchers, and non-disabled individuals (e.g. family members, service providers, and researchers) connected to the disability community. In these studies, community advisory boards create guidelines for conducting research with disabled participants, participate in focus groups, guide participant selection, develop research instruments, analyze data, and discuss findings with participants (Minkler *et al.*, 2002; McDonald and Stack, 2016; Stack and McDonald, 2018). In a particularly rare case, interviews were conducted, recorded and transcribed by a research team member with a disability. Findings from this study were also returned to participants and discussed in a community forum, where participants could suggest alternative interpretations and additional uses of the findings to best help the community (Minkler *et al.*, 2002). The above examples from participatory research provide foundations for equitable collaboration with disabled participants.

6. Critical pedagogy

The theories of knowledge in critical pedagogy provide frameworks for equitable partnerships with disabled people, and actively work against the epistemic violence that is prevalent in research on disability Ymous *et al.* (2020). Critical pedagogy is a philosophy of education that concerns issues of social justice and liberation as central to educational endeavors (Duncan-Andrade and Morrell, 2008; Liasidou, 2012; Reindl *et al.*, 2022; Scott *et al.*, 2015). Critical pedagogy has taken inspiration from multiple arenas such as The Frankfurt School, anticolonial activism in Latin America, and Marxist cultural criticism (Miskovic and Hoop, 2006). Fundamental to critical pedagogy is the connection between knowledge and power. Additionally, critical pedagogy aims to highlight the knowledge of those who have been oppressed as a result of interlocking systems of domination such as racism, sexism, and classism. An integral component of critical pedagogy is the understanding that the development of a critical consciousness leads to praxis. The philosopher Paulo Freire describes the formation of a critical consciousness—or conscientization—as "coming to terms with the roots of your oppression as you come into

your subjecthood" (Freire, 1970, as cited in Reindl *et al.*, 2022). Praxis, which can be described as the combination of action and reflection, emerges as a result of conscientization (Reindl *et al.*, 2022). Through praxis, individuals can reflect upon and transform their realities.

A key concept of critical pedagogy is that of Freire's dialogue (Freire, 1970; Miller and Hafner, 2008; Reindl *et al.*, 2022). More than simply two-way communication, Freire defines dialogue as an equal engagement between mutually respectful individuals that guides them toward positive social transformation. Dialogue is comprised of four tenets: humility, faith, hope, and critical thinking (Freire, 1970). In this context, humility refers to those in traditional positions of power acting without arrogance. Faith encompasses a deep confidence and trust in individuals. Miller and Hafner (2008, p. 76) further explain that "dialogue is characterized by intense faith in the inherent capabilities of all people to name their realities and to transform them". Hope denotes the belief that individuals' actions can lead to social transformation, especially when they mobilize with one another (Freire, 1970; Miller and Hafner, 2008; Reindl *et al.*, 2022). Lastly, conscientization involves the emergence of a critical consciousness that challenges systems of domination, oppressive institutions, and social structures. While these sentiments are reflected in participatory research methodologies, they are rarely explicitly discussed in the context of participatory research with disabled people despite their connection to current research aims to collaborate "with and for" disabled people (Meissner *et al.*, 2017, p. 1055).

Numerous studies have made connections between principles of critical pedagogy and participatory research practices. Participatory research draws upon marginalized forms of knowledge rather than commonly valorized forms of knowledge such as traditional academic scholarship. Additionally, both approaches are based upon principles of liberation and social transformation. Participatory and critical pedagogy methods alike challenge oppressive practices in education through their critical consciousness-raising practices and how they challenge traditional understandings of authority and control (Duncan-Andrade and Morrell, 2008; Miskovic and Hoop, 2006). This can be seen in the context of a university-school-community partnership, wherein critical pedagogy-engaged PAR projects "understood youth as community assets rather than problems to be dealt with" (Miskovic and Hoop, 2006, p. 277). Miskovic and Hoop note that PAR, implemented in combination with principles of critical pedagogy, provides opportunities for students to "question the principles of social and political life and equip[s] them with strategies to shape and change social, political, and economic constraints in their environment" (Miskovic and Hoop, 2006). In the similar context of a youth-focused, critical pedagogy-informed PAR project, Scott *et al.* (2015) argue that the PAR approach:

> Moves students towards praxis by helping them develop more authoritative voices, renegotiate identity as part of a social process of belonging, and begin to envision their roles in creating a more just world (p. 139).

In other words, PAR and critical pedagogy uphold students as key figures in the research process and open up possibilities for student-initiated sociopolitical change.

In the context of PAR with youth, Duncan-Andrade and Morrell (2008) argue that PAR can be bolstered by critical pedagogy approaches. The authors argue that combining the approaches that draw upon participant perspectives helps them to develop multifaceted understandings of power as integral research collaborators. Duncan-Andrade and Morrell argue that "instead of doing research 'on' [participants], which makes them the objects of our research gaze", the shared critical aspects of PAR and critical pedagogy:

> Holds the potential to reposition [participants] as the subjects of their own research, research that matters to them and larger empirical questions that require their important, but often missing, perspective (p. 106).

In conclusion, one can understand critical pedagogy and participatory approaches as not only complementary to one another, but providing an imperative challenge to marginalizing deficit-based thinking in education and exclusionary understandings of knowledge that undergird such thinking.

There is also a small subset of disability studies literature that makes connections between critical pedagogy and disability studies. Liasidou (2012) links principles of critical pedagogy to the inclusive education movement. Liasidou (2012, p. 168) describes inclusive education as similarly:

> Concerned with challenging [how] educational systems reproduce and perpetuate social inequalities with regard to marginalized and excluded groups of students across a range of abilities, characteristics, developmental trajectories, and socioeconomic circumstances.

While there is a dearth of critical pedagogy literature that focuses on disability, Liasidou notes how critical pedagogy underscores the connections between disability and other forms of marginalization as a result of its overarching concern with dismantling oppressive institutional and ideological structures. Furthermore, Liasidou argues that critical pedagogy approaches can shed light on the often-overlooked linkages between disability, race, socioeconomic status, and systems of power. Moreover, the connections between these various categories of identity are not frequently discussed in the critical pedagogy or disability studies-grounded educational literature.

Echoing the literature that utilizes community-based and participatory research methods to counter deficit thinking (Alemán *et al.*, 2017; Cammarota and Romero, 2009; Miskovic and Hoop, 2006), Liasidou (2012) argues that educational equality requires a critical examination of "individual pathology perspectives" (i.e. deficit thinking). Additionally, Liasidou argues that educational equality requires institutional change that actively challenges and is cognizant of systemic oppression and other injustices. The author notes that inclusive education efforts not only foster the redistribution of educational resources for students who have been routinely disadvantaged in their schooling, but also provides integral opportunities for accountability on the part of schools and educators. Liasidou argues that inclusive education efforts can be bolstered by principles of critical pedagogy that guide educators and schools toward a critical examination of educational institutions as embedded in systems of power that reproduce conditions of oppression and inequality. This critical orientation paves the way for ideological and institutional changes in education, which will ultimately provide more educational opportunities for disabled students and other marginalized students more broadly.

As previously noted, there is little research that makes connections between critical pedagogy, participatory research, and disability studies. Reindl *et al.* (2022) is one of the few studies that utilizes principles of critical pedagogy to analyze a community-based participatory project. The aim of the study was to examine the connections between the theoretical underpinnings of each discipline. The article concludes that critical pedagogy's materially-based analyses augment the calls for the recognition of disabled peoples' agency within disability studies. Additionally, disability studies can orient critical pedagogy toward multidimensional understandings of conscientization and praxis that take into account the many forms of subjecthood and identity locations of the "oppressed". In other words, scholarship within disability studies that challenges one-dimensional and binaristic understandings of agency and power (i.e. power/powerless) provides both a crucial critique

and opportunities for the reinterpretation of key principles in critical pedagogy. As for the participatory elements of the study, the findings of Reindl *et al.* echo other critical pedagogy-informed participatory research projects. The authors note that the participatory and critical pedagogy approaches were complementary to one another (Duncan-Andrade and Morrell, 2008; Miskovic and Hoop, 2006; Scott *et al.*, 2015). Moreover, the combined approaches led both disabled and non-disabled participants to realize their impact within the research process and capacity to foster social change. This initial study underscores the potential of a combined disability studies and critical pedagogy approach to participatory research. In short, Reindl *et al.* exemplify how a combined approach provides frameworks for equitable partnerships.

7. Participatory curriculum development

Participatory curriculum development is an approach to curriculum development that draws upon participatory research techniques. As such, this method of curriculum development involves the engagement of end users in the design process (Standley *et al.*, 2022; University of Montana Rural Institute, 2020). Similar to participatory design methods, there is an emphasis on stakeholder collaboration in the design and implementation processes. Participatory curriculum development originated in research about agricultural education and sustainable development (Taylor, 2008, as cited in Standley *et al.*, 2022). There is a growing body of research that concerns participatory curriculum development in health-related domains of healthcare administration and medical professionals (Standley *et al.*, 2022). However, there is little research that concerns the involvement of disabled people in participatory curriculum development. The limited existing research explores the development of an open access curriculum for paraeducators (Parker *et al.*, 2017), and the creation of curricula about independent living (Standley *et al.*, 2022; University of Montana Rural Institute, 2020). While the paraeducator curriculum concerns educators, the independent living curricula is specifically designed for disabled people, with disabled people as co-designers.

Standley *et al.* (2022) is an example of a study that utilizes participatory curriculum development to build upon the "unique knowledge of disabled people to develop curriculums supportive of their needs, as informed by their experiences" (p. 4). Using participatory curriculum development approaches, Standley *et al.* (2022) both developed a new curriculum and revised an existing curriculum about independent living (IL) skills. The authors partnered with a local IL organization to develop the curriculum. Disabled staff of the organization were included as "partners" in the curriculum design process. Although participants reflected that the design process was a valuable learning and collaborative experience, there were still issues that arose during the study. In post-hoc interviews, Standley *et al.* (2022, p. 17) note that participants describe an "experience of unequal sharing of power" that "conflicted with [their] expectations for the empowering and participatory nature of participatory curriculum development". While Standley *et al.* (2022) is a unique example of participatory curriculum development *with* and *for* disabled people (Meissner *et al.*, 2017), issues of the unequal distribution of power in research are nonetheless present.

8. Developments in critical HCI research with disabled people

There is an emergent subset of participatory design and HCI research that examines disability through critical approaches from interdisciplinary fields such as disability studies and feminist studies. One of the first attempts to connect disability studies and assistive technology research in HCI is "Disability Studies as a Source of Critical Inquiry for the Field of Assistive Technology" by Mankoff, Hayes, and Kasnitz. Mankoff *et al.* (2010, p. 8) note

that despite the intentions of researchers and designers to "do good", they may nonetheless fail to respond to complex and multilayered problems and further ableist ideas. Moreover, Mankoff *et al.* (2010, p. 8) state that "there may not even be a "right" problem to tackle or a "right" approach to take". The authors argue that approaches from disability studies can respond to these issues and positively inform research on assistive technology. For example, Mankoff *et al.* argue that existing research operates within the medical model of disability, which emphasizes fixing supposed disability-related impairments and privilege "normalcy". Similarly, Wobbrock *et al.*'s (2011) Ability-Based Design departs from deficit-based understandings of disability to focus on user abilities, while emphasizing the importance of recognizing ability as contextual. Mankoff *et al.* (2010) and Wobbrock *et al.* (2011) can be understood both precursors to critical assistive technology research and early attempts to connect interdisciplinary critical scholarship and HCI research.

Since the publication of Mankoff *et al.*'s "Disability Studies as a Source of Critical Inquiry for the Field of Assistive Technology" in 2010, there is a subfield of HCI research that explores disability through interdisciplinary critical approaches (Barbareschi and Inakage, 2022; Hofmann *et al.*, 2020; Spiel and Angelini, 2022; Williams and Boyd, 2019; Williams and Gilbert, 2019; Ymous *et al.*, 2020). Furthermore, it is indicative of what Meissner *et al.* (2017, p. 1055) describe as a "conceptual shift" in assistive technology research. As a result, there have been increasing efforts to utilize participatory design approaches to collaborate "with and for" disabled people. Such interventions have explored the participatory design of assistive technologies in mixed-ability groups, and how identities affect knowledge production in participatory design with disabled children (Baldwin *et al.*, 2019; Brulé and Spiel, 2019). This developing domain of HCI research calls for the inclusion of disabled people as active participants in design processes that center their experiential knowledge and lived experiences, rather than dismiss their roles as knowledge producers and co-creators of access-making technologies (Bennett *et al.*, 2018; Williams and Park, 2023; Ymous *et al.*, 2020). This strand of literature underscores the importance of design and research practices that enhance disabled people's agency and self-determination through validating their experiential knowledge (Bennett and Rosner (2019); Spiel *et al.*, 2020, 2019). Recently, there have been calls for this work to broaden its attention to how racism, sexism, and classism affect ableism in HCI research (Harrington *et al.*, 2023).

Despite increased calls for the inclusion of disabled people in research, Spiel *et al.* (2020, p. 2) note that many HCI studies concerning accessibility still employ much-critiqued "medicalized or interventional approach[es]". Additionally, Spiel *et al.* note that many HCI studies focus on reducing the effects of disability without meaningful engagement with disabled participants. The authors also note that while there are additional participatory design-informed and "people-centered" approaches to HCI research with disabled people, these efforts lack an epistemological and political grounding (Spiel *et al.*, 2020, p. 2). In response to these continued shortcomings, the authors argue for a *critical* disability studies-informed approach to HCI research. Critical disability studies examines how disability is affected by systems of power that undergird multiple structural inequalities and intersections of identities and oppressions. Similar to other critical scholarly disciplines, critical disability studies is a form of activism and scholarship that interrogates the systems of power that oppress all marginalized people with an overarching goal of social transformation (Goodley, 2013). Spiel *et al.* (2020) suggest that critical disability studies could not only serve as an epistemological foundation for HCI, but as a means to orient the field toward more politically- and social justice-driven research practices.

One example is Williams and Park's (2023) "cyborg assemblages", which brings together interdisciplinary approaches from feminist science and technology studies and critical

disability studies to explore how autistic people form embodied, communal knowledge that results from their everyday experiences and mutually constitutive relationships with sociotechnical systems. The concept extends theories of crip technoscience and design justice. Crip technoscience is a mode of critical scholarship and activism that explores how disabled people's everyday experiences and communal knowledge are integral to technoscience (Hamraie and Fritsch, 2019). Design justice is a theory, practice, and social movement oriented toward establishing design practices that foster equitable participation and highlight the community-based knowledge of those historically marginalized within design processes and in society more broadly, while leveraging design to interrogate differentials in power, maintain accountability, foster collaboration, and center communities most affected by such practices (Costanza-Chock, 2020). Williams and Park (2023) extend the above multidisciplinary frameworks to challenge dominant approaches to designing "technologies" for "autism", opting to highlight their communal expertise based on lived experience (p. 11). While still a relatively small subfield within HCI, there is a growing subfield of research that explores ableist epistemic violence within research (Spiel *et al.*, 2022; Spiel and Angelini, 2022; Ymous *et al.*, 2020).

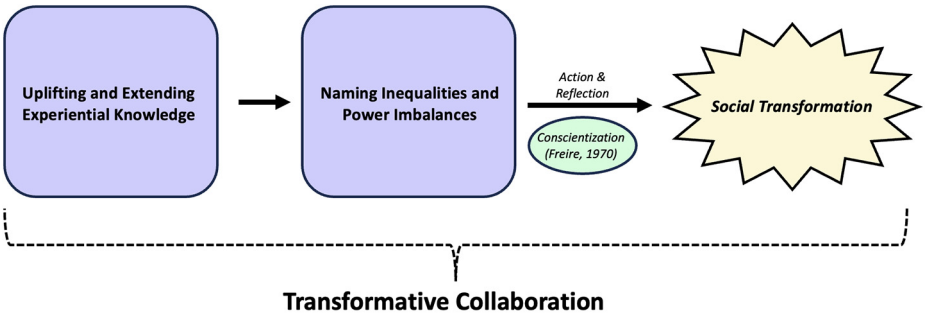
Building upon work in community-engaged research, there is also a growing subset of HCI literature more broadly that concerns setting a foundation for more inclusive and equitable design research. Hayes (2020, p. 28) argues that engaged projects in HCI are built upon "cross-disciplinary partnerships" and are not only cognizant but *reflective* of "the values, experiences, and goals of everyone impacted". Additionally, Hayes (2020, p. 30) emphasizes the importance of community outcomes in HCI research, which directly address "community expertise and community challenges". In the context of participatory design research, Harrington *et al.* (2019, p. 2) notes that while such community-engaged approaches were created as a means to interrogate power imbalances, they may nonetheless "exacerbate inequities by leading to infeasible solutions that ultimately frustrate underserved individuals". Harrington *et al.* outline a number of additional concerns with participatory design research. Researchers lack knowledge about the communities they partner with and often further value-laden and exclusionary notions of what constitutes creativity. Design projects are often temporary, which limits sustained engagement with partnering communities. Harrington *et al.* (2019, p. 17) argue that such research "require[s] us to hold researchers accountable for the ways in which we insert ourselves into these communities". The ongoing inequities described by critical HCI researchers such as Harrington *et al.* exemplify that a mixed-methods or community-engaged approach to design research with marginalized peoples is not enough. As Spiel *et al.* (2020) argue, there must be strong epistemological and *political* foundations to guide design research toward its emancipatory potential.

9. Transformative collaboration

This review proposes the framework of transformative collaboration that can be applied in design-based research projects with disabled people. Transformative collaboration is a step-by step process and a literature-based framework for design-based research practices with disabled people that leads to social transformation. The framework connects critical pedagogy principles to participatory research methods in the context of design-based research centering disabled people. With few exceptions, these connections have been underexplored in the literature (Williams and Gilbert, 2019; Reindl *et al.*, 2022) Transformative collaboration centers the tenets of conscientization and transformation in critical pedagogy (Freire, 1970). In short, the transformative collaboration framework connects participatory research with critical pedagogy principles to provide a step-by-step blueprint for equitable partnerships in design-based research that center disabled peoples' knowledge.

Transformative collaboration is an orientation towards research based on critical pedagogy principles and best practices for research partnerships across disciplines (Freire, 1970; Williams and Gilbert, 2019; Kinnula and Iivari, 2021; Reindl *et al.*, 2022; Stack and McDonald, 2018; Zavala, 2016). The framework combines complementary approaches from critical pedagogy and multidisciplinary participatory research to form a foundation for equitable partnerships with disabled people. Throughout the literature, there are biases concerning disabled people's communicational, emotional, and physical capacities that supposedly hinder their engagement in participatory research (Chinn and Pelletier, 2020; Hussain *et al.*, 2012; McDonald and Stack, 2016; Sharma *et al.*, 2022). However, the transformative collaboration framework is primarily derived from literature that challenges this deficit thinking through validating participants' experiential knowledge (Cammarota and Romero, 2009; Williams and Gilbert, 2019; Liasidou, 2012; Ymous *et al.*, 2020). The framework of transformative collaboration draws from literature on equitable engagement and genuine participation in participatory research that underscores the imperative for researchers to name and interrogate power differentials at play (Williams and Gilbert, 2019; Kinnula and Iivari, 2021; Zavala, 2016). More than an acknowledgement of inequalities, this requires researchers to directly confront power differentials throughout the research process. This can include critical examination of outcomes and whom they benefit (Williams and Gilbert, 2019; Reindl *et al.*, 2022). Extending critical pedagogy principles, transformative collaboration entails the formation of critical consciousness where participants not only reflect upon their lived realities, but reimagine and transform them (Freire, 1970; Reindl *et al.*, 2022). The overarching objective of the framework is to foster collaborative partnerships that lead to social transformation (Freire, 1970; Williams and Gilbert, 2019; Reindl *et al.*, 2022). The framework can be applied in design-based research settings, including those involving educational design.

The framework of transformative collaboration encompasses four cumulative stages. As illustrated in Figure 1, each stage is connected by arrows that show the progression of the overall framework wherein each stage necessitates the prior to advance to the subsequent stage. The first stage (uplifting and extending experiential knowledge) entails producing knowledge grounded in participants' lived experiences. This step requires researchers to challenge dominant conceptualizations of knowledge, and center knowledge based on lived experience (Cammarota and Romero, 2009; Chinn and Pelletier, 2020; Ymous *et al.*, 2020). This can be carried out through the participant-led development of research activities and themes, particularly with concern to those that are relevant to participants' own lives.



Source: Figure by author

Figure 1. The four-stage framework of transformative collaboration

The second stage (naming inequalities and power imbalances) concerns attunement to "power differentials in participatory praxis" (Williams and Gilbert, 2019, p. 118). Researchers should acknowledge the power that they hold, and foster open and inclusive dialogue concerning differences among participants and researchers (Williams and Gilbert, 2019; Kinnula and Iivari, 2021). As such, this step extends the principle of dialogue within critical pedagogy. Dialogue requires equitable engagement among participants. This departs from the "banking" approach to education critiqued by Freire, wherein teachers are all-knowing, disciplinarian authorities and students are passive receivers of their knowledge (Freire, 1970; Williams and Gilbert, 2019; Miller and Hafner, 2008; Reindl *et al.*, 2022). The "banking" approach often reveals itself in research practices where researchers extract data from participants with otherwise limited engagement (Williams and Gilbert, 2019). To counteract this, researchers can share results with participants and include participants as co-authors of publications. Maintaining an environment that is "open and explicit" about power differentials makes the following step of conscientization possible (Kinnula and Iivari, 2021, p. 10). Moreover, the third stage of transformative collaboration refers to conscientization wherein participants reflect on their lived experiences to change their realities through praxis. As defined by Freire, praxis is the combination of reflection and action that directly follows conscientization (Reindl *et al.*, 2022; Freire, 1970). In design-based research, this can be implemented through activities that enhance dialogue, agency, and shared reflection that encourage participants and researchers alike to critically examine their positionalities (Reindl *et al.*, 2022; Spiel *et al.*, 2019).

Conscientization requires more than an understanding of how one's subjecthood is shaped by oppression; it necessitates the dismantling oppression through social transformation. Social transformation is the fourth and final stage of the transformative collaboration framework. Williams and Gilbert (2019) note that social transformation is fostered in research practices that situate disability communities and their contributions at the forefront, with the overarching objective of ending oppression. Social transformation is enabled by practices grounded in accountability, which interrogate unequal power dynamics that infiltrate research partnerships. Examples of research practices that engender social transformation include those that center communal concerns and encourage active dialogue and negotiation with participants throughout the research process (Williams and Gilbert, 2019; Kinnula and Iivari, 2021; Reindl *et al.*, 2022*)*. Altogether, these practices underscore how design-based research provides opportunities to "desettle" interconnected norms and assumptions around knowledge production (Zavala, 2016). In essence, the literature-based framework of transformative collaboration works toward the empowerment, inclusion, and best interests of those who have been—for far too long—ignored and harmed by researchers.

10. Conclusion

Taken together, participatory research methods and critical pedagogy provide useful frameworks for disabled peoples' participation in educational design and research practices. In existing participatory research with disabled people, power imbalances and assumptions about disabled peoples' capacities and knowledge abound. While there are issues inherent in both participatory design and critical pedagogy, they allow for the genuine participation of disabled people in the research process. The proposed framework of transformative collaboration connects theories from participatory research with principles of critical pedagogy to challenge deficit thinking and draw upon often-overlooked forms of knowledge (Cammarota and Romero, 2009; Miskovic and Hoop, 2006; Liasidou, 2012; Reindl *et al.*, 2022). Transformative collaboration draws from

critical pedagogy and participatory research practices in its acknowledgement of collective knowledge-building as integral to social transformation. Importantly, transformative collaboration is an inherently political approach to research as it is concerned with relations of power and participants' empowerment. These are also crucial concerns within disability studies, and have yet to be examined together with participatory and critical pedagogy approaches. While there are few examples in the literature that bring together critical pedagogy, participatory research approaches, and disability studies, a combined approach has the potential to radically transform multiple realms of research.

Notes

1. The author is a graduate student with cerebral palsy who uses identity-first language to refer to themselves, as they understand disability as a political orientation that is integral to their identity. As such, the author uses identity-first language throughout the article. Within disability communities, there are varying perspectives regarding identity-first language (i.e., "disabled people") and people-first language (i.e., "people with disabilities"). Recent studies on the topic note that language preference varies at the individual and community levels (Bury *et al.*, 2023; Sharif *et al.*, 2022). Sharif *et al.* 2022 also note that preferences differ throughout disabilities, age groups, and gender identities.
2. Journals incorporated into the review include: *Counterpoints, Cognition and Instruction, International Journal of Inclusive Education, International Journal of Social Research Methodology, Journal of Critical Pedagogy, Multicultural Education, Qualitative Inquiry, Theory Into Practice, Transactions on Computer-Human Interaction,* and *The Urban Review,* among others.

References

Aceves, T.C. (2014), "Supporting latino families in special education through community agency-school partnerships", *Multicultural Education*, Vol. 21 Nos 3/4, pp. 45-50.

Alemán, E., Freire, J.A., McKinney, A. and Delgado Bernal, D. (2017), "School–university–community pathways to higher education: teacher perceptions, school culture and partnership building", *The Urban Review*, Vol. 49 No. 5, pp. 852-873, doi: 10.1007/s11256-017-0424-y.

Arksey, H. and O'Malley, L. (2005), "Scoping studies: towards a methodological framework", *International Journal of Social Research Methodology*, Vol. 8 No. 1, pp. 19-32, doi: 10.1080/1364557032000119616.

Baldwin, M.S., Hirano, S.H., Mankoff, J. and Hayes, G.R. (2019), "Design in the public square: Supporting assistive technology design through public mixed-ability cooperation", *Proceedings of the ACM on Human-Computer Interaction*, Vol. 3 No. CSCW, pp. 1-22.

Bang, M., Warren, B., Rosebery, A.S. and Medin, D. (2013), "Desettling expectations in science education", *Human Development*, Vol. 55 Nos 5/6, pp. 302-318.

Barbareschi, G. and Inakage, M. (2022), "Assistive or artistic technologies? Exploring the connections between art, disability and wheelchair use", *Proceedings of the 24th International ACM SIGACCESS Conference on Computers and Accessibility*, pp. 1-14, doi: 10.1145/3517428.3544799

Bennett, C.L. and Rosner, D.K. (2019), "The promise of empathy: design, disability, and knowing the 'other'", *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, pp. 1-13.

Bennett, C.L., Brady, E. and Branham, S.M. (2018), "Interdependence as a frame for assistive technology research and design", *Proceedings of the 20th International ACM SIGACCESS Conference on*

Computers and Accessibility, ASSETS '18, *New York, NY*, Association for Computing Machinery, pp. 161-173, doi: 10.1145/3234695.3236348.

Bentley, J.K.C. (2008), "Lessons from the 1%: children with labels of severe disabilities and their peers as architects of inclusive education", *International Journal of Inclusive Education*, Vol. 12 Nos 5/6, pp. 543-561, doi: 10.1080/13603110802377599.

Brulé, E. and Spiel, K. (2019), "Negotiating gender and disability identities in participatory design", *Proceedings of the 9th International Conference on Communities and Technologies-Transforming Communities*, pp. 218-227.

Bury, S.M., Jellett, R., Haschek, A., Wenzel, M., Hedley, D. and Spoor, J.R. (2023), "Understanding language preference: autism knowledge, experience of stigma and autism identity", *Autism*, Vol. 27 No. 6, pp. 1588-1600, doi: 10.1177/13623613221142383.

Cammarota, J. and Romero, A.F. (2009), "A social justice epistemology and pedagogy for Latina/o students: transforming public education with participatory action research", *New Directions for Youth Development*, Vol. 2009 No. 123, pp. 53-65, doi: 10.1002/yd.314.

Castrodale, M.A. (2017), "Critical disability studies and mad studies: enabling new pedagogies in practice", *Canadian Journal for the Study of Adult Education*, Vol. 29 No. 1, pp. 49-66.

Chinn, D. and Pelletier, C. (2020), "Deconstructing the co-production ideal: dilemmas of knowledge and representation in a co-design project with people with intellectual disabilities", *Journal of Intellectual and Developmental Disability*, Vol. 45 No. 4, pp. 326-336.

Costanza-Chock, S. (2020), "Design practices: 'nothing about Us without Us'", *Design Justice*, MIT Press, Cambridge, MA.

De Schauwer, E., *et al.* (2009), "'I need help on mondays, it's not My day. The other days, I'm OK'.—perspectives of disabled children on inclusive education", *Children and Society*, Vol. 23 No. 2, pp. 99-111, doi: 10.1111/j.1099-0860.2008.00159.x.

Duncan-Andrade, J.M. and Morrell, E. (2008), "Youth participatory action research as critical pedagogy", *Counterpoints*, Vol. 285, pp. 105-131.

Foth, M. and Axup, J. (2006), "Participatory design and action research: Identical twins or synergetic pair?", *Expanding Boundaries in Design: Proceedings Ninth Participatory Design Conference 2006*, Vol. 2, Computer Professionals for Social Responsibility, pp. 93-96.

Freire, P. (1970), *Pedagogy of the Oppressed*, Continuum Publishing, New York, NY.

Goodley, D. (2013), "Dis/entangling critical disability studies", *Disability and Society*, Vol. 28 No. 5, pp. 631-644, doi: 10.1080/09687599.2012.717884.

Hamraie, A. and Fritsch, K. (2019), "Crip technoscience manifesto", *Catalyst: Feminism, Theory, Technoscience*, Vol. 5 No. 1, pp. 1-33, doi: 10.28968/cftt.v5i1.29607.

Harrington, C.N., Erete, S. and Piper, A.M. (2019), "'Deconstructing community-based collaborative design: towards more equitable participatory design engagements", Proceedings of the ACM on Human-Computer Interaction (CSCW), pp. 216:1-216:25, doi: 10.1145/3359318.

Harrington, C.N., Desai, A., Lewis, A., Moharana, S., Ross, A.S. and Mankoff, J. (2023), "Working at the intersection of race, disability and accessibility", *proceedings of the 25th International ACM SIGACCESS Conference on Computers and Accessibility*, pp. 1-18, doi: 10.1145/3597638.3608389

Hayes, G.R. (2011), "The relationship of action research to human-computer interaction", *ACM Transactions on Computer-Human Interaction*, Vol. 18 No. 3, pp. 1-20, doi: 10.1145/1993060.1993065.

Hayes, G.R. (2020), "Inclusive and engaged HCI", *Interactions*, Vol. 27 No. 2, pp. 26-31, doi: 10.1145/3378561.

Hofmann, M., Kasnitz, D., Mankoff, J. and Bennett, C.L. (2020), "Living disability theory: reflections on access, research, and design", *Proceedings of the 22nd International ACM SIGACCESS Conference on Computers and Accessibility*, pp. 1-13, doi: 10.1145/3373625.3416996

Hussain, S., Sanders, E.B.N. and Steinert, M. (2012), "Participatory design with marginalized people in developing countries: challenges and opportunities experienced in a field study in Cambodia", *International Journal of Design*, Vol. 6 No. 2, pp. 91-109, available at: www.ijdesign.org/index.php/IJDesign/article/view/1054

Kensing, F. and Blomberg, J. (1998), "Participatory design: issues and concerns", *Computer Supported Cooperative Work (CSCW)*, Vol. 7, pp. 167-185.

Kinnula, M. and Iivari, N. (2021), "Manifesto for children's genuine participation in digital technology design and making", *International Journal of Child-Computer Interaction*, Vol. 28, p. 100244, doi: 10.1016/j.ijcci.2020.100244.

Kuhn, S. and Muller, M.J. (1993), "Participatory design", *Communications of the ACM*, Vol. 36 No. 6, pp. 24-29.

Liasidou, A. (2012), "Inclusive education and critical pedagogy at the intersections of disability, race, gender and class", *Journal for Critical Education Policy Studies (JCEPS)*, Vol. 10 No. 1, pp. 168-184.

McDonald, K.E. and Stack, E. (2016), "You say you want a revolution: an empirical study of community-based participatory research with people with developmental disabilities", *Disability and Health Journal*, Vol. 9 No. 2, pp. 201-207, doi: 10.1016/j.dhjo.2015.12.006.

Mankoff, J., Hayes, G.R. and Kasnitz, D. (2010), "Disability studies as a source of critical inquiry for the field of assistive technology", *Proceedings of the 12th International ACM SIGACCESS Conference on Computers and Accessibility*, pp. 3-10.

Martin, G.P. (2008), "'Ordinary people only': knowledge, representativeness, and the publics of public participation in healthcare", *Sociology of Health and Illness*, Vol. 30 No. 1, pp. 35-54, doi: 10.1111/j.1467-9566.2007.01027.x.

Meissner, J.L., Vines, J., McLaughlin, J., Nappey, T., Maksimova, J. and Wright, P. (2017), "Do-it-yourself empowerment as experienced by novice makers with disabilities", *Proceedings of the 2017 Conference on Designing Interactive Systems*, pp. 1053-1065, doi: 10.1145/3064663.3064674.

Miller, P.M. and Hafner, M.M. (2008), "Moving toward dialogical collaboration: a critical examination of a university—school—community partnership", *Educational Administration Quarterly*, Vol. 44 No. 1, pp. 66-110, doi: 10.1177/0013161X07309469.

Minkler, M., Fadem, P., Perry, M., Blum, K., Moore, L. and Rogers, J. (2002), "Ethical dilemmas in participatory action research: a case study from the disability community", *Health Education and Behavior*, Vol. 29 No. 1, pp. 14-29, doi: 10.1177/109019810202900104.

Miskovic, M. and Hoop, K. (2006), "Action research meets critical pedagogy: theory, practice, and reflection", *Qualitative Inquiry*, Vol. 12 No. 2, pp. 269-291, doi: 10.1177/1077800405284367.

Moll, L.C., Amanti, C., Neff, D. and Gonzalez, N. (1992), "Funds of knowledge for teaching: using a qualitative approach to connect homes and classrooms", *Theory into Practice*, Vol. 31 No. 2, pp. 132-141, doi: 10.1080/00405849209543534.

Parker, A.T., Schalock, M., Steele, N., Chopra, R., Cook, L., Sobel, D., Kennedy, B., Monaco, C. and Zobel, G. (2017), "Participatory curriculum development to meet community needs: open hands, open access: deaf-blind intervener learning modules", *DBI Review*, Vol. 58, pp. 69-73.

Reindl, M.-S., Schippers, A. and Hove, G.V. (2022), "From object to subject: a call for the radicalization of participatory community development in The Netherlands", *The International Journal of Critical Pedagogy*, Vol. 12 No. 1, pp. 77-98, available at: http://libjournal.uncg.edu/ijcp/article/view/1659 (accessed 23 October 2022).

Reynolds, R., Chu, S., Ahn, J., Buckingham Shum, S., Hansen, P., Haythornthwaite, C., Huang, H., Meyers, E.M. and Rieh, S.Y. (2019), "Inaugural issue perspectives on information and learning sciences as an integral scholarly nexus", *Information and Learning Sciences*, Vol. 120 Nos 1/2, pp. 2-18, doi: 10.1108/ILS-01-2019-138.

Schwartz, A.E., Kramer, J.M., Cohn, E.S. and McDonald, K.E. (2020), "'That felt like real engagement': fostering and maintaining inclusive research collaborations with individuals with intellectual disability", *Qualitative Health Research*, Vol. 30 No. 2, pp. 236-249, doi: 10.1177/1049732319869620.

Scott, M.A., Pyne, K.B. and Means, D.R. (2015), "Approaching praxis: YPAR as critical pedagogical process in a college access program", *The High School Journal*, Vol. 98 No. 2, pp. 138-157, doi: 10.1353/hsj.2015.0003.

Sharif, A., McCall, A.L. and Bolante, K.R. (2022), "Should I say 'disabled people' or 'people with disabilities'? language preferences of disabled people between identity- and Person-First language", *Proceedings of the 24th International ACM SIGACCESS Conference on Computers and Accessibility*, pp. 1-18, doi: 10.1145/3517428.3544813

Sharma, S., Achary, K., Kinnula, M., Norouzi, B., Kinnula, H., Iivari, N., Ventä-Olkkonen, L. and Holappa, J. (2022), "To empower or provoke? Exploring approaches for participatory design at schools for neurodiverse individuals in India", *International Journal of Child-Computer Interaction*, Vol. 34, p. 100521, doi: 10.1016/j.ijcci.2022.100521.

Spiel, K. and Angelini, R. (2022), "Expressive bodies engaging with embodied disability cultures for collaborative design critiques", *Proceedings of the 24th International ACM SIGACCESS Conference on Computers and Accessibility*, pp. 1-6, doi: 10.1145/3517428.3551350

Spiel, K., Frauenberger, C., Keyes, O. and Fitzpatrick, G. (2019), "Agency of autistic children in technology research—a critical literature review", *ACM Transactions on Computer-Human Interaction (TOCHI)*, Vol. 26 No. 6, pp. 1-40, doi: 10.1145/3344919.

Spiel, K., Gerling, K., Bennett, C.L., Brulé, E., Williams, R.M., Rode, J. and Mankoff, J. (2020), "Nothing about us without us: Investigating the role of critical disability studies in HCI", *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems, New York, NY*, Association for Computing Machinery, (CHI EA '20), pp. 1-8, doi: 10.1145/3334480.3375150.

Spiel, K., Hornecker, E., Williams, R.M. and Good, J. (2022), "ADHD and technology research–investigated by neurodivergent readers", *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems*, pp. 1-21, doi: 10.1145/3491102.3517592.

Stack, E.E. and McDonald, K. (2018), "We are 'both in charge, the academics and Self-Advocates': empowerment in community-based participatory research", *Journal of Policy and Practice in Intellectual Disabilities*, Vol. 15 No. 1, pp. 80-89, doi: 10.1111/jppi.12236.

Standley, K., Sage, R., Hargrove, T., Willard, M., Boehm Barrett, T., Ender, J. and Ravesloot, C. (2022), "Participatory curriculum development for health and independent living for disabled people: a qualitative study of participant experiences", *Disability and Society*, pp. 1-23, doi: 10.1080/09687599.2022.2087489.

University of Montana Rural Institute (2020), "Creating educational opportunities for independent living through participatory curriculum development: a toolkit for centers for independent living", pp. 1-65, available at: https://scholarworks.umt.edu/ruralinst_health_wellness/52

Valencia, R.R. and Solórzano, D.G. (1997), "'Contemporary deficit thinking", in Valencia, R.R. (Ed.), *The Evolution of Deficit Thinking: Educational Thought and Practice*, The Falmer Press, London, pp. 160-210.

Vaughn, L.M. and Jacquez, F. (2020), "Participatory research methods–choice points in the research process", *Journal of Participatory Research Methods*, Vol. 1 No. 1, p. 13244.

Williams, R.M. and Boyd, L.E. (2019), "Prefigurative politics and passionate witnessing", *Proceedings of the 21st International ACM SIGACCESS Conference on Computers and Accessibility*, pp. 262-266, doi: 10.1145/3308561.3355617.

Williams, R.M. and Gilbert, J.E. (2019), "Nothing about us without us: transforming participatory research and ethics in human systems Engineering", *Advancing Diversity, Inclusion, and Social Justice through Human Systems Engineering*, CRC Press, Boca Raton, pp. 113-134.

Williams, R.M. and Park, C. (2023), "Cyborg assemblages: how autistic adults construct sociotechnical networks to support cognitive function", *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems*, pp. 1-15, doi: 10.1145/3544548.3581556.

Wobbrock, J.O., Kane, S.K., Gajos, K.Z., Harada, S. and Froehlich, J. (2011), "Ability-based design: concept, principles and examples", *ACM Transactions on Accessible Computing*, Vol. 3 No. 3, pp. 1-27, doi: 10.1145/1952383.1952384.

Ymous, A., Spiel, K., Keyes, O., Williams, R.M., Good, J., Hornecker, E. and Bennett, C.L. (2020), "'I am just terrified of my future' epistemic violence in disability related technology research", *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems*, *New York, NY*, Association for Computing Machinery, (CHI EA '20), pp. 1-16, doi: 10.1145/3334480.3381828.

Zavala, M. (2016), "Design, participation, and social change: what design in grassroots spaces can teach learning scientists", *Cognition and Instruction*, Vol. 34 No. 3, pp. 236-249, doi: 10.1080/07370008.2016.1169818.

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