FROM INSIDER/OUTSIDER IDENTITY TO COLLECTIVE OPPRESSION/LIBERATION: NAVIGATING POSITIONALITY IN DISABILITY RESEARCH

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ABSTRACT

The primacy of experiential knowledge is an undisputed foundation of disability activism and scholarship. Identity politics and intersectionality draw attention to the limited range of voices, interests and experiences represented in first wave disability organizing. Meanwhile, an emergent second wave urges a shift in focus from disabled identity to the interconnected systems of domination and exploitation that shape our embodied experience. Through critically reflexive interrogation of the author's amorphous positionality, as a neurodivergent but otherwise non-disabled care worker turned health professional and disability scholar, this paper explores the relationship between disabled identity, membership in disability culture and experiential knowledge. A relational understanding of disability opens space to consider the legitimacy and value of disability-adjacent identities and perspectives. Limitations of participatory methodological approaches are considered and the emancipatory potential of reflexive ethnographic methodology is discussed.

KEYWORDS
Positionality; Intersectionality; Disability Studies; Reflexive Ethnography; Experiential Knowledge.

DA IDENTIDADE INTERNA/EXTERNA À OPRESSÃO/LIBERTAÇÃO COLETIVA: NAVEGANDO NA POSICIONALIDADE NA PESQUISA SOBRE DEFICIENCIA

RESUMO

A primazia do conhecimento experimental é um fundamento indiscutível do ativismo e da pesquisa sobre deficiência. A política de identidade e a interseccionalidade chamam a atenção para a gama limitada de vozes, interesses e experiências representadas na primeira onda de estudos sociais da deficiência. Enquanto isso, uma segunda onda emergente exige uma mudança de foco da identidade de pessoas com deficiência para os sistemas interconectados de dominação e exploração que moldam nossa experiência corporificada. Por meio de um questionamento criticamente reflexivo da posicionalidade amorfa da autora, como cuidadora neurodivergente, mas não sendo uma pessoa com deficiência, que se tornou profissional de saúde e pesquisadora da deficiência, este artigo explora a relação entre identidade com a deficiência, participação na cultura da deficiência e conhecimento experiencial. Uma compreensão relacional da deficiência abre espaço para considerar a legitimidade e o valor das identidades e perspectivas adjacentes à deficiência. Consideram-se as limitações das abordagens metodológicas participativas e discute-se o potencial emancipatório da metodologia etnográfica reflexiva.

PALAVRAS-CHAVE
Posicionalidade; Interseccionalidade; Estudos da Deficiência; Etnografia Reflexiva; Conhecimento Experiencial.

DE L'IDENTITÉ D'INITIÉ/ÉTRANGER À L'OPPRESSION/LIBÉRATION COLLECTIVE: NAVIGUER DANS LA POSITIONNALITÉ DANS LA RECHERCHE SUR LE HANDICAP

RÉSUMÉ

La primauté de la connaissance expérientielle est un fondement incontesté de l'activisme et de l'érudition des personnes handicapées. La politique identitaire et l'intersectionnalité attirent l'attention sur l'éventail limité de voix, d'intérêts et d'expériences représentés dans la première vague de l'organisation des personnes handicapées. Pendant ce temps, une deuxième vague émergente appelle à un changement d'orientation de l'identité handicapée vers les systèmes interconnectés de domination et d'exploitation qui façonnent notre expérience incarnée. À travers une interrogation réflexive critique de la position amorphe de l'auteur, en tant que travailleur de soins neurodivergent mais autrement non handicapé, devenu professionnel de la santé et spécialiste du handicap, cet article explore la relation entre l'identité handicapée, l'appartenance à la culture du handicap et les connaissances expérientielles. Une compréhension relationnelle du handicap ouvre un espace pour considérer la légitimité et la valeur des identités et des perspectives adjacentes au handicap. Les limites des approches méthodologiques participatives sont examinées et le potentiel émancipateur de la méthodologie ethnographique réflexive est discuté.

MOTS-CLÉS

Positionnalité; Intersectionnalité; Études sur le handicap; Ethnographie reflexive; Savoir Expérientiel.

DE LA IDENTIDAD ENTERADA/FORASTERA A LA OPRESIÓN/LIBERACIÓN COLECTIVA: NAVEGANDO POR LA POSICIONALIDAD EN LA INVESTIGACIÓN SOBRE DISCAPACIDAD

RESUMEN

La primacía del conocimiento experiencial es una base indiscutible del activismo y la erudición sobre la discapacidad. Las políticas de identidad y la interseccionalidad llaman la atención sobre la gama limitada de voces, intereses y experiencias representadas en la primera ola de organización de personas con discapacidad. Mientras tanto, una segunda ola emergente insta a un cambio de enfoque de la identidad de la discapacidad a los sistemas interconectados de dominación y explotación que dan forma a nuestra experiencia encarnada. A través de una interrogación críticamente reflexiva de la posición amorfa del autor, como un cuidador neurodivergente pero sin discapacidad convertido en profesional de la salud y estudioso de la discapacidad, este artículo explora la relación entre la identidad discapacitada, la pertenencia a la cultura de la discapacidad y el conocimiento experiencial. Una comprensión relacional de la discapacidad abre espacio para considerar la legitimidad y el valor de las identidades y perspectivas adyacentes a la discapacidad. Se consideran las limitaciones de los enfoques metodológicos participativos y se discute el potencial emancipador de la metodología etnográfica reflexiva.

PALAVRAS CLAVE

Posicionalidad; Interseccionalidad; Estudios de la Discapacidad; Etnografía Reflexiva; Conocimiento Experiencial.

"We believe that the most profound and potentially most radical politics come directly out of our own identity, as opposed to working to end somebody else's oppression" (COMBAHEE RIVER COLLECTIVE, 1977)

"The true focus of revolutionary change is never merely the oppressive situations that we seek to escape, but that piece of the oppressor which is planted deep within each of us" (AUDRE LORDE, 2007 [1984])

INTRODUCTION

For five years prior to the commencement of my graduate education and ongoing throughout the process, I worked as a personal care attendant to a small number of physically disabled women who organize and manage their own support services. In Ontario, Canada direct-funded attendant services[1] offers an alternative to conventional agency-managed supports. The model empowers individual service users to customize their attendant care by taking direct responsibility to recruit, hire, train and schedule their staff. From my employers, I *heard* a fairly consistent narrative of praise for this arrangement: direct funding facilitated increased autonomy through an unparalleled opportunity to distance their everyday lives from the institutionalized structure, supervision and paternalistic guidance of agency-managed supports. Oftentimes, what I *saw* and *felt* from my attendant perspective cohered with this optimistic view. At other times, however, I witnessed and experienced this arrangement from another vantage, observing the cognitive and emotional resources, energy and time poured into the mundane tasks of organizing and managing a team of attendants. Sharing in the stresses of life lived with an extra layer of unpredictability, with the potential to affect everything from physical comfort and well-being to social participation and relationships, led me to focus my dissertation on the "invisible work" service users, their attendants and support systems do to organize and manage direct-funded attendant care (KATZMAN; KINSELLA, 2018; KATZMAN; KINSELLA; POLZER, 2019).

At the outset of my dissertation, I forayed into disability studies and learned that a service-user led independent living movement had laid groundwork for the direct funding model (YOSHIDA; WILLI; PARKER; LOCKER, 2004). I also learned about the role researchers, particularly in health sciences and social services, have played in the historical and ongoing objectification, medicalization and essentialization of disability and disabled people (LINTON, 1998). I heard a clear call for research lead by disabled people (STONE; PRIESTLY, 1996) and,

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[1] In different geographic and policy contexts, variations of direct funded or self-managed supports are also called personal assistance, cash-for-care, individualized, self-directed, or personalized attendant services.

recognizing my positionality as a non-disabled[2] researcher come to study the experiences of disabled people, began to question the appropriateness of the role I had stepped into. I sought answers in literature on critical and emancipatory research and proceeded with a reflexive ethnographic methodology. I was guided throughout the project by returning constantly to the disability rights edict *nothing about us without us*. One unanticipated outcome of this approach was critical interrogation of who is included in the proverbial *us*: in other words, whose lived experience counts? In this paper I ground a discussion on the intersectional and amorphous nature of positionality and its relationship to knowledge production in reflections on my journey from personal care attendant to critical disability scholar.

LIFE WITH DEB: MY INTRODUCTION TO CARE WORK AND DISABILITY CULTURE

As a non-disabled arts and humanities undergraduate student, I knew very little about living with disability and even less about the world of support work—both of which would soon become inextricable parts of my everyday life and being. In October of 2006, Deb[3], a woman with a high-level spinal cord injury, hired me to work for her as a personal care attendant. While completing my degree, I was also learning my way around a new world; one at times seamlessly integrated with the non-disabled world around it, and at other times contrasting sharply. In many ways, attendant support communities function as distinctive subcultures in which lifeworlds are navigated a little bit differently than in the dominant culture. Deb and the team of attendants she hand-picked and trained to understand the intricacies of her body and social context collaborated to show me the way. Deb would describe, explain, instruct, or direct an attendant to demonstrate a particular routine or skill. She allowed the other attendants to fill in the gaps, and occasionally another attendant would pull me aside to quietly share tips. This

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[2] Throughout this this paper, I share reflections on my evolving understanding of and relationship to disabled identity. As someone who lives with episodic symptoms, and for whom success with various forms of treatment have decreased the frequency with which I meet diagnostic criteria, I find myself identifying with disability in a complicated way. In keeping with cultural conventions shaped by binary logic, I am accustomed to identifying myself as non-disabled. Through engagement with disability activism and scholarship, however, I have begun to question my reflexive (automatic or compulsory) self-identification as non-disabled. Thinking with theories of liminal disability identity, such as Brueggemann's (2008) "betweenity" and Kafer's (2013) "crip affiliation", I am increasingly unconvinced that not identifying as disabled automatically renders one non-disabled.

[3] Pseudonym.

inculturation was never complete; forever a student in this increasingly familiar but always strange world[4], I became part of a community that centred around my employer.

During these years, I spent hours each day with a woman twice my age who was sage and savvy, clever and kind, who had known real struggle in her life, yet lived with immense privilege, of which she was acutely aware. Deb was injured as a teenager in the 1980s. Her story, of a young, white woman paralyzed by a random act of gun violence in the suburbs outside a large Canadian city made headlines. Deb's became a household name and an outpouring of public support left her with resources enough to support a comfortable life, including funding to purchase many more supports than the publicly funded health care system provides. Having grown up in a low-income, single-parent household and coming into financial means as an adult, Deb was extraordinarily generous. On top of a fulltime job and the work she did to manage her attendant care, she lent time to executive boards and social capital to various causes; she spoke at events and donated abundantly to fundraisers; she made efforts to take good care of her staff, inviting us to share meals, supplementing our income with small gifts or occasional help (i.e., recognizing the physically demanding nature of the work I did for her while earning relatively low income and no health benefits, she paid for a few sessions of physiotherapy and massage after I injured myself on the job), lending her vehicle, and occasionally extending invitations to join in social events. In twenty-some years of relying on other people to support her physical mobility, Deb had mastered the arts of relationship and communication. By her side, I learned about people, about the complexities of relationships, and about myself. I learned about disability: technical knowledge about wheelchairs and other assistive technology, about manual transfers, and mechanical lifts, about the human body, its bowels, bladders, and skin. More significantly, though, I learned about the nuances of life with disability, the challenges of living within often-unaccommodating physical and social environments, and the inadequacy of my knowledge of disability hitherto.

Attendant care became my first full-time job, the first time I was able to save and spend money, to achieve some financial independence. My father, the child of Russian Jewish immigrants, and my mother, the first in her white settler family to achieve a postsecondary degree, earned enough to provide many comforts to my siblings and me. They maintained financial stability in part by choosing to live and work in a small, politically conservative, and

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[4] My use of "familiar" and "strange" is an intentional reference to the sociological/anthropological maxim "to make the familiar strange". This word play nods to my complex positionality, as a becoming-insider to a new culture. The differences between Deb's world and mine are sometimes non-existent and at other times pronounced. What I encounter as strangeness (unfamiliarity) in her world also serves to unsettle taken-for-granted familiarities in my own world, suddenly apparent (or rendered strange) through encounter with an unfamiliar alternative.

predominantly Christian city. Growing up queer and neurodivergent in this context, I was well acquainted with feelings of difference and non-belonging; feelings that followed me when I moved to a large urban centre to study at a prestigious university. When Deb hired me, she explained that she preferred to employ open-minded young people instead of health professionals who had been trained to see themselves as experts where disability, care and her body were concerned. My lacking knowledge of disability, and the survival skills I had refined in my own life—downplaying or hiding aspects of my identity, masking my neurodivergent traits, people pleasing and minimizing my own needs—were valuable in this context. Moving through the world at Deb's side, carefully positioned outside of her spotlight but always within earshot, brought exciting opportunities for travel to new cities and across social realms. I was constantly meeting new people, a curious mix of those with high social status (doctors, researchers, politicians, professional artists, radio and television personalities) and care workers (precariously employed women and/or femmes, many queer and/or people of colour, some immigrants, most all representing lower socioeconomic classes).

Not yet aware of disability studies, though increasingly familiar with disability politics and activism, I began to recognize a chasm between common perceptions about both care work and disability, and the ways in which I had come to understand them through experience. Though manifesting in innumerable forms, this disconnect was perhaps most pronounced when people in my life would commend what they construed as the "benevolent" work I was doing "caring for" a disabled person. Equally fascinated and infuriated, I was struck by the wild inaccuracy of their assumption that Deb was helplessly dependent on my generosity. Deb not only lived a full life but, in many ways, lived with more privilege than me or even *them*; family, friends and acquaintances of mine, knowing very little about Deb's life, would at worst make cliché comments like "I'd rather die than live like that". The unusual character of the employer-attendant relationship (KELLY, 2013) created a "rare opportunity" for me as a non-disabled person to see beyond pervasive cultural constructions and stereotypes about disability; to appreciate Deb's full and complex humanity (WEDGEWOOD *et al.*, 2018). Recognizing the intricacy of the power dynamics that operated through our relationship, including the reciprocal nature of care, I began to understand myself less as Deb's non-disabled helper and more as part of a "dyad" (HUGHES; MCKIE; HOPKINS; WATSON, 2005).

WHO KNOWS? EXPERIENTIAL KNOWLEDGE IN (EMANCIPATORY) DISABILITY RESEARCH

Beginning my graduate education under the supervision of Dr. Elizabeth Anne Kinsella, a health professional scholar well-versed in feminist literature and passionate about

epistemology, I learned about positionality as it relates to the situatedness of knowledge (HARDING, 1991). Dr. Kinsella encouraged and supported me to theorize embodied reflexivity (KATZMAN, 2015) as a path of access to recognize, communicate, and legitimize the experiential knowledge of attendant care that shaped my doctoral work. Soon thereafter, I became conflicted as I encountered a different take on positionality in disability studies. While feminist epistemological literature touted the subversive value of my gender minority standpoint, from disability studies I sensed deep suspicion if not outright disavowal of my perspective. I internalized the message that mine was the wrong kind of lived experience: I was a care worker, an attendant and, by that time, a health professional trainee, living with no apparent disabilities and experiencing related privilege. Plagued by a chronic sense of non-belonging in disability studies, I took exceptional care to craft a methodological approach that balanced arguments for and critiques of participatory approaches (BARNES, 2009; LENNIE; HATCHER; MORGAN, 2003). Given my research focus on invisible work, I was concerned about the time and energy participatory methods would demand of participants. Recognizing the value of research participants' contributions, I was not confident I would have sufficient resources to compensate people fairly for their contributions. With some skepticism, I contemplated whether it was truly possible to shed the powerful influence of my status as an institutionally affiliated researcher, and whether there was time to do participatory research well within the limitations of a doctoral study.

Trepidatious, I proceeded with a reflexive ethnographic methodology that enabled me to "use [my] own experiences in the culture reflexively to bend back on self and look more deeply at self-other interactions" (ELLIS; BOCHNER, 2003, p. 211). I adopted reflexivity as a principle to guide "a continuous process of critical scrutiny" (GUILLEMIN; GILLAM, 2004, p. 275) of operations of power throughout the research process; "a scientific approach that challenges the status quo" (O'BYRNE, 2007, p. 1387) and a means "to achieve the goals of emancipation that are intrinsic to qualitative research conducted within a critical paradigm" (McCABE; HOLMES, 2009, p. 1518) through the "illumination" of "dominating truths" (p. 1522). I used reflexive journaling to support transparency: to situate myself as an attendant, friend, and ally to several individuals who use attendant services; to interrogate my positionality as "a non-disabled person holding certain cultural assumptions about disability" (MORRIS, 1992, p. 159); to identify individual and social factors shaping the research process; and to engage in ongoing consideration of my contextual sensitivity to participant perspectives. Recognizing the inevitable multiplicity and partiality of all perspectives (LATHER, 2007; RICHARDSON, 1994), I conducted interviews with stakeholders in different relationships to direct funding: service users

(11), attendants (3), other support people (3), and program administrators (2). I was guided by emancipatory research principles (STONE; PRIESTLY, 1996; MORRIS, 1992) and returned constantly to the refrain, *nothing about us without us.*

While concerns about research process were forefront at this time, I was simultaneously dealing with my own bodymind. Like many before me (if not most? if not all?), I struggled a great deal through the process of completing my dissertation. The physical and psychological stress at some point became too much for me to navigate on my own. I sought help and was treated first for depression, then anxiety, then an eating disorder. I managed to keep up with my work for the most part, but as I tried out medications and therapies, took time to see specialists and attended support groups, I began to recognize a dire need to find space and time—to dedicate personal resources—towards my physical and mental health care. I considered taking a leave from the dissertation but, amid data collection, feared the potential consequences of delaying the doctoral process further; not to mention reservations surrounding disclosure. As I sat and talked with research participants during this time, I felt a visceral resonance with their stories: descriptions of the disability-related work of navigating health care systems, of taking time to tend to bodily needs, of curating supportive social networks, and of navigating sometimes unsafe social worlds. I recognized a parallel between their accounts and something in my own lived experience, a deep understanding of what it is like to live with a sometimes-challenging bodymind. I began to grapple with a new question related to those words, still etched into my consciousness: *nothing about us without us.* Who, I began to wonder, is *us?*

De-essentializing 'Us': Beyond binary (disabled) identity

The use of *us* in the famous disability rights edict evokes disability. Specifically, it is an appeal to centre disabled voices and perspectives, which have historically been excluded from disability-related policy (CHARLTON, 2000). The binary logic underpinning constructions of *us* implies some degree of commonality among an ostensibly cohesive ingroup. Acknowledging the political power that this kind of "strategic essentialism" can afford, Voronka (2016) cautions that "universalized notions of 'lived experience' … risk erasing fundamental differences among us that matter" (p. 197). Consider, for example, the positionalities of the white, physically disabled women I worked for as an attendant. Apparent similarities notwithstanding, their differences abound: congenital and acquired disabilities, family and kinship structures that provide varying levels and kinds of support, sexuality, marital status, employment status, income, socioeconomic status, education, age, body shape and size. As I reflect on the identities I ascribe to these

women, I wonder how well my perceptions align with their internal experiences of themselves. I think about the material and cultural factors shaping the ways they live with and know disability, with awareness that these influences barely begin to capture the constellations of identity and experience that might nuance one's orientation to disability identity and politics: the intersections with race, gender, sexuality, immigration/citizenship status, and other embodied experiences/identities that are neglected in first wave disability organizing that "centers people who can achieve status, power and access through a legal or rights-based framework" (SINS INVALID, 2019, p. 15). Through engagement with disability justice (PIEPZNA-SAMARASINHA, 2018; SINS INVALID, 2019), I am learning how my experiential knowledge of disability is shaped by the specific intersections of whiteness, physical disability, femininity, sociopolitical context, and relative economic privilege shared by the women I worked for, and by my own whiteness, femininity, sociopolitical context, and relative economic privilege.

Troubling binary logic creates space not only to "confront the interlocking [and materially significant] differences" (VORONKA, 2016, p. 196) among people who identify as disabled, but also to consider the lived experiences of people whose identities exceed the disabled/non-disabled binary (KAFER, 2013): disability adjacent experiences and identities, including people whose conditions haven't conventionally been labelled as disabilities; those living with chronic illness and/or mental illness; who struggle to access diagnoses, for instance those with inequitable access to gatekeeping physicians, or whose presentations exceed conventional diagnostic criteria; who claim cultural identities, such as Deaf, Mad, Autistic or Neurodivergent; and those who are hesitant to claim disability labels due to consequences associated with disclosure, or with the historical and ongoing pathologization of gender, sexuality and race (LEWIS, 2019). Pushing back on an independent living movement that "idealizes masculinist notions of autonomy" (HUGHES *et al.,* 2005, p. 263) and against emancipatory paradigm proponents' "writing out of non-disabled people" as stakeholders in disability research (SHAKESPEARE, 2006, p. 186), we might also include people who live with disability in a political-relational sense (KAFER, 2013); people who know disability by virtue of living within disability cultural spaces, or those who develop "affective relationalities" through care work relationships (NISHIDA, 2016). Ever cautious not to appropriate disability culture or identity, ongoing explorations of "crip affiliation" (KAFER, 2013) have enabled me to better understand and communicate the nuances of my own positionality, including my relationship to and knowledge of care work and disability.

The first wave of disability activism, including disability rights, independent living and disability studies, adopted a "single-issue" focus on disability (SINS INVALID, 2019). In addition to

reinforcing a disabled/non-disabled binary, these movements were inadvertently complicit in essentializing disabled identity by erasing non-white and other non-dominant disabled experiences and perspectives (PIEPZNA-SAMARASINHA, 2018; SINS INVALID, 2019). A second wave of disability organizing now calls to "center the interests and contributions of disabled people of color and other marginalized people with disabilities" (MILES; NISHIDA; FORBER-PRATT, 2017). Challenging the binary logic of the first wave, disability justice calls to "acknowledge the ways we *all* are embedded in—thus perpetuate and internalize—systems of oppressions and work collectively to dismantle them" (MILES; NISHIDA; FORBER-PRATT, 2017, emphasis added). As a white, non-disabled scholar in disability studies I find this insight, like TL Lewis's (2022) contention that "you do not have to be disabled to experience ableism", instructive. The message I receive is not "you don't (your identity doesn't) belong here" but rather "here's how you can support the creation of safer spaces and our collective liberation—regardless of, but with critical awareness of, your identity". This guidance reflects understanding that identity, experience and political orientation are not mutually determinant; that our identities and political orientations to disability are complicated by medicalized discourses and often mired in internalized ableism, sanism and other inextricable systems of power (LEWIS, 2022; VORONKA, 2016); that we are stronger in solidarity than we are in isolation, with the caveat that cross-disability and cross-movement solidarity require a commitment to recognize, confront and end complicity in upholding oppressive systems by grappling with our internalized oppressions.

Conclusion

Locating myself within the *us* has been a difficult, at times uncomfortable, journey. While I have identified one source of that discomfort within a gatekeeping tendency of first wave disability politics, I appreciate the historical situatedness of those politics and acknowledge their ongoing evolution. I also recognize the value in some level of embodied "dis-ease", opening pathways to learning, growth, and the development of new ideas. What I interpreted from the first wave of disability politics as insistence on critical engagement with disabled identity led me to interrogate my positionality relative to disability in ways that benefited my self-understanding and primed me for the more nuanced, intersectional identity politics of the second wave.

Through engagement with a reflexive ethnographic methodology, I came to understand myself as a cultural insider with valid and valuable, though certainly always partial knowledge of care work and disability. Thinking beyond a disabled/non-disabled binary, I came

to recognize similarities that bound my employers and me, coexisting with as many differences. This helped me to understand the value of my contributions to the literature on direct-funded attendant services and to disability studies, *and* to comprehend the limits of my specific experiential knowledge of care work and disability. These insights have inspired me to think critically about constructions of "lived experience", highlighting the necessity of specificity where positionality is concerned to safeguard against the erasure of non-dominant experiences. While the shift from organizing around disabled identity to confronting the interconnected systems of domination and exploitation that shape all our experience creates space for people like me—whose interests have historically been constructed in opposition, and who benefit from white supremacy and ableism—the struggle for collective liberation must always centre the knowledge and support the leadership of "those most impacted by the systems we fight against" (SINS INVALID, 2019).

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